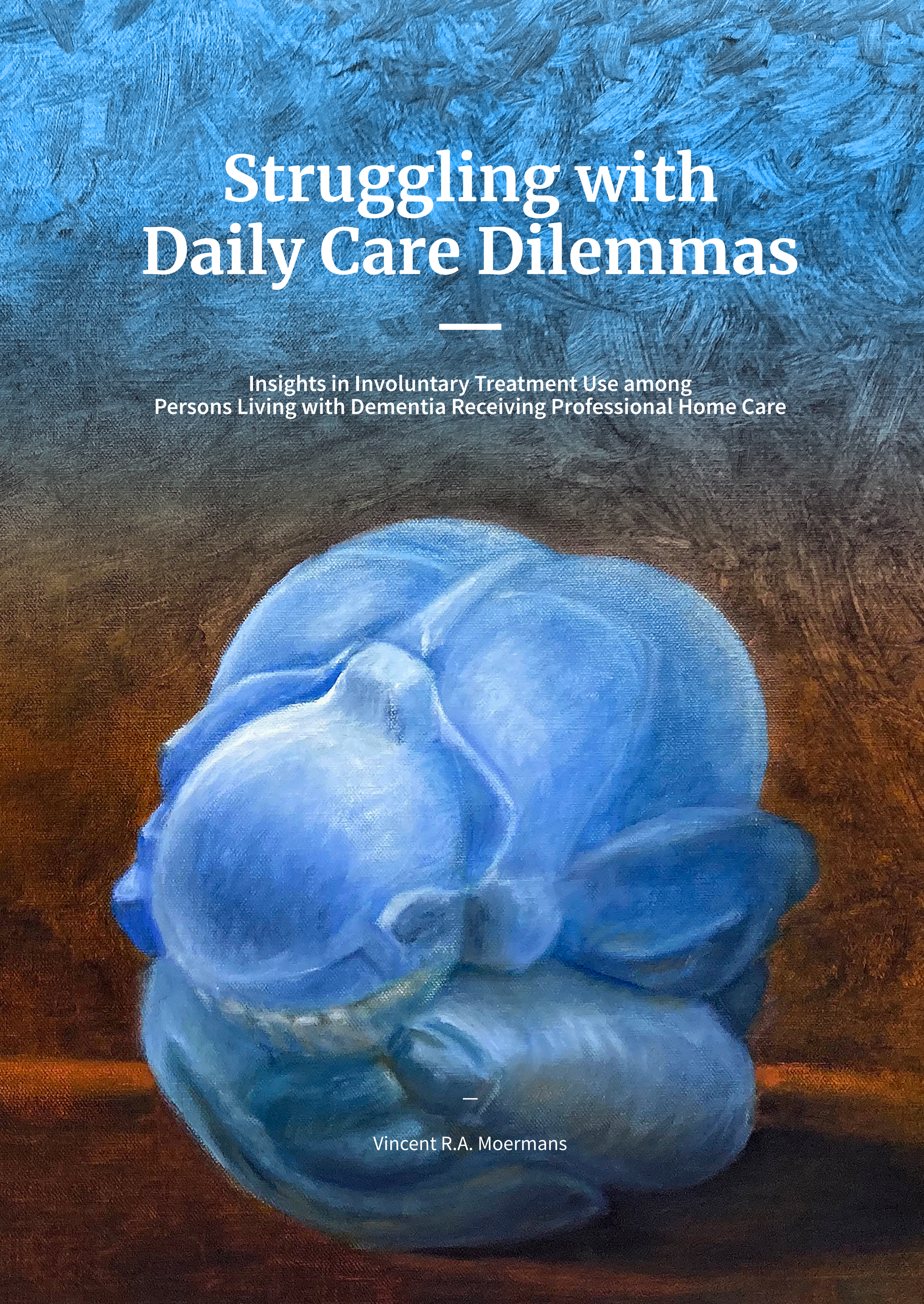
Struggling with Daily Care Dilemmas

Insights in Involuntary Treatment Use among Persons Living with Dementia Receiving Professional Home Care



Vincent R.A. Moermans

Struggling with Daily Care Dilemmas

Insights in Involuntary Treatment Use among Persons Living with Dementia Receiving Professional Home Care

Vincent Roger Albert Moermans

Colophon

The research presented in this thesis was conducted at the Care and Public Health Research Institute (CAPHRI), Department of Health Service Research, Maastricht University (The Netherlands). CAPHRI participates in the Netherlands School of Public Health and Care Research (CaRe), which has been acknowledged by the Royal Netherlands Academy of Arts and Sciences. This research was conducted within and co-funded by the Living Lab in Ageing and Long-Term care and the With-Yellow Cross Limburg (Belgium). The studies in this dissertation were conducted in close collaboration with the Academic Centre for Nursing and Midwifery of KU Leuven (Belgium).

Maastricht University

CAPHRI

Health Services Research
Focusing on Value-based Care and Ageing

living lab
in ageing and
long-term care

KU LEUVEN

wit-gele kruis
LIMBURG

Cover design: Vincent Moermans (painting) and Joël Neelen (lay-out)

Lay-out: Joël Neelen

Printing: Drukkerij Gijsemberg

Struggling with Daily Care Dilemmas

Insights in Involuntary Treatment Use among Persons Living with Dementia Receiving Professional Home Care

—

PROEFSCHRIFT

Ter verkrijging van de graad van doctor aan de Universiteit Maastricht,
op gezag van de Rector Magnificus, Prof. dr. Pamela Habibović
volgens het besluit van het College van Decanen,
in het openbaar te verdedigen op
donderdag 23 november 2023 om 16 uur

—

door
Vincent Roger Albert Moermans

geboren op 4 november 1975
te Hasselt

Promotores
Prof. dr. J.P.H. Hamers
Prof. dr. H. Verbeek
Prof. dr. K. Milisen *(Katholieke Universiteit Leuven)*

Co-promotor
Dr. M.H.C. Bleijlevens

Beoordelingscommissie
Prof. dr. M. E. de Vugt *(voorzitter)*
Prof. dr. C. Gastmans *(Katholieke Universiteit Leuven)*
Prof. dr. S. Köpke *(Universität zu Köln)*
Prof. dr. J. W.M. Muris
Prof. dr. S.M.G. Zwakhalen

—

Contents

CHAPTER 1 General introduction 7

CHAPTER 2 The use of involuntary treatment among older adults with cognitive impairment receiving nursing care at home: A cross-sectional study 25
Published in International Journal of Nursing Studies, 2018

CHAPTER 3 Involuntary treatment in dementia care at home: Results from the Netherlands and Belgium 49
Published in Journal of Clinical Nursing, 2020

CHAPTER 4 Caregiver decision-making concerning involuntary treatment in dementia care at home. 73
Published in Nursing Ethics, 2021

CHAPTER 5 District nurses' attitudes towards involuntary treatment in dementia care at home: A cross-sectional study 97
Published in Geriatric Nursing, 2022

CHAPTER 6 District nurses' experiences with involuntary treatment in dementia care at home: A qualitative descriptive study 131
Submitted for publication

CHAPTER 7 General discussion 163

ADDENDA
Summary 185
Samenvatting 195
Impact 205
Dankwoord 215
About the author 221
List of publications 225
Living Lab in Ageing and Long-Term care 231

CHAPTER 1

General introduction

Introduction

Persons living with dementia wish, like all other persons, to stay at home as long as possible, have a meaningful life, and to remain engaged in daily life.[1-4] Due to cognitive decline caused by dementia, persons living with dementia will, at a certain point, need the extensive support of caregivers.[4] Person-centred care is a fundamental principle in providing this support.[5, 6] However, providing person-centred care in dementia care at home can be challenging. For example, persons living with dementia may want to do something (e.g., go on a walk alone), while the professional and/or family caregiver will not allow this due to safety concerns. Dealing with such conflicting opinions may involve ethical concerns with regard to respecting the voice of persons with dementia.[5] As dementia further evolves, persons living with dementia experience more problems with expressing their wishes, and eventually they may lose (part of) their decision-making capacity.[7] Then, caregivers often decide which care is in the best interest of the person living with dementia.[8] When the person living with dementia is not involved in decision-making and/or does not give his consent for the care provided and/or resists care, it's referred as involuntary treatment in this thesis. This thesis examines the use of involuntary treatment among persons living with dementia receiving professional home care. This chapter starts with a general background on dementia, followed by aging in place, person-centred care, involuntary treatment, then family caregiving and involuntary treatment, and finally professional home care nursing and involuntary treatment is discussed. At the end of this chapter, the main objectives and outline of this thesis are described.

Dementia

Dementia is the umbrella term for several neurological conditions of which the major symptoms are neuropsychiatric (i.e., complex attention, executive function, behavioural problems, learning and memory, language, perceptual motor, or social cognition). The most common underlying pathology of dementia is Alzheimer's disease at 60%.[9, 10] Worldwide, the number of people living with dementia is increasing.[10] It is estimated that the number of persons living with dementia will increase from 57.4 million cases globally in 2019 to 152.8 million cases in 2050.[11] In Belgium, in 2020, it was estimated that 202,402 persons were living with dementia.[12] In the Netherlands, it is estimated that 290,000 persons are currently living with dementia.[13] The majority live in their in their own home and wish to age in place in an environment that feels safe and familiar.[14, 15]

Aging in place

The World Health Organization defines aging in place as: *"Meeting the desire and ability of people, through the provision of appropriate services and assistance, to remain living relatively independently in the community in his or her current home or an appropriate level of housing. Ageing in place is designed to prevent or delay more traumatic moves to a residential facility, such as a nursing home."*[16] Worldwide, governments wish to stimulate persons living with dementia aging in place. Therefore, in 2013 and 2015, a G8 summit was organized with stakeholders from the G8 countries to discuss, among other things, how dementia care and quality of life can be improved for persons living with dementia and their caregivers. In 2017, the global action plan on the public health response to dementia 2017–2025 was adopted by the Seventieth World Health Assembly in Geneva, Switzerland.[10, 17] This has resulted in worldwide governmental policies being developed to foster the maintenance of persons living with dementia of their self- and personhood, and asserting they can live well in spite of their cognitive impairment.[17] In Flanders, in 2022, the Government of Flanders stated in its 2021–2025 dementia action plan that people living with dementia must be able to be part of society. That is why the Flemish government wishes to develop initiatives to improve person-centred care and optimize the support of family caregivers of persons living with dementia, to enable people living with dementia to age in place as long as possible,[18] because aging in place has several benefits for persons living with dementia. Living in their own home provides persons living with dementia a sense of independence, security, privacy, and comfort. Also, home is a place for hosting meaningful social activities and making a contribution to others.[19, 20] However, aging in place can have a downside, and can be accompanied by negative experience due to cognitive and functional decline caused by dementia, such as social isolation, intense loneliness, safety related problems (e.g., fall risk, wandering), decreased self-reliance (e.g., problems regarding basic tasks of daily living such as bathing, toileting, eating), lack of day structure, and caregiver burden due to high load of care responsibility.[19-21] As a result, persons living with dementia will eventually need 24/7 extensive support from family or professional caregivers, or a combination of both, to age in place.[4, 21]

Person-centred dementia care

Person-centred care is a fundamental principle in dementia.[5, 22, 23] Central to person-centred care is knowing the other in the relation, and not about confronting the other in their otherness.[24] Therefore, person-centred care refers to care in which the *"individual's values and preference are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals"*. [5] It involves meeting the needs and preferences of persons living with dementia by acknowledging the caregivers, as well as the family, taking into account each individual's needs, goals, and abilities.[5] Person-centred dementia care guides caregivers in providing care that supports personhood and well-being of persons living with dementia throughout the course of dementia.[25] Crucial in this approach is that caregivers do not provide routine care, but focus on who the persons living with dementia are and what they want. Person-centred care helps the involved caregivers to focus less on what is done and more on how it is done. Therefore, it is crucial that nurses consider the themes of knowing the person, the centrality of values, biography, relationships, seeing beyond the immediate needs, and authenticity.[23] Further, recognizing and maintaining selfhood is key to person-centred care. In addition, selfhood is more than memory and cognitive abilities, since persons living with dementia could express their personhood in spite of cognitive impairments.[6, 25] Key components of person-centred care interventions are social contact, physical activities, cognitive training, sensory enhancement, daily living assistance, life history-oriented emotional support, training and support for professional and non-professional caregivers, environmental adjustments, and care organization.[26] Recent systematic reviews found that individualized person-centred care interventions can reduce agitation, neuropsychiatric symptoms, and depression, and improve the quality of life for persons living with dementia and their caregivers.[5, 27] However, providing person-centred care to persons living with dementia is challenging due to several barriers. Persons living with dementia are often not involved in decisions about their care because family caregivers often function in the traditional role of principal decision-maker and do not always respect the wishes of their next of kin, due to safety concerns. Oftentimes they also have insufficient experience in dealing with the behavioural symptoms of dementia in a person-centred manner.

Finally, due to a lack of advanced care planning, family caregivers are often not aware of the wishes of their next of kin and receive insufficient support to provide person-centred care.[5, 28] As dementia evolves, caregivers may experience difficulties communicating with persons living with dementia and involving them care decisions. This could lead to situations in which persons living with dementia may refuse activities of daily living, creating a tension between providing a safe environment and respecting their autonomy.[29-32] As a result, the persons living with dementia could receive care without their consent, resist or refuse care.[33]

Involuntary treatment

Definition of involuntary treatment

Several terms are used in the literature to describe care that persons resist or do not provide consent for, like coercive care, restiveness to care, forced treatment, refusal of care, and involuntary treatment.[8, 32-35] This study uses the term ‘involuntary treatment’. Involuntary treatment is defined as care provided without the consent of the person receiving it and/or to which this person resists.[33] Involuntary treatment includes the use of:

1) Physical restraints, defined as any action or procedure that prevents a person’s free bodily movement to a position of choice or normal 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;[19]

2) Psychotropic medications, defined as substances that act directly on the central nervous system, affecting mood, cognition, and behaviour, including antidepressants, anti-epileptics, anti-psychotics, anxiolytics, and hypnotics (sedatives);[20] and

3) Non-consensual care, defined as any type of care that limits the organization of a person’s own life and to which a person resists (e.g., locking in a room, use of electronic surveillance, forcing or pressuring into activities of daily living).

Inappropriate dementia care

Involuntary treatment can be considered as inappropriate dementia care for several reasons. Involuntary treatment conflicts with the basic rights of persons living with dementia, which are determined by the United Nation Convention on the Rights of Persons with Disabilities, because when caregivers apply involuntary treatment, they go against the choices of persons living with dementia. Moreover, having dementia is no reason to be treated differently. Therefore, caregivers must involve and support persons living with dementia when making decisions about their care, to have a dignified life and protect them against degrading care or abuse.[36, 37] Moreover, if a person living with dementia is not competent to make decisions, health care providers must adequately protect, support, and care for them, to ensure that the person living with dementia has a dignified life. Every human being, with or without cognitive disabilities, is entitled to equal rights and dignity.[36, 37] In addition, certain cases of involuntary treatment can be seen as elder abuse, if it is an intentional act or failure to act that causes or creates a risk of harm to an older adult and it is applied by a caregiver or a person the elder trusted.[38, 39] Also, studies show that involuntary treatment has a negative impact on the physical and psychological well-being of persons living with dementia and their caregivers.[21–24] For persons living with dementia, involuntary treatment increases the risk of serious injury, lowers self-respect, and fosters feelings of imprisonment, dependency in activities of daily living, etc.[40-43] For caregivers, dealing with measures of involuntary treatment could lead to burnout and attrition.[44, 45] Finally, involuntary treatment is in conflict with the principles of person-centred care since, if persons living with dementia are not involved in the decisions about their care or resist it, caregivers could have dismissed their needs and preferences regarding care and in respecting their selfhood.[5, 6, 25] Recently, several studies found alternatives for involuntary treatment that are more in line with person-centred care, such as interventions involving music, approaching persons living with dementia bathing techniques, ability-focused approach, and distraction approach.[27, 46-48]

Legislation and regulation

Worldwide, countries have adopted policies and laws to prevent or regulate the use of measures we defined as involuntary treatment, like coercive care, forced treatment, or refusal of care.[8, 34, 49] Currently, in the Netherlands, there is a national law, *"Law care and force"*, that specifically focuses on preventing involuntary treatment use.[50] This law is based on the principle that no treatment may be provided without the consent of the person receiving it. If health care professionals wish to apply involuntary treatment, they need to follow a multi-disciplinary step-by-step plan. Only if there are no other alternatives possible may involuntary treatment be applied. Before applying physical restraints, psychotropic medications, and locking-up, this step-by-step plan must be followed regardless of consent, because these methods are hurtful and greatly restrict the freedom of the person receiving them.[50] In Belgium, there is no specific legislation like in the Netherlands. There are only indirect articles of law that that could regulate the use of involuntary treatment. Article 5 (law of 22/02/2002) of Belgian law that regulates the rights of patients states that: *"The patient has, with respect to his dignity and his self-determination, and without any discrimination, the right to quality care that is tailored to his needs"*. Further, Article 12 of the Belgian Constitution ensures the freedom of every person and only a judge may deprive someone of their liberty. However, in the context of health care, certain health care professionals like nurses are authorized to deprive a patient of their freedom without the consent of a judge, if they deem this clinically necessary to guarantee the patient's safety. This is regulated by the law that defines which technical nursing activities (18/06/1990) nurses may apply. If Belgian nurses wish to restrain a patient, they need to follow the policy of their health care organisation.[41] In 2016, a practical guideline was published regarding the use of physical restraints in Belgian home care.[51] Recently, the Government of Flanders declared, in the 2021–2025 dementia care plan, that it wishes to reduce the use of chemical and physical restraints.[18]

Current state of affairs in involuntary treatment research

In contrast to studies about physical and chemical restraints in acute and residential care settings, studies about involuntary treatment use in home care (e.g., physical restraints, psychotropic medication use, compulsion to take part in activities of daily living) are scarce and limited.[34, 52-56] Studies in acute and residential settings found that despite regulations to limit or prevent involuntary treatment measures like restraints or psychotropic medications, the prevalence rate ranged from 9% to 65%; however, nurses had negative feelings using them, though they perceived a need to use them to provide good and safe nursing.[34, 52-56] In the field of home care, only a few studies are published about the use of physical restraint and psychotropic medication research.[40, 57] Regarding involuntary treatment use, only one study has been published.[33] Hamers et al. (2016) conducted a study among older adults with cognitive impairment receiving professional home care and found that involuntary treatment was used in 39% of the sample. Mostly measures of non-consensual care (79%) were used, followed by psychotropic medications (41%), and finally physical restraints (7%). The associated factors of involuntary treatment were caregiver burden, greater dependency in activities of daily living, poorer cognitive ability, living alone, and having a formal diagnosis of dementia. In Western countries, the prevalence of these risk factors is growing due to demographic and socioeconomic evolutions.[58, 59] Moreover, in most cases, the family of the persons with a cognitive impairment requested involuntary treatment use (74%) and used it (72%). This signals that family caregivers are crucial in reducing or preventing involuntary treatment use.

Family caregiving and involuntary treatment

In Belgium and the Netherlands, 70–80% of persons living with dementia receive care from unpaid caregivers such as family, friends and neighbors.[12, 13] This means that family caregivers are crucial for persons living with dementia to age in place.[4] However, family caregivers are often unaware of the harmful effects of involuntary treatment like physical restraints because of a lack of knowledge and skill.[60] In addition, family caregivers do not always have sufficient skills, knowledge, or support to respond to this resistance or rejection of care in a person-centred manner.[28, 34] Also, family caregivers often find the use of involuntary treatment appropriate dementia care. They perceive its use as less restrictive for persons living with dementia and feel comfortable when using it compared to professional caregivers.[61] If we combine these findings, with the associated factors that Hamers et al. (2016) identified, it becomes important that family caregivers receive support in dealing with daily care decisions that can evolve involuntary treatment use into more person-centred care. In the past, a few qualitative studies were conducted that focused on how family caregivers deal with these decisions.[31, 62, 63] These studies showed that family caregivers apply protective measures to prevent or reduce the risk of harm and alleviate damage from harm that occurs.[31, 62] Smeybe et al. (2016) found that when the autonomy of the person living with dementia conflicted with family caregivers' need to prevent harm, often a hard paternalistic approach was applied in order to prevent harm. For example, installing technical devices (e.g., GPS-tracking, real-time observations, or camera surveillance).[63] However, insights that focus on how family caregivers experience and deal with care situations that can lead to involuntary treatment in dementia care at home are missing. These insights are needed so that professional caregivers, like district nurses who have a pivotal role in dementia nursing care at home, can support unpaid caregivers in dealing with dilemmas regarding safety and autonomy in a person-centred manner.

Professional nursing care at home and involuntary treatment

In Belgium, when family caregivers experience that caring for their next of kin with dementia becomes too difficult and more support is needed due to increased care dependency in activities of daily living (i.e., clothing, hygiene, transferring, walking, toileting, bladder and bowel continence), they can receive support from district nurses — if the person living with dementia has a certain care dependency level in activities of daily living.[64, 65] Besides support in activities of daily living, district nurses administer technical nurse interventions (e.g., injections, wound care, stoma care) and provide psychosocial support for patients and family, including health assessment and monitoring.[66-68] District nurses are responsible for planning, coordinating, performing, and evaluating the nursing care provided in the homes belonging to their district.[67, 68] Because of this, they have a key role in the care of persons living with dementia at home who are care-dependent. They play a crucial role in detecting daily practical problems that people living with dementia and their family caregivers are facing, which can evolve into involuntary treatment usage. Moreover, they can advise families on how to manage these problems in a person-centred manner.[21] However, studies in residential settings indicate that nurses do not always have sufficient skills and knowledge to appropriately and timely detect and address behavioural symptoms of dementia in a person-centred manner, which can also lead to involuntary treatment.[34, 52, 55, 56] Furthermore, research suggest that nurses are not always sufficiently aware of the ethical dimensions in daily dementia care, and as a result they could provide care without the consent of the person receiving it, like the use of physical restraint.[69, 70] Studies in home care confirm this and found that district nurses often applied involuntary treatment on request of the family caregivers or on their own initiative.[33] Haut et al. (2010) suggest that nursing staff attitudes influence the decision to use physical restraints.[71] Also, studies in nursing homes found that although nurses have negative feelings towards the use of physical restraint, they perceive its use appropriate nursing care.[53, 72, 73] However, thorough knowledge of district nurses' attitudes and opinions towards the use of involuntary treatment in home care is scarce. To our knowledge, there is only one study available regarding this topic.[61] This study suggests that district nurses had no outspoken attitudes or opinions towards the use of involuntary treatment in dementia care at home. If we want district nurses to support family caregivers in dealing with situations that can evolve into involuntary treatment use in a more person-centred manner, we need more insights into how district nurses experience involuntary treatment use and deal with it in practice. In contrast to residential and hospital settings, qualitative studies that focus on how district nurses experience involuntary treatment use at home are lacking. The published qualitative studies in residential and hospital settings focus mainly on the use of physical restraints and found that nurses' decision-making in cases of physical restraint was a complex process that primarily focused on safety from harm.[69, 74]

Objectives

Involuntary treatment is inappropriate dementia care at home. Two recent studies published about it indicated that involuntary treatment is commonly used in home care and district nurses have no outspoken attitudes and opinions towards it.[33, 61] To generalize previous findings and increase understanding in involuntary treatment, insights from other countries are needed. Further, if we want to support family caregivers and district nurses in dealing with involuntary treatment in a more person-centred manner, insights are needed into how they experience it and deal with it in practice. Therefore, the three main objectives of this study are:

- To gain insight into the prevalence and associated factors of involuntary treatment use among older adults with cognitive impairment and persons living with dementia receiving professional home care.
- To describe how family caregivers experience the decision-making process within care dilemmas that can lead to involuntary treatment use.
- To investigate the attitudes and opinions of district nurses towards the use of involuntary treatment and to describe their experiences with involuntary treatment use among persons living with dementia at home.

Outline

In **chapter 2**, we report on a cross-sectional study on the prevalence of involuntary treatment, the associated factors, and who requests and applies their use among older adults with cognitive impairment (e.g., dementia, congenital brain injury, stroke, or brain tumour) receiving nursing care at home, in Belgium. In **chapter 3**, we present the results of secondary data analyses of two cross-sectional surveys that specifically focus on the prevalence of involuntary treatment use, the associated factors, and who requests and applies them among people living with dementia receiving professional home care in the Netherlands and Belgium. In **chapter 4**, we describe the findings of a qualitative descriptive study that provides more insights into how family caregivers deal with and make decisions in care situations that can lead to involuntary treatment. In **chapter 5**, based on a cross-sectional study using the Maastricht Attitude Questionnaire — Home Care, we analyse district nurses' attitudes towards the use of involuntary treatment and their opinions about the restrictiveness and discomfort of involuntary treatment measures in dementia care at home. Also, we report on the determinants that influence district nurses' attitudes and opinions towards involuntary treatment. In **chapter 6**, we describe a qualitative descriptive study that gives insight into how district nurses experience involuntary treatment use among persons living with dementia at home. Finally, in **chapter 7**, we summarise the main findings of this dissertation and discuss the methodological and theoretical aspects. Lastly, we provide several implications for research and home care practice.

References

1. von Kutzleben M, Schmid W, Halek M, et al. Community-dwelling persons with dementia: what do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia. *Aging Ment Health* 2012; 16: 378-390. 2012/01/19. DOI: 10.1080/13607863.2011.614594.
2. van Vliet D, Persoon A, Bakker C, et al. Feeling useful and engaged in daily life: exploring the experiences of people with young-onset dementia. *Int Psychogeriatr* 2017; 29: 1889-1898. 2017/07/14. DOI: 10.1017/S1041610217001314.
3. van Corven CT, Bielderman A, Wijnen M, et al. Defining empowerment for older people living with dementia from multiple perspectives: A qualitative study. *Int J Nurs Stud* 2021; 114: 103823. 2020/12/01. DOI: 10.1016/j.ijnurstu.2020.103823.
4. Alzheimer Association. 2021 Alzheimer's disease facts and figures. A*lzheimers Dement* 2021; 17: 327-406. 2021/03/24. DOI: 10.1002/alz.12328.
5. Brummel-Smith K, Butler D, Frieder M, et al. Person-centered care: A definition and essential elements. *J Am Geriatr Soc* 2016; 64: 15-18. DOI: 10.1111/jgs.13866.
6. Fazio S, Pace D, Flinner J, et al. The Fundamentals of Person-Centered Care for Individuals With Dementia. *Gerontologist* 2018; 58: S10-S19. DOI: 10.1093/geront/gnx122.
7. Miller LM, Whitlatch CJ and Lyons KS. Shared decision-making in dementia: a review of patient and family carer involvement. *Dementia* 2016; 15: 1141-1157. DOI:10.1177/1471301214555542.
8. Gjellestad Å, Oksholm T and Bruvik F. Forced treatment and care in home-dwelling persons with dementia. *Nurs Ethics* 2020; 28: 372-386. DOI: 10.1177/0969733020948107.
9. Prince M, Bryce R, Albanese E, et al. The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimers Dement* 2013; 9: 63-75. e62. DOI:https://doi.org/10.1016/j.jalz.2012.11.007.
10. World Health Organization. *Towards a dementia plan: a WHO guide*. Geneva, Switzerland: World Health Organization, 2018.
11. Nichols E, Steinmetz JD, Vollset SE, et al. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health* 2022; 7: e105-e125. DOI: 10.1016/S2468-2667(21)00249-8.
12. Expertisecentrum Dementie Vlaanderen vzw. Prevalence of Dementia, https://www.dementie.be/home/wat-is-dementie/prevalentie/ (2022, accessed 18-08-2022).

13. Nederland A. Factsheet cijfers en feiten over dementie, https://www.alzheimer-nederland.nl/factsheet-cijfers-en-feiten-over-dementie (2022, accessed 18-08-2022).
14. Gitlin LN, Hodgson N, Piersol CV, et al. Correlates of quality of life for individuals with dementia living at home: the role of home environment, caregiver, and patient-related characteristics. *Am J Geriatr Psychiatry* 2014; 22: 587-597. DOI:https://doi.org/10.1016/j.jagp.2012.11.005.
15. Gitlin LN. Conducting research on home environments: Lessons learned and new directions. *Gerontologist* 2003; 43: 628-637. DOI: https://doi.org/10.1093/geront/43.5.628.
16. World Health Organization. A glossary of terms for community health care and services for older persons, https://apps.who.int/iris/handle/10665/68896 (2004, accessed 12-11-2022).
17. Hampson C and Morris K. Dementia: Normal ageing, political cause or social construction. *Gerontol Geriat Med* 2017; 1: 555568.
18. Crevits H. Dementieplan 2021 - 2025, https://www.zorg-en-gezondheid.be/nieuw-dementieplan-2021-2025 (2022, accessed 26-12-2022 2022).
19. Horner B and Boldy DP. The benefit and burden of "ageing-in-place" in an aged care community. *Aust Health Rev* 2008; 32: 356-365. DOI: doi.org/10.1071/AH080356.
20. Sixsmith A and Sixsmith J. Ageing in place in the United Kingdom. *Ageing Int* 2008; 32: 219-235. DOI: doi.org/10.1007/s12126-008-9019-y.
21. Thoma-Lürken T, Bleijlevens MH, Lexis MA, et al. Facilitating aging in place: A qualitative study of practical problems preventing people with dementia from living at home. *Geriatr Nurs* 2018; 39: 29-38. DOI: 10.1016/j.gerinurse.2017.05.003.
22. Fazio S, Pace D, Maslow K, et al. Alzheimer's Association dementia care practice recommendations. *Gerontologist* 2018; 58: S1-S9. DOI: 10.1093/geront/gnx182.
23. McCormack B. Person-centredness in gerontological nursing: an overview of the literature. *J Clin Nurs* 2004; 13: 31-38. DOI: https://doi-org.mu.idm.oclc.org/10.1111/j.1365-2702.2004.00924.x.
24. Kitwood TM. *Dementia reconsidered: The person comes first.* Open university press Buckingham, 1997.
25. Manthorpe J and Samsi K. Person-centered dementia care: current perspectives. *Clin Interv Aging* 2016; 11: 1733-1740. DOI: 10.2147/CIA.S104618.
26. Mohr W, Rädke A, Afi A, et al. Key intervention categories to provide person-centered dementia care: A systematic review of person-centered inter-

ventions. *J Alzheimer's Dis* 2021; 84: 343-366. DOI: 10.3233/JAD-210647.

27. Kim SK and Park M. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clin Interv Aging* 2017; 12: 381-397. DOI: 10.2147/CIA.S117637.
28. Chiao CY, Wu HS and Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: a systematic review. *Int Nurs Rev* 2015; 62: 340-350. DOI: doi.org/10.1111/inr.12194
29. Giertz L, Emilsson UM and Vingare E-L. Family caregivers and decision-making for older people with dementia. *J Soc Welf and Fam Law* 2019; 41: 321-338. DOI: 10.1080/09649069.2019.1627087.
30. van Manen AS, Aarts S, Metzelthin SF, et al. A communication model for nursing staff working in dementia care: Results of a scoping review. *Int J Nurs Stud* 2021; 113: 1-14. DOI: 10.1016/j.ijnurstu.2020.103776.
31. Häikiö K, Sagbakken M and Rugkåsa J. Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services. *BMC Health Serv Res* 2019; 19: 1-13. DOI: 10.1186/s12913-019-4478-2.
32. Backhouse T, Dudzinski E, Killett A, et al. Strategies and interventions to reduce or manage refusals in personal care in dementia: A systematic review. *Int J Nurs Stud* 2020; 109: 103640. DOI: 10.1016/j.ijnurstu.2020.103640.
33. Hamers JP, Bleijlevens MH, Gulpers MJ, et al. Behind Closed Doors: Involuntary Treatment in Care of Persons with Cognitive Impairment at Home in the Netherlands. *J Am Geriatr Soc* 2016; 64: 354-358. DOI: 10.1111/jgs.13946.
34. Lejman E, Westerbotn M, Pöder U, et al. The ethics of coercive treatment of people with dementia. *Nurs Ethics* 2013: 248-262. DOI: 10.1177/0969733012463721.
35. Spigelmyer PC, Hupcey JE, Smith CA, et al. Resistiveness to Care as Experienced by Family Caregivers Providing Care for Someone With Dementia. *Journal of Nursing Scholarship* 2018; 50: 36-46.
36. Nations U. Convention on the rights of persons with disabilities., http://www.un.org/disabilities/convention/conventionfull.shtml (2006).
37. Vandenbulcke M, Dröes R-M and Schokkaert E. *Dementia and Society.* Cambridge University Press, 2022.
38. Centers for Disease Control Prevention. Elder Abuse, https://www.cdc.gov/violenceprevention/elderabuse/fastfact.html (2022, accessed 22-08-2022).
39. World Health Organisation. Abuse of older people, https://www.who.int/news-room/fact-sheets/detail/abuse-of-older-people (2022, accessed 22-08-2022).
40. Beerens HC, Sutcliffe C, Renom-Guiteras A, et al. Quality of life and quality of

care for people with dementia receiving long term institutional care or professional home care: the European RightTimePlaceCare study. *JAMA* 2014; 15: 54-61. DOI: https://doi.org/10.1016/j.jamda.2013.09.010.

41. Gastmans C and Milisen K. Use of physical restraint in nursing homes: clinical-ethical considerations. *J Med Ethics* 2006; 32: 148-152. DOI: 10.1136/jme.2005.012708.
42. Hofmann H and Hahn S. Characteristics of nursing home residents and physical restraint: a systematic literature review. *J Clin Nurs* 2014; 23: 3012-3024. DOI: 10.1111/jocn.12384.
43. Voyer P, Cohen D, Lauzon S, et al. Factors associated with psychotropic drug use among community-dwelling older persons: A review of empirical studies. *BMC Nurs* 2004; 3: 1-13. DOI: 10.1186/1472-6955-3-3.
44. Pijl-Zieber E, Hagen B, Armstrong-Esther C, et al. Moral distress: an emerging problem for nurses in long-term care? *Qual Ageing* 2008; 9: 39-48. DOI: doi.org/10.1108/14717794200800013.
45. Scheepmans K, Dierckx de Casterlé B, Paquay L, et al. Restraint use in home care: a qualitative study from a nursing perspective. *BMC Geriatr* 2014; 14: 1-7. DOI: 10.1186/1471-2318-14-17.
46. Backhouse T, Dudzinski E, Killett A, et al. Strategies and interventions to reduce or manage refusals in personal care in dementia: A systematic review. *Int J Nurs Stud* 2020; 109: 1-15. DOI: 10.1016/j.ijnurstu.2020.103640.
47. Dyer SM, Harrison SL, Laver K, et al. An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioral and psychological symptoms of dementia. *Int psychogeriatr* 2018; 30: 295-309. DOI: 10.1017/S1041610217002344.
48. Cruise CE and Lashewicz BM. Dementia and dignity of identity: A qualitative evidence synthesis. *Dementia* 2022; 21: 1233-1249. DOI: 10.1177/14713012211072929.
49. Backhouse T. Understanding and reducing refusals of personal care in dementia. *Nursing and Residential Care* 2021; 23: 1-8. DOI: doi.org/10.12968/nrec.2021.23.3.8.
50. Wet zorg en dwang voor personen met een psychogeriatrische aandoening of een verstandelijke handicap 2018.
51. Scheepmans K, Dierckx de Casterlé B, Paquay L, et al. S*treven naar een fixatiearme thuiszorg, praktijkrichtlijn.* Leuven: Acco, 2016.
52. Pu L and Moyle W. Restraint use in residents with dementia living in residential aged care facilities: A scoping review. *J Clinl Nurs* 2020; 31: 2008-2023. DOI: 10.1111/jocn.15487.

53. Möhler R and Meyer G. Attitudes of nurses towards the use of physical restraints in geriatric care: A systematic review of qualitative and quantitative studies. *Int J Nurs Stud* 2014; 51: 274-288. DOI: 10.1016/j.ijnurstu.2013.10.004.
54. Thomann S, Zwakhalen S, Richter D, et al. Restraint use in the acute-care hospital setting: A cross-sectional multi-centre study. *Int J Nurs Stud* 2021; 114. DOI: 10.1016/j.ijnurstu.2020.103807.
55. Vaismoradi M, Vizcaya Moreno F, Sletvold H, et al. PRN medicines management for psychotropic medicines in long-term care settings: a systematic review. *Pharmacy* 2019; 7: 157. DOI: https://doi.org/10.3390/pharmacy7040157.
56. Ozaki T, Katsumata Y and Arai A. The use of psychotropic drugs for behavioral and psychological symptoms of dementia among residents in long-term care facilities in Japan. *Aging Ment Health* 2016: 1-8. DOI: https://doi-org.mu.idm.oclc.org/10.1080/13607863.2016.1220922.
57. Scheepmans K, Dierckx de Casterlé B, Paquay L, et al. Restraint Use in Older Adults Receiving Home Care. *J Am Geriatr Soc* 2017; 65: 1769-1776. DOI: 10.1111/jgs.14880.
58. Etters L, Goodall D and Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Assoc Nurse Pract* 2008; 20: 423-428. DOI: https://doi-org.mu.idm.oclc.org/10.1111/j.1745-7599.2008.00342.x.
59. Koller D, Schön G, Schäfer I, et al. Multimorbidity and long-term care dependency — a five-year follow-up. *BMC geriatr* 2014; 14: 70. DOI: https://doi.org/10.1186/1471-2318-14-70.
60. Kurata S and Ojima T. Knowledge, perceptions, and experiences of family caregivers and home care providers of physical restraint use with home-dwelling elders: a cross-sectional study in Japan. *BMC Geriatr* 2014; 14: 1-11. DOI: 10.1186/1471-2318-14-39.
61. Mengelers AM, Bleijlevens MH, Verbeek H, et al. Professional and family caregivers' attitudes towards involuntary treatment in community-dwelling people with dementia. *J Adv Nurs* 2018; 75: 96-107. DOI: 10.1111/jan.13839.
62. Lach HW and Chang Y-P. Caregiver perspectives on safety in home dementia care. *West J Nurs Res* 2007; 29: 993-1014. DOI: 10.1177/0193945907303098.
63. Smebye KL, Kirkevold M and Engedal K. Ethical dilemmas concerning autonomy when persons with dementia wish to live at home: a qualitative, hermeneutic study. *BMC Health Serv Res* 2016; 16: 1-12. DOI: 10.1186/s12913-015-1217-1.
64. Rijksinstituut voor ziekte- en invaliditeitsverzekering. Evaluatieschaal (Katz), http://www.riziv.fgov.be/nl/professionals/individuelezorgverleners/verpleegkundigen/verzorging/Paginas/evaluatieschaal-katz.aspx#.V9xDTuRf2Hk (2016).

65. Katz S, Ford AB, Moskowitz RW, et al. Studies of illness in the aged: the index of ADL: a standardized measure of biological and psychosocial function. *JAMA* 1963; 185: 914-919. DOI: 10.1001/jama.1963.03060120024016.
66. De Vliegher K, Declercq A, Aertgeerts B, et al. The activity profile of home nurses: a systematic review. *Health Care Manag Pract* 2014; 26: 257-265. DOI: 10.1177/1084822314527293.
67. Flemish Government. District Nursing, https://www.vlaanderen.be/thuisverpleging (2022, accessed 23-06-2022).
68. De Vliegher K, Paquay L, Grypdonck M, et al. A study of core interventions in home nursing. *Int J Nurs Stud* 2005; 42: 513-520. DOI: 10.1016/j.ijnurstu.2004.09.013.
69. Goethals S, Dierckx de Casterlé B and Gastmans C. Nurses' decision-making in cases of physical restraint: a synthesis of qualitative evidence. *J Adv Nurs* 2012; 68: 1198-1210. DOI: 10.1111/j.1365-2648.2011.05909.x.
70. Goethals S, Gastmans C and de Casterlé BD. Nurses' ethical reasoning and behaviour: A literature review. I*nt J Nurs Stud* 2010; 47: 635-650. DOI: 10.1016/j.ijnurstu.2009.12.010.
71. Haut A, Kolbe N, Strupeit S, et al. Attitudes of relatives of nursing home residents toward physical restraints. *J Nurs Scholarsh* 2010; 42: 448-456. DOI: 10.1111/j.1547-5069.2010.01341.x.
72. Ferrão SAdS, Bleijlevens MH, Nogueira PJ, et al. A cross-sectional study on nurses' attitudes towards physical restraints use in nursing homes in Portugal. *Nurs Open* 2021. DOI: https://doi-org.mu.idm.oclc.org/10.1002/nop2.769.
73. Mayerl H, Trummer T, Stolz E, et al. Nursing professionals' attitudes toward use of physical restraints in Styrian nursing homes Austria. *Pflege* 2018; 2018: 1-7. DOI: 10.1024/1012-5302/a000649.
74. Goethals S, Dierckx de Casterlé B and Gastmans C. Nurses' ethical reasoning in cases of physical restraint in acute elderly care: a qualitative study. *Med Health Care Philos* 2013; 16: 983-991. DOI: 10.1007/s11019-012-9455-z.

CHAPTER 2

The use of involuntary treatment among older adults with cognitive impairment receiving nursing care at home: A cross-sectional study

This chapter was published as:

Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Tan F.E.S, Milisen K. & Hamers J.P.H (2018). *The Use of Involuntary Treatment among Older Adults with Cognitive Impairment Receiving Nursing Care at Home: A Cross-sectional Study.* International Journal of Nursing Studies, 88, 135-142.
DOI: 10.1016/j.ijnurstu.2018.09.004

Abstract

Background

Respect for inherent dignity and individual autonomy is a basic principle in health care. However, several studies indicate that care-dependent older adults with a cognitive impairment, receiving nursing care at home, are at risk of care without their consent, referred to as 'involuntary treatment'. This includes the application of physical restraints (e.g. measures to prevent leaving bed or chair), psychotropic drugs (e.g. antidepressants, sedatives) and non-consensual care (e.g. forced hygiene, hiding medication). Research about involuntary treatment is scarce and only recently first studies have been conducted.

Objective

To investigate 1) the prevalence of involuntary treatment, 2) associated factors and 3) who requests and applies their use among older adults with cognitive impairment receiving nursing care at home.

Design

Cross- sectional study.

Setting

Homes of older adults receiving nursing care from district nurses in the eastern part of Belgium.

Participants

Data were collected from 1,194 randomly selected older adults with cognitive impairments receiving nursing care at home (mean age 83; 67% female).

Method

District nurses completed an online questionnaire for each selected older adult in their caseload. Involuntary treatment was measured using a questionnaire identifying use of physical restraints, psychotropic medication and non-consensual care. In addition who requests involuntary treatment and who applies it was examined. Older adults sociodemographic characteristics, diag-

nosis of dementia, activities of daily living (ADL), cognitive status and informal caregiver burden were assessed.

Results

Involuntary treatment was used in 52% (95%; CI 49–55) of the total sample. Non-consensual care was most often used (73%; 95% CI 70–77), followed by psychotropic drugs (43%; 95% CI 39–47) and physical restraints (38%; 95% CI 35–42). The use of involuntary treatment was associated with dependency for activities of daily life (OR 1.50; 95% CI 1.33–1.69), cognitive impairment (1.39; 95% CI 1.25–1.55), informal caregiver burden (OR 1.05; 95% CI 1.01–1.10) and aging (OR 0.97; 95% CI 0.95–0.99). Informal caregivers (71%), followed by general practitioners (47%) most frequently requested the use of involuntary treatment, and nurses (81%) mostly applied it.

Conclusion

In Belgium, involuntary treatment is often used in older adults with a cognitive impairment receiving nursing care at home. The implication of this study for clinical practice is that it confirms the need to develop an approach to prevent and reduce it. Further research is needed to plan and develop such an approach, in order to prevent and reduce the use of involuntary treatment.

Introduction

Respect for inherent dignity and individual autonomy is a basic principle in health care. This principle justifies the moral rule that health professionals should provide help based on the patient's consent.[1] Therefore, a patient should have a voice in the care he or she receives: 'no decision about me without me'.[2] However, several studies indicate that older care-dependent adults with a cognitive impairment, in both nursing homes and home care, are at risk of receiving care without their consent.[3-7] Several definitions are used to describe this kind of care: coercion care [4], restraint [7] or involuntary treatment.[6] For this study, the term 'involuntary' treatment is used. Involuntary treatment is defined as treatment that professional and informal caregivers provide without the consent of the person receiving the treatment and/or this person resists to.[6] The application and interpretation of involuntary treatment vary from country to country.[8] In the Netherlands, as well as in other West- European countries, regulations to prevent and reduce involuntary treatment are being developed.[6] These regulations, are based on the principle that no treatment may be provided without the consent of the person receiving it.[9] Furthermore, these regulations state that in some conditions involuntary treatment can be applied, but only if a multi-disciplinary step-by-step plan shows that there is no other alternative. Before applying the following measures, physical restraints, psychotropic medication and locking up, this step-by-step plan must be followed regardless of consent, because they are hurtful and greatly restrict the freedom of older adults. For this study, the definition of involuntary treatment is operationalized as the application of:

1) Physical restraints, defined as any action or procedure that prevents 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 that is attached or adjacent to a person's body and that he/she cannot control or remove easily;[10]

2) Psychotropic medication, defined as substances that act directly on the central nervous system, affecting mood, cognition and behaviour;[11]

3) and Non-consensual care, defined as any type of care that limits the organization of a person's own life and to which a person resists to (e.g. locking in a room, use of electronic surveillance, force or pressure in activities of daily living (ADL).[6, 12]

Involuntary treatment has a negative impact on the quality of life of those who are subjected to it. For older adults, involuntary treatment increases the risk of death, falls and serious injury, feeling a loss of dignity, lower self-respect, loss of personal autonomy and feelings of imprisonment, cognitive impairment, ADL-dependency and hospitalizations.[3, 11-13] Additionally, involuntary treatment is also positively associated with informal caregiver burden.[6] For the nursing staff, the request or use of measures of involuntary treatment could lead to burnout and attrition, because they are confronted with an ethical dilemma of freedom versus safety.[14, 15] The reasons why older adults receive involuntary treatment can be various but include the respite of informal caregivers, postpone an admission in a nursing home [7] or for safety reasons (e.g. to prevent falls, wandering or aggressive behaviour). Caregivers do not always have sufficient knowledge about appropriate safety interventions or who to apply them. As a result safety measures (e.g. sedatives) could be incorrectly applied, applied for too long or applied for the wrong reasons.[16, 17] Furthermore, evidence that home safety interventions are effective to prevent falls are inconclusive for adults with cognitive impairment living at home.[18] For these reasons, the emphasis of the concept involuntary treatment in our study lies on its inappropriateness rather than the lack of the consent of the older adult. It is therefore important that, before involuntary treatment is applied, this is thoroughly discussed with all caregivers involved, so that recommendations can be proposed to prevent and reduce it.

In the field of home care, research about involuntary treatment is scarce and only recently first studies have been conducted.[3, 6, 7] There is only one study investigating the prevalence of involuntary treatment among cognitive impaired older adults at home.[6] The studies of Beerens, Sutcliffe [3] and Scheepmans, Dierckx de Casterlé [7] focus on the prevalence of certain aspects of involuntary treatment such as physical restraint or psychotropic medication. The study Hamers, Bleijlevens [6] showed that in a Dutch sample of 837 persons with cognitive impairment receiving professional care at home, 39% received involuntary treatment. If involuntary treatment was applied, measures of non-consensual care (79%) was most commonly used on older adults, followed by psychotropic medication (41%) and physical restraints (7%). Caregiver burden, greater ADL dependency, poorer cognitive ability, living alone and having a formal diagnosis of dementia are factors that were strongly associated with involuntary treatment. In Western countries, the prevalence of these factors is growing, due to demographic and socio-economic evolutions.[19, 20] For these reasons the risk of the application of involuntary treatment will increase in the coming years. Therefore, it is necessary to gain more insight into its application, so we can prevent and reduce it. Because research about involuntary treatment is recent and scarce,[6] we do not have enough insight to draw conclusions about its prevalence, which factors are associated with its application and who requests and uses it. To generalize previous research, it is necessary to gain an insight into the use of involuntary treatment in other countries. These insights will help caregivers and researchers to develop interventions to prevent and reduce its use.

The objective of this study was to gain an insight into the use of involuntary treatment among older adults with cognitive impairment receiving nursing care at home, in Belgium. The following research questions will be answered:

1) What is the prevalence of the use of involuntary treatment?
2) Which of the observed factors are associated with the use of involuntary treatment?
3) Who requests the use of involuntary treatment and who applies it?

Methods

Design

A cross-sectional survey was conducted in the eastern part of Belgium. Data were collected from April to July 2017.

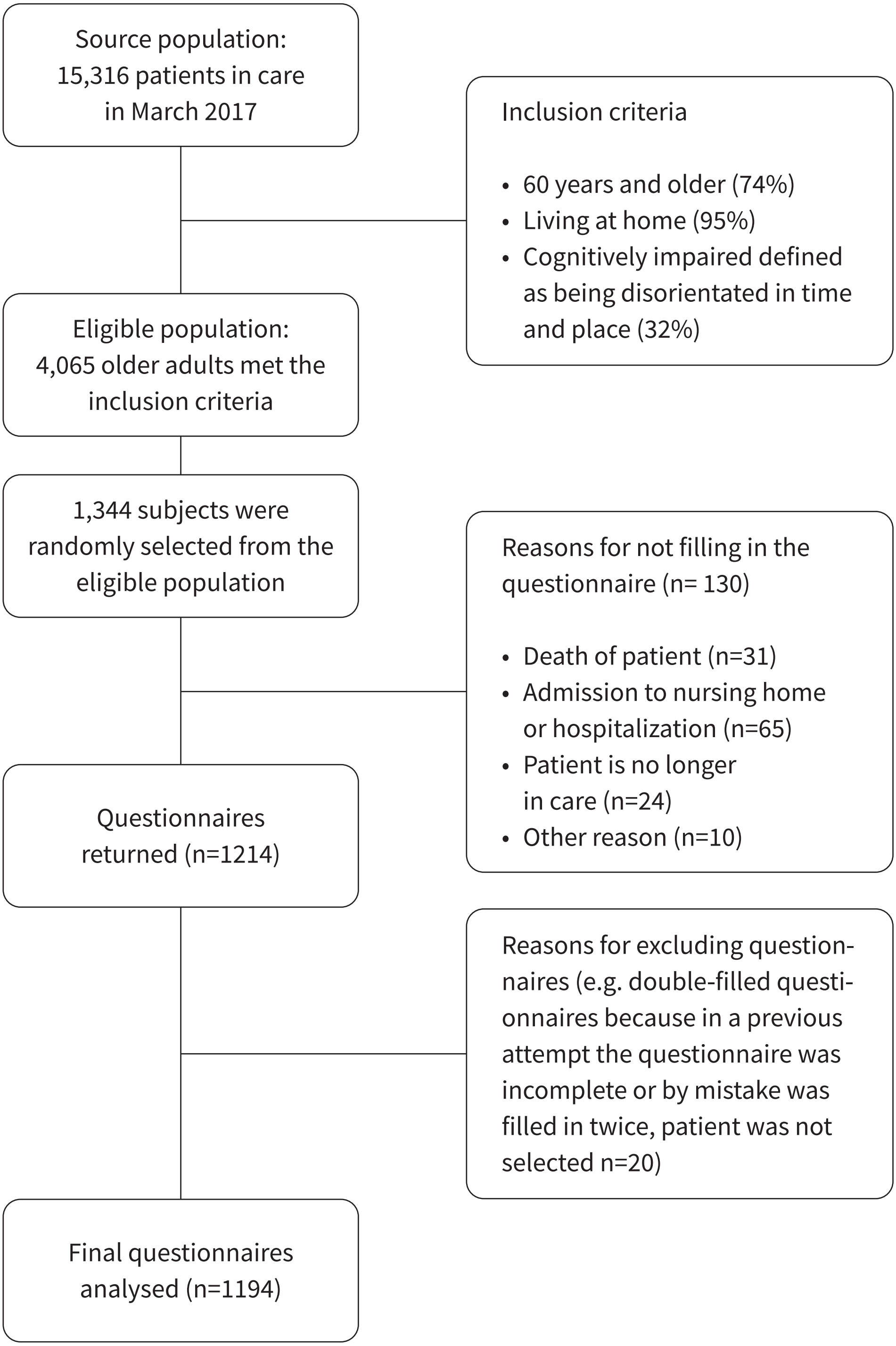
Study setting

The study was conducted in a home nursing organization that provides professional nursing care at home, in the eastern part of Belgium. The home nursing organization comprises 28 regional nursing departments. A regional nursing department comprises 20 to 27 districts. The number of patients in each regional department and district were approximately equal. Every district has a team, comprised of a responsible district nurse, assisted by permanent district nurses to ensure 24/7 care continuity. In Belgium, district nurses are mostly registered nurses with a bachelor's degree or an associate degree.[15] The district team is responsible for planning, coordinating, performing and evaluating the care in their district.

Sample

The participants of this study were older adults who met the following inclusion criteria: 1) being 60 years or older; 2) having a cognitive impairment, defined as having a score of 2 or more on the items disorientation in time and place of the Weckx scale [21] 3) living at home; and 4) receiving professional nursing care at home. In this study the older adult could have a cognitive impairment due to several reasons, such as diagnosis of dementia, cardiovascular problems, brain tumour, stroke, alcohol or drug addiction. Exclusion criterion was: living in a residential care setting. In March 2017, the home health-care organization had 15,316 persons in care. A total of 4,065 of them met the inclusion

Figure 1. Study flowchart.



criteria. Based on a sample size calculation with an assumed prevalence rate of between 30 and 40% [6], a 95% confidence interval (CI) and a half width of 0.3, a sample size of 1,200 older adults receiving home care was calculated. Because a 10 per cent non-response rate was expected, 1,344 older adults were needed. The older adults were selected from the existing database of the home healthcare organization. In order to distribute the workload of the research across the 28 regional departments, the 1,344 older adults were evenly distributed over the regional departments. The participants were then randomly selected per regional department using Microsoft Excel®.

Data collection

In total, 578 responsible district nurses were asked to complete a questionnaire, using the online tool SurveyMonkey®, for each selected older adult in their caseload. The average number of questionnaires per district nurse was 2.3 (SD = 1.3).

The procedure was as follows: 1) Before the start of the data collection, the district nurses and their head nurses were informed about the study by the principal researcher (VM) during meetings and by email; 2) All information (manual, example questionnaire, information letters, frequently asked questions, list of the included patients per department) about the research was shared using an online platform; 3) To complete the questionnaire, the responsible district nurse used information from the patient records and information received from the district team during weekly meetings; 4) To help the nurses fill in the questionnaire, there was a manual. In this manual, each question and measure of involuntary care was in detail described. If the measure that was applied matched the description in the manual, the nurse indicated this; 5) On the list per department, the district nurse recorded when a questionnaire was filled in or the reason when it could not be filled in. All lists of completed questionnaires vis-à-vis target sample size were integrated into a general online overview of the state of affairs; 6) By weekly checking, this overview and the database of the online survey tool, the principal researcher (VM) could monitor the progression of the survey, 6) If the progression of the survey was not according to schedule, the researcher contacted the head nurse and discussed actions for improvement.

The district nurses had 10 weeks to complete the questionnaires. No incentives were given to the district nurses for filling in the questionnaires. When the responsible district nurse of the selected patient could not complete the questionnaire, due to sickness, vacation or other reasons, another district nurse of the district team who knew the older adult completed the questionnaire.

Measurements

Involuntary treatment

The primary outcome of the study was involuntary treatment, including physical restraints, psychotropic medication, and non-consensual care. Our questionnaire is based on the questionnaire that was developed by Hamers, Bleijlevens.[6] Table 1 presents the measures that were included in this study. The measures regarding physical restraint were based on the definition of Bleijlevens, Wagner.[10] For psychotropic drugs, a detailed list was composed in collaboration with a pharmacist based on the Anatomical Therapeutic Chemical Classification of the drugs that are prescribed in Belgium. Using this list, the nurse reviewed the medication list in the patient records to determine whether psychotropic medication was used, and if so, which kind. In our study we included psychotropic drugs as measures of involuntary treatment, for the following reasons: 1) older adults are vulnerable to adverse effects of psychotropic medication (e.g. memory impairment, psychomotor slowing, delirium, falls with a risk of hip fracture, psychiatric hospitalization); 2) there is little evidence of the effectiveness of psychotropic drugs in relation to the reasons they are used among older adults; 3) studies indicate that psychological well-being of the older adult is not the principal reason that psychotropic drugs are prescribed.[11] Due to practical reasons, only the appropriateness for antipsychotic medication was determined. If the older adult had a formal diagnosis of delirium, schizophrenia and/or psychosis, the use of antipsychotics was recorded as appropriate [22]. The measures regarding non-consensual care were based, on the measures used in the study of Hamers, Bleijlevens,[6] it concerns measures that limit the organization of a person's own life and to which a person resists to.

Table 1. Use of involuntary treatment in older adults receiving nursing care at home

Types of Involuntary Treatment	Number of measures [1]	% (n = 625) [2]
Physical restraints		
Waist belt in a (wheel)chair	16	2.6
Waist belt in bed	4	0.6
Wrist or ankle ties	1	0.2
Chair with fixed tray table	22	3.5
Deep, overturned, or reclined chair [a]	27	4.3
Measures to prevent leaving the chair [b]	47	7.5
Locked (wheel)chair	78	12.5
Bilateral fully enclosed bedrails [c]	183	29.3

Special sheet [d]	6	1.0
Sleep suit [e]	2	0.3
Restraint vest	1	0.2
Gloves [f]	49	7.8
Psychotropic medication		
Antidepressants	163	26.1
Anti-epileptic	29	4.6
Anti-psychotics	80	12.8
Anxiolytics	42	6.7
Hypnotics – sedatives	101	16.2
Non-consensual care		
Forced or camouflaged medication administration	57	9.1
Hiding medication [g]	160	25.6
Forced food or fluid intake	40	6.4
Forced hygiene [h]	173	27.7
Restricting communication [i]	50	8.0
Locking older adult in house [j]	77	12.3
Separation in another room without locking	164	26.2
Inappropriate clothing [k]	17	2.7
Electronic supervision [l]	37	5.9
Shutting off gas or electricity [m]	5	0.8
Restricting transportation [n]	48	7.7
Removing walking aids	3	0.5

[1] Multiple measures could be used with one older adult, so percentages do not add to 100.

[2] Percentage of the measures is calculated in relation to the 625 people who received involuntary treatment.

[a] Chair preventing from getting up.

[b] Chair with legs fixed on a board and setting chair against table to prevent leaving it.

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

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

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

[f] Gloves that prevent an older adult from picking up objects.

[g] Hiding away all types of medication to prevent access to own medication.

[h] Forced hygiene or restraint during hygienic care.

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

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

[k] For instance, not dressing an older adult to prevent them leaving the house, reversing a belt or trouser to prevent an older adult undressing them self

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

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

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

Involuntary treatment that included at least one measure as described above, and that was used at least once during the previous 30 days, was recorded as absent (0) or present (1). Finally, the persons who asked and applied involuntary treatment were recorded. These persons are listed in Table 2.

Table 2. Persons involved with the request and application of involuntary treatment in older adults receiving nursing care at home

Person	**Request** [1]	**Application** [1]
	n (%)	n (%)
Older adult	69 (11)	
Informal caregiver	443 (71)	416 (67)
Nurse / nursing aide	271 (43)	504 (81)
Domestic aide	29 (5)	33 (5)
General practitioner	292 (47)	86 (14)
Physician specialist	25 (4)	23 (4)
Physiotherapist	13 (2)	
Occupational therapist	1 (0)	
Social worker	12 (2)	
Neighbour	2 (0)	
I do not know	15 (2)	7 (1)

[1] Multiple persons could be involved in by the request and application of involuntary treatment by with one person, therefore percentages do not add up to 100% and so more than 625 persons were involved in the request or application of involuntary treatment.

A category labelled 'other' was added for each question, allowing the district nurses to list additional measures or persons. Multiple answers were possible for all the above questions.

Associated factors

The sociodemographic characteristics gathered in this study population were gender, age in years and living situation (alone or not alone).

To assess functional dependency and cognitive ability, two subscales (Activity of Daily Living Hierarchy (ADL-H) and Cognitive Performance Scale (CPS)) from the Inter Resident Assessment Instrument Home Care Belgium (InterRAI HC) [23] were used.

ADL-H Scale measures the ADL performance and classifies ADL performance according to the stages at which they can no longer be performed. Based on four ADL items (i.e. personal hygiene, toilet use, mobility, and eating), an algorithm was used to compute a 7-point scale, ranging from independent (0) to totally dependent (6).[24]

The Cognitive Performance Scale (CPS) has a predictive algorithm based on a decision tree. It used four items: short-term memory; decision-making; expression; and self-performance in eating. The result was a 7-point scale where scores ranged from intact (0) to very severely impaired (6).[25]

In order to determine whether the older adult had a formal diagnosis of dementia or not, the district nurse checked the patient record to see whether a physician (for example a general practitioner or psychiatrist) had determined the diagnosis of dementia.

Finally, to assess informal caregiver burden we used the Self-Perceived Pressure from Informal Care Scale (SPPIC) (range 0–9). A high score indicates a higher perceived informal caregiver burden.[26] In the context of standard data collection to determine care goals, this scale had already been filled in by the informal caregiver and this information was therefore available in the patient record.

Ethical approval

The Social and Societal Ethics Committee, one of the Medical Ethics Committees of the Leuven University Hospitals approved the study protocol on 23 February 2017 (G- 2017 03 794).

Data analysis

To describe the prevalence of involuntary treatments and who requested and applied it, a descriptive analysis was conducted. Continuous data were expressed in means and standard deviations (SD). Categorical data were expressed in percentages. Percentages were calculated based on the actual number of answers. The prevalence of involuntary treatments was calculated by adding up the scores of all individual measures. If the older adult received at least one measure of involuntary treatment, they scored present (1); if no measures were used they scored absent (0). This was also done for the prevalence of physical restraints, psychotropic medication and non-consensual care.

To compare the characteristics of persons with and without involuntary treatment, independent-sample t-tests were used for the continuous variables (age, ADL-H, SPPIC, CPS-score) and chi-square tests for categorical variables (gender, living situation and diagnosis of dementia). Two-tailed tests with a significance of $P< 0.05$ were used. If there was no informal caregiver present, the question regarding informal care pressure (SPPIC-score) was omitted. If the SPPIC-score was missing, pairwise deletion was used for handling this missing data. The other questions were drafted in such a way that no questions could be omitted and so missing data were prevented.

To gain insight into the associated factors a random intercept logistic regression with regional departments as a second level random factor was conducted. This method was used to correct regional department differences.[27] All associated factors (age, CPS-score, ADL-H, SPPIC, gender, living situation and diagnosis of dementia) were included as independent variables and the application of at least one measure of involuntary treatment (present, absent) as the dependent variable. A backward procedure was performed. Factors with $P > .10$ were removed one by one, with the least contributing factor being removed first. The significance of each estimated model parameter was tested with a significance level of $p < 0.05$. We used SPSS, version 24 (SPSS, Inc., Chicago, IL).

Results

Sample

Figure 1 shows that a total of 1,344 older adults were selected for this study and for each of them a questionnaires had to be filled in. A total of 130 questionnaires were not returned due to various reasons and 20 were excluded. All other questionnaires (n=1,194) were included for analysis. The majority of the older adults were women (67%, n=798); mean age was 83 years (SD 7.9). For 74 (6%) older adults, there was no informal caregiver present. Table 3 shows the characteristics for the whole sample and for the two groups older adults receiving and not receiving involuntary treatment.

Involuntary Treatment

In total, 1,639 individual measures of some type of involuntary treatment were used in 625 older adults (52%, confidence interval (CI) = 0.49–0.55) of the total sample. Table 1 provides an overview of all involuntary treatment measures used. Most often (38%), one measure of involuntary treatment was used. In 24% of the cases two measures were used, followed by four or more (20%), and lastly, three (18%) individual measures.

In 52% of the total sample (n-625) one or more involuntary treatment measures were applied. In 240 out of those 625 persons (38%, 95% CI = 0.35–0.42) a physical restraint measure was used. In 115 older adults, two or more different physical restraints were used. In total, 270 older adults (43%, 95% CI = 0.39–0.47) received some type of psychotropic drugs. In 101 older adults, two to three different types of psychotropic drugs were used. In 1 older adult five different types of psychotropic drugs were used. In 22 of 80 older adults (27.5%) who received anti-psychotic drugs there was no diagnosis of schizophrenia, delirium or psychosis. In total, 831 measures of non-consensual care were used in 457 older adults (73%, 95 CI = 0.70–0.77). In 195 older adults, two to four and in 17 older adults five or more different measures of non-consensual care were used.

Factors associated with involuntary treatment

Table 3 shows the results of the unadjusted analyses. Involuntary treatment was more likely to be applied with persons who were of a younger age, formally diagnosed with dementia, lived together and had a poorer cognitive ability, higher ADL-dependency and an informal caregiver who perceived a higher burden. Table 4 shows the result of random intercept logistic regression with regional departments as a second level random factor. The risk of involuntary treatment increases with a greater informal caregiver burden, poorer cognitive ability, higher ADL dependency and younger age.

Table 3. Sample characteristics according to involuntary treatment use in older adults receiving nursing care at home

	Overall = 1,194	**Older adults without involuntary treatment n = 569 (47.7%)**	**Older adults with involuntary treatment n= 625 (52.3%)**	**P-value**
Mean age (SD)	82.5 (7.9)	83 (7.4)	82 (8.4)	p = 0.034
Female, n (%)	798 (67)	381 (67)	417 (67)	p = 0.930
Living alone, n (%)	501 (42)	278 (49)	223 (36)	p < 0.001
Dementia diagnosis, n (%)[a]	217 (18)	69 (12)	148 (24)	p < 0.001
Cognitive Performance score, mean (SD) (range 0–6)[b,c]	2.5 (1.7)	2.0 (1.4)	3.1 (1.7)	p < 0.001
Activity of Living-Hierarchy, mean (SD) (range 0–6)[b,c]	2.8 (1.4)	2.3 (1.3)	3.2 (1.4)	p < 0.001
Self-Perceived Pressure Informal Care scale burden), mean (SD) (range 0–9)[c]	3.7 (3.4)	2.9 (3.2)	4.4 (3.4)	p < 0.001

[a] As recorded in the nursing records and confirmed by a medical doctor.

[b] Subscale of the Resident Assessment Instrument Home Care Belgium.

[c] Lower scores are more favourable.

SD = standard deviation.

Table 4. Characteristics associated with involuntary treatment use in older adults receiving nursing care at home, a two-level logistic regression

Variables in the Equation	**Coefficient**	**Odds Ratio (OR)**	**Standard Error**	**p-value**	**95% CI Odds Ratio**	
					Lower	**Upper**
Diagnosis of dementia	0.335	1.40	0.2	p = 0.094	0.94	2.07
Cognitive Performance Scale score [a]	0.332	1.39	0.054	$p < 0.001$	1.25	1.55
Self-Perceived Pressure from informal care service	0.053	1.05	0.022	p = 0.018	1.01	1.10
Activity of Daily Living – Hierarchy [a]	0.404	1.50	0.061	$p < 0.001$	1.33	1.69
Age of the older adult	-0.032	0.97	-3.41	p = 0.001	0.95	0.99

Intraclass Correlation Coefficient (ICC) = 0.21.
Variable(s) entered in step 1: sex, age in years, living situation, diagnosis of dementia, Self-Perceived Pressure from informal care service (SPPIC), Cognitive Performance Scale score (CPS), Activity of Daily Living – Hierarchy (ADLH).
Dependent variable is involuntary treatment: No = 0, Yes = 1.
[a] Subscale of the Resident Assessment Instrument Home Care Belgium.

Request and application of involuntary treatment

Table 2 shows an overview of who requests and who applies involuntary treatment. Of the 625 older adults who received involuntary treatment, the informal caregiver most frequently asked for the use of involuntary treatment followed by the general practitioner and district nurse.

District nurses mostly applied the involuntary treatment, followed by informal caregivers. Frequently applied measures by informal caregivers were bedrails and placing the bed against the wall (48%; n= 202), for district nurses (43%; n= 217) and general practitioners (72%; n=62) this was giving psychotropic medication. Also, district nurses were mostly involved in preventing leaving the bed (35 %; n= 179), hiding medication (27%; n=138) and forced hygiene (31%; n=157) .

Discussion

This study provided an insight into the use of involuntary treatment among older adults with cognitive impairment receiving nursing care at home, in Belgium. We found that one out of two older adults were subject to at least one measure of involuntary treatment. Factors that were associated with involuntary treatment were informal caregiver burden, ADL-dependency, cognition and age. Informal caregivers most often requested the use of involuntary treatment and the district nurse most often applied it.

The results of our study are in line with previous studies and confirm that involuntary treatment is commonly used in home care. However, the prevalence of involuntary treatment in our study seems to be higher compared to previous studies on home care.[3, 6, 7] Comparing our study results with these studies is difficult, due to differences in the overall sample, health-care systems, culture, characteristics and method. The study by Hamers, Bleijlevens [6] found that involuntary treatment was used in 39% of older adults with a cognitive impairment who were followed up by dementia case managers. The study by Scheepmans, Dierckx de Casterlé [7] found a prevalence of 24% among older adults receiving nursing care at home. In contrast with our study, no psychotropic medication and only a few measures of non-consensual care were included in this study. The European RightTimePlaceCare study [3] found an overall prevalence of 55.9% for the use of psychotropic medication (antipsychotics, anxiolytics, hypnotics/sedatives and antidepressants) and 9.9% for the use of physical restraints among persons with dementia receiving formal home care. But compared to our study, only four measures (belt restraints, locked chair/table, deep/overturned chair, bedrails) were included as physical restraint and anti-epileptic drugs were not included in this study.

In our study, factors strongly associated with involuntary treatment were higher ADL-dependency, poorer cognition and greater informal caregiver burden. This is in line with earlier research in home care and confirms that ADL-dependent older adults with a cognitive impairment living at home are at risk of involuntary treatment.[5, 6, 28] This can be explained by the fact that measures of involuntary treatment are often used to safeguard older adults who are more ADL-dependent and cognitively impaired, from physical harm.[29] Therefore it is important that we can manage the neuropsychiatric symptoms (e.g. aggression, depression) associated with reduced cognitive ability. Research shows that a person-centred care approach can effectively reduce these symptoms and so prevent and reduce involuntary treatment. However this approach must go along with continuous training and education so that all caregivers are motivated to apply it.[30, 31] Furthermore, the study Karlsson, Bleijlevens [32] shows that a trusting relationship, a single point of contact and individualized tailored-made care plan are also key-elements to support cognitive impaired older adults and their informal caregivers.

In agreement with earlier studies, we found that informal caregivers played the most crucial role in requesting involuntary treatment.[6, 7, 29] One reason for this could be that they sometimes experience delivering care as a situation of enduring stress and frustration.[19] Whenever their situation becomes hopeless, they look for solutions to handle this situation. Due to their lack of knowledge of the negative impact of involuntary treatment and adequate care, they often choose it.[17] An additional problem is that informal caregivers are not authorized to apply most of the measures of involuntary treatment (e.g. physical restraints), according to Belgian legislation. In contrast with a previous study,[7] we found a greater involvement of the general practitioner in the request for involuntary treatment. This could be explained by the fact that the general practitioner might focus on the prevention of the informal caregiver's burden and therefore support the request of the informal caregiver for involuntary treatment, or the general practitioner suggests it. The fact that psychotropic drugs were included in this study, and that these must be prescribed by a general practitioner, could also explain a greater involvement of the general practitioner. The Belgian legislation in combination with the fact that receiving nursing care at home was an inclusion criterion could explain the high involvement of the district nurses in the application of involuntary treatment. In Belgium, only registered nurses or general practitioners are authorized to apply most of the measures (e.g. physical restraints, psychotropic medication) that we included as involuntary treatment.

The results of the current study demonstrate that there were several factors associated with the use of involuntary treatment and different caregivers were involved in the request and application of it. For these reasons, we need an approach that is multifactorial. Several studies [33, 34] indicate that a multifactorial approach with the following components: policy, education, consultation and alternatives is effective to reduce physical restraint in nursing homes. Because, if caregivers have the skills and knowledge about alternative methods to protect older adults from harm, there is no reason to apply measures that hurt them.[33] At this moment there are no such studies known in home care. That's why we need to gain more insight into the effect and feasibility of multifactorial approaches to prevent and reduce involuntary treatment at home.

One of the strengths of the current study is the inclusion of a large randomized sample of 1,194 older adults and the high response rate (89%). Therefore, it can be assumed that we have a representative sample of our study population and the risk of selection bias is low. The high response rate (see

Figure 1) demonstrates an accurately performed data collection. However, there are also limitations that need to be mentioned: first, the research was conducted in only one region of Belgium, in which the average ADL-dependency was higher compared to the rest of Belgium [35] and therefore one must be careful generalizing these results. Nonetheless, this study showed that ADL-dependency is strongly related to involuntary treatment. Therefore, it is logical that in a region and regional departments where there is a higher level of ADL-dependency, the prevalence of involuntary treatment will be higher. This fact might also explain the existing variability in the use of involuntary treatment between the regional departments in our study. Furthermore, one can argue whether the measures that are reported should be considered as involuntary treatment or not. In some cases, certain measures do not always have a negative effect and can even increase the freedom of the older adult. For instance, electronic mobile supervision system can reduce the fear of falling and thereby increase the mobility of the older adult. However, involuntary treatment has a negative impact on the quality of life and these examples do not legitimize their automatic use to all older adults in our sample.[6] In contrast to the use and effects of physical restraints, little is known about the use and effect of non-consensual care. We agree that some measures that are listed in table 1 could be in certain conditions appropriate care. However, if a patient openly resists to care and therefore become aggressive, because no proper alternative is provided one can discuss its safety and comfort.[30] Furthermore, caregivers are not always aware that they are providing non-consensual care and appropriate alternatives exist, due to a lack of knowledge. For these reasons, we choose a broad interpretation of the concept of non-consensual care, in order to get sufficient insight into the use of involuntary treatment. Our study found that is the most common form of involuntary treatment. Therefore, further studies should especially focus on the consequences of non-consensual care for the patient and his caregivers. Finally, we included a broad range of psychotropic drugs as involuntary treatment. Although psychotropic drugs are often inappropriate for older adults living at home,[11] in certain cases they could be appropriate. In our study, three out of four older adults received anti-psychotic drugs in the treatment of delirium, schizophrenia or psychosis. As not all psychotropic medication that was included in our study might have been inappropriate, because it was needed for treatment, this could increase the risk of an overestimating of the prevalence of involuntary treatment in our study. However, in 70% of the cases, psychotropic medication was combined with other measures of involuntary treatment. Therefore, it is unlikely that this led to a large overestimation of the prevalence of involuntary treatment.

In conclusion, this cross-sectional study provides more insight into the use of involuntary treatment. We demonstrated that it is common among older adults with a cognitive impairment receiving nursing care at home. The implication of this study for clinical practice is that it confirms the need to develop an approach to prevent and reduce the use of involuntary treatment. Therefore, this information is valuable for nurses and other caregivers who focus on patient-centred care. Further research is needed to plan and develop an approach to change the behaviour of the caregivers involved, in order to prevent and reduce the use of involuntary treatment.

Acknowledgements

We thank the participating district nurses, head nurses and staff of the White Yellow Cross Limburg, in Belgium.

Conflict of interest

None declared.

Funding

No external source of funding.

References

1. Brodtkorb K, Skisland AV-S, Slettebø Å, et al. Ethical challenges in care for older patients who resist help. *Nurs Ethics* 2015; 22: 631-641. DOI: 10.1177/0969733014542672.
2. Joseph-Williams N, Elwyn G and Edwards A. Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns* 2014; 94: 291-309. DOI: 10.1016/j.pec.2013.10.031.
3. Beerens HC, Sutcliffe C, Renom-Guiteras A, et al. Quality of life and quality of care for people with dementia receiving long term institutional care or professional home care: the European RightTimePlaceCare study. *JAMA* 2014; 15: 54-61. DOI: https://doi.org/10.1016/j.jamda.2013.09.010.
4. Gjerberg E, Hem MH, Førde R, et al. How to avoid and prevent coercion in nursing homes: A qualitative study. *Nurs ethics* 2013: 0969733012473012. DOI: https://doi-org.mu.idm.oclc.org/10.1177/0969733012473012.
5. Hamers J and Huizing AR. Why do we use physical restraints in the elderly? *Z Gerontol Geriatr* 2005; 38: 19-25. DOI: https://doi.org/10.1007/s00391-005-0286-x.
6. Hamers JP, Bleijlevens MH, Gulpers MJ, et al. Behind Closed Doors: Involuntary Treatment in Care of Persons with Cognitive Impairment at Home in the Netherlands. *J Am Geriatr Soc* 2016; 64: 354-358. DOI: 10.1111/jgs.13946.
7. Scheepmans K, Dierckx de Casterlé B, Paquay L, et al. Restraint Use in Older Adults Receiving Home Care. *J Am Geriatr Soc* 2017; 65: 1769-1776. DOI: 10.1111/jgs.14880.
8. Wickremsinhe MN. Emergency involuntary treatment law for people with mental disorders: A comparative analysis of legislation in LMICs. *Int J Law Psychiatry* 2018; 56: 1-9. DOI: 10.1016/j.ijlp.2017.09.003.
9. Wet van 24 januari 2018, houdende regels voor het kunnen verlenen van verplichte zorg aan een persoon met een psychische stoornis (Wet verplichte geestelijke gezondheidszorg). 2018.
10. Bleijlevens MH, Wagner LM, Capezuti E, et al. Physical Restraints: Consensus of a Research Definition Using a Modified Delphi Technique. *J Am Geriatr Soc* 2016; 64: 2307-2310. DOI: 10.1111/jgs.14435.
11. Voyer P, Cohen D, Lauzon S, et al. Factors associated with psychotropic drug use among community-dwelling older persons: A review of empirical studies. *BMC Nurs* 2004; 3: 1-13. DOI: 10.1186/1472-6955-3-3.
12. Gastmans C and Milisen K. Use of physical restraint in nursing homes: clinical-ethical considerations. *J Med Ethics* 2006; 32: 148-152. DOI: 10.1136/jme.2005.012708.

13. Hofmann H and Hahn S. Characteristics of nursing home residents and physical restraint: a systematic literature review. *J Clin Nurs* 2014; 23: 3012-3024. DOI: 10.1111/jocn.12384.
14. Pijl-Zieber E, Hagen B, Armstrong-Esther C, et al. Moral distress: an emerging problem for nurses in long-term care? *Qual Ageing* 2008; 9: 39-48. DOI: doi.org/10.1108/14717794200800013.
15. Scheepmans K, Dierckx de Casterlé B, Paquay L, et al. Restraint use in home care: a qualitative study from a nursing perspective. *BMC Geriatr* 2014; 14: 1-7. DOI: 10.1186/1471-2318-14-17.
16. Lach HW and Chang Y-P. Caregiver perspectives on safety in home dementia care. *West J Nurs Res* 2007; 29: 993-1014. DOI: 10.1177/0193945907303098.
17. Kurata S and Ojima T. Knowledge, perceptions, and experiences of family caregivers and home care providers of physical restraint use with home-dwelling elders: a cross-sectional study in Japan. *BMC Geriatr* 2014; 14: 1-11. DOI: 10.1186/1471-2318-14-39.
18. Stubbs B, Brefka S and Denkinger MD. What works to prevent falls in community-dwelling older adults? Umbrella review of meta-analyses of randomized controlled trials. *Phys Ther* 2015; 95: 1095-1110. DOI: https://doi-org.mu.idm.oclc.org/10.2522/ptj.20140461.
19. Etters L, Goodall D and Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Assoc Nurse Pract* 2008; 20: 423-428. DOI: https://doi-org.mu.idm.oclc.org/10.1111/j.1745-7599.2008.00342.x.
20. Koller D, Schön G, Schäfer I, et al. Multimorbidity and long-term care dependency—a five-year follow-up. *BMC geriatr* 2014; 14: 70. DOI: https://doi.org/10.1186/1471-2318-14-70.
21. Lepeleire J, Paquay L and Jacobs M. De verschillende schalen voor ADL-activiteiten voor volwassen in de Vlaamse gezondheidszorg. *Huisarts nu* 2005; 34: 11.
22. Halfens R, Meijers RJG, Meesterberends E, et al. Landelijke prevalentiemeting zorgproblemen: Rapportage resultaten 2015. *Maastricht: Universiteit Maastricht* 2016.
23. FOD Volksgezondheid Veiligheid van de Voedselketen en Leefmilieu. BelRAI - Een uniforme en web based (online) registratie van interRAI-beoordelingsinstrumenten, https://www.ehealth.fgov.be/nl/application/applications/BELRAI.html (2016, accessed 19-11-2016 2016).
24. Morris JN, Fries BE and Morris SA. Scaling ADLs within the MDS. *J Gerontol* 1999; 54: M546-M553. DOI: https://doi-org.mu.idm.oclc.org/10.1093/gerona/54.11.M546.

25. Morris JN, Howard EP, Steel K, et al. Updating the cognitive performance scale. *J Geriatr Psychiatry Neurol* 2016; 29: 47-55. DOI: https://doi-rg.mu.idm.oclc.org/10.1177/0891988715598231.
26. Pot A. Family caregiving to older adults (side study) Self-perceived pressure from informal burden, http://www.lasa-vu.nl/themes/care/burden-informal-caregiver.html (2017).
27. Snijders T and Bosker R. *Multilevel analysis. An introduction to basic and advanced multilevel modeling., 2nd edition.* Los Angeles: Sage, 2012.
28. Scheepmans K, Dierckx de Casterlé B, Vanbrabant K, et al. Factors associated with use of restraints on older adults with home care: A secondary analysis of a cross-sectional survey study. *Int J Nurs Stud* 2017; 89: 39-45. DOI: https://doi.org/10.1016/j.ijnurstu.2018.07.019.
29. De Veer AJ, Francke AL, Buijse R, et al. The use of physical restraints in home care in the Netherlands. *J Am Geriatr Soc* 2009; 57: 1881-1886. DOI: https://doi-Org.mu.idm.oclc.org/10.1111/j.1532-5415.2009.02440.x.
30. Konno R, Kang HS and Makimoto K. A best-evidence review of intervention studies for minimizing resistance-to-care behaviours for older adults with dementia in nursing homes. *J Adv Nurs* 2014; 70: 2167-2180. DOI: https://doi-org.mu.idm.oclc.org/10.1111/jan.12432.
31. Kim SK and Park M. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clin Interv Aging* 2017; 12: 381-397. DOI: 10.2147/CIA.S117637.
32. Karlsson S, Bleijlevens M, Roe B, et al. Dementia care in European countries, from the perspective of people with dementia and their caregivers. *J Adv Nurs* 2015; 71: 1405-1416. DOI: https://doi-org.mu.idm.oclc.org/10.1111/jan.12581.
33. Lan S-H, Lu L-C, Lan S-J, et al. Educational intervention on physical restraint use in long-term care facilities–Systematic review and meta-analysis. *Kaohsiung J Med Sci* 2017; 33: 411-421. DOI: 10.1016/j.kjms.2017.05.012.
34. Gulpers MJ, Bleijlevens MH, Ambergen T, et al. Belt restraint reduction in nursing homes: effects of a multicomponent intervention program. *J Am Geriatr Soc* 2011; 59: 2029-2036. DOI: https://doi-org.mu.idm.oclc.org/10.1111/j.1532-5415.2011.03662.x.
35. Cloots H, De kind H and Smets H. Zorgzwaarte in de thuisverpleging. In: gezondheid Aze, (ed.). Brussel: Vlaamse overheid, 2017.

CHAPTER 3

—

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

This chapter was published as:

Mengelers A.M.H.J., **Moermans V.R.A.**, Bleijlevens M.H.C., Verbeek H.,
Capezuti E., Tan F.E.S. Milisen K. & Hamers J.P.H. (2020).
Involuntary treatment in dementia care at home: Results from the Netherlands and Belgium. Journal of Clinical Nursing.
DOI: 10.1111/jocn.15457.

Abstract

Aims and objectives

To gain insight into the request, use and associated factors of involuntary treatment in persons living with dementia (PLWD) receiving professional home care in the Netherlands and Belgium.

Background

Most of the PLWD 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 PLWD in their caseload. This study included data of 627 PLWD 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 PLWD (50.7%) living at home received involuntary treatment (Belgium 68.2% and the Netherlands 44.7%). Non-consensual 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 PLWD, which is in line with pre-

vious 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.

Relevance to clinical practice

To provide person-centred care, it is important to study ways to prevent involuntary treatment in PLWD and to stimulate dialogue between professional and family caregivers for alternative interventions.

Introduction

With the ageing population, dementia is a significant healthcare challenge worldwide.[1, 2] Dementia is a clinical syndrome characterized by progressive cognitive and functional impairment. Most persons living with dementia (PLWD) 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).[2-4] As a result, PLWD experience difficulties expressing their needs and wishes, which can lead to restless behaviour or restiveness to care.[5] Dealing with these symptoms and changes can be very challenging for PLWD and their caregivers.[3, 6] The majority (70%) of PLWD age in place and wish to stay home as long as possible, where they feel comfortable and safe.[7] Most Western countries support this by an active 'Ageing in place' policy.[8] However, maintaining PLWD 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.[4] Multiple studies have shown that many family caregivers experience stress, frustration and/or high caregiver burden.[3, 6, 9, 10] The needs for care can differ between PLWD 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 PLWDs' quality of life.[11, 12] 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,[13] coercion,[14] resistiveness to care [5, 15] and involuntary treatment. [11, 12, 16] In this study, measures to which the client resists and/or does not provide consent for are defined as involuntary treatment. Involuntary treatment includes 1) physical restraints, defined as "any action or procedure that prevents 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 that is attached or adjacent to a person's body and that he/she cannot control or remove easily",[17] 2) psychotropic medication, defined as "drugs that act directly on the central nervous system, affecting mood, cognition and behaviour",[12, 18] and 3) non-consensual 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).[11, 19]

Background

Caregivers may use involuntary treatment because they believe that these measures can prevent falls, wandering and aggressive behaviour [20] or postpone nursing home admission.[13] Another reason for caregivers to use involuntary treatment is to respite from other caregiving activities.[21] 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.[22] Involuntary treatment is associated with negative effects including aggression, agitation[23] and even injuries.[24, 25] Involuntary treatment is also in conflict with the values of person-centred dementia care that emphasizes high-quality, individualized interpersonal care, which incorporates recognition, respect and trust.[26] 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.[11, 12, 16] With the growing population of PLWD 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 PLWD.

This study aimed to gain insight into involuntary treatment use in PLWD, 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 PLWD.

Methods

Sampling and setting

We conducted secondary data analyses of two cross-sectional surveys: one study conducted in the south of the Netherlands[11] and one study conducted in the eastern part of Belgium.[12] 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 and July 2014 and in Belgium between April and 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 PLWD 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.[27, 28] 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,[29] an independent professional caregiver, often with a nursing background, who coordinates the care for PLWD. 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.[30] In both countries the organization 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 organization (White Yellow Cross).

Measures

The primary outcome of this study was involuntary treatment use, consisting of physical restraints, psychotropic medication and non-consensual 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.[31, 32] 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 PLWD in their caseload.[11, 12] No incentives were provided for participating in this study.

Table 1. Involuntary treatments used

	The Netherlands (n=627)	Belgium (n=217)	Total (n=844)
Types of involuntary treatment †,‡ *Number of measures (number of PLWD receiving the measure, percentage in relation to PLWD 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%**)
Non-consensual 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

† Number of measures (number of PLWD 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.

[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.

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 PLWD. To assess functional and cognitive ability, two subscales (Activity of Daily Living Hierarchy (ADLH)) and Cognitive Performance Scale (CPS)) from the Resident Assessment Instrument Minimum Data Set (RAI-MDS) in the Netherlands [33] and the Inter Resident Assessment Instrument Home Care Belgium (InterRAI HC) In Belgium.[34] 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) to 6 (totally dependent). The CPS addresses short-term memory, decision-making, making oneself understood, coma and eating dependency. Scores range from 0 (intact) to 6 (very severe impairment).[35] Finally, the Self-Perceived Pressure from Informal Care Scale (SPPIC) was used to assess family caregiver burden. Scores range from 0-9 with a higher score indicating greater perceived burden.[36] 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 (Supplementary File 1).[37]

Ethics

The Dutch study was exempt from human subjects review because only anonymous data from health records were used.[11] The Belgium study was reviewed and approved by an institutional review board.[12]

Statistical analysis

The prevalence of involuntary treatment was calculated by adding the scores of all individual measures reported and dichotomized as 0 (absent) or 1 (present). The same procedure was used to calculate the prevalence of physical restraints, psychotropic medication and non-consensual 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 $P > 0.10$ were removed one by one, with the least contributing factor being removed first. All analyses were conducted with SPSS, version 25 (SPSS, Inc, Chicago, IL). A P-value ≤ 0.05 was considered statistically significant.

Results

Sample

Analyses were conducted of a total sample of 844 people with a formal diagnosis of dementia. The sample consisted of 627 PLWD receiving professional home care in the Netherlands and 217 in Belgium. The mean age was 82.0 (SD 6.7), ranging from 51 to 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.

Table 2. Sample characteristics

Variable	The Netherlands	Belgium	Total	P-value
	n = 627	n = 217	n=844	
Age, mean (SD)	81.5 (6.8)	83.4 (6.4)	82.0 (6.7)	<0.001
Women, n (%)	366 (58.4%)	141 (65.0%)	507 (60.1%)	0.002
Living alone, n (%)	292 (46.6%)	57 (26.3%)	349 (41.4%)	<0.001
Cognition †, mean (SD) median (25th, 75th percentile)	3.2 (1.3)	4.0 (1.4)	3.4 (1.3)	<0.001
	3 (2, 4)	5 (3, 5)	3 (2, 5)	
ADL ‡, mean (SD) median (25th, 75th percentile)	1.8 (1.3)	3.2 (1.3)	2.1 (1.5)	<0.001
	2 (1,3)	3 (3, 4)	2 (1, 3)	
Caregiver burden §, mean (SD) median (25th, 75th percentile)	6.1 (2.6)	5.0 (3.2)	5.8 (2.8)	<0.001
	7 (4, 8)	5 (2, 8)	6 (4, 8)	

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

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%) PLWD. The majority of PLWD received one (n=200), two (n=99) or three (n=69) involuntary treatments. In two PLWD, 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 non-consensual 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 = 0.047). Non-consensual 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%).

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 = 0.011), higher ADL dependency (OR = 1.33, 95% CI 1.16-1.53, P-value < 0.001), lower cognitive ability (OR = 1.71, 95% CI 1.47-1.97, P-value <0.001), greater family caregiver burden (OR = 1.08, 95% CI 1.02-1.15, P-value = 0.013) and receiving home care in Belgium (OR = 1.65, 95% CI 1.01-2.69, P-value = 0.047). There was no evidence supporting that age and gender were associated with involuntary treatment use (P-value of 0.70 and 0.95 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 0.105. The differences between regions were not greater than the differences within regions. Although the ICC value was small according to Cohen (1988) 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.[38]

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)	0.011
Cognitive status ‡	0.53 (0.08)	1.71 (1.47 - 1.97)	<0.001
ADL dependency §	0.29 (0.07)	1.33 (1.16 - 1.53)	<0.001
Informal caregiver burden ¶	0.08 (0.03)	1.08 (1.02 – 1.15)	0.013
Country ††	0.50 (0.25)	1.65 (1.01 – 2.69)	0.047

Intraclass Correlation Coefficient (ICC) = 0.05.
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).

Request and use of involuntary treatment

Of the 428 PLWD 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.

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%)	(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%.

Discussion

Involuntary treatment is common practice in PLWD receiving professional home care. In one out of two PLWD at least one measure of involuntary treatment was used. In both the Netherlands and Belgium non-consensual 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 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 PLWD 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% to 52% in Belgium [12, 21] and 39% in the Netherlands.[11] This clearly indicates that PLWD 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. [11, 12, 21] Due to impaired cognitive and functional ability the neuropsychiatric symptoms of dementia,[3] caring for a PLWD has a great impact on the family caregivers, who may experience the care as a situation of long-lasting frustration and stress.[6] The implementation of person-centred care is effective in decreasing neuropsychiatric symptoms in PLWD, thereby increasing their quality of life [39] 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.[11, 12, 21] Involuntary treatment use is mostly requested by 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.[13] In addition, according to Belgian legislation only registered nurses or general practitioners are authorized to use most measures (e.g. physical restraints, psychotropic medication) that we refer to as involuntary treatment.[12] 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.[16] Family caregivers have different ethical perspectives and attitudes towards involuntary treatment: they find physical restraints and non-consensual care less restrictive for PLWD and feel more comfortable using these measures compared to nursing staff.[16] 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.[16, 40]

Providing care for a PLWD is often a task that continues day and night and puts a lot of pressure on family caregivers, who often feel highly burdened.[3, 6] 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.[20, 41] 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.[23, 39] Other key elements to support PLWD and their caregivers are a trusting relationship, one single point of contact (e.g. dementia case manager) and a tailored care plan.[42]

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, differences in the organization of health care between these two countries [43] should be studied to investigate its effect on involuntary treatment use. All PLWD from the Dutch sample were selected via the dementia case manager, while in Belgium they were selected by nurses from the home care organization, 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 PLWD and their family caregiver and provides emotional guidance and support.[44] 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 PLWD 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 generalizing 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 organization’s policy or regulations regarding involuntary treatment use. Participants in the Netherlands were included by dementia case managers, 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 are that data on involuntary treatment use was collected in the same way in both countries, by a questionnaire filled in by professional caregivers for PLWD 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 PLWD (n = 844), who are particularly at risk for involuntary treatment use.[45]

Conclusions

Involuntary treatment is often used in PLWD 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 PLWD 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.

Relevance To Clinical Practice

Involuntary treatment is commonly used in PLWD 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 PLWD, it occurs in other settings, including hospitals [46, 47] or nursing homes [14, 31, 48] and in other people in need of care too, including mental health care [49, 50] and care for people with intellectual disabilities.[51] 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 individualized 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.

Author Contributions

Data collection: VM, HV, JH and MB; data analysis under supervision of FT: AM and VM; data interpretation and discussion with all other authors: AM and VM; and draft of the manuscript: AM. All authors were involved in the development of the research protocol, and all other authors provided feedback and approved the final version.

References

1. Prince M, Bryce R, Albanese E, et al. The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's & Dementia* 2013; 9: 63-75. e62. DOI: https://doi.org/10.1016/j.jalz.2012.11.007.
2. Wu Y-T, Fratiglioni L, Matthews FE, et al. Dementia in western Europe: epidemiological evidence and implications for policy making. *The Lancet Neurology* 2016; 15: 116-124. DOI: https://doi.org/10.1016/S1474-4422(15)00092-7.
3. Ballard C and Corbett A. Management of neuropsychiatric symptoms in people with dementia. *CNS drugs* 2010; 24: 729-739. DOI: 10.2165/11319240-000000000-00000.
4. Unson C, Flynn D, Glendon MA, et al. Dementia and caregiver stress: An application of the reconceptualized uncertainty in illness theory. *Issues in mental health nursing* 2015; 36: 439-446. DOI: https://doi-org.mu.idm.oclc.org/10.3109/01612840.2014.993052.
5. Galik E, Resnick B, Vigne E, et al. Reliability and Validity of the Resistiveness to Care Scale Among Cognitively Impaired Older Adults. *J Am Med Dir Assoc* 2017; 18: 59-64. DOI: 10.1016/j.jamda.2016.08.008.
6. Etters L, Goodall D and Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Academy of Nurse Practitioners* 2008; 20: 423-428. DOI: https://doi-org.mu.idm.oclc.org/10.1111/j.1745-7599.2008.00342.x.
7. Morley JE. Aging in place. Journal of the American Medical Directors Association 2012; 13: 489-492. DOI: https://doi.org/10.1016/j.jamda.2012.04.011.
8. Afram B, Verbeek H, Bleijlevens MH, et al. Predicting institutional long-term care admission in dementia: a mixed-methods study of informal caregivers' reports. *Journal of advanced nursing* 2015; 71: 1351-1362. DOI: https://doi-org.mu.idm.oclc.org/10.1111/jan.12479.
9. Bleijlevens MH, Stolt M, Stephan A, et al. Changes in caregiver burden and health-related quality of life of informal caregivers of older people with Dementia: evidence from the European RightTimePlaceCare prospective cohort study. *Journal of advanced nursing* 2015; 71: 1378-1391.
10. Chiao CY, Wu HS and Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: a systematic review. *Int Nurs Rev* 2015; 62: 340-350. DOI: doi.org/10.1111/inr.12194
11. Hamers JP, Bleijlevens MH, Gulpers MJ, et al. Behind Closed Doors: Involuntary Treatment in Care of Persons with Cognitive Impairment at Home in the Netherlands. *J Am Geriatr Soc* 2016; 64: 354-358. DOI: 10.1111/jgs.13946.
12. Moermans VR, Bleijlevens MH, Verbeek H, et al. The Use of Involuntary Treatment among Older Adults with Cognitive Impairment Receiving Nursing Care

at Home: A Cross-sectional Study. *Int J Nurs Stud* 2018; 88: 135-142. DOI: 10.1016/j.ijnurstu.2018.09.004.

13. Scheepmans K, Dierckx de Casterlé B, Paquay L, et al. Restraint use in home care: a qualitative study from a nursing perspective. *BMC Geriatr* 2014; 14: 1-7. DOI: 10.1186/1471-2318-14-17.
14. Gjerberg E, Hem MH, Førde R, et al. How to avoid and prevent coercion in nursing homes: A qualitative study. *Nursing ethics* 2013: 0969733012473012. DOI: https://doi-org.mu.idm.oclc.org/10.1177/0969733012473012.
15. Spigelmyer PC, Hupcey JE, Smith CA, et al. Resistiveness to care as experienced by family caregivers providing care for someone with dementia. *Journal of Nursing Scholarship* 2018; 50: 36-46. DOI: https://doi-org.mu.idm.oclc.org/10.1111/jnu.12345.
16. Mengelers AM, Bleijlevens MH, Verbeek H, et al. Professional and family caregivers' attitudes towards involuntary treatment in community-dwelling people with dementia. *J Adv Nurs* 2018; 75: 96-107. DOI: 10.1111/jan.13839.
17. Bleijlevens MH, Wagner LM, Capezuti E, et al. Physical Restraints: Consensus of a Research Definition Using a Modified Delphi Technique. *J Am Geriatr Soc* 2016; 64: 2307-2310. DOI: 10.1111/jgs.14435.
18. Voyer P, Cohen D, Lauzon S, et al. Factors associated with psychotropic drug use among community-dwelling older persons: A review of empirical studies. *BMC Nurs* 2004; 3: 1-13. DOI: 10.1186/1472-6955-3-3.
19. Gastmans C and Milisen K. Use of physical restraint in nursing homes: clinical-ethical considerations. *J Med Ethics* 2006; 32: 148-152. DOI: 10.1136/jme.2005.012708.
20. Lach HW and Chang Y-P. Caregiver perspectives on safety in home dementia care. *West J Nurs Res* 2007; 29: 993-1014. DOI: 10.1177/0193945907303098.
21. Scheepmans K, Dierckx de Casterlé B, Paquay Lo, et al. Restraint use in older adults in home care: A systematic review. *Int J Nurs Stud* 2017; 79: 122-136. DOI: 10.1016/j.ijnurstu.2017.11.008.
22. Stubbs B, Brefka S and Denkinger MD. What works to prevent falls in community-dwelling older adults? Umbrella review of meta-analyses of randomized controlled trials. *Physical therapy* 2015; 95: 1095-1110. DOI: https://doi-org.mu.idm.oclc.org/10.2522/ptj.20140461.
23. Konno R, Kang HS and Makimoto K. A best-evidence review of intervention studies for minimizing resistance-to-care behaviours for older adults with dementia in nursing homes. *Journal of advanced nursing* 2014; 70: 2167-2180. DOI: https://doi-org.mu.idm.oclc.org/10.1111/jan.12432.
24. Evans D, Wood J and Lambert L. Patient injury and physical restraint devices:

a systematic review. *Journal of advanced nursing* 2003; 41: 274-282. DOI: https://doi-org.mu.idm.oclc.org/10.1046/j.1365-2648.2003.02501.x.

25. Hofmann H and Hahn S. Characteristics of nursing home residents and physical restraint: a systematic literature review. *J Clin Nurs* 2014; 23: 3012-3024. DOI: 10.1111/jocn.12384.
26. Fazio S, Pace D, Flinner J, et al. The Fundamentals of Person-Centered Care for Individuals With Dementia. *Gerontologist* 2018; 58: S10-S19. DOI: 10.1093/geront/gnx122.
27. Cockrell JR and Folstein MF. Mini-mental state examination. *Principles and practice of geriatric psychiatry* 2002: 140-141.
28. Mitchell AJ. A meta-analysis of the accuracy of the mini-mental state examination in the detection of dementia and mild cognitive impairment. *Journal of psychiatric research* 2009; 43: 411-431. DOI: https://doi.org/10.1016/j.jpsychires.2008.04.014.
29. van Mierlo LD, MacNeil-Vroomen J, Meiland FJ, et al. Implementatie en (kosten-) effectiviteit van casemanagement voor mensen met dementie en hun mantelzorgers: resultaten van de COMPAS-studie. *Tijdschrift voor gerontologie en geriatrie* 2016; 47: 223-233.
30. Lepeleire J, Paquay L and Jacobs M. De verschillende schalen voor ADL-activiteiten voor volwassen in de Vlaamse gezondheidszorg. *Huisarts nu* 2005; 34: 11.
31. Gulpers MJ, Bleijlevens MH, Ambergen T, et al. Belt restraint reduction in nursing homes: effects of a multicomponent intervention program. *Journal of the American Geriatrics Society* 2011; 59: 2029-2036. DOI: https://doi-org.mu.idm.oclc.org/10.1111/j.1532-5415.2011.03662.x.
32. Huizing AR, Hamers JP, Gulpers MJ, et al. A Cluster-Randomized Trial of an Educational Intervention to Reduce the Use of Physical Restraints with Psychogeriatric Nursing Home Residents. *Journal of the American Geriatrics Society* 2009; 57: 1139-1148. DOI: https://doi-org.mu.idm.oclc.org/10.1111/j.1532-5415.2009.02309.x.
33. InterRAI. RAI for Nursing Home Care (RAI 2.1). *InterRAI Corporation.* Utrecht2002.
34. FOD Volksgezondheid Veiligheid van de Voedselketen en Leefmilieu. BelRAI - Een uniforme en web based (online) registratie van interRAI-beoordelingsinstrumenten, https://www.ehealth.fgov.be/nl/application/applications/BELRAI.html (2016, accessed 19-11-2016 2016).
35. Morris JN, Fries BE, Mehr DR, et al. MDS cognitive performance scale©. *Journal of Gerontology* 1994; 49: M174-M182. DOI: https://doi-org.mu.idm.oclc.org/10.1093/geronj/49.4.M174.

36. Pot A, Deeg D, Van Dyck R, et al. Psychological distress of caregivers: the mediator effect of caregiving appraisal. *Patient education and counseling* 1998; 34: 43-51. DOI: https://doi.org/10.1016/S0738-3991(98)00048-2.
37. Von Elm E, Altman DG, Egger M, et al. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies. *International journal of surgery* 2014; 12: 1495-1499. DOI: https://doi.org/10.1016/j.ijsu.2014.07.013.
38. Cohen MP. Determining sample sizes for surveys with data analyzed by hierarchical linear models. *Journal of Official Statistics* 1998; 14: 267.
39. Kim SK and Park M. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clin Interv Aging* 2017; 12: 381-397. DOI: 10.2147/CIA.S117637.
40. Kurata S and Ojima T. Knowledge, perceptions, and experiences of family caregivers and home care providers of physical restraint use with home-dwelling elders: a cross-sectional study in Japan. *BMC Geriatr* 2014; 14: 1-11. DOI: 10.1186/1471-2318-14-39.
41. Evans D and FitzGerald M. Reasons for physically restraining patients and residents: a systematic review and content analysis. *International journal of nursing studies* 2002; 39: 735-743. DOI: https://doi.org/10.1016/S0020-7489(02)00015-9.
42. Karlsson S, Bleijlevens M, Roe B, et al. Dementia care in European countries, from the perspective of people with dementia and their caregivers. *Journal of advanced nursing* 2015; 71: 1405-1416. DOI: https://doi-org.mu.idm.oclc.org/10.1111/jan.12581.
43. Kringos DS, Boerma WG, Hutchinson A, et al. *Building primary care in a changing Europe.* WHO Regional Office for Europe, 2015.
44. Van Mierlo LD, Meiland FJ, Van Hout HP, et al. Towards personalized integrated dementia care: a qualitative study into the implementation of different models of case management. *BMC geriatrics* 2014; 14: 1. DOI: https://doi.org/10.1186/1471-2318-14-84.
45. Lang L, Clifford A, Wei L, et al. Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis. *BMJ Open* 2017; 7: e011146. DOI: 10.1136/bmjopen-2016-011146.
46. Kalula SZ and Petros SG. Use of physical restraint in hospital patients: A descriptive study in a tertiary hospital in South Africa. *Curationis* 2016; 39: 1-8. DOI: 10.4102/curationis.v39i1.1605.
47. Lay B, Nordt C and Rössler W. Variation in use of coercive measures in psychiatric hospitals. *European Psychiatry* 2011; 26: 244-251.

DOI: https://doi.org/10.1016/j.eurpsy.2010.11.007.

48. Wagner LM, Capezuti E, Brush B, et al. Description of an advanced practice nursing consultative model to reduce restrictive siderail use in nursing homes. R*esearch in nursing & health* 2007; 30: 131-140. DOI: https://doi-org.mu.idm.oclc.org/10.1002/nur.20185.
49. O'Brien AJ and Golding CG. Coercion in mental healthcare: the principle of least coercive care. *Journal of psychiatric and mental health nursing* 2003; 10: 167-173. DOI: https://doi-org.mu.idm.oclc.org/10.1046/j.1365-2850.2003.00571.x.
50. Pelto-Piri V, Kjellin L, Lindvall C, et al. Justifications for coercive care in child and adolescent psychiatry, a content analysis of medical documentation in Sweden. *BMC health services research* 2016; 16: 1-8. DOI: https://doi.org/10.1186/s12913-016-1310-0.
51. Fitton L and Jones DR. Restraint of adults with intellectual disabilities: A critical review of the prevalence and characteristics associated with its use. *Journal of Intellectual Disabilities* 2020; 24: 268-283. DOI: https://doi-org.mu.idm.oclc.org/10.1177/1744629518778695.

CHAPTER 4

—

Caregiver decision-making concerning involuntary treatment in dementia care at home.

This chapter was published as:

Moermans V.R.A., Mengelers A.M.H.J., Bleijlevens M.H.C., Verbeek H., Dierckx de Casterlé B., Milisen K., Capezuti E., & Hamers J.P.H. (2021). *Caregiver decision-making concerning involuntary treatment in dementia care at home.* Nursing Ethics, 29, 330-343. DOI: 10.1177/09697330211041742.

Abstract

Background

Dementia care at home often involves decisions in which the caregiver must weigh safety concerns with respect for autonomy. These dilemmas can lead to situations where caregivers provide care against the will of persons living with dementia (PLWD), referred to as involuntary treatment. To prevent this, insight is needed into how family caregivers of PLWD deal with care situations that can lead to involuntary treatment.

Objective

To identify and describe family caregivers' experiences regarding care decisions for situations that can lead to involuntary treatment use in PLWD at home.

Research design

A qualitative descriptive interview design. Data were analysed using the Qualitative Analysis Guide of Leuven.

Participants and research context

A total of 10 family caregivers providing care for 13 PLWD participated in in-depth semi-structured interviews. Participants were recruited by registered nurses via purposive sampling.

Ethical consideration

The study protocol was approved by the Ethics Committee of the University Hospitals Leuven and the Medical Ethical Test Committee Zuyderland.

Findings

Family caregivers experience the decision-making process concerning care dilemmas that can lead to involuntary treatment as complicated, stressful and exhausting. Although they consider safety and autonomy as important values, they struggle with finding the right balance between them. Due to the progressive and unpredictable nature of dementia, they are constantly seeking

solutions while they adapt to new situations. Family caregivers feel responsible, and experience social pressure for the safety of PLWD. They may be blamed if something adverse happens to the PLWD, which increases an already stressful situation. Their experience is influenced by characteristics of the care triad (PLWD, professional and family caregivers) such as practical and emotional support, knowledge and previous experiences.

Discussion and conclusion

To prevent involuntary treatment, professionals need to proactively inform family caregivers, and they need to support each other in dealing with complex care situations.

Introduction

Worldwide, dementia has a profound health impact on those who have it and on their caregivers as well. The number of people living with dementia (PLWD) worldwide will triple from 35.6 million to 115.4 million by 2050.[1] The majority of PLWD age in place, and wish to live there as long as possible, making family caregiving a major portion of dementia care provision.[1, 2] However, caring for PLWD can be stressful and difficult to manage for family caregivers. Dementia involves progressive loss of mental and physical abilities [2] and decision-making capacity [3] and behavioural and psychological symptoms which can lead to caregiver burden.[4]

When family caregivers perceive that the cognitive skills of PLWD decline to a point, where they find that the PLWD is no longer able to make decisions about everyday life themselves, they gradually take a dominant role in these decisions.[5, 6] Making proxy decisions is complex and can involve ethical dilemmas for family caregivers. The needs and wishes of family caregivers and PLWD can differ, especially since the PLWD may not appreciate their vulnerabilities.[7, 8] Family caregivers want to ensure a safe environment because they regard their family member as vulnerable to potential dangers, such as (injurious) falls, getting lost or health problems due to insufficient body hygiene or incorrect medication intake.[8-11] According to Kitwood,[12] PLWD are in need of comfort, attachment, inclusion, occupation and identity, which form the basis of person-centred care (PCC). The PCC approach enables caregivers to understand, and provide support for, the unmet needs and wishes of the person receiving care.[13] However, family caregivers may find it essential to take safety measures [7-9] that may lead to situations to which PLWD resist.[14] Family caregivers do not always have sufficient skills, knowledge or support to respond to care for resistance [15-17] in a manner that is aligned with a PCC approach.[13]

Several terms are used in the literature to describe care to which PLWD resist or do not provide consent for, such as coercive care,[17] restiveness to care [18] and involuntary treatment.[19, 20] This study uses the term 'involuntary treatment', defined as care provided without the consent of the person receiving it and/or to which this persons resists. Involuntary treatment includes the use of physical restraints, psychotropic medication and non-consensual care.[19] Recent research[21] shows that one out of two PLWD living at home receive involuntary treatment, mostly requested and used by family caregivers and nursing staff. Also, family caregivers are more accepting of involuntary treatment use than professional caregivers.[22] Commonly reported reasons to apply involuntary treatment are safety related such as protection of the PLWD and/or his environment.[10] However, involuntary treatment can be considered as inappropriate because it can have negative influence on the physical and psychological well-being of the PLWD [23] and often alternative interventions exist that are less restrictive, safer, more effective and in line with PCC.[13] In addition, involuntary treatment is associated with higher care burden by family caregivers.[21]

In order to prevent and/or reduce involuntary treatment use in PLWD living at home, more insight is needed into how family caregivers deal with and make decisions in care situations that can lead to involuntary treatment. These insights can be used to develop an individualized, person-centred approach to support family caregivers in dealing with these dilemmas. This study aims to identify and describe family caregivers' experiences regarding care decisions concerning situations that can lead to involuntary treatment use in PLWD at home.

Methods

Design

To perform a straight description of the experiences from family caregivers of PLWD and to stay close to the findings, we used a qualitative descriptive research design.[24]

Setting and sampling

Data was collected between November 2019 and February 2020 among family caregivers of PLWD receiving professional dementia care at home. 'Family caregiver' was broadly defined as a non-paid caregiver who has a significant emotional relationship with the PLWD. This could be a family member or friend, who offers emotional-expressive, instrumental and tangible support and assistance to PLWD.[25] Participants were selected through maximum variation sampling.[24, 26] The recruiters purposefully approached those family caregivers that had rich experiences with care situations regarding safety versus autonomy, which might have or actually led to involuntary treatment, and the recruiter informed them using an information letter. The main inclusion criteria were:
1) being a family caregiver for a PLWD living at home, 2) Dutch speaking and 3) having experience with dealing with care dilemmas that could lead to involuntary treatment. If the family caregivers were interested in the study, they were contacted by the researchers to further inform them and plan an appointment to conduct the interview. Additionally, based on the insights during the data-analysis, we purposefully contacted family caregivers based on their demographic

characteristics such as, age, gender, relation to PLWD, living together with PLWD and the use of involuntary treatment. The research team has experience with care for older people, home care nursing, dementia care, falls prevention, involuntary treatment, (physical) restraint use, qualitative research and the Qualitative Analysis Guide of Leuven (QUAGOL).[27]

Data collection

Interviews were conducted by the principal researchers (VM and AM) at the participants' home or researchers' office. All interviews were conducted in Dutch, audio-recorded with participants' permission and transcribed by the principal researchers. It was anticipated that interviews would last approximately 60 minutes. The interviews were performed using an informal interview technique including an open and broad conversation focusing on participant experiences. Spontaneous follow-up questions were asked during the interview. The interview guide is presented in Table 1. After each interview, the researcher took field notes documenting the details of the observations and the process of interactions. After eight interviews (describing 11 cases of PLWD were conducted, results were discussed with the research team. To further enrich data and reach saturation, two more interviews were conducted. The results of the two last cases confirmed the themes without any new or additional themes or information. Since redundancy was achieved, the research group decided that data saturation was met. The final sample consisted of ten family caregivers (8 female) that cared for 13 PLWD at home (7 female). Three participants had experience with providing family care for two PLWD, thus data was collected from 13 care situations with PLWD. The average age of the family caregivers was 58 years (range: 44–70 years), and of the PLWD, 73 years (range: 59–90 years). In 7 of the 13 cases the family caregivers was the partner and in 6 cases it was the daughter/son. Tables 2 and 3 provide an overview of the family caregivers' and PLWD's characteristics. Table 4 shows family caregivers' experiences with the use of involuntary treatment or alternatives. In 10 of the 13 cases, at least one type of involuntary treatment was applied.

Table 1. Interview guide

- What is your experience and knowledge in caring for PLWD?
- What do you find important in the care for your loved one?
- Tell me about the first time that you were confronted with the fact that your opinion about safety differs from the person you care for?
- How did you deal with it?
- How did this effect you?
- How did that effect your environment?
- Who was involved in care of your loved one?
- What support did you receive from others (family, professional caregivers) in dealing with these situations?
- How did you experience this support?
- Follow-up question:
  - *Can you tell me more about it?*
  - *What happened next?*
  - *What were you thinking then?*
  - *How did that effect you?*
  - *How did you feel?*
  - *What do you mean by that?*

Table 2. Family caregivers personal characteristics (N=13)*

Item	Response	Amount
Gender	Male	4
	Female	9
Age	30-39	1
	40-49	1
	50-59	5
	60-69	5
	70-79	1
Education	Associate’s degree	5
	Bachelor’s degree	7
	Master’s degree	1
Experience as family caregiver (years)	0-2	4
	3-4	3
	5-6	3
	7-8	2
	9-10	1
Relationship to PLWD	Partner	7
	Daughter/son	6

*Because three family caregivers provided care for two PLWD, the total is 13.

Table 3. Persons with dementia personal characteristics (N=13)*

Item	Response	Amount
Gender	Male Female	6 7
Age	50-59 60-69 70-79 80-89 90-99	1 4 5 2 1
Living situation	Alone With the caregiver	3 10
Resistance	No resistance mentioned One or more instances	3 10
Perceived safety risks	Getting lost Falling Physical aggressive PLWD could not be left alone Other (f.e., inappropriate medication intake, injury through sharp objects, traffic accidents, cooking accidents)	5 4 3 3 7
Mentioned safety incidents	Getting lost Falling Physically aggressive	6 3 2

Table 4. Involuntary treatment measures and alternatives

Item	Response	Amount
Involuntary treatment: Physical restraints	Waist belt in a (wheel)chair	1
Psychotropic medication	Antidepressants Anti-psychotics	1 2
Non-consensual care	Forced hygiene Locking older adult in house	9 6
Alternatives	Enhance supervision	5
	Home adaptation	6
	Distracting PLWD	5
	Doing activities together	7
	Wait and see attitude (not intervening immediately)	8
	Engage in dialogue with PLWD Frequent calls/visits with PLWD	7 4

Data analysis

Data analysis was based on the Quagol,[27] an iterative guidance tool for qualitative data analysis consisting of two parts: a) the preparation for the coding process by paper and pencil work and b) the actual coding process using qualitative software. During the first part, three researchers (VM, AM, MB) and a research assistant applied a case-oriented approach and identified the essential and common themes throughout the data. First, the researchers (re)read the transcripts individually and thoroughly, then developed a list of preliminary themes. Similarities, differences, and connections among different themes within and across individual conceptual schemes were discussed by the four researchers. Using the method of constant comparison, they eventually found potentially relevant themes that can be used as codes. On the basis of this code list, all data was coded with qualitative software (Maxqdata 2020®). All data was coded by linking each fragment of text to one of the themes from the preliminary code list. This resulted in a list of isolated themes and their meaning and characteristics. This list was discussed by the four researchers in the group in response to the research question. Then they distilled the storyline from the findings and themes. The final findings were discussed as a group and then submitted to the research team (VM, AM, MB, HV, JPH) to reach consensus. They also discussed if data-saturation was met.

Ethical considerations

The Ethics Committee of the University Hospitals Leuven (reference G-2019 09 1735 on 10/7/2019) and the Medical Ethical Test Committee Zuyderland (reference METCZ20190118 on 12/09/2019) approved the study. All family caregivers received written and verbal information about the study. Before each interview, the participant filled in a consent form. Participation was on a voluntary basis and participants were free to withdraw at any time. Only the interviewers knew the participants' identities. Data of participants were anonymised after transcription and treated confidentially.

Rigour/Trustworthiness

To ensure the trustworthiness of the study, several strategies were used [28]: 1) We maintained a detailed audit trail such as interview transcripts, field notes; 2) Thick description (i.e., relevant citations to illustrate the generated themes); 3) We performed member checking by summarising participants' responses at the end of each interview; 4) The process of analysis was frequently reviewed within the research team to establish uniformity in themes and relationships and to explore the interviewers' reflexivity; 5) Peer group discussion: the results were discussed with two district nurses specialised in guiding PLWD and their family caregivers; they recognised the themes from their own practice and acknowledged the findings of this study; 6) Triangulation such as constant comparison, case-oriented approach, open coding techniques; 7) Persistent observation; and 8) Prolonged engagement (i.e., researchers' experience and duration of data collection).

Results

The interviews revealed that family caregivers experience the decision-making process concerning care dilemmas that can lead to involuntary treatment use as complicated, stressful and exhausting. This was due to 1) the constant trade-off between safety versus autonomy, 2) constantly adapting and being prepared, and 3) feeling responsible. How family caregivers experienced this decision-making process, was influenced by characteristics of the care triad (PLWD, professional and family caregivers).

Trade-off between safety versus autonomy

All family caregivers indicated that they found safety and autonomy important aspects in the care for PLWD. As long as the PLWD had no severe behavioural problems, safety risks or incidents, they supported the autonomy of the PLWD. Autonomy was described as involving PLWD in the decisions being made and supporting the PLWD to live a pleasant and meaningful life in their own home. As the mental and physical capabilities of PLWD deteriorate, more safety incidents often arise such as getting lost or injurious falls. As a result, family caregivers experienced that their and the PLWD's opinions started to differ and they reported struggling with finding the right compromise between safety and autonomy. This was due to the increased safety risks experienced when respecting the wishes of the PLWD. At a certain point, often after an incident such as an injury or police intervention, safety outweighed the wishes of the PLWD. In some cases, this led to involuntary treatment (see Table 4) and/or the request for (more) professional help. Family caregivers indicated that this constant trade-off between safety and autonomy continuously affected their decisions and made it complicated and stressful to decide what was best. In care situations where involuntary treatment was applied, such as locking inside a house, the use of physical restraints or psychotropic medication, the family caregiver did not mention the negative impact of their actions such as feelings of imprisonment, on the PLWD and they justified them by saying that it was necessary to prevent falling and to reduce their own stress. On the other hand, in care situations where it was not applied, the family caregivers indicated that it was a deliberate choice not to intervene. For example, some accepted possible safety risks such as wandering and so they did not lock the PLWD in the house. They felt the safety risk did not outweigh the loss of dignity.

> “*At some point, my stepmother started to deteriorate rapidly, she did not recognise my father anymore. She also started collecting scissors and all kinds of sharp objects in their bed and bedroom. At a certain point, we decided for my father's safety that it couldn't go on like this anymore.*”
> *— 50-year-old stepson of 77-year-old PLWD*

Constantly adapting and being prepared

Family caregivers reported that due to the progressive and unpredictable nature of dementia, including behavioural changes and ongoing cognitive decline, they must constantly seek solutions that support a balance between safety and autonomy. However, these solutions, such as locking windows or doors, were limited and only applicable for a short period of time until new problems arose that could lead to involuntary treatment. Therefore, most of the family caregivers constantly needed to reflect on the situation and indicated that it was difficult to prepare for and adapt to unpredictable situations and found it hard to continuously look for ‘new solutions’. This combination of constantly seeking solutions and adapting to new situations makes dealing with these care situations challenging, exhausting and stressful. In contrast, a few family caregivers indicated that they did not anticipate what would happen and instead, lived in the moment.

> “*The decline occurs in stages. One moment you think now I have found it, and the next moment there is something else again, and then you have to adapt to that. This is so exhausting that it breaks you.*”
> *— 67-year-old wife of 78-year-old PLWD*

> *“Three weeks ago, I had the impression that I could get through to her, that she understood me and that she could be still alone at night. I went home with peace of mind, and that is not the case anymore.”*
> *— 51-year-old daughter of 80-year-old PLWD*

Feeling responsible

Family caregivers mentioned that they felt obliged to take up the role as the primary caregiver for several reasons: 1) they could give back what their loved one had given them, 2) an earlier promise , 3) it was expected or 4) it was an expression of their love for the PLWD. They indicated that being the primary caregiver for the safety and well-being of their loved-one was hard to bear. They were often worried about what could happen, especially if previous experiences in which they respected the wishes of PLWD (for example, going for a walk or living alone) led to safety risks or incidents. They felt responsible ‘24/7’, meaning they were constantly on the alert for any problems. This resulted in both inadequate time to recover and persistent exhaustion. However, most of them also indicated they did not want to trouble, for instance, children and friends with their problems because they had their own life. For those that shared responsibility with others, decisions were made together, and the family caregiver felt supported, resulting in less burden and stress. But in some cases, family caregivers indicated that opinions regarding safety and autonomy differed between relatives, which they perceived as social pressure. Most family caregivers indicated that they were making plans and preparing themselves for the moment when would need to reject the wishes of the PLWD for safety reasons. By making these plans, they felt they could justify their decisions to tolerate safety risks, to themselves and others. Dealing with this social pressure to ‘do the right thing’ in combination with the feeling of possibly being blamed, was described as stressful and a great responsibility.

> *“He [my partner living with dementia] does feel the need to go out alone. But because he has already fallen several times and people have called me about this, I’m afraid to let him go out alone. I'm afraid he'll fall at some point and maybe break his neck.”*
>
> *— 70-year-old partner of 72-year-old PLWD*

> *“I would like that he [my partner with dementia] live as long as possible in his own house, but I’m afraid that something could happen. I will feel guilty then, although I shouldn’t feel guilty because I offered him to come live with me.”*
>
> *— 57-year-old partner of 61-year-old PLWD*

Characteristics of the care triad

Data analyses showed that family caregivers' experiences with dealing with care dilemmas that can lead to involuntary treatment are influenced by several background characteristics of the care triad, including the PLWD, professional and family caregivers.

Characteristics of the PLWD: Family caregivers mentioned several patient-related characteristics that influenced their experience, including: 1) changes in the PLWD's behaviour (e.g., aggression, irritation, disorientation), 2) blurred boundaries between behaviour that arises from someone's character versus the disease, 3) the frequency and severity of safety incidents and 4) the personality of the PLWD (i.e., the PLWD followed their advice and did not resist due to their docile nature).

Characteristics of the family caregivers: Family caregivers revealed that several characteristics influenced the way they dealt with care situations including: 1) previous experience with providing care for PLWD, 2) their knowledge of alternatives (see Table 4), 3) their relationship to the PLWD, 4) their professional status (for example, retired, employed) and 5) their coping strategies. Family caregivers who provided care for a parent with dementia in the past and had experience with involuntary treatment use indicated that they felt it was important to respect the autonomy and wishes of the PLWD. Family caregivers with knowledge of dementia, those that know how to manage behavioural symptoms and are aware of alternative measures experienced less difficulty dealing with care situations that could lead to involuntary treatment. Their relationship to the PLWD and living arrangement also influenced their experience. All family caregivers that did not live with the PLWD indicated that they could leave the situation and better cope with the stress than if they lived together. Family caregivers found it hard to balance the care for PLWD with their professional work and some took sick leave because they felt too stressed. Finally, family caregivers felt less stress if they regularly took rest breaks (for example, use of a volunteer sitter or day care), or reduced the amount of time of in person assistance such as checking on the PLWD by phone or by providing care either in the evening or morning.

Professional support: Family caregivers indicated that they needed more emotional support in the decision-making process from professional caregivers (listed in Table 5) because professionals 1) often underestimated the severity of caring for a PLWD, 2) lacked the time or knowledge to support them or 3) support was too late or too early. Additionally, it took family caregivers much effort and time to find out what kind of support was available and they preferred more individualized information regarding their rights and possibilities to receive (professional) support. However, several family caregivers cited that they did not want or need professional support because 1) they wished to keep the care completely in their own hands, 2) providing care was still feasible, 3) they knew their loved one best and did not see how professionals could support them or 4) they did not want to bother others or ask for help. Instead, they sought solutions from the internet and books and by talking to others in the same situation. In contrast, other family caregivers indicated that practical support from professionals was helpful and valuable. This support included 1) explaining the behaviour symptoms of PLWD and providing approaches to manage difficult situations, 2) providing care at home or day care so family caregivers had some respite from their care responsibilities and 3) medical management from the general practitioner (for example, prescription of medication).

> *"I think more guidance would have been an advantage and it would have helped. But on the other hand, I think you will also receive a lot of information that is not relevant in my case, because you are going to receive a lot of general information. I think in many cases it would be good to receive a little more guidance."*
>
> *— 64-year-old wife of a 67-year-old PLWD*

Informal support (listed in Table 5) included both practical assistance and emotional support. All family caregivers indicated they feel emotionally supported by talking with family and friends about their situation and sharing their experiences. The practical support included help with care-related tasks or going for a walk with the PLWD, which provided respite for the family caregivers. Most family caregivers attended caregiver support groups, which was recognised as very supportive because they could share experiences and advice in managing care dilemmas that could lead to involuntary treatment. The latter included the use of alternative measures such as a GPS-tracker, involvement of home care nursing or adaptations in the environment.

> *"I am now part of a support group for family caregivers of PLWD and you learn a lot there. There are severe cases, very serious, but also light cases and you hear stories from everyone. When I leave these meetings, I go home with peace of mind and think to myself, oh but I am not that far yet, she is still an easy one."*
>
> *— 67-year-old husband of a 68-year-old PLWD*

Table 5. Professional and family caregivers supporting primary caregiver

Item	Response	Amount
Professional caregivers		
	General practitioner	7
	Dementia centre	8
	District nurse	8
	Psychologist	4
	Specialist physician	8
	Dementia case manager	2
	Day care for PLWD	2
	Domestic worker	3
Family caregivers		
	Family or neighbours	10
	Volunteer sitters	2
	Others in same situation, support groups	9

Discussion

To our knowledge, this is the first study that focuses on the experiences of family caregivers regarding care decisions that could lead to the use of involuntary treatment. The current study links and confirms results from previous research regarding the decision-making process in dementia care at home,[3, 6, 9] with the use of involuntary treatment. We provided new insights into how family caregivers experience this and how balancing safety with autonomy could evolve into the use of involuntary treatment. We found that the constant struggle with balancing safety with autonomy, constantly searching for solutions, adapting to new situations and being responsible for their safety, was experienced as a complicated, stressful and exhausting process. Depending on the characteristics of the care triad, knowledge and experience regarding dementia and involuntary treatment use, the associated behavioural symptoms of PLWD and the received support, dealing with safety versus autonomy could all lead to the application of involuntary treatment.

We found that family caregivers recognised the need for autonomy of the PLWD and that they felt responsible to respect their wishes. However, at a certain point in the caregiving process, family caregivers experienced that their own needs and those of the PLWD's regarding safety and autonomy started to differ and reported struggling with finding the right compromise between them, and conflicts thus started to arise. The ethical framework provided by Joan Tronto [29] describes caregiving as a complicated, holistic process that does not always occur in a perfect way or end in 'good care', due to inherent conflicts between the needs of the caregivers and PLWD regarding attentiveness, responsibility, competence and responsiveness. We found these conflicts in our results as well. Several family caregivers mention that out of filial obligation [30] such as tradition, gratitude or an expression of love, they felt responsible to take care for their loved one as long as possible at home in order to avoid admission to a nursing home. When the behavioural symptoms of dementia increased, family caregivers felt responsible to create a safe environment. Due to a lack of knowledge and/or experience, they did not always have enough competence to respond to these changing needs in a person-centred manner. This, in combination with previously observed safety risks and/or incidents, family caregivers tended to choose potentially harmful solutions such as forced hygiene, locking PLWD in their home or administering psychotropic medication. This is because family caregivers consider safety of great importance and were not always aware that the care they provided was involuntary and could have negative consequences.[23] Dealing with these situations in combination with being 24/7 alert and concerned about what could happen, was experienced as a stressful situation and hard to bear. Also, family caregivers did not always respond to these stressful situations by taking time for themselves or involving professional support. In some cases, they perceived professional help as a threat to their autonomy. Family caregivers were afraid to lose control of the caregiving process or that professionals would interfere in the caregiving process since they felt they knew their loved one the best.[31] Additionally, if professional help was involved, professionals did not sufficiently recognise and respond to their emotional care needs.[29] All of these conflicts resulted in family caregivers' finding the experience of dealing with safety versus autonomy in the care of PLWD as a complicated, stressful and exhaustive situation.[29] These results underscore the importance that every member in the care triad recognise each other's needs, seek insight into the interrelationship between family caregiver and PLWD,[30] identify possible care conflicts and pursue dialogue with each other so that timely support and advice can be given to each other to prevent involuntary treatment.

Although all family caregivers experience care dilemmas as complicated, some deliberately choose not to intervene and accept possible (safety) risks. This can be explained by a difference in attitudes regarding involuntary treatment [22] due to previous negative care experiences with the application of it, but also by the extent to which they feel supported by professional caregivers and their social network. As long as there are no safety issues or behavioural symptoms, family caregivers indicated that they respected the autonomy of the PLWD and wished to care for the PLWD themselves, without professional support. In the early stage of dementia, family caregivers do not acknowledge their needs and overestimate their capabilities because they struggle with accepting and adapting to their new role as caregiver.[32] All of this highlights the importance of early interventions that inform, guide and support family caregivers on how to handle care dilemmas in a more person-centred manner.[31-33]

By increasing awareness through counselling such as by informing family caregivers about caregiver burden, behavioural problems, discussing alternatives and strengthening their social network (for example by attending support groups, involving formal and informal care support), family caregivers can be supported in the prevention and reduction of the underlying factors such as caregiver burden, lack of knowledge, skills and support that could lead to the application of involuntary treatment.[3, 33-35] District nurses play a pivotal role since they often are involved in the application of involuntary treatment.[21, 36] Therefore, they require education concerning alternative approaches as well as assistance in their own ethical reflection regarding the use of involuntary treatment.[37] A multicomponent, person-centred, dementia care intervention is needed for district nurses so they can recognise the needs of PLWD and their caregivers and effectively support them. This multidisciplinary approach should focus on education, coaching and alternatives that can support both professional and family caregivers in discussing complex care dilemmas and making informed decisions regarding treatment.[38, 39] Further studies are needed to focus on the development and effectiveness of such approaches.

Limitations and strengths

A limitation of our study was the relatively small sample size of 13 cases. In addition, three of the ten participants provided information about earlier experiences and one could question the accuracy of their recollections due to the time gap between the actual experience and the interviews. Another limitation of this study was that involuntary treatment is a difficult concept to discuss. Family caregivers may not be aware of this term and, therefore, not recognise certain measures as involuntary. For this reason, we did not use the term ‘involuntary treatment’ in the interviews. Instead, we referred to care dilemmas in which the PLWD and family caregiver had different wishes and care was provided against the PLWD’s will. Participants, however, were very willing to describe their experiences and provided detailed answers to our questions. This contributed to the richness and saturation of the data collected. A strength of this study was the use of purposive sampling, which led to a heterogeneous sample representative of family caregivers providing care for PLWD.

Conclusion

The results from this study indicated that dealing with care dilemmas was experienced as complicated, stressful and exhausting. To prevent involuntary treatment, professionals caregivers need to provide anticipatory guidance that supports family caregivers when caring for PLWD, especially when behavioural symptoms with safety implications emerge. In addition, family caregivers should be supported in finding the right balance between safety and autonomy and in handling their feelings of responsibility. Interventions are needed for both professional and family caregivers to acknowledge the ethically complex decision-making process in a more person-centred manner.

Acknowledgements

Thanks to all family caregivers who were willing to share their experiences. Thanks to all registered nurses who supported the principal researchers during recruitment. Special thanks to Jules Willems for his assistance during the data analysis of this study.

Author contributions

Study design was performed by VM, AM, MB, HV, BDdC, KM, EC and JPH; data collection by VM and AM; data analysis by VM, AM and MB and manuscript preparation by VM, AM, MB, HV, BDdC, KM, EC and JPH.

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

References

1. Alzheimer's Association. 2018 Alzheimer's disease facts and figures. *Alzheimer's & Dementia* 2018; 14: 367-429.
2. Førsund LH, Grov EK, Helvik A-S, et al. The experience of lived space in persons with dementia: a systematic meta-synthesis. *BMC Geriatr* 2018; 18: 1-27. DOI: 10.1186/s12877-018-0728-0.
3. Van Wijngaarden E, Van der Wedden H, Henning Z, et al. Entangled in uncertainty: The experience of living with dementia from the perspective of family caregivers. *PloS one* 2018; 13: e0198034. DOI: 10.1371/journal.pone.0198034.
4. Braun A, Trivedi DP, Dickinson A, et al. Managing behavioural and psychological symptoms in community dwelling older people with dementia: 2. A systematic review of qualitative studies. *Dementia* 2019; 18: 2950-2970. DOI: 10.1177/1471301218762856.
5. Fetherstonhaugh D, McAuliffe L, Shanley C, et al. "Did I make the right decision?": The difficult and unpredictable journey of being a surrogate decision maker for a person living with dementia. *Dementia* 2019; 18: 1601-1614. DOI: 10.1177/1471301217721862.
6. Miller LM, Whitlatch CJ and Lyons KS. Shared decision-making in dementia: a review of patient and family carer involvement. *Dementia* 2016; 15: 1141-1157. DOI: 10.1177/1471301214555542.
7. Rapaport P, Burton A, Leverton M, et al. "I just keep thinking that I don't want to rely on people." a qualitative study of how people living with dementia achieve and maintain independence at home: stakeholder perspectives. *BMC Geriatr* 2020; 20: 5. DOI: 10.1186/s12877-019-1406-6.
8. Smebye KL, Kirkevold M and Engedal K. Ethical dilemmas concerning autonomy when persons with dementia wish to live at home: a qualitative, hermeneutic study. *BMC Health Serv Res* 2016; 16: 1-12. DOI: 10.1186/s12913-015-1217-1.
9. Häikiö K, Sagbakken M and Rugkåsa J. Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services. *BMC Health Serv Res* 2019; 19: 1-13. DOI: 10.1186/s12913-019-4478-2.
10. Scheepmans K, Dierckx de Casterlé B, Paquay Lo, et al. Restraint use in older adults in home care: A systematic review. *Int J Nurs Stud* 2017; 79: 122-136. DOI: 10.1016/j.ijnurstu.2017.11.008.
11. Soilemezi D, Drahota A, Crossland J, et al. The role of the home environment in dementia care and support: Systematic review of qualitative research. *Dementia* 2019; 18: 1237-1272. DOI: https://doi-org.mu.idm.oclc.org/10.1177/1471301217692130.

12. Fazio S, Pace D, Flinner J, et al. The Fundamentals of Person-Centered Care for Individuals With Dementia. *Gerontologist* 2018; 58: S10-S19. DOI: 10.1093/geront/gnx122.
13. Kim SK and Park M. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clin Interv Aging* 2017; 12: 381-397. DOI: 10.2147/CIA.S117637.
14. Giertz L, Emilsson UM and Vingare E-L. Family caregivers and decision-making for older people with dementia. *J Soc Welf and Fam Law* 2019; 41: 321-338. DOI: 10.1080/09649069.2019.1627087.
15. Chiao CY, Wu HS and Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: a systematic review. *Int Nurs Rev* 2015; 62: 340-350. DOI: doi.org/10.1111/inr.12194
16. Kurata S and Ojima T. Knowledge, perceptions, and experiences of family caregivers and home care providers of physical restraint use with home-dwelling elders: a cross-sectional study in Japan. *BMC Geriatr* 2014; 14: 1-11. DOI: 10.1186/1471-2318-14-39.
17. Lejman E, Westerbotn M, Pöder U, et al. The ethics of coercive treatment of people with dementia. *Nurs Ethics* 2013: 248-262. DOI: 10.1177/0969733012463721.
18. Galik E, Resnick B, Vigne E, et al. Reliability and Validity of the Resistiveness to Care Scale Among Cognitively Impaired Older Adults. *J Am Med Dir Assoc* 2017; 18: 59-64. DOI: 10.1016/j.jamda.2016.08.008.
19. Hamers JP, Bleijlevens MH, Gulpers MJ, et al. Behind Closed Doors: Involuntary Treatment in Care of Persons with Cognitive Impairment at Home in the Netherlands. *J Am Geriatr Soc* 2016; 64: 354-358. 2016/01/26. DOI: 10.1111/jgs.13946.
20. Van der Meulen APS, Hermsen MA and Embregts PJ. Restraints in daily care for people with moderate intellectual disabilities. *Nurs ethics* 2018; 25: 54-68. DOI: https://doi-org.mu.idm.oclc.org/10.1177/0969733016638141.
21. Mengelers AM, Moermans VR, Bleijlevens MH, et al. Involuntary treatment in dementia care at home: Results from the Netherlands and Belgium. *J Clin Nurs* 2022; 31: 1998-2007. DOI: 10.1111/jocn.15457.
22. Mengelers AM, Bleijlevens MH, Verbeek H, et al. Professional and family caregivers' attitudes towards involuntary treatment in community- dwelling people with dementia. *J Adv Nurs* 2018; 75: 96-107. DOI: 10.1111/jan.13839.
23. Hofmann H and Hahn S. Characteristics of nursing home residents and physical restraint: a systematic literature review. *J Clin Nurs* 2014; 23: 3012-3024. DOI: 10.1111/jocn.12384.

24. Kim H, Sefcik JS and Bradway C. Characteristics of qualitative descriptive studies: A systematic review. *Res Nurs Health* 2017; 40: 23-42. DOI: 10.1002/nur.21768.
25. Toledano-Toledano F, Rodríguez-Rey R, de la Rubia JM, et al. A Sociodemographic variables questionnaire (Q-SV) for research on family caregivers of children with chronic disease. *BMC Psychol* 2019; 7. DOI: https://doi.org/10.1186/s40359-019-0350-8.
26. Palinkas LA, Horwitz SM, Green CA, et al. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health* 2015; 42: 533-544. DOI: 10.1007/s10488-013-0528-y.
27. Dierckx de Casterlé B, Gastmans C, Bryon E, et al. QUAGOL: a guide for qualitative data analysis. *Int J Nurs Stud* 2012; 49: 360-371. DOI: 10.1016/j.ijnurstu.2011.09.012.
28. Polit DF and Beck CT. Nursing research: Generating and assessing evidence for nursing practice. Lippincott Williams & Wilkins, 2012.
29. Tronto JC. An ethic of care. *J Am Soc Aging* 1998; 22: 15-20. DOI: https://www.jstor.org/stable/44875693.
30. McCarty EF, Hendricks CS, Hendricks DL, et al. Ethical dimensions and filial caregiving. *Journal of Health Ethics* 2008; 5. DOI: 10.18785/ojhe.0501.03.
31. Stephan A, Bieber A, Hopper L, et al. Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. *BMC Geriatr* 2018; 18. DOI: https://doi.org/10.1186/s12877-018-0816-1.
32. Boots LM, Wolfs CA, Verhey FR, et al. Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *Int Psychogeriatr* 2015; 27: 927-936. DOI: 10.1017/S1041610214002804.
33. Abrahams R, Liu KP, Bissett M, et al. Effectiveness of interventions for co-residing family caregivers of people with dementia: Systematic review and meta-analysis. *Aust Occup Ther J* 2018; 65: 208-224. DOI: https://doi-org.mu.idm.oclc.org/10.1111/1440-1630.12464.
34. McCabe M, You E and Tatangelo G. Hearing their voice: a systematic review of dementia family caregivers’ needs. *Gerontologist* 2016; 56: e70-e88. DOI: https://doi-org.mu.idm.oclc.org/10.1093/geront/gnw078.
35. Whitlatch CJ and Orsulic-Jeras S. Meeting the informational, educational, and psychosocial support needs of persons living with dementia and their family caregivers. *Gerontologist* 2018; 58: S58-S73. DOI: 10.1093/geront/gnx162.

36. Moermans VR, Bleijlevens MH, Verbeek H, et al. The Use of Involuntary Treatment among Older Adults with Cognitive Impairment Receiving Nursing Care at Home: A Cross-sectional Study. *Int J Nurs Stud* 2018; 88: 135-142. DOI: 10.1016/j.ijnurstu.2018.09.004.
37. Goethals S, Dierckx de Casterlé B and Gastmans C. Nurses' decision-making in cases of physical restraint: a synthesis of qualitative evidence. *J Adv Nurs* 2012; 68: 1198-1210. DOI: 10.1111/j.1365-2648.2011.05909.x.
38. Gulpers MJ, Bleijlevens MH, Ambergen T, et al. Reduction of Belt Restraint Use: Long-Term Effects of the EXBELT Intervention. *J Am Geriatr Soc* 2013; 61: 107-112. DOI: 10.1111/jgs.12057.
39. Scheepmans K, Dierckx de Casterle B, Paquay L, et al. Reducing physical restraints by older adults in home care: development of an evidence-based guideline. *BMC Geriatr* 2020; 20: 169. DOI: 10.1186/s12877-020-1499-y.

CHAPTER 5

District nurses' attitudes towards involuntary treatment in dementia care at home: A cross-sectional study

This chapter was published as:

Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Lima Passos V.,
Milisen K. & Hamers J.P.H. (2022).
*District nurses' attitudes towards involuntary treatment in dementia care at home:
a cross-sectional study.* Geriatr Nurs 2022; 47: 107-115.
DOI: 10.1016/j.gerinurse.2022.07.009

Abstract

One in two persons living with dementia (PLWD) at home receive care which they resist to and/or have not given consent to, defined as involuntary treatment. District nurses play a key role in the use of involuntary treatment. However, little is known how their attitudes and opinions influence the use of involuntary treatment. This cross-sectional study aims to investigate the attitudes of district nurses towards the use of involuntary treatment in dementia care at home, determinants and their opinion about its restrictiveness and discomfort. Results show that district nurses perceive involuntary treatment as regular part of nursing care, having neither positive nor negative attitude towards its appropriateness. They consider involuntary treatment usage as moderately restrictive to PLWD and feel moderately uncomfortable when using it. These findings underscore the need to increase the awareness of district nurses regarding the negative consequences of involuntary treatment use to PLWD at home.

Introduction

Worldwide, the number of people living with dementia is increasing.[1] Most of them live in their own home and wish to stay there as long as possible to have a meaningful life, and to remain engaged in daily life.[2-5] Due to cognitive and functional decline, persons living with dementia (PLWD) at home experience several problems, such as safety-related problems (e.g. wandering and falling), decreased self-reliance (e.g. problems related to self-care and lack of day structure) and/or informal caregiver-related problems due to the high load of care responsibility.[6, 7] Therefore, PLWD are in need of extensive support of (in)formal caregivers.[2] However, caring for them at home can be complicated and stressful for caregivers because of the progressive and unpredictable nature of dementia.[8] This especially affects caregivers who have insufficient experience and competences in dealing with the behavioural symptoms of dementia.[9] Moreover, when dementia further evolves, caregivers can experience problems in communicating with them and refusals of assistance with personal care, creating a dilemma between the creation of a safe environment and respecting their autonomy.[8, 10-13] As a result, PLWD can sometimes increasingly resist or refuse care.

Several terms are used in the literature to describe the care that persons resist or do not provide consent for, such as coercive care, resistiveness to care, forced treatment and involuntary treatment.[13-18] This study uses the term ‘involuntary treatment’, which is defined as care provided without the consent of the person receiving it and/or to which this person resists.[16] Involuntary treatment includes the use of: 1) Physical restraints, defined as any action or procedure that prevents 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 that is attached or adjacent to a person’s body and that he/ she cannot control or remove easily; [19] 2) off label use of psychotropic medication, defined as substances that act directly on the central nervous system, affecting mood, cognition and behaviour; [20] 3) and Non-consensual care, defined as any type of care that limits the organization of a person’s own life and to which a person resists to (e.g. locking in a room, use of electronic surveillance, force or pressure in activities of daily living (ADL). Recent research shows that involuntary treatment is provided to one out of two PLWD at home. The care that was provided by family caregivers and/or district nurses and was not mal-intended.[21] However, studies show that involuntary treatment has a negative impact on the physical and psychological well-being of PLWD.[21-24] Therefore, it is important that the use of involuntary treatment is prevented.

Recent research in dementia care at home shows that involuntary treatment is mostly requested by family caregivers (79%), followed by district nurses (39%) and general practitioners (30%), and used by family caregivers, (74%), district nurses (58%) and general practitioners (14%).[21] District nurses, in particular, are often involved in the application of involuntary treatment.[21, 25, 26] In Belgium, most of the technical nursing interventions activities that we defined as involuntary treatment, such as the use of physical restraints or forced hygiene, can be applied autonomously by district nurses, if they find it necessary to use them, for example for safety reasons.[27, 28] Since district nurses have a pivotal role in community dementia care, due to the strong relationship between them and their patients and their ability for assessing problems in daily care and the use of involuntary treatment, they could play a pivotal role in the prevention of it.[6, 29] The research of Haut et al. (2010) suggest that nursing staff attitudes influence the decision to use physical restraints.[30] Quantitative and qualitative studies in nursing homes show that although nurses have negative feelings towards the use of physical restraint, they perceive the need to use them in clinical practice and find the use of it an appropriate health care practice.[26, 30-33] However, thorough knowledge of district nurses' attitudes and opinions towards the use of involuntary treatment is scarce. To our knowledge, there is only one study available regarding this topic.[34] This study suggests that district nurses had no outspoken attitudes or opinions towards the use of involuntary treatment in dementia care at home. To generalize these results and gain further knowledge, we need to gain insight in the attitudes and opinions of district nurses in other countries. This knowledge, is needed to develop possible interventions that are aimed at obtaining a more negative attitude towards the acceptance of involuntary treatment.

The aim of this study is twofold. First, we want to explore district nurses' attitudes towards the use of involuntary treatment and their opinions about the restrictiveness and discomfort of involuntary treatment measures in dementia care at home. Second, we want to explore determinants that influence district nurses' attitudes and opinions towards involuntary treatment. Based on the literature, we formulated the following hypotheses: [26, 30-34]

1. District nurses have a neutral to positive attitude towards the appropriateness of involuntary treatment in dementia care at home.
2. The characteristics (age, experience, educational background, caregiver burden) of district nurses are associated with the attitude towards the use of involuntary treatment.
3. District nurses perceive involuntary treatment moderately restrictive for PLWD and felt moderately discomfortable when using them.
4. The characteristics (age, experience, educational background, caregiver burden) of district nurses are associated perceiving these measures restrictive for PLWD and feeling discomforting when using them.

Material and methods

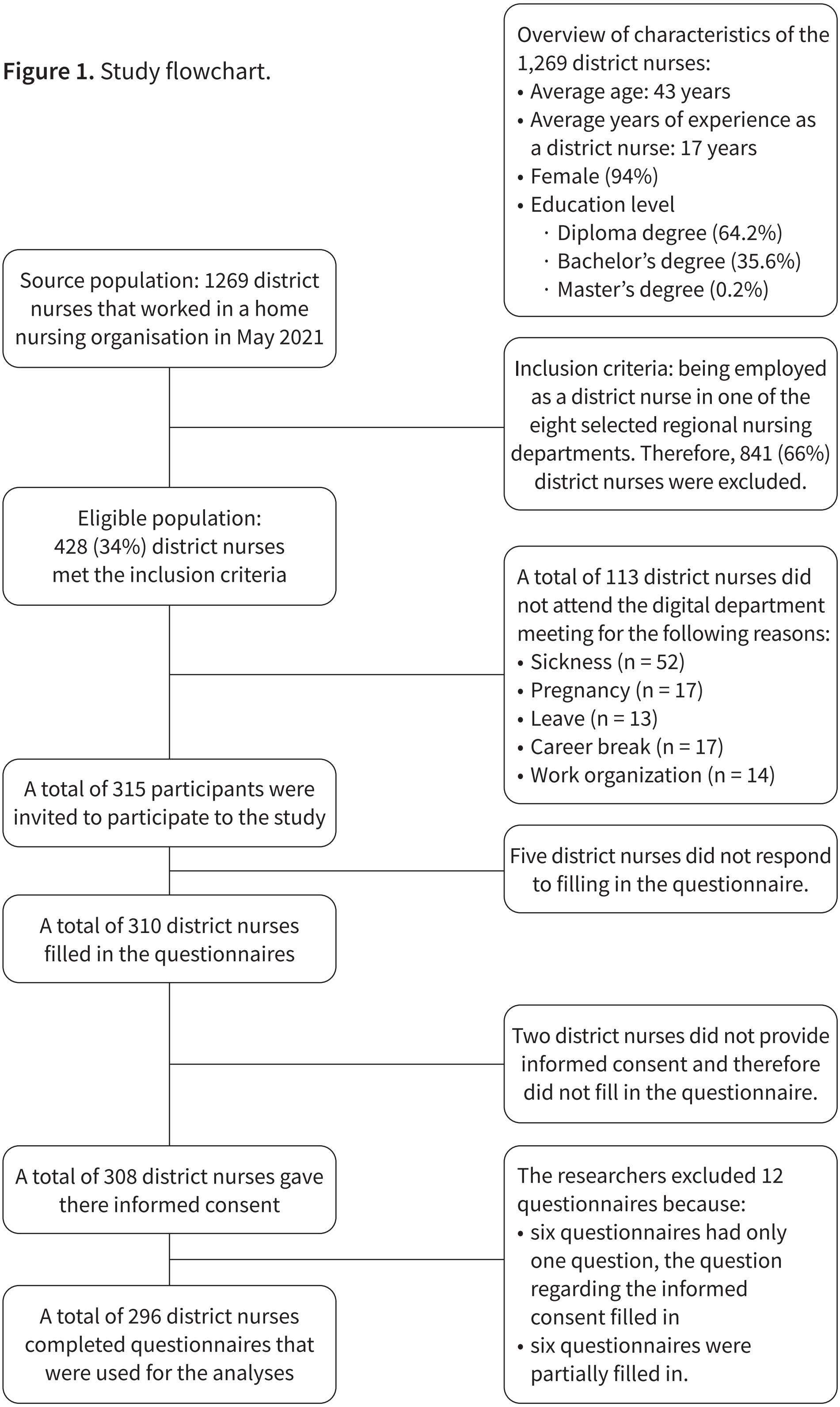
Settings and participants

We performed a cross-sectional study using an online-survey with a convenience sample of Belgium district nurses that are employed in an organisation that provides professional nursing care at home in the eastern part of Belgium. The home nursing organisation comprises [29] regional nursing departments. On average, 44 district nurses work in a regional nursing department who care for 542 patients. In Belgium, professional home care nursing is intended for persons who are in need of nursing care at home and is provided by district nurses. They can administer bathing and hygienic care, injections, wound care, stoma care, blather care, airway care, gastro-intestinal care and specific technical nursing interventions like intravenous perfusion. In addition to nursing care, the nurses also pay attention to family and social circumstances. District nurses are responsible for planning, coordinating, performing and evaluating the nursing care provided at a patient's home environment, belonging to their district.[18, 36, 37] Figure 1 shows that eight nursing departments of this home nursing organisation are selected through convenience sampling. In the eligible eight departments are 428 district nurses employed. In Belgium, district nurses are mostly registered nurses with a bachelor's degree or a diploma degree. Nurses with a diploma degree followed a more practical and vocational nursing training programme compared to nurses with a bachelor's or master's degree in nursing.[27, 35] All district nurses have experience in caring for PLWD.

Procedure

Data were collected during a regularly scheduled digital training of the eight eligible regional nursing departments between May 2021 and June 2021. A total of 315 of the 428 district nurses were scheduled to follow this digital meeting. Several weeks before the departmental meetings, the eligible district nurses and their head nurses were informed about background, aim and method of this the study by the principal researcher (VM) during digital meeting, by phone and by email. At the start of the digital training, the principal researcher repeated previous information using a pre-recorded informational video. Subsequently the participants were invited to complete an online questionnaire, using the online tool SurveyMonkey®. The participants could only start the online questionnaire, when they gave their written informed consent to participate in this study.

Figure 1. Study flowchart.



Ethical considerations

The Social and Societal Ethics Committee, one of the Medical Ethics Committees of the Leuven University Hospitals, approved the study protocol on 20 April 2021 (G- 2021 04 2053). All procedures were performed in accordance with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Participation was entirely voluntary. Anonymous answers guaranteed data confidentiality. No incentives were given to the district nurses for filling in the questionnaires. Informed consent was obtained from each participant.

Measurement

Table 1 provides an overview of the outcome variables and how they are measured. The outcome variables were district nurses' attitudes towards the use of involuntary treatment and their opinions about the restrictiveness and discomfort of the measures. To measure these, the Maastricht Attitude Questionnaire—Home Care (MAQ-HC) was used.[34] The MAQ-HC is based on the MAQ, which measures attitudes and opinions towards the use of physical restraints in nursing homes.[32] The MAQ-HC consists of two sections. The first section measures the attitudes towards the use of involuntary treatment and comprises four subscales, namely 1) involuntary treatment in general, 2) non-consensual care, 3) psychotropic medication and 4) physical restraints. The four subscales together comprise a total of 52 statements. Each statement is rated on a 5-point Likert scale, ranging from "totally disagree (score 1)" to "totally agree (score 5)". Examples of the statements were: *"You apply involuntary treatment to protect PLWD from danger", "PLWD should never be forced to wash" and "Physical restraint measures reduce the risk of injury for PLWD".* Several items have to be recoded, and for every item, a higher score represents a more positive attitude towards involuntary treatment. The mean scores of the subscale scores are calculated by adding up all the scores of the items in that subscale divided by the number of items in that subscale. A higher score represents a more positive attitude towards the use of involuntary treatment in general, physical restraints, psychotropic medication and non-consensual care, meaning that that the use was more accepted.

The second part of the MAQ-HC includes a 26-items on opinions regarding different measures of involuntary treatment (see supplemental material Table A for more information). Each measure is evaluated on a 3-point scale with regard to their restrictiveness for the person living with dementia (1 = not restrictive, 2 = moderately restrictive, and 3 = highly restrictive) and the extent of discomfort experienced by the district nurse when using this measure (1 = no discomfort, 2 = moderate discomfort, and 3 = high discomfort).

In 2016, the MAQ HC was developed based on the MAQ and has shown good validity and reliability.[34] The first section of the MAQ-HC had an Cronbach's alpha that ranged from 0.78 to 0.82 and for the second section from 0.84 to 0.86, indicating a good reliability.[34] The internal consistency results in our study were similar.

We collected the following background characteristics as independent variables: age (in years), years of experience as a district nurse in home care, gender, educational background and perceived burden of caring for a person living with dementia.

Table 1. Measures and outcome variables used in the study and their results.

Table 1a. Attitudes towards the use of involuntary treatment		
Outcome	**Nr. of questions**	**Range**
Attitude towards involuntary treatment in general (Mean Scores)[a]	15 items (5 points/item)	1-5
Attitude towards non-consensual care (Mean Scores)[a]	15 items (5 points/item)	1-5
Attitude towards psychotropic medication (Mean Scores)[a]	11 items (5 points/item)	1-5
Attitude towards physical restraints (Mean Scores)[a]	11 items (5 points/item)	1-5

Table 1b. Opinions towards the restrictiveness and discomfort of non-consensual care and physical restraints		
Outcome	**Nr. of questions**	**Range**
Opinion towards the restrictiveness of non-consensual care (Sum Scores) [b]	11 items (3 points/item)	11-33
Opinion towards the restrictiveness of physical restraints (Sum Scores) [b]	14 items (3 points/item)	14-42
Opinion towards the discomfort of non-consensual care (Sum Scores) [b]	11 items (3 points/item)	11-33
Opinion towards the discomfort of physical restraints (Sum Scores) [b]	14 items (3 points/item)	14-42

Table 1b. Opinions towards the restrictiveness and discomfort of psychotropic medication		
Outcome	**Nr. of questions**	**Range**
Opinion towards the restrictiveness of psychotropic medication (Score) [c]	1 item (3 points/item)	1-3
Opinion towards the discomfort of psychotropic medication (Score) [c]	1 item (3 points/item)	1-3

Note:

[a] For all attitude outcomes, a higher average sum of scores indicates higher acceptability of the applied treatment.

[b] For all opinion outcomes towards non-consensual care and physical restraints, a lower sum of scores indicates higher acceptability of the applied treatment.

[c] For all opinion outcomes towards psychotropic medication, a lower score indicates higher acceptability of the applied treatment.

Data analysis

Before the start of the data analyses, a total of 27 negative items were reverse coded, and for every item, a higher score represents a more positive attitude towards involuntary treatment. Only fully completed questionnaires were included in the analyses. Therefore, no missing items had to be handled.

Statistical analyses were performed using SPSS, version 26 (SPSS, Inc., Chicago, IL). Summaries descriptive of categorical data were expressed in terms of numbers and percentages for categorical variables and means and standard deviations (SDs) for continuous variables. Unadjusted associations were tested by means of Pearson's correlation coefficients, independent T-tests and one-way ANOVAs, as appropriate. Tukey's HSD corrections were used for post hoc analyses.

Adjusted analyses were conducted with multiple linear regression and multinomial logistic models for continuous (sum of score averages and sum scores) and categorical outcomes, respectively. We included all background variables in the model and performed a manual backward variables selection procedure. Multicollinearity was detected between 'years of experience' as a district nurse and 'age'; thus, the latter was not included in the models. Because of sparsity issues, 'gender' was also not considered in the multinomial logistic model. For all tests, a significance criterion of $p < 0.05$ (two-sided) was used.

Results

Sample characteristics

Figure 1 shows that, of the 315 district nurses that were invited to fill in the questionnaires, 296 district nurses (94%) returned fully completed questionnaires. **Figure 1** indicates that the distribution of age, years of experience and educational background of the participating 296 district nurses were similar to those of the 1,269 district nurses that were employed in the home health care organisation at the time the questionnaire was administered.

Table 2 provides an overview of the characteristics of the 296 district nurses that participated in this study. The mean age of participants was 42 years (95% confidence interval (CI): 41.07-43.73), and their mean years of working experience as a district nurse was 16 years (95% CI: 14.89-17.73). The vast majority of participants were female (96%).

Table 2. Sample characteristics.

	M (SD)/ N(%)
N	296
Age (years)	42 (11.7)
Experience as a district nurse in home care (years)	16 (12.4)

Note: Values are numbers (SD).

	M (SD)/ N(%)
N	296
Gender	
Male	12 (4%)
Female	284 (96%)
Educational background	
Diploma degree	184 (62%)
Bachelor’s degree	109 (37%)
Master’s degree	3 (1%)
Perceived burden of caring for persons living with dementia	
Never	10 (3%)
Rarely	48 (16%)
Now and then	188 (64%)
Often	47 (16%)
Always	3 (1%)

Note: The table shows absolute frequencies and proportions (in percent) in brackets.

District nurses’ attitudes regarding involuntary treatment

The mean of the average sum scores for attitudes towards involuntary treatment in general (Mean: 2.96; 95% CI: 2.91-3.00; SD: 0.35), non-consensual care (Mean: 3.08; 95% CI: 3.04-3.12; SD: 0.33), psychotropic medication (Mean: 2.95; 95% CI: 2.90-2.99; SD: 0.40) and physical restraints (Mean: 2.77; 95% CI: 2.72-2.83; SD: 0.44) indicated that district nurses had a rather neutral attitude towards the appropriateness of the use of involuntary treatment in dementia care at home.

Table 3. Multiple linear regression on nurses characteristics and attitudes towards involuntary treatment.

	Unstandardized coefficients		**p value**	**95% confidence interval for B**	
	B	**Std. Error**	**Sig.**	Lower Bound	Upper Bound
Involuntary treatment in general (a)					
(Constant)	2.791	0.057	<0.001	2.679	2.903
What is your experience as a district nurse (in years)?	**0.006**	0.002	0.001	**0.002**	**0.009**
Educational background (reference = diploma degree)	**-0.085**	0.041	0.037	**-0.166**	**-0.005**
Perceived burden of caring for persons living with dementia (reference = never/rarely)	**0.136**	0.050	0.008	**0.037**	**0.235**
Non-consensual care (b)					
(Constant)	2.947	0.054	<0.001	2.841	3.053
What is your experience as a district nurse (in years)?	**0.005**	0.002	0.002	**0.002**	**0.008**
Educational background (reference = diploma degree)	-0.071	0.039	0.067	-0.147	0.005
Perceived burden of caring for persons living with dementia (reference = never/rarely)	**0.101**	0.048	0.036	**0.007**	**0.195**
Psychotropic medication (c)					
(Constant)	2.557	0.123	<0.001	2.316	2.798
What is your experience as a district nurse (in years)?	**0.009**	0.002	<0.001	**0.005**	**0.012**
Gender (reference = male)	**0.235**	0.113	0.039	**0.012**	**0.457**
Educational background (reference = diploma degree)	**-0.115**	0.046	0.012	**-0.205**	**-0.025**
Perceived burden of caring for persons living with dementia (reference = never/rarely)	0.084	0.056	0.137	-0.027	0.194
Physical restraints (d)					
(Constant)	2.526	0.070	<0.001	2.387	2.664
What is your experience as a district nurse (in years)?	**0.009**	0.002	<0.001	**0.005**	**0.013**
Perceived burden of caring for persons living with dementia (reference = never/rarely)	**0.132**	0.064	0.040	**0.006**	**0.258**

Note: Included independent variables in Step 1: age (years), experience (years), gender, educational background (bachelor's/master's degree vs. diploma degree) and perceived burden of

caring for persons living with dementia (sometimes/often/always vs. never/rarely).
Dependent variables:
(a) Mean sum scores of involuntary treatment in general – Note Model: R = 0.254; R^2 = 0.064; p<0.001.
(b) Mean sum scores of non-consensual care – Note Model: R = 0.221; R^2 = 0.049; p = 0.002.
(c) Mean sum scores of psychotropic medication – Note Model: R = 0.333; R^2 = 0.111; p<0.001.
(d) Mean sum scores of physical restraints – Note Model: R = 0.254; R^2 = 0.065; p<0.001.

Associations between attitudes towards involuntary treatment and characteristics of district nurses

Table 3 shows the results of the multiple linear regression analyses (unadjusted comparisons are in supplemental material Table B). Nurses with more years of experiences as a district nurse had, in general, a more accepting attitude towards the use of involuntary treatment in general, non-consensual care, psychotropic medication and physical restraints. Each year increase in work experience was associated with a more accepting attitude towards these measures. District nurses with a higher educational background had, in general, a less accepting attitude towards the use of involuntary treatment, in general, and psychotropic medication. Finally, we found that district nurses who perceived the care for PLWD as burdensome had, in general, a more accepting attitude towards involuntary treatment in general, non-consensual care and physical restraints.

District nurses’ opinions towards the restrictiveness and discomfort of involuntary treatment

The mean of the sum scores of restrictiveness of non-consensual care (Mean: 23.11; 95% CI: 22.68-23.53; SD: 3.71) and physical restraints (Mean: 31.68; 95% CI: 31.12-32.23; SD: 4.89) and the mean score of restrictiveness of the use of psychotropic medication (Mean: 2.13; 95% CI: 2.07-2.20; SD: 4.89) indicate that district nurses perceive these measures as moderately restrictive for PLWD. Table A, included as supplemental material, shows that district nurses especially perceived measures that were attached or adjacent to the body and restricted freedom of movement, such as a fixation, ankle or wrist belt, as well as locking in, as highly restrictive. In addition, certain measures of non-consensual care, such as withholding walking aids, telephone or mail, were also perceived as highly restrictive. In contrast, measures that were used more covertly, such as camera surveillance, sensor mats or hiding medication, were perceived as less restrictive.

The mean of the sum scores of discomfort of non-consensual care (Mean: 23.84; 95% CI: 23.36-24.32; SD: 4.18), psychotropic medication (Mean: 2.04; 95%

CI: 1.98-2.11; SD: 0.57) and physical restraints (Mean: 31.06; 95% CI: 30.42-31.71 SD: 5.67) indicated that district nurses felt moderately uncomfortable when using these measures. Table A, included as supplemental material, indicates that district nurses felt very uncomfortable using measures that they perceive as highly restrictive for the person living with dementia when compared to measures they perceive as less restrictive.

Associations between opinions towards the restrictiveness and discomfort of involuntary treatment and characteristics of district nurses

Table 4 shows the results of the multiple linear regression analyses (unadjusted comparisons are in the supplemental material Table C.1 to C.2). We found that each year of increase in experience as a district nurse was associated with perceiving the application of non-consensual care and physical restraints as less restrictive for PLWD and feeling less uncomfortable when using them. In addition, perceiving the care of dementia patients as burdensome was associated with finding the use of physical restraints less restrictive for PLWD.

Table 5 shows the results of the multiple multinomial logistic regression analyses (unadjusted comparisons are in the supplemental material Table C.1 to C.3). Our results shows that each year of increase in experience as a district nurse was associated with a reduction in odds for finding the use of psychotropic medication as moderately or highly restrictive for PLWD. Our results show that there were no relevant associations between the characteristics of district nurses and finding the use of psychotropic medication in PLWD moderately or highly uncomfortable.

Table 4. Multiple linear regression on nurses characteristics and opinions towards restrictiveness and discomfort towards non-consensual care and physical restraints.

	Unstandardized coefficients		**p value**	**95% confidence interval for B**	
	B	**Std. Error**	**Sig.**	Lower Bound	Upper Bound
Restrictiveness					
Non-consensual care (a)					
(Constant)	24.732	0.597	<0.001	23.556	25,908
What is your experience as a district nurse (in years)?	**-0.047**	**0.017**	0.007	**-0.081**	**-0,013**
Perceived burden of caring for persons living with dementia (reference = never/rarely)	-1.065	0.544	0.051	-2.136	0.005
Physical restraints (b)					
(Constant)	36.872	1.510	<0.001	33.900	39.844
What is your experience as a district nurse (in years)?	**-0.080**	0.023	0.001	**-0.125**	**-0.035**
Gender (reference = male)	-2.629	1.412	0.064	-5.407	0.149
Perceived burden of caring for persons living with dementia (reference = never/rarely)	**-1.702**	0.703	0.016	**-3.086**	**-0.318**
Discomfort					
Non-consensual care (c)					
(Constant)	24.911	0.394	<0.001	24.135	25.687
What is your experience as a district nurse (in years)?	**-0.066**	0.019	0.001	**-0.103**	**-0.028**
Physical restraints (d)					
(Constant)	32.114	0.540	<0.001	31.052	33.177
What is your experience as a district nurse (in years)?	**-0.064**	0.026	0.015	**-0.116**	**-0.013**

Included independent variables in Step 1: age (years), experience (years), gender, educational background (bachelor's/master's degree vs. diploma degree) and perceived burden of caring for persons living with dementia (sometimes/often/always vs. never/rarely).
Dependent variables:

(a) Sum scores of restrictiveness non-consensual care – Note Model: $R = 0.179$; $R^2 = 0.032$; $p = 0.009$.

(b) Sum scores of restrictiveness of physical restraints – Note Model: $R = 0.262$; $R^2 = 0.069$; $p<0.001$.

(c) Sum scores of discomfort non-consensual care – Note Model: $R = 0.195$; $R^2 = 0.038$; $p = 0.001$.

(d) Sum scores of discomfort of physical restraints – Note Model: $R = 0.141$; $R^2 = 0.020$; $p = 0.015$.

Table 5. Multinomial logistic regression on nurses characteristics and opinions towards restrictiveness and discomfort towards psychotropic medication.

	Unstandardized coefficients		**p value**		**95% confidence interval for B**	
	B	**Std. Error**	**Sig.**	Odds Ratio	Lower Bound	Upper Bound
Restrictiveness psychotropic medication (a)						
Moderately restrictive vs. not restrictive						
What is your experience as a district nurse (in years)?	**-0.038**	0.015	0.015	0.963	**0.934**	**0.993**
Highly restrictive vs. not restrictive						
What is your experience as a district nurse (in years)?	**-0.067**	0.018	<0.001	0.935	**0.903**	**0.968**
Discomfort psychotropic medication (b)						
Moderate discomfort vs. no discomfort						
Educational background (reference = diploma degree)	-0.662	0.383	0.084	0.516	0.244	1.093
Perceived burden of caring for persons living with dementia (reference = never/rarely)	-0.757	0.395	0.056	0.469	0.216	1.018
High discomfort vs. no discomfort						
Educational background (reference = diploma degree)	0.568	0.405	0.491	0.730	0.299	1.785
Perceived burden of caring for persons living with dementia (reference = never/rarely)	-0.314	0.456	0.563	0.762	0.304	1.910

Note:
Included independent variables in Step 1: age (years), experience (years), gender, educational background (bachelor's/master's degree vs. diploma degree) and perceived burden of caring for persons living with dementia (sometimes/often/always vs. never/rarely).
Dependent variables:

(a) Scores of restrictiveness of psychotropic medication (Reference = not restrictive (coded as 1), moderately restrictive (coded as 2) and highly restrictive (coded as 3)) – Note Model: R^2 = 0.051 (Cox & Snell); 0.062 (Nagelkerke); Model X^2 (2) = 15.47; p<0.001.

(b) Sum scores of discomfort psychotropic medication (Reference = not discomfort (coded as 1), moderate discomfort (coded as 2) and high discomfort (coded as 3)). – Note Model: R^2 = 0.027 (Cox & Snell); 0.033 (Nagelkerke); Model X^2 (4) = 7.95; p = 0.093.

Discussion

This study was conducted to gain insight in the attitudes and opinions of district nurses towards the use of involuntary treatment in dementia care at home and to identify determinants that influence the same. The results of this study confirmed the formulated hypotheses that district nurses had no outspoken attitudes towards the appropriateness of involuntary treatment in dementia care at home. Furthermore, they perceive the application of involuntary treatment as moderately restrictive for the person living with dementia and felt moderately uncomfortable when using it. We also identified that having more years of experience in dementia care at home, a lower educational background or perceiving care for PLWD as burdensome, were associated with finding involuntary treatment use: 1) more appropriate to use; 2) less restrictive for the person living with dementia; and 3) less uncomfortable to use.

First, the finding that district nurses had no outspoken attitudes towards the appropriateness of the use of involuntary treatment in dementia care at home and had a slightly more positive attitude towards the application of non-consensual care and psychotropic medication when compared to the use of physical restraints confirms our hypotheses and could indicate that district nurses are not fully aware of the negative consequences of its use for PLWD. Similar results were found in studies conducted in home care and nursing home care.[26, 31, 33, 34]

Previous studies have shown that district nurses often perceive measures we define as the use of involuntary treatment as appropriate care. They consider their usage necessary and inevitable in order to let PLWD stay longer at home, to prevent greater harm and to provide respite for the family caregiver.[25, 38] Another reason why the use of involuntary treatment is seen as a good clinical practice by district nurses is that these measures are prescribed by a physician.[21, 25] Since district nurses have a key role in care planning and provision of person-centred dementia care at home, it is necessary that they adopt a more critical attitude when confronted with the application of and the decision-making process towards the use of involuntary treatment.[29] First, they should consider other safer and more person-centred alternatives. Especially in dementia care at home, where the vulnerability of their patients who are living with dementia is increased and where time for daily care is limited, critical reflection is needed.[39] Therefore, we need timely and continuous education and training (i.e. face to face and/or online workshops to increase awareness and knowledge about involuntary treatment and its alternatives), and support (i.e. consultation sessions to discuss case studies with and coaching on the job by a specialized nurse in dementia care) district nurses and all involved caregivers, so that they are in a better informed position and have the skills and attitudes to critically deal with decisions regarding the use of involuntary treatment in a person-centred manner.[13, 22, 40-43]

Our results also confirmed the hypothesis that district nurses perceive involuntary treatment moderately restrictive for PLWD and felt moderately discomfortable when using them. District district nurses experienced measures that were closely attached to the body (e.g., belts) or restrict freedom of living (e.g., withholding walking aids, telephone or mail) as more restrictive for PLWD and felt more uncomfortable using them when compared to more covert measures, such as camera surveillance, sensor mats or hiding medication. This finding, is similar to studies conducted in nursing homes that found nurses accept physical restraints that are attached to the body less readily than technical devices.[30, 31, 33] A possible explanation for these findings is that district nurses are more aware of the negative consequences of the application of physical restraints, such as pressure ulcers, injury or urinary and faecal incontinence.[44] These measures are more directly visibly compared to the indirect psychosocial consequences of long-term non-consensual care, such as loss of autonomy and self-esteem. This could indicate that district nurses approach their patients according to a rather traditional biomedical model instead of applying a more biopsychosocial approach, including the principles of person-centred care. If district nurses act more task-oriented and narrow their focus on self-care deficiency and safety to avoid health problems among PLWD, the risk exists that routine care, such as hygienic care, takes priority over the psychosocial aspects of the care provided, hindering them from observing the behaviour of their patients and how they respond to the care provided. As a result, district nurses will be unaware that non-consensual care can have serious consequences on the social, psychosocial and moral well-being of their patients.[45] They could perceive these measures as less restrictive for the person with dementia and feel less uncomfortable using them. Therefore, home health care organisations should invest in transforming into a true person-centred organisation. Furthermore, district nurses need to be trained in focusing less on what is done and more on how things are done. In addition, they need support in recognizing the needs and maintaining the selfhood of PLWD at home.[46]

Finally, our study results confirmed the hypotheses that years of experience as a district nurse, their educational background and caregiver burden were associated with their attitude and opinion towards the use of involuntary treatment. Our study found an association with educational background and the attitudes of nurses. District nurses with a diploma degree had a more accepting attitude towards involuntary treatment than nurses with a bachelor's or master's degree. These findings are consistent with studies in other nursing settings.[32, 47, 48] A possible reason for this is that educational background influences the professional values of practising nurses.[49] This finding is interesting, because it suggests that, if we increase the expertise level of district nurses, especially those with a diploma degree and if district nurses with bachelor's or master's degree support them, we could influence their professional values in dealing with the use of involuntary treatment in a more person-centred manner.[41, 50] Furthermore, several studies in nursing homes confirmed our finding that more experienced nurses had a more positive attitude towards accepting the use of physical restraints.[31, 33] In addition, the study of Mengelers et al. (2018) confirms the association between perceiving caring for a person living with dementia as burdensome and a positive attitude towards the use of involuntary treatment.[34] A possible explanation for this finding could be that the use of involuntary treatment could be an inappropriate coping mechanism for dealing with long-term moral distress. Studies suggest that finding the care for persons with dementia as burdensome could be a source for moral distress.[23, 51] The consequences of nurse moral distress identified in the literature include desensitization and depersonalization of patients.[23, 28, 51] This could mean that, through long-term caregiver burden, district nurses could become less sensitive towards the negative consequences of involuntary treatment for PLWD and thus become more accepting of its use. Therefore, we should provide continuous support and training to all involved caregivers regarding interaction and communication with PLWD, interventions involving music, approaching PLWD like bathing techniques, ability focused approach, distraction approach, knowledge about person-centred care and dementia care mapping. In this way, they can learn to deal with the behavioural symptoms of dementia in a timely and person-centred manner in order to apply quality dementia care and avoid moral distress for themself.[13, 22, 40, 52]

Methodological considerations

A limitation of this study is the sampling strategy, as the eight regional departments were a convenience sample. This could increase the risk for sampling bias. For this reason, we analysed if the heterogeneity of our sample was similar to those of the organisation where the study was performed. Our analysis showed that the variation in our sample was the same. In addition, the high willingness of the regional departments to participate and high response rate (94%) of the participants could contributed to a low risk of self-selection bias.

Another limitation is that this study is that it was performed in one region in Belgium. Therefore, one must be careful not to generalize the results of our study to other regions in Belgium and other countries. However, the results of our study were in line with a similar study performed in the Netherlands and confirm that district nurses have a rather neutral attitude towards the acceptance of involuntary treatment.[13, 34]

Implications for clinical practice and research

Despite numerous known negative effects of measures we defined as involuntary treatment, it is commonly used in dementia care at home, worldwide.[13, 15, 21, 25, 53, 54] To prevent its use and to deliver person-centred care, several multicomponent interventions like PRITAH, EIT-4-BPSD were developed and tested, recently.[55-57] These interventions had most often the following components: 1) assessment of environment and policies; 2) staff education, 3) person-centred care plans and 4) mentoring staff. Although some results were promising, no effect could be found and several barriers were identified such as care interactions, delivering true person-centred care or a lack of common vision.[55-57] A possible explanation for these barriers could be found in the results of this study, namely that caregivers felt neutral about involuntary treatment and considered its use an appropriate clinical practice. Studies in nursing homes, found similar results.[26, 30-34, 54] If we want to increase the effect rate of multicomponent intervention, caregivers and researchers need to gain a more negative attitude towards the use of these measures. Therefore, it is crucial that we increase their sensitivity and awareness of the negative consequences and mal-conceptions of involuntary treatment use in all caregivers involved and increase their knowledge about person-centred alternatives.[13, 52] In addition, all caregivers should be stimulated to critical reflect and discuss on decisions regarding involuntary treatment within their multidisciplinary teams. Moreover, we suggest that evidence based governmental policies encourage and impose these multidisciplinary discussion and person-centred alternatives, when caregivers are confronted with care situations that can evolve in involuntary treatment use. District nurses could have a pivotal role in these discussions. Therefore, we must foster their communication skills and value-based leadership, so they can engage in dialogue with them.[39, 58] When training and supporting professional caregivers, we should address the determinants that are associated with more accepting attitudes and opinions. Otherwise, they could become possible impediments or even barriers for successful implementing multicomponent interventions.

To gain further insights as to how district nurses can be supported in dealing with involuntary treatment, qualitative research is needed that identifies and describes the experiences of district nurses in dealing with the decision-making process towards the use of involuntary treatment in dementia nursing care at home.

Conclusion

This cross-sectional study found that district nurses have no outspoken attitudes or opinions towards the use of involuntary treatment. We identified that having more experience in dementia care at home, perceiving care as burdensome or having a lower educational background influenced their attitudes and opinions towards the use of involuntary treatment. These insights can help researchers and/or health professionals to develop and successfully implement nursing interventions that prevent and reduce the use of involuntary treatment in dementia care at home.

Conflict of interest

None declared.

Funding

No external source of funding.

Acknowledgments

We thank the participating district nurses, head nurses and staff of the White and Yellow Cross Limburg in Belgium.

References

1. World Health Organization. Towards a dementia plan: a WHO guide. 2018.
2. Alzheimer Association. 2021 Alzheimer's disease facts and figures. *Alzheimers Dement* 2021; 17: 327-406. 2021/03/24. DOI: 10.1002/alz.12328.
3. von Kutzleben M, Schmid W, Halek M, et al. Community-dwelling persons with dementia: what do they need? What do they demand? What do they do? A systematic review on the subjective experiences of persons with dementia. *Aging Ment Health* 2012; 16: 378-390. 2012/01/19. DOI: 10.1080/13607863.2011.614594.
4. van Vliet D, Persoon A, Bakker C, et al. Feeling useful and engaged in daily life: exploring the experiences of people with young-onset dementia. *Int Psychogeriatr* 2017; 29: 1889-1898. 2017/07/14. DOI: 10.1017/S1041610217001314.
5. van Corven CT, Bielderman A, Wijnen M, et al. Defining empowerment for older people living with dementia from multiple perspectives: A qualitative study. *Int J Nurs Stud* 2021; 114: 103823. 2020/12/01. DOI: 10.1016/j.ijnurstu.2020.103823.
6. Thoma-Lürken T, Bleijlevens MH, Lexis MA, et al. Facilitating aging in place: A qualitative study of practical problems preventing people with dementia from living at home. *Geriatr Nurs* 2018; 39: 29-38. DOI: 10.1016/j.gerinurse.2017.05.003.
7. Black BS, Johnston D, Rabins PV, et al. Unmet Needs of Community-Residing Persons with Dementia and Their Informal Caregivers: Findings from the Maximizing Independence at Home Study. *J Am Geriatr Soc* 2013; 61: 2087-2095. DOI: 10.1111/jgs.12549.
8. Moermans VR, Mengelers AM, Bleijlevens MH, et al. Caregiver decision-making concerning involuntary treatment in dementia care at home. *Nurs Ethics* 2021; 29: 330-343. DOI: 10.1177/09697330211041742.
9. Chiao CY, Wu HS and Hsiao CY. Caregiver burden for informal caregivers of patients with dementia: a systematic review. *Int Nurs Rev* 2015; 62: 340-350. DOI: doi.org/10.1111/inr.12194
10. Giertz L, Emilsson UM and Vingare E-L. Family caregivers and decision-making for older people with dementia. J *Soc Welf and Fam Law* 2019; 41: 321-338. DOI: 10.1080/09649069.2019.1627087.
11. van Manen AS, Aarts S, Metzelthin SF, et al. A communication model for nursing staff working in dementia care: Results of a scoping review. *Int J Nurs Stud* 2021; 113: 1-14. DOI: 10.1016/j.ijnurstu.2020.103776.
12. Häikiö K, Sagbakken M and Rugkåsa J. Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services. *BMC Health Serv Res* 2019; 19: 1-13.

DOI: 10.1186/s12913-019-4478-2.

13. Backhouse T, Dudzinski E, Killett A, et al. Strategies and interventions to reduce or manage refusals in personal care in dementia: A systematic review. *Int J Nurs Stud* 2020; 109: 103640. DOI: 10.1016/j.ijnurstu.2020.103640.
14. Galik E, Resnick B, Vigne E, et al. Reliability and Validity of the Resistiveness to Care Scale Among Cognitively Impaired Older Adults. J *Am Med Dir Assoc* 2017; 18: 59-64. DOI: 10.1016/j.jamda.2016.08.008.
15. Gjellestad Å, Oksholm T and Bruvik F. Forced treatment and care in home-dwelling persons with dementia. *Nurs Ethics* 2020; 28: 372-386. DOI: 10.1177/0969733020948107.
16. Hamers JP, Bleijlevens MH, Gulpers MJ, et al. Behind Closed Doors: Involuntary Treatment in Care of Persons with Cognitive Impairment at Home in the Netherlands. *J Am Geriatr Soc* 2016; 64: 354-358. DOI: 10.1111/jgs.13946.
17. Lejman E, Westerbotn M, Pöder U, et al. The ethics of coercive treatment of people with dementia. *Nurs Ethics* 2013: 248-262. DOI: 10.1177/0969733012463721.
18. Moermans VR, Bleijlevens MH, Verbeek H, et al. The Use of Involuntary Treatment among Older Adults with Cognitive Impairment Receiving Nursing Care at Home: A Cross-sectional Study. *Int j Nurs Stud* 2018; 88: 135-142. DOI: 10.1016/j.ijnurstu.2018.09.004.
19. Bleijlevens M, Wagner L, Capezuti E, et al. A Delphi consensus study to determine an internationally accepted definition on physical restraints. In: *Gerontologist* 2012, pp.136-136.
20. Voyer P, Cohen D, Lauzon S, et al. Factors associated with psychotropic drug use among community-dwelling older persons: A review of empirical studies. *BMC Nurs* 2004; 3: 1-13. DOI: 10.1186/1472-6955-3-3.
21. Mengelers AM, Moermans VR, Bleijlevens MH, et al. Involuntary treatment in dementia care at home: Results from the Netherlands and Belgium. *J Clin Nurs* 2022; 31: 1998-2007. DOI: 10.1111/jocn.15457.
22. Kim SK and Park M. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clin Interv Aging* 2017; 12: 381-397. DOI: 10.2147/CIA.S117637.
23. Oh Y and Gastmans C. Moral distress experienced by nurses: a quantitative literature review. *Nurs Ethics* 2015; 22: 15-31. DOI: 10.1177/0969733013502803.
24. Thyrian JR, Hertel J, Wucherer D, et al. Effectiveness and Safety of Dementia Care Management in Primary Care: A Randomized Clinical Trial. *JAMA Psychiatry* 2017; 74: 996-1004. DOI: 10.1001/jamapsychiatry.2017.2124.

25. Scheepmans K, Dierck de Casterlé B, Paquay L, et al. Restraint use in older adults in home care: A systematic review. *Int J Nurs Stud* 2018; 79: 122-136. DOI: 10.1016/j.ijnurstu.2017.11.008.
26. Möhler R and Meyer G. Attitudes of nurses towards the use of physical restraints in geriatric care: A systematic review of qualitative and quantitative studies. *Int J Nurs Stud* 2014; 51: 274-288. DOI: 10.1016/j.ijnurstu.2013.10.004.
27. Scheepmans K, Dierckx de Casterlé B, Paquay L, et al. Restraint use in home care: a qualitative study from a nursing perspective. *BMC Geriatr* 2014; 14: 1-7. DOI: 10.1186/1471-2318-14-17.
28. Gastmans C and Milisen K. Use of physical restraint in nursing homes: clinical-ethical considerations. *J Med Ethics* 2006; 32: 148-152. DOI: 10.1136/jme.2005.012708.
29. Gibson C, Goeman D, Hutchinson A, et al. The provision of dementia care in general practice: practice nurse perceptions of their role. *BMC Fam Pract* 2021; 22: 1-13. 2021/06/11. DOI: 10.1186/s12875-021-01467-z.
30. Haut A, Kolbe N, Strupeit S, et al. Attitudes of relatives of nursing home residents toward physical restraints. *J Nurs Scholarsh* 2010; 42: 448-456. DOI: 10.1111/j.1547-5069.2010.01341.x.
31. Ferrão SAdS, Bleijlevens MH, Nogueira PJ, et al. A cross-sectional study on nurses' attitudes towards physical restraints use in nursing homes in Portugal. *Nurs Open* 2021; 8: 1571-1577. DOI: 10.1002/nop2.769.
32. Hamers JP, Meyer G, Köpke S, et al. Attitudes of Dutch, German and Swiss nursing staff towards physical restraint use in nursing home residents, a cross-sectional study. *Int J Nurs stud* 2009; 46: 248-255. DOI: 10.1016/j.ijnurstu.2008.06.007.
33. Mayerl H, Trummer T, Stolz E, et al. Nursing professionals’ attitudes toward use of physical restraints in Styrian nursing homes Austria. *Pflege* 2018; 2018: 1-7. DOI: 10.1024/1012-5302/a000649.
34. Mengelers AM, Bleijlevens MH, Verbeek H, et al. Professional and family caregivers’ attitudes towards involuntary treatment in community- dwelling people with dementia. *J Adv Nurs* 2018; 75: 96-107. DOI: 10.1111/jan.13839.
35. Rafferty AM, Busse R, Zander-Jentsch B, et al. *Strengthening health systems through nursing: Evidence from 14 European countries.* World Health Organization. Regional Office for Europe, 2019.
36. Flemish Government. District Nursing, https://www.vlaanderen.be/thuisverpleging (2022, accessed 23-06-2022).
37. De Vliegher K, Paquay L, Grypdonck M, et al. A study of core interventions in home nursing. *Int J Nurs Stud* 2005; 42: 513-520.

DOI: 10.1016/j.ijnurstu.2004.09.013.
38. Scheepmans K, Dierckx de Casterlé B, Paquay L, et al. Restraint Use in Older Adults Receiving Home Care. *J Am Geriatr Soc* 2017; 65: 1769-1776. DOI: 10.1111/jgs.14880.
39. Goethals S, Dierckx de Casterlé B and Gastmans C. Nurses' ethical reasoning in cases of physical restraint in acute elderly care: a qualitative study. *Med Health Care Philos* 2013; 16: 983-991. DOI: 10.1007/s11019-012-9455-z.
40. Sefcik JS, Boltz M, Dellapina M, et al. Are Interventions for Formal Caregivers Effective for Improving Dementia Care? A Systematic Review of Systematic Reviews. *Innov Aging* 2022; 6: 1-16. DOI: 10.1093/geroni/igac005.
41. Eskandari F, Abdullah KL, Zainal NZ, et al. The effect of educational intervention on nurses' knowledge, attitude, intention, practice and incidence rate of physical restraint use. *Nurse Educ Pract* 2018; 32: 52-57. DOI: 10.1016/j.nepr.2018.07.007.
42. Lan S-H, Lu L-C, Lan S-J, et al. Educational intervention on physical restraint use in long-term care facilities–Systematic review and meta-analysis. Kaohsiung *J Med Sci* 2017; 33: 411-421. DOI: 10.1016/j.kjms.2017.05.012.
43. Mengelers AM, Bleijlevens MHC, Verbeek H, et al. Prevention and reduction of involuntary treatment at home: A feasibility study of the PRITAH intervention. *Geriatr Nurs* 2020; 41: 536-543. DOI: 10.1016/j.gerinurse.2020.02.001.
44. Hofmann H and Hahn S. Characteristics of nursing home residents and physical restraint: a systematic literature review. *J Clin Nurs* 2014; 23: 3012-3024. DOI: 10.1111/jocn.12384.
45. Goethals S, Dierckx de Casterlé B and Gastmans C. Nurses' decision-making in cases of physical restraint: a synthesis of qualitative evidence. *J Adv Nurs* 2012; 68: 1198-1210. DOI: 10.1111/j.1365-2648.2011.05909.x.
46. Fazio S, Pace D, Flinner J, et al. The Fundamentals of Person-Centered Care for Individuals With Dementia. *Gerontologist* 2018; 58: S10-S19. DOI: 10.1093/geront/gnx122.
47. Eskandari F, Abdullah KL, Zainal NZ, et al. Use of physical restraint: Nurses' knowledge, attitude, intention and practice and influencing factors. *J Clin Nurs* 2017. DOI: 10.1111/jocn.13778.
48. Kassew T, Dejen Tilahun A and Liyew B. Nurses' Knowledge, Attitude, and Influencing Factors regarding Physical Restraint Use in the Intensive Care Unit: A Multicenter Cross-Sectional Study. *Crit Care Res Pract* 2020; 2020: 1. DOI: 10.1155/2020/4235683.
49. Sibandze BT and Scafide KN. Among nurses, how does education level impact professional values? A systematic review. *Int Nurs Rev* 2018; 65: 65-77.

DOI: 10.1111/inr.12390.

50. Gulpers MJ, Bleijlevens MH, Ambergen T, et al. Reduction of Belt Restraint Use: Long-Term Effects of the EXBELT Intervention. *J Am Geriatr Soc* 2013; 61: 107-112. DOI: 10.1111/jgs.12057.
51. McAndrew NS, Leske J and Schroeter K. Moral distress in critical care nursing: the state of the science. *Nurs Ethics* 2018; 25: 552-570. DOI: 10.1177/0969733016664975.
52. Mohr W, Rädke A, Afi A, et al. Key intervention categories to provide person-centered dementia care: A systematic review of person-centered interventions. *J Alzheimer's Dis* 2021; 84: 343-366. DOI: 10.3233/JAD-210647.
53. Fauth EB, Femia EE and Zarit SH. Resistiveness to care during assistance with activities of daily living in non-institutionalized persons with dementia: associations with informal caregivers' stress and well-being. *Aging Ment Health* 2016; 20: 888-898. DOI: 10.1080/13607863.2015.1049114.
54. Pu L and Moyle W. Restraint use in residents with dementia living in residential aged care facilities: A scoping review. *J Clinl Nurs* 2020; 31: 2008-2023. DOI: 10.1111/jocn.15487.
55. Resnick B, Van Haitsma K, Kolanowski A, et al. Implementation of the Evidence Integration Triangle for behavioral and psychological symptoms of dementia (EIT-4-BPSD) in care communities. *Nurs outlook* 2021; 69: 1058-1071. DOI: 10.1016/j.outlook.2021.06.004.
56. Vandervelde S, Scheepmans K, Milisen K, et al. Reducing the use of physical restraints in home care: development and feasibility testing of a multicomponent program to support the implementation of a guideline. *BMC Geriatr* 2021; 21: 1-18. DOI: 10.1186/s12877-020-01946-5.
57. Mengelers AM, Bleijlevens MH, Verbeek H, et al. A Quasi-experimental study on prevention and reduction of involuntary treatment at home (PRITAH) in people with dementia. *J Clin Nurs* 2021 2021/12/09. DOI: 10.1111/jocn.16163.
58. Denier Y, Dhaene L and Gastmans C. 'You can give them wings to fly': a qualitative study on values-based leadership in health care. *BMC Med Ethics* 2019; 20: 35. DOI: 10.1186/s12910-019-0374-x.

Supplemental material:

Table A. Mean scores of opinions about restrictiveness and discomfort of every participant.

	Restrictiveness mean (SD)	Discomfort mean (SD)
Non-consensual care		
1. Withholding aids (e.g., walking aids)	2.65 (0.60)	2.68 (0.52)
2. Withholding the telephone	2.39 (0.64)	2.50 (0.58)
3. Withholding the mail	2.28 (0.70)	2.39 (0.68)
4. Forced hygiene	2.19 (0.59)	2.42 (0.59)
5. Withholding car(keys)	1.95 (0.77)	1.93 (0.77)
6. Forced administration of food/fluids	2.12 (0.58)	2.39 (0.57)
7. Forced administration of medication	2.10 (0.54)	2.36 (0.58)
8. Shutting off gas	1.93 (0.71)	1.92 (0.75)
9. Hidden administration of medication (e.g., in food)	1.96 (0.67)	1.99 (0.70)
10. Hiding prescribed medication	1.71 (0.70)	1.74 (0.65)
11. Hiding medication (painkillers)	1.82 (0.65)	1.59 (0.66)
Psychotropic medication		
12. Use of psychotropic medication	2.13 (0.59)	2.06 (0.57)
Physical restraints		
13. Fixation belt	2.62 (0.54)	2.55 (0.60)
14. Vest with fixation belt	2.58 (0.56)	2.55 (0.58)
15. Ankle belt	2.52 (0.66)	2.56 (0.60)
16. Wrist belt	2.44 (0.68)	2.52 (0.64)
17. Locking in house	2.46 (0.59)	2.41 (0.62)
18. Tightly tucked sheet	2.43 (0.58)	2.41 (0.64)
19. Bilateral bedrails	2.32 (0.62)	2.11 (0.68)
20. Sleep suit	2.30 (0.59)	2.22 (0.67)
21. (Wheel)chair with locked tray table	2.25 (0.61)	2.00 (0.67)
22. Special sheet	2.20 (0.60)	2.20 (0.66)
23. Deep/overturned chair	2.18 (0.59)	2.10 (0.63)
24. (Wheel)chair on a board	2.14 (0.59)	2.13 (0.65)
25. Camera surveillance	1.66 (0.67)	1.73 (0.72)
26. Sensor mat	1.58 (0.63)	1.63 (0.63)

Note: The table shows mean scores. Items were rated on a 3-point Likert scale indicating the following for restrictiveness: 1 = not restrictive, 2 = moderately restrictive and 3 = highly restrictive and for discomfort: 1 = no discomfort, 2 = moderate discomfort and 3 = high discomfort. Values are mean (standard deviation).

Table B. Unadjusted analyses of the attitudes towards involuntary treatment.

Table B.1. Unadjusted analyses of the correlations between attitudes towards involuntary treatment and age and experience as a district nurse in home care.

	Involuntary treatment in general	p value	Non-consensual care	p value	Psychotropic medication	p value	Physical restraints	p value
Age (years)	**0.127**	0.029	**0.096**	0.098	**0.296**	< 0.001	**0.153**	0.008
Experience as a district nurse in home care (years)	**0.165**	0.004	**0.153**	0.008	**0.264**	< 0.001	**0.226**	< 0.001

Note: Items were rated on a 5-point Likert scale indicating 1 as strong disagreement or negative attitude and 5 as strong agreement or positive attitude. The correlation between age (years), experience (years) and the MAQ-HC scores were calculated using Pearson correlation coefficients.

Table B.2. Unadjusted analyses of the differences in the attitudes towards involuntary treatment and gender, educational background and perceived burden of caring for persons living with dementia.

	Involuntary treatment in general*	p value	Non-consensual care*	p value	Psychotropic medication*	p value	Physical restraints*	p value
	2.96 (0.35)		3.08 (0.33)		2.95 (0.40)		2.77 (0.44)	
Gender**								
Male	2.83 (0.35)	0.207	3.08 (0.22)	0.956	**2.64 (0.40)**	0.006	2.57 (0.38)	0.100
Female	2.96 (0.35)		3.08 (0.33)		**2.96 (0.39)**		2.78 (0.45)	
Educational background**								
Diploma degree (N = 184)	**2.99 (0.32)**	0.064	3.10 (0.31)	0.102	**2.99 (0.37)**	0.024	2.80 (0.41)	0.274
Bachelor's/ Master's degree (N = 112)	**2.91 (0.39)**		3.04 (0.36)		**2.88 (0.43)**		2.74 (0.49)	
Perceived burden of caring for persons living with dementia***								
Never and seldom (N = 58)	**2.87 (0.47)**	$0.001^{a,b,c,d}$	**3.02 (0.39)**	$0.003^{a,b,c,d}$	**2.92 (0.48)**	$0.034^{b,c}$	**2.70 (0.50)**	$0.001^{a,b,c,d}$
Now and then (N = 188)	**2.94 (0.31)**		**3.06 (0.31)**		**2.92 (0.37)**		**2.74 (0.42)**	
Often and Always (N = 50)	**3.11 (0.29)**		**3.22 (0.29)**		**3.08 (0.40)**		**2.98 (0.43)**	

Note:

* Items were rated on a 5-point Likert scale indicating 1 as strongly disagree or negative attitude and 5 as strongly agree or positive attitude. Values are mean (standard deviation).

** Difference between gender and educational background was analysed using the independent T-test.

*** Difference between perceived burden and MAQ-HC scores was analysed using one-way ANOVAs and post hoc Tukey HSD tests.

[a] Significant difference between 'Never and seldom' and 'Often and always'.

[b] Significant difference between 'Now and then' and 'Often and always'.

[c] Significant difference between 'Often and always' and 'Now and then'.

[d] Significant difference between 'Often and always' and 'Never and seldom'.

Table C. Unadjusted analyses of the opinions towards the restrictiveness and discomfort of involuntary treatment.

Table C.1. Unadjusted analyses of the correlations between opinions towards involuntary treatment and age and experience as a district nurse in home care.

	Restrictiveness						**Discomfort**					
	Non-consensual care	p value	Psychotropic medication	p value	Physical restraints	p-value	Non-consensual care	p value	Psychotropic medication	p value	Physical restraints	p value
Age (years)	**-0.115**	0.048	**-0.226**	<0.001	**-0.155**	0.008	**-0.130**	0.025	-0.002	0.973	**-0.114**	0.051
Experience as a district nurse in home care (years)	**-0.139**	0.017	**-0.225**	<0.001	**-0.196**	0.001	**-0.195**	0.001	-0.027	0.649	**-0.141**	0.015

Note: Items were rated on a 3-point Likert scale indicating the following for restrictiveness: 1 = not restrictive, 2 = moderately restrictive and 3 = highly restrictive and for discomfort: 1 = no discomfort, 2 = moderate discomfort and 3 = high discomfort. The correlation between age (years), experience (years) and the MAQ-HC scores were calculated using Pearson correlation coefficients.

Table C.2. Unadjusted analyses of the differences in the opinions towards involuntary treatment and gender, educational background and perceived burden of caring for persons living with dementia.

	Restrictiveness						Discomfort					
	Non-consensual care	p value	Psychotropic medication	p value	Physical restraints	p value	Non-consensual care	p value	Psychotropic medication	p value	Physical restraints	p value
	23.11 (3.71)		2.13 (0.58)		31.68 (4.89)		23.84 (4.18)		2.04 (0.57)		31.06 (5.67)	
Gender **												
Male	23.58 (2.64)	0.652	**2.75** **(0.45)**	<0.001	**34.83** **(4.22)**	0.022	23.83 (3.51)	0.995	**2.33** **(0.49)**	0.070	32.58 (4.50)	0.344
Female	23.09 (3.75)		**2.11** **(0.57)**		**31.54** **(4.88)**		23.84 (4.21)		**2.03** **(0.57)**		31.00 (5.71)	
Educational background **												
Diploma degree (N = 184)	23.10 (3.51)	0.977	2.13 (0.60)	0.798	31.44 (5.00)	0.289	23.82 (4.25)	0.891	2.03 (0.60)	0.660	30.73 (5.70)	0.192
Bachelor’s/Master’s degree (N = 112)	23.12 (4.04)		2.14 (0.55)		32.06 (4.69)		23.88 (4.08)		2.06 (0.51)		31.62 (5.60)	
Perceived burden of caring for persons living with dementia ***												
Never and seldom (N = 58)	**23.78** **(4.10)**	0.065	2.17 (0.60)	0.450	32.71 (4.42)	0.143	23.95 (4.06)	0.229	2.02 (0.66)	0.915	31.38 (5.33)	0.736
Now and then (N = 188)	**23.16** **(3.53)**		2.14 (0.56)		31.56 (4.90)		24.05 (4.10)		2.05 (0.55)		31.11 (5.66)	
Often and always (N = 50)	**22.12** **(3.78)**		2.04 (0.64)		31.92 (5.26)		22.92 (4.56)		2.06 (0.51)		30.54 (6.12)	

Note:

* Items were rated on a 3-point Likert scale indicating the following for restrictiveness: 1 = not restrictive, 2 = moderately restrictive and 3 = highly restrictive and for discomfort: 1 = no discomfort, 2 = moderate discomfort and 3 = high discomfort. Values are sum scores (standard deviation). Non-consensual care: sum score of 11 items (range 11-33), psychotropic medication: score of 1 item (range 1-3) and physical restraints: sum score of 14 items (range 14-42).

** Difference between gender and educational background was analysed using independent T-tests.

*** Difference between perceived burden and MAQ-HC scores was analysed using one-way ANOVAs and post-hoc Tukey HSD tests.

Table C.3. Distribution of the proportions of the variables of restrictiveness and discomfort towards psychotropic medication.

	Restrictiveness to psychotropic medication			**Discomfort to psychotropic medication**		
	1 = Not restrictive	2 = Moderately restrictive	3 = Highly restrictive	1 = No discomfort	2 = Moderate discomfort	3 = High discomfort
Gender						
Male	0 (0)	3 (25)	9 (75)	0 (0)	8 (67)	4 (33)
Female	33 (12)	188 (66)	64 (22)	41 (14)	193 (68)	50 (18)
Educational level						
Diploma degree (N = 184)	23 (13)	115 (63)	46 (25)	30 (16)	118 (64)	36 (20)
Bachelor's/Master's degree (N = 112)	10 (9)	76 (68)	26 (23)	11 (10)	83 (74)	18 (16)
Perceived burden of caring for persons living with dementia						
Never and seldom (N = 58)	6 (10)	36 (62)	16 (28)	12 (21)	33 (57)	13 (22)
Now and then (N = 188)	18 (10)	125 (66)	45 (24)	24 (13)	131 (70)	33 (18)
Often and always (N = 50)	9 (18)	30 (60)	11 (22)	5 (10)	37 (74)	8 (16)

Note: The table shows absolute frequencies and proportions (in percent) in brackets.

CHAPTER 6

District nurses' experiences with involuntary treatment in dementia care at home: A qualitative descriptive study

This chapter was published as:

Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Dierckx de Casterlé B.,
Milisen K. & Hamers J.P.H. (2023).
District nurses experiences in dealing with involuntary treatment in dementia care
at home, A qualitative descriptive study.
Submitted for publication

Abstract

Background

Research shows that half of person(s) living with dementia (PLWD) receive care which they resist and/or have not given consent to, defined as involuntary treatment. District nurses play a key role in providing this care. Knowledge about how district nurses experience involuntary treatment is lacking. Therefore, the aim of this study was to describe the experiences of district nurses who used involuntary treatment for PLWD at home.

Methods

A qualitative descriptive design using semi-structured interviews. Sixteen district nurses with experience in involuntary treatment for PLWD were recruited through purposive sampling. Data were analysed using the Qualitative Analysis Guide of Leuven.

Results

District nurses' experiences with involuntary treatment were influenced by their involvement in the decision-making process. When they were involved, they considered involuntary treatment use to be appropriate care. However, at the moment that involuntary treatment use was started, district nurses were worried that its use was unjust since they wished to respect the wishes of the PLWD. Eventually, district nurses found, from a professional perspective, that involuntary treatment use was necessary, and that safety outweighed the autonomy of the PLWD. District nurses experienced dealing with this dilemma as stressful, due to conflicting values. If district nurses were not involved in the decision-making process regarding the use of involuntary treatment, family caregivers generally decided on its use. Often, district nurses perceived this request as inappropriate dementia care and they first tried to create a dialogue with the family caregivers to reach a compromise. However, in most cases, family caregivers stood by their request and the district nurse still provided involuntary treatment and found this difficult to tolerate.

Conclusions

Our results show that district nurses experience involuntary treatment use as stressful due to dealing with obverse values of safety versus autonomy. To

prevent involuntary treatment use and obverse values, we need to increase their ethical awareness, communication skills, knowledge and skills with person-centred care so they can deal with situations that can evolve into involuntary treatment use in a person-centred manner.

Introduction

Person(s) living with dementia (PLWD) wish to age in place and have a voice in their care.[1] Person-centred care (PCC) is a fundamental principle in providing high-quality dementia care at home.[2, 3] PLWD have the right to receive person-centred, coordinated and quality care throughout their illness.[4] PCC involves meeting the needs and preferences of PLWD, and taking into consideration the needs, goals and abilities of all caregivers involved. However, providing PCC in dementia care at home is confronted with several barriers related to the caregiver such as lack of practical and emotional support and lack of knowledge about PCC and attitudes about dementia.[5, 6] When dementia evolves further, PLWD experience problems with expressing their wishes, and eventually they may lose (part of) their decision-making capacity.[6] Thus, caregivers often decide what care is in the best interest of PLWD.[7, 8] According to the ethical code of nurses, it is important that, in these situations, nurses be their patients' advocates and assist the PLWD in the decisions made in order to deliver person-centred and dignified care.[9] When a PLWD does not agree with the provided care, this can lead to agitation and/or resistance to the care. This can be distressing for the PLWD, their family caregivers and the nursing staff.[7, 10-12]

Background

Several terms are used in the literature to describe the care that persons resist or do not provide consent for, such as coercive care, resistiveness to care, refusal of care, forced treatment and involuntary treatment.[8, 13-15] This study uses the term 'involuntary treatment', which is defined as care provided without the consent of the person receiving it and/or to which this person resists, including the use of physical restraints, psychotropic medication and non-consensual care.[13] Recent research shows that involuntary treatment is provided to half of the PLWD receiving professional home care in Belgium and the Netherlands.[12] In Western countries, the presence of known risk factors for involuntary treatment use, such as caregiver burden, living alone, greater activities of daily living (ADL) dependency and poorer cognitive ability, are increasing due to demographic and socio-economic evolutions.[12, 16] Family caregivers and district nurses play a key role in the decision-making process regarding the use of involuntary treatment.[7, 12] District nurses perceive involuntary treatment as a regular part of nursing care, having neither a positive nor negative attitude towards its appropriateness.[17] Since involuntary treatment is in conflict with person-centred dementia care and ethics of nursing, and more person-centred alternatives exist, involuntary treatment needs to be prevented.[2, 4, 5, 9]

If we wish to prevent involuntary treatment, insight is needed into caregivers' experiences regarding the decision-making process and its application. Recently, several studies have been published on family caregivers' experiences regarding measures defined as involuntary treatment.[7, 18-20] Family caregivers consider safety and autonomy as important values. However, they struggle with finding the right balance between them and experience dealing with these dilemmas as stressful.[7, 18] They apply several strategies to deal with the resistance towards their care and the creation of a safe environment.[18-20] Recently, a study was published concerning how district nurses experience and encounter resistance to care from PLWD.[21] This study showed that district nurses tried to avoid forced treatment and to provide adapted care to PLWD who resisted care. However, little is known about the experiences and decision-making processes of (district) nurses, when involuntary treatment was actually applied in dementia care at home. Therefore, insight is needed into how district nurses perceive involuntary treatment usage and how they deal with care situations in which involuntary treatment is used. Based on these insights, person-centred interventions can be developed for district nurses in order to prevent involuntary treatment use.

This study focuses on involuntary treatment use among PLWD at home. Therefore, the research questions are:

- What are the experiences of district nurses regarding the application of involuntary treatment use?
- To what extent are district nurses involved in the decision-making processes concerning involuntary treatment usage?

Methods

Design

A qualitative descriptive approach was adopted based on naturalistic inquiry to gain a straight and rich description of the experiences of district nurses regarding involuntary treatment usage.[22] Semi-structured interviews were conducted with district nurses in Belgium. Data were analysed using the Qualitative Analysis Guide of Leuven (QUGOL), a method that is inspired by the constant comparative method of the Grounded Theory Approach.[23] To ensure rigour, we followed the "Consolidated criteria for reporting qualitative research (COREQ)" guidelines.[24]

Setting

Participants were district nurses from an organisation that provided professional at-home nursing care in the eastern part of Belgium. They administered nursing care at home and paid attention to family and social circumstances. District nurses were responsible for planning, coordinating, performing and evaluating the nursing care provided in a patient's home environment and who belonged to their district.[25] They provided this care together with family caregivers and other professional caregivers like general practitioners (GP).[25] Every district had a team of nurses, comprising a responsible district nurse, assisted by permanent district nurses to ensure 24/7 care continuity. This meant that several nurses provided care for one PLWD. To ensure continuity and uniformity of the given care, these nurses communicated with each other through an online electronic patient record.

Sampling

Maximum variation sampling was used to create a diverse sample of participants (having few or many years' experience as a district nurse, of young and older ages, male and female nurses, having a lower or higher educational background, perceiving caring for PLWD as burdensome or not, having an educational background in dementia care at home and involuntary treatment or not), who had experience with involuntary treatment use among PLWD in the past 12 months.[26]

Method of approach

Prior to this study, from May to June 2021, we conducted a cross-sectional study using an online survey tool among 296 district nurses to explore their attitudes towards the use of involuntary treatment and their opinions about the restrictiveness and discomfort of involuntary treatment measures in dementia care at home.[17] At the end of this online survey, information was given about the researchers, aim, method and context of the current study. If district nurses were interested, they could voluntarily apply to participate in this study by completing an online application form that requested the following information: age, years of experience as a district nurse and how many times in the past 12 months they were confronted with the use of involuntary treatment in PLWD. Sixty-one district nurses indicated that they were interested in participating in the current study and 51 district nurses met the inclusion criterion, namely having experience with involuntary treatment use in the past 12 months. Using maximum variation sampling, 16 district nurses were selected for interview. Table 1 provides an overview of the district nurses' characteristics. The researcher (V.M.) contacted the selected district nurses by phone to inform them about the study and plan an appointment to conduct the interview. Participation was entirely voluntary and participants were free to withdraw at any time. None of the participants dropped out during the study. All district nurses received written and verbal information about the study in advance.

Table 1. Characteristics of district nurses (N=16)

	Number
Age	
20–29 years	2
30–39 years	8
40–49 years	2
50–59 years	4
Years of experience as a district nurse	
0–1 years	2
2–5 years	3
6–10 years	2
11–20 years	4
21–30 years	2
More than 30 years	3
Gender	
Male	1
Female	15
Educational background	
Diploma degree	7
Bachelor’s/Master’s degree	9
Did the participant receive an education in dementia care at home	
Yes	9
No	7
Did the participant receive an education in involuntary treatment use	
Yes	6
No	10
Perceived burden of caring for persons living with dementia	
Seldom	2
Now and then	11
Often	3

Data collection

In October 2021, all interviews were conducted by the researcher (V.M.) at the participants' work office. Only the participant and the researcher (V.M.) were present during the interviews. The interviewer (V.M.) was a male PhD student, who also worked as a staff member in the organisation where the participants were employed. However, he had no direct relationship with the participants, at the time of the interviews. The interviewer had a background in district nursing, experience in dementia care, involuntary treatment, conducting and analysing qualitative research. A literature review [7, 13, 17, 27, 28] and two pilot interviews guided the development of the interview guide, which was further revised in response to emerging insights and discussions within the research team. Informed consent was obtained from each participant before the start of their interview. All interviews were conducted in Dutch, audio-recorded with the participants' permission and transcribed by the researchers. It was anticipated that interviews would last approximately 45 minutes. Only the principal researcher knew the participants' identities. Data from participants were anonymised after transcription and treated confidentially. The interviews were performed using an informal interview technique including an open and broad conversation focusing on the participant's experiences. First, the interviewer explained what involuntary treatment use is to the participant. Then, the interviewer asked the participant to briefly describe some situations of involuntary treatment use among PLWD at home in which they was involved as a district nurse. Next, the participant was asked to describe one of these care situations in detail. Subsequently, the interviewer asked spontaneous follow-up questions, based on the interview guide (see Table 2). After 16 interviews (describing 34 cases of involuntary treatment use among PLWD were conducted, the results were discussed with the research team. They concluded that data saturation had been reached, as the last four interviews confirmed the themes previously found without introducing new or additional themes or information.

Table 2. Interview guide

Main question:
Can you describe to me which kind of involuntary treatment use in dementia care at home you're mostly involved in as a district nurse?
Can you describe to me in detail one of these care situations that you just mentioned?

Based on the information provided, the following follow-up questions were asked:

1) Regarding the use of involuntary treatment
    - What just happened?
    - Which events led to the use of involuntary treatment? What preceded it?
    - How did you deal with this?

2) Decision-making process and actors involved
    - Who made the decision to use involuntary treatment?
    - How was the decision to use involuntary treatment made?
    - Who was involved in the decision-making process?
    - What was everyone's role in the decision-making process?
    - What was your role?
    - What was the role of the other nurses and professional caregivers?
    - How did the other nurses and healthcare professionals deal with the decision to use involuntary treatment?
    - How was the PLWD and/or their representative involved in this decision?

3) Feelings of the caregiver
    - How did you experience the use of involuntary treatment with this patient?
    - What did you think when you first used involuntary treatment for this patient?
    - How do you feel now about the use of involuntary treatment with this patient?
    - What influence has this care situation had on you as a person?
    - How did the patient and their loved ones experience the use of involuntary treatment? And to what extent has this influenced your actions?

4) (Experienced) support
    - What support did you have in dealing with this care situation?
    - How did you experience this support?
    - Who helped you the most in dealing with this care situation?
    - How did you experience the support from the organisation?
    - What helps you the most in dealing with such care situations?
    - What did you miss concerning being able to provide good care in this situation?
    - Can you briefly describe what good care means to you?

5) Closing question
    - If you look back on this care situation, how would you have dealt with it now?
    - What did you learn from this care situation?
    - What advice would you give to new employees to deal with such situations?

Depending on the remaining time, the interviewer will ask for another situation to be described. The interviewer takes into account that the interview will not last longer than 45 minutes.

Data analysis

Data analysis was based on the Qualitative Analysis Guide of Leuven (QUAGOL), an iterative guidance tool for qualitative data analysis that consists of a preparatory coding process and an actual coding process.[23] During the preparatory part, four researchers (V.M., M.B. and two research assistants) applied a case-oriented approach that stimulated them to first analyse and understand each case as a whole. They individually read the transcripts and developed a list of preliminary themes. Similarities, differences and connections among different themes within and across interview schemes were discussed by the four researchers. By discussing the different themes, they gradually identified common themes within and across the interviews, which resulted in a final list of themes for the actual coding procedure using qualitative software (Maxqdata 2022®). One researcher (V.M.) performed the actual coding process. The coding process was guided by a list of codes that organised the themes within a tree structure with different levels. First, all data were coded by linking each fragment of text to one of the themes from the list. Then, the usability of the codes and themes were discussed by the four researchers. In the following step, two researchers (V.M., M.B.) individually distilled the storyline from the findings and themes. These findings were discussed and submitted to the research team (V.M., M.B., H.V., B.D.d.C., K.M., J.H.) until consensus was reached.

Rigour/Trustworthiness

The study's trustworthiness was examined in terms of credibility, dependability, confirmability and transferability as described by Lincoln and Guba.[29, 30] For credibility, the analysis process was peer reviewed (i.e. frequently reviewed within the research team to establish uniformity in themes and relationships and to encourage the researchers' reflexivity. The research team was systematically and continually encouraged to be attentive to the context of knowledge development and, more specifically, to their own impacts on the collection, analysis, and interpretation of data). In addition, the results were peer debriefed (i.e. results were discussed with five district nurses who specialised in dementia care at home and who acknowledged the findings of this study. These five district nurses did not belong to the group of nurses interviewed). Concerning dependability, we maintained a detailed audit trail (e.g. audio files, interview transcripts, field notes, notes of the preparation of the coding process, list of contextual and analytical themes and description of themes). Additionally, we conducted researcher triangulation (i.e. four members of the research team held discussions throughout the data analytic process to ensure the selection of consistent themes). To ensure confirmability, we provided thick descriptions (i.e. relevant citations to illustrate the generated themes) and performed member checking by summarising participants' responses at the end of each interview. Finally, to guarantee transferability, thorough descriptions of the research setting, characteristics of the participants, applied measures and processes were provided.

Results

Figure 1 illustrates that district nurses' experiences with involuntary treatment usage depended on the extent to which they were involved in the decision-making process. Table 3 shows the district nurses' experiences with the use of involuntary treatment. When they were involved, they considered involuntary treatment use to be appropriate care. Initially, they were worried that involuntary treatment was unjust since they wished to respect the wishes of the PLWD. However, after a while, district nurses found, from a professional perspective, that involuntary treatment use was necessary and that safety outweighed the autonomy of the PLWD. If district nurses were not involved in the decision-making process regarding the use of involuntary treatment, family caregivers usually decided on its use. Often, district nurses perceived this request as inappropriate dementia care and they first tried to create a dialogue with family caregivers to reach a compromise. However, in most cases, family caregivers stood by their request and the district nurse still provided involuntary treatment and found this difficult to tolerate.

Figure 1. District nurses' experiences with involuntary treatment in dementia care at home

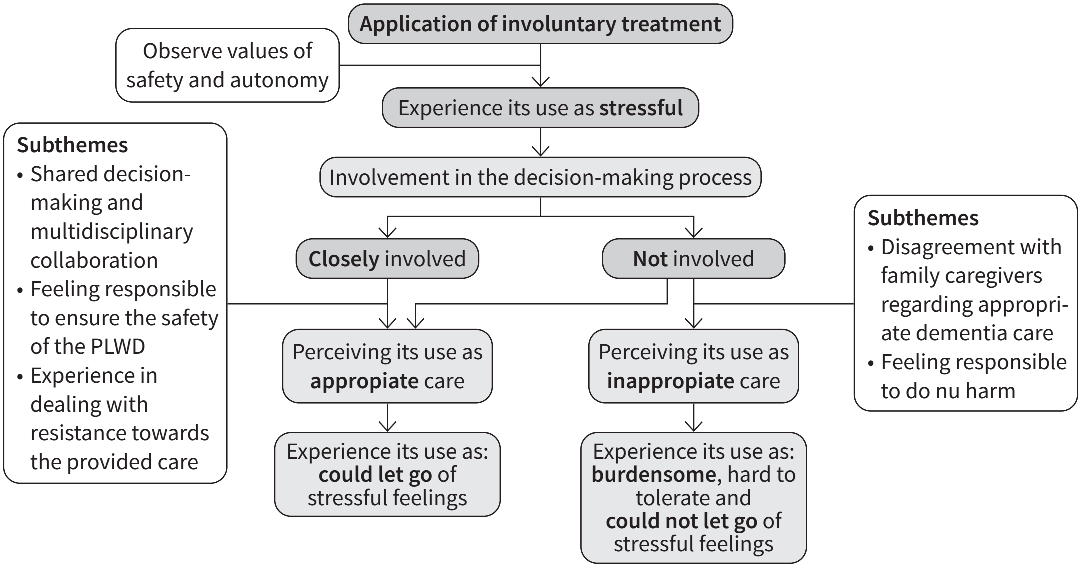


Table 3. Applied measures of involuntary treatment

	Closely involved in the decision made	Not Involved in decision made		Total
	Perceived as appropriate care		Perceived as NOT appropriate	
Non-consensual care				
1. Forced hygiene	10	6	8	24
2. Hiding and administration of medication	2	2	4	8
3. Shutting off gas, water and/or electricity			1	1
4. Restriction of fluids			1	1
Psychotropic medication				
5. Use of sedatives	5	1	3	9
6. Use of anti-psychotics	1		1	2
Physical restraints				
7. Bilateral bedrails	6		6	12
8. Locking in house		1	4	5
9. Camera surveillance	1		2	3
10. (Wheel)chair with locked tray table	2			2
11. Fixation belt	1			1
12. Gloves			1	1
13. Sleep suit	1			1
14. Special sheet			1	1
15. Fixating arms and hands during care	1			1

Note: In two thirds of the cases, multiple measures were applied.

1) Experiences of district nurses closely involved in the decision-making process

In 14 of the 34 described cases, involuntary treatment use was a deliberate and shared decision between district nurses, family caregivers and/or general practitioner. In their experience, involuntary treatment was mostly stressful due to opposing feelings. If they were first confronted with resistance, they were in most cases worried that they were providing care that was unjust because they wished to respect the autonomy and dignity of the PLWD. However, after a while, they indicated that, from a professional perspective, the safety of the PLWD outweighed respecting their wishes. Therefore, in all the discussed cases, they perceived involuntary treatment as appropriate care and could justify for themselves the necessity of involuntary treatment use and let go of their mixed feelings regarding safety versus autonomy. These experiences were influenced by: a) shared decision-making and multidisciplinary collaboration; b) their sense of responsibility to ensure the safety of the PLWD; and/or c) their experiences in dealing with involuntary treatment use:

> *"I think respecting a patient's wishes is an instinctive feeling for me. I always think, you do nursing with your heart, and only if you do that, can you be a good nurse. But, at that moment [applying involuntary treatment] I know in my head that it has to be done for the safety of the patient, but in my heart, it hurts. It's a mixed feeling."*
>
> *— 33-year-old district nurse with 12 years' experience*

> *"I find it very difficult to force medication. On the one hand, I think it's important to respect the wishes of the PLWD, but on the other hand, I think it's important that the patient takes his medication for his health. Because imagine if he doesn't take it. It's double."*
>
> *— 36-year-old district nurse with 4 years' experience*

a) Shared decision-making and multidisciplinary collaboration

When the PLWD came into care, they mostly agreed with the provided care such as being washed by district nurses or the administration of medication. A nursing care plan was drawn up by the district team for each patient that came into care. This nursing care plan was accessible for every caregiver that has a therapeutic relationship with the PLWD. However, the district team were not always aware of the treatment plan of the other involved healthcare providers such as the general practitioner (GP), specialist physician or psychologist.

When the functional and cognitive capabilities of the PLWD declined and district nurses determined that more nursing care was needed (hygienic care for example due to self-care deficiency or to prevent family caregiver burden), they almost always discussed this bilaterally with one of the members of the multidisciplinary team of the PLWD and an agreement was reached to apply involuntary treatment. In most cases this was a family member and the rest of the team was then informed about the decision made. These decisions were, in most cases, practical, effective and short-term solutions, based on former experiences of the involved caregivers like forced hygienic care or the use of physical restraints. Almost always, the multidisciplinary team of the PLWD consisted of the district nurse, family and/or GP, who met with each other if one of the members deemed it necessary. However, the PLWD was mostly not involved in these decisions. In these cases, the PLWD often started to openly question and/or oppose the necessity of the care received. District nurses found this to be stressful to deal with because they did not expect it, understand the behaviour of the PLWD, did not know how to react to the resistance and/or deal with it. In general, they indicated that they found it difficult to connect with the PLWD and to gain insights into why the PLWD rejected their care, which was most often due to insufficient verbal skills of the PLWD:

> *"At the request of the son, we started administering the medication once a week. In the beginning it went well, and she needed a little support from us. Then after a year, we saw that she (PLWD had more problems with her medication. Also, we doubted if she washed herself regularly, because we noticed that she no longer had on clean clothes. At the start, it was very difficult to wash her, because she did not allow it. She always said, I've already been washed. She did not know that she had not washed herself. Together with the other involved caregivers, we tried to convince her to wash herself. Yes, I think that sometimes, someone said look, we're going to wash you now. And that this happened under force."*
>
> *— 42-year-old head nurse with 21 years' experience*

In almost all discussed cases where the PLWD verbally and/or non-verbally resisted or rejected the care (e.g. shouting, swearing and/or bodily harm [e.g. passive attitude, pushing away, hitting]), district nurses often experienced this as more stressful and discussed with their colleagues, the family and GP of the PLWD how they should deal with it. They exchanged advice and a mutual agreement was reached on how to deal with this resistance:

> *"When the PLWD resists its care, I sometimes think it's just me, or it's something else. That is sometimes difficult. That I don't know if I'm doing something wrong, or if it's up to me personally. But by reading the observations in the electronic patient record, I notice that other nurses also experience this problem. That they say this week it went well and the next day it was arduous. Then I know it has nothing to do with us. Then I can better place the behaviour of the PLWD and then I am reassured and can let go of my doubts."*
>
> *— 45-year-old district nurse with 23 years' experience*

Additionally, in several cases, family caregivers assisted district nurses during involuntary treatment by distracting their next of kin or clamping their arms during hygienic care. District nurses experienced this assistance as very supportive and indicated that although involuntary treatment was sometimes stressful, they experienced it as bearable:

> *"The family involves us closely in the care and help us. We were not alone and they were not alone. When the PLWD was taken care of, I never feel like that I'm exhausted or tired."*
> *— 36-year-old district nurse with 4 years' experience*

b) Feeling responsible to ensure the safety of the PLWD

At first, most of the participants perceived involuntary treatment use as difficult. They were mostly worried that involuntary treatment was unjust because as a human they found it important to respect the autonomy and dignity of another human being and mentioned that involuntary treatment drastically restricted their freedom. On the other hand, all the district nurses found it professionally necessary to apply involuntary treatment to ensure the safety of the PLWD, protect the PLWD against wandering, incorrect medication intake, skin damage due to urine burns and/or caregiver burden:

> *"Above all the safety of the patient comes first. Because suppose you do not physically restrain him [PLWD], to respect his self-esteem and he gets up and he falls, then yes, that's not okay. Then the situation is worse than it already was."*
> *— 45-year-old nurse with 23 years' experience*

Furthermore, they all perceived involuntary treatment usage to be appropriate care since it was: 1) discussed by a multidisciplinary team and an agreement was reached (family, GP, fellow district nurses); 2) needed in the context of PLWD safety needs; 3) planned and delivered in a qualitative manner; and/or 4) in accordance with the personal values/norms of the nurses:

> *"I think we were able to provide good care. We have always been able to anticipate in time. By discussing how we were going to do it. Both with the doctor, with the family, with everyone. I think we acted correctly and in a timely manner for the safety of the PLWD."*
> *— 35-year-old district nurse with 12 years' experience*

In addition, district nurses often indicated that they experienced the resistance towards the care they delivered as a behavioural symptom of dementia. However, when they were first confronted with this resistance towards their care, district nurses were confused and asked themselves whether the use of involuntary treatment was unjust. Eventually, they indicated that they could easily let go of this feeling when they went home. They mentioned that they could justify its use, as not using involuntary treatment would cause more harm to the PLWD than respecting their voice:

> *"It still remains difficult to lock someone up, but on the other hand if you look at it professionally, you understand that it is necessary. But from a human point of view I think yes … you do deprive someone of their freedom. If you've been working for a while, then yes, you understand why it is done. Then you can place it better."*
>
> *— 32-year-old district nurse with 10 years' experience*

c) Experience dealing with resistance towards the provided care

If district nurses could not bend and/or handle the resistance to or rejection of their care, they often experienced involuntary treatment use as more stressful. Table 1 shows that two thirds of the participants had some knowledge regarding dementia care and one third had once received education regarding involuntary treatment use. These district nurses, who had several years of experience and/or who knew the PLWD well, said that they found the application of involuntary treatment in general to be less stressful because they could better anticipate and/or bend the resistance towards their care by, for example, being firm, leaving and returning later, distracting or persuading them. Early career district nurses and/or those who did not know the PLWD usually found it more difficult to deal with resistance from the PLWD and therefore, were not always able to provide the planned care because: 1) they did not know how to approach the PLWD; and/or 2) they questioned the use of involuntary treatment more. Early career nurses found the support and advice of colleagues with more experience to be very helpful:

> *"It helps if you can rely on someone who knows the PLWD through and through and has experience. I think that's an important point, that you just need to know how to approach someone. Because that is difficult to know in advance, because everyone differs in character."*
>
> *— 29-year-old district nurse with 1 years' experience*

> *"Colleagues who have been working here for 30 years are more likely to apply involuntary care than younger colleagues. Because older colleagues just perform and ask less questions compared to younger nurses. Younger colleagues often ask the question, is it okay what we do? They will question that more."*
>
> *— 34-year-old district nurse with 12 years' experience*

2) Experiences of district nurses that are not involved in the decision-making process

In 20 of the 34 cases described, district nurses were not involved in the decision to apply involuntary treatment. Often the decision had been made by others (e.g. family, GP and other professional caregivers) before the PLWD came into care and district nurses were requested to provide involuntary treatment and did so. In seven of the 20 cases described, district nurses agreed with the family that involuntary treatment was necessary and that it was appropriate care. In these cases, they experienced involuntary treatment as described above. However, in 13 of the 20 cases, district nurses found the request for involuntary treatment to be inappropriate dementia care and experienced its use as burdensome and struggled with providing it. In these cases, district nurses often first tried to create a dialogue with the PLWD's family to reach a compromise regarding appropriate dementia care. In most cases, however, they said that the family stood by their request. In these situations, district nurses found the use of involuntary treatment difficult to tolerate. This experience was influenced by: a) disagreement with family caregivers regarding appropriate dementia care; and b) their responsibility to do no harm:

> *"I find it difficult when a PLWD has to stay in bed. Because it's too dangerous, according to others. While the PLWD says he wants out. I have a hard time with that, it conflicts with my values and norms because those people can also sit up. This I struggle with."*
>
> *— 35-year-old district nurse with 12 years' experience*

a) Disagreement with family caregivers regarding appropriate dementia care

If district nurses disagreed with the family caregivers about the use of involuntary treatment, this was mainly because they perceived their requests as too far-reaching and to be irresponsible care and therefore, experienced it as inappropriate. This mostly involved the use of physical restraints like locking the PLWD in the house or bilateral bedrails. Moreover, when it involved forced hygienic care, district nurses described that they were not aware that the PLWD would resist or reject their hygienic care when they started with the care. When they were confronted with resistance to their care, they usually tried first to provide it. They mentioned that the family expected that they took up their responsibility as a nurse and administer the required hygienic care or locking the PLWD up in their own house. Additionally, they wanted to meet this expectation. However, they usually perceived the use of physical restraints as more far-reaching than the use of non-consensual care. Subsequently, they tried to be an advocate of the PLWD by creating a dialogue with the family to discuss their request and reach a compromise regarding appropriate dementia care:

> *"Because Mrs. [PLWD] says no, I'd rather not have that bilateral bedrails raised. But, the daughter says, that they must be raised. While you have people with dementia, who are still okay, where there is no danger. Who still have bright moments. You listen to both the family and the patient. And you try to find a compromise. I asked myself, when are you doing well, sometimes you don't know it."*
>
> *— 38-year-old district nurse with 1 years' experience*

However, compromise was often not reached; the family stuck to their decision and the district nurse provided the requested care. In addition, district nurses indicated that in those cases, there was often a lack of support and/or mutual agreement between the nursing staff and the family. In these situations, they referred to the family's decision to justify why involuntary treatment was used:

> *"It is different if you are a district nurse or a hospital nurse. You enter someone else's house and therefore you cannot set your own rules and laws. You can only try to enter into a dialogue, but if the family says that's the rule, then that's the rule."*
>
> *— 27-year-old district nurse with 6 years' experience*

> *"The decision to close the gate was a decision of the children, for safety reasons. In our opinion, the children did not know that alternatives were available. But for us, it was especially difficult that we as nurses were expected to carry out the requested care. While no one in the team felt comfortable with providing that care. We were not involved in the decision-making process, we were instructed."*
>
> *— 34-year-old district nurse with 12 years' experience*

In all these cases, district nurses described involuntary treatment use as burdensome and hard to tolerate. By discussing these situations within the nursing staff, they were able to vent and usually, they could gradually accept the decisions made, although they still had reservations about them:

> *"That [locking up the PLWD] was discussed a number of times, during team meetings. In the beginning, this was discussed very frequently, but after a while, we resigned ourselves to it."*
>
> *— 54-year-old head nurse with 33 years' experience*

b) Feeling responsible to do no harm

If the district nurse felt that by providing the requested involuntary treatment there was a potential risk that the PLWD could have an accident and be injured, they found it very hard to apply. Usually this involved locking the PLWD in their home or using bilateral bedrails. District nurses were worried that the PLWD could die of suffocation or burns since they could not leave their home or bed. Because district nurses stated that they felt responsible for the safety of the PLWD and to do no harm and they also realised that they could be held liable and even be blamed for something that they did not want to do, they struggled with their feelings and could not let go of it when they went home:

> *"I find it difficult to lock someone up in the house because if a fire breaks out, those people are locked up there. Should something happen, I was the last person to see that person and I made sure he couldn't go outside. Then it was me. Then it was my responsibility and that rankles with me."*
>
> *— 53-year-old district nurse with 33 years' experience*

Discussion

The results from this study indicate that many district nurses found the application of involuntary treatment stressful and had dilemmas when applying it, especially in the beginning or when they felt it might do more harm than good. District nurses' experiences depended on their involvement in the decision-making process. When they were involved, they considered involuntary treatment use to be appropriate care despite mixed feelings and perceived it as stressful. Initially, they were worried that involuntary treatment was unjust since they wished to respect the wishes of the PLWD. However, eventually they found professionally that involuntary treatment use was necessary and that safety outweighed the autonomy of the PLWD. If district nurses were not involved in the decision-making process, they considered the request for involuntary treatment inappropriate dementia care. However, they still provided it and experienced its use as burdensome and struggled with it.

Our results suggest that when district nurses were confronted with involuntary treatment they experienced this as stressful due to cognitive dissonance, as they experienced obverse feelings regarding autonomy and safety.[10] Cognitive dissonance is a phenomenon that arises when persons experience psychological discomfort when they are trying to meet two or more opposing demands at the same time or engage in activities that conflict with their beliefs or values. When persons experience these obverse cognitions, they perceive it as psychologically uncomfortable, and wish to reduce this dissonance by rationalising their actions.[10, 31] We found indications that district nurses did this by: 1) changing their cognition regarding involuntary treatment by perceiving it as appropriate dementia care by referring to the clinical picture of dementia, medical knowledge or personal values; 2) managing of refusals of care (e.g. leaving and returning later, changing the right moment of care, being firm, bringing in others, distracting or persuading them; or 3) creating new consonant cognitions by finding that providing safe care was more important than respecting the voice of the PLWD.[20, 31] The finding that safety outweighed the autonomy of the PLWD showed that the normative arguments district nurses used to decide which care was needed were generally based on a biomedical ethical approach.[32] Since they mainly focused on the bodily needs of the PLWD like protecting against harm and less on their moral needs like involving them in decisions about their care, making the principles of non-maleficence (e.g. protection from harm) and beneficence (e.g. enhancing the safety or personal well-being of the PLWD and/or family) leading in their normative arguments. Further, district nurses were not always sufficiently aware that the resistance during their care could be a signal of the bodily autonomy of the PLWD to indicate that they did not agree with how their care was provided and/or it did not correspond to their habits and needs.[33] When district nurses used a biomedical approach rather than a biopsychosocial one like PCC, this increased the risk that routine care like hygienic care takes priority over psychosocial aspects of the care provided like respecting the bodily autonomy of the PLWD. Consequently, district nurses were hindered from observing the behaviour of the PLWD and how they responded to their care. As a result, district nurses were unaware that, for example, non-consensual care can have serious consequences on the social, psychosocial and moral well-being of the PLWD. These results indicate that if we want to provide dignity-enhancing dementia care and prevent cognitive dissonance, it is important that district nurses are more aware of the bodily signals of autonomy and discuss and evaluate their care with the PLWD.[34] These findings and the fact that several participants were not educated in dementia care and/or involuntary treatment usage, underpins the necessity that more education and training in this is needed. Therefore, health care organisations and nurse education curricula need to focus more on increasing the ethical awareness and knowledge of nurses regarding the negative consequences of involuntary treatment and support them in recognising the moral needs of the PLWD and maintaining their selfhood at home.[2] Further, to reduce the risk for cognitive dissonance and/or alleviated it, district nurses need to be trained and provided with continuous support regarding alternatives for involuntary treatment (e.g. negotiation, preventing sensory over load or under stimulation),[35-37] interactions and communications with the

PLWD, approaching the PLWD during hygienic care, ability-focused approaches, distraction approach, and knowledge about PCC.[38-44] As a result, district nurses will gain more insights and skills to approach a PLWD in a more person-centred manner and to align their values and actions with each other In addition, since it was not always clear to the nursing staff how to react when confronted with involuntary treatment and/or doubted whether they had acted correctly, nursing management need to develop and provide clear written guidelines and targeted intervention strategies on how to deal with situations concerning involuntary treatment.[35, 45]

Further, our results show that the multidisciplinary team of the PLWD (i.e. nurses, family caregivers and/or GPs) used a rather intuitive or heuristic decision-making process when confronted with stressful dilemmas regarding safety and autonomy, as their decisions and applied solutions in most cases were based on their own personal experiences and/or perceptions. Heuristic decision-making is optimal for simple, routine and low impact tasks to reduce the cognitive load of thought processes associated with complex and analytical thinking, and to guide decisions which are perceived as most efficient. However, when confronted with complex dilemmas regarding involuntary treatment, a rather analytical reasoning is needed, which requires evidence-based reasoning.[46] To reduce the risk of heuristic decision-making, the multidisciplinary team needs to critically reflect upon decisions to broaden their knowledge. Effective strategies for this are following a working procedure with a step by step plan, increasing the expertise of the multidisciplinary team by involving expert nurses, psychologists, advice of an ethics committee, shared decision-making and increasing knowledge regarding alternatives to involuntary treatment.[46, 47]

In addition, the findings that district nurses with more years' experience found it easier to deal with and/or bend the resistance of the PLWD and apply involuntary treatment compared to starting nurses suggest that, due to long-term exposure to stressful situations, district nurses could become desensitised or passive towards the negative consequences of involuntary treatment use and therefore, more accepting of it.[10, 48]

Our findings highlight and confirm the dominant role of family in the decision-making process regarding involuntary treatment like physical restraints and that nurses mostly provided the requested involuntary treatment, although they often found it inappropriate care; also shown in earlier studies in home care and acute and residential settings.[7, 12, 28, 49] Earlier studies indicate that family caregivers often have insufficient knowledge and skills to deal properly with dilemmas regarding safety and autonomy in a person-centred manner, due to insufficient emotional support in the decision-making process from professional caregivers. This results in them relying on previous experiences, knowledge of alternatives and the practical assistance and support from family, friends and caregiver support groups.[1, 7] In addition, often, district nurses could not convince the family to change their opinion about the requested care. Eventually, they put their own professional opinion aside and provided the requested care due to a conventional way of reasoning, as was found in other studies.[49, 50]

Based on the insights of this study, we formulated the following recommendations for practice, research and education. For practice: firstly, home care organisations need to foster communication skills and knowledge about PCC of district nurses so that they can successfully discuss requests regarding involuntary treatment in a person-centred manner.[5, 51] Secondly, a multidisciplinary team (general practitioner, family) must be timely in discussing decisions regarding involuntary treatment. District nurses must have a pivotal role in these discussions as the patient advocate by providing person-centred alternatives for the requested involuntary treatment. Thirdly, professional caregivers need to support family members of the PLWD in dealing with situations that can lead to involuntary treatment use in a timelier and more PCC-manner. District nurses can support family caregivers in this by discussing alternatives of involuntary treatment usage [35-37] and the underlying factors of involuntary treatment with the family caregivers of the PLWD such as caregiver burden, lack of knowledge, skills and support. Fourthly, increasing the awareness of family caregivers about caregiver burden, behavioural problems, discussing alternatives of involuntary treatment and strengthening their social network is also required.[52] Worldwide, several studies regarding multicomponent combined support programmes for the PLWD and their caregivers have been shown to be effective in emotionally and socially supporting them both.[53] With regard to research, first of all, more research is needed into how the insights and previous recommendations of this study can be integrated into existing multicomponent programmes to increase their effectiveness, in order to prevent involuntary treatment in home and residential care.[38, 45, 54-58] Secondly, our results underpin the need for studies to be conducted in order to explore possible strategies that district nurses can use to reduce the risk of cognitive dissonance and/or moral distress in a person-centred manner when confronted with involuntary treatment. Further, this study points out that interventions should be developed aimed at district nurses on order to increase their awareness, knowledge and skills regarding supporting PLWD with a diminishing decision capacity and assist them in the decisions concerning their care, in order to be their patient advocate. Finally, for education, we recommend that nurse education curricula, make it a priority to strengthen the critical ethical reflection and dialogue skills of nursing students, in order to engage in dialogue about involuntary treatment.

Methodological considerations

Some limitations of this study must be considered. First, a limitation is the transferability of this study to other nursing settings because all participants were district nurses that worked in a professional home nursing organisation.[29] However, thick descriptions, characteristics of the participants, applied measures and processes were provided, in a way that other researchers and caregivers can assess if the findings and recommendations of this research provide valid information for their own settings. In addition, we found similar results in international studies regarding physical restraints in psychiatric care, nursing homes and hospital units.[49, 50, 59] Therefore, we believe that our findings can be transferable to other healthcare workers and settings. Second, sampling bias can be considered a limitation because we only interviewed nurses who volunteered to participate in this research, so we could have missed district nurses that had different experiences (e.g. no mixed feeling) with involuntary treatment use.[60] Thirdly, however, while several strategies were used to ensure the credibility and dependability of our results, we could not fully exclude the risk of interview bias. Interview bias (e.g. as errors by the participants, appearance or unintentional errors of interviewer) could have influenced the internal validity our study results.[60] Finally, this research only focused on the experience of district nurses. To get a thorough insight into involuntary treatment use, observations of district nurses could increase the credibility of our finding (triangulation). Further, a case-study of several ecosystems (PLWD, family, family caregivers, general practitioner, domestic carer, district nurses, etc…) regarding involuntary treatment would provide more detailed insights into its use and the decision-making process.

Conclusion

The results from this study suggest that, depending on their involvement in the decision-making process, district nurses experienced involuntary treatment use differently. In general, they experienced its use as stressful due to cognitive dissonance regarding obverse values of safety versus autonomy. To prevent these obverse cognitions and involuntary treatment use, we need to increase district nurses' communication skills, knowledge and skills about person-centred dementia care. Further, we need to foster ethical awareness regarding daily ethical situations of all caregivers involved in order to deal with situations that could lead to involuntary treatment use in a more PCC-manner.

List of abbreviations

- ADL: Activities of Daily Living
- e.g.: exempli gratia – ‘for example’
- GP: General Practitioner
- i.e.: id est – ‘that is’
- PCC: Person-centred Care
- PLWD: Persons Living With dementia

Declarations

Ethics approval and consent to participate

The Ethics Committee of the University Hospitals Leuven (reference G-2021-3729 on 08/07/2021) approved the study. All procedures were performed in accordance with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Informed consent was obtained from each participant before the start of their interview.

Consent for publication

Not applicable

Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available due to restrictions in the ethical approval but are available from the corresponding author upon reasonable request.

Competing interests

The author(s) declare(s) that there is no conflict of interest.

Funding

The author(s) received no financial support for the research, authorship and/or publication of this article.

Author contributions

Study design was performed by Vincent R.A. Moermans, Jan P.H. Hamers, Hilde Verbeek, Bernadette Dierckx de Casterlé, Koen Milisen and Michel H.C. Bleijlevens; data collection by Vincent R.A. Moermans; data analysis by Vincent R.A. Moermans and Michel H.C. Bleijlevens and manuscript preparation by Vincent R.A. Moermans, Jan P.H. Hamers, Hilde Verbeek, Bernadette Dierckx de Casterlé, Koen Milisen and Michel H.C. Bleijlevens.

Acknowledgements

Thanks to all the district nurses who were willing to share their experiences. Special thanks to Maud Hamers and Audrey Beaulen for their assistance during the data analysis of this study. This manuscript was professional proofread and edited by ‘Proof-Reading-Services.com’.

Authors’ Information – ORCID ID

The research team consisted of four professors, one assistant professor and one PhD student. They had experience with care for older people, home care nursing, nursing home care, dementia care, falls prevention, involuntary treatment, (physical) restraint use, quantitative and qualitative research, and the Qualitative Analysis Guide of Leuven (QUAGOL). For more information regarding the research team background, see their ORCID ID below:

- Vincent RA Moermans, MSc, RN
  https://orcid.org/0000-0002-6667-3238
- Jan PH Hamers, PhD, RN
  https://orcid.org/0000-0003-1228-3493
- Hilde Verbeek, PhD
  https://orcid.org/0000-0002-3740-5162
- Bernadette Dierckx de Casterlé, PhD
  https://orcid.org/0000-0002-1887-8407
- Koen Milisen, PhD, RN
  https://orcid.org/0000-0001-9230-1246
- Michel HC Bleijlevens, RN
  https://orcid.org/0000-0003-1707-704X

References

1. Wehrmann H, Michalowsky B, Lepper S, et al. Priorities and preferences of people living with dementia or cognitive impairment – a systematic review. *Patient Prefer Adher* 2021: 2793-2807. DOI: https://doi.org/10.2147/PPA.S333923.
2. Terkelsen AS, Petersen JV and Kristensen HK. Mapping empirical experiences of Tom Kitwood's framework of person-centred care for persons with dementia in institutional settings. A scoping review. *Scand J Caring Sci* 2020; 34: 6-22. DOI: https://doi-org.mu.idm.oclc.org/10.1111/scs.12709.
3. Martin A, O'Connor S and Jackson C. A scoping review of gaps and priorities in dementia care in Europe. *Dementia* 2020; 19: 2135-2151. DOI: 10.1177/1471301218816250.
4. Alzheimer Europe. Glasgow Declaration 2014, https://www.alzheimer-europe.org/policy/campaign/glasgow-declaration-2014 (2014, accessed 26-03-2023).
5. Marulappa N, Anderson NN, Bethell J, et al. How to implement person-centred care and support for dementia in outpatient and home/community settings: Scoping review. *BMC Health Serv Res* 2022; 22: 541. 2022/04/24. DOI: 10.1186/s12913-022-07875-w.
6. Bosco A, Schneider J, Coleston-Shields DM, et al. Agency in dementia care: systematic review and meta-ethnography. *Int Psychogeriatr* 2019; 31: 627-642. 2018/12/07. DOI: 10.1017/S1041610218001801.
7. Moermans VR, Mengelers AM, Bleijlevens MH, et al. Caregiver decision-making concerning involuntary treatment in dementia care at home. *Nurs Ethics* 2021; 29: 330-343. DOI: 10.1177/09697330211041742.
8. Gjellestad Å, Oksholm T and Bruvik F. Forced treatment and care in home-dwelling persons with dementia. *Nurs Ethics* 2021; 28: 372-386. DOI: 10.1177/0969733020948107.
9. International Council of Nurses. The ICN Code of Ethics for Nurses, https://www.icn.ch/publications?year=2021&category=_all (2021, accessed 31-03-2023).
10. Mortensen AH, Stojiljkovic M and Lillekroken D. Strategies to manage cognitive dissonance when experiencing resistiveness to care in people living with dementia: A qualitative study. *J Adv Nurs* 2022; 78: 486-497. 2021/08/26. DOI: 10.1111/jan.15030.
11. Featherstone K, Northcott A and Bridges J. Routines of resistance: An ethnography of the care of people living with dementia in acute hospital wards and its consequences. *Int J Nurs Stud* 2019; 96: 53-60. 2019/01/27. DOI: 10.1016/j.ijnurstu.2018.12.009.
12. Mengelers AM, Moermans VR, Bleijlevens MH, et al. Involuntary treatment in

dementia care at home: Results from the Netherlands and Belgium. *J Clin Nurs* 2022; 31: 1998-2007. DOI: 10.1111/jocn.15457.

13. Hamers JP, Bleijlevens MH, Gulpers MJ, et al. Behind Closed Doors: Involuntary Treatment in Care of Persons with Cognitive Impairment at Home in the Netherlands. *J Am Geriatr Soc* 2016; 64: 354-358. DOI: 10.1111/jgs.13946.
14. Spigelmyer PC, Hupcey J and Kitko L. A concept analysis of resistiveness to care. *Clin Nurs Res* 2021; 30: 50-58. DOI: 10.1177/1054773818789862.
15. Backhouse T, Killett A, Mioshi E, et al. What are the factors associated with people with advanced dementia refusing assistance with personal care? *Int J Geriatr Psychiatry* 2023; 38: e5857. 2022/12/10. DOI: 10.1002/gps.5857.
16. Koller D, Schön G, Schäfer I, et al. Multimorbidity and long-term care dependency — a five-year follow-up. *BMC geriatr* 2014; 14: 70. DOI: https://doi.org/10.1186/1471-2318-14-70.
17. Moermans VR, Bleijlevens MH, Verbeek H, et al. District nurses’ attitudes towards involuntary treatment in dementia care at home: A cross-sectional study. *Geriatr Nurs* 2022; 47: 107-115. DOI: 10.1016/j.gerinurse.2022.07.009.
18. Spigelmyer PC, Hupcey JE, Smith CA, et al. Resistiveness to care as experienced by family caregivers providing care for someone with dementia. *J Nurs Scholarsh* 2018; 50: 36-46. DOI: https://doi-org.mu.idm.oclc.org/10.1111/jnu.12345.
19. Häikiö K, Sagbakken M and Rugkåsa J. Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services. *BMC Health Serv Res* 2019; 19: 1-13. DOI: 10.1186/s12913-019-4478-2.
20. Backhouse T, Jeon YH, Killett A, et al. How do family carers and care-home staff manage refusals when assisting a person with advanced dementia with their personal care? *Dementia* 2022; 21: 2458-2475. 2022/09/03. DOI: 10.1177/14713012221123578.
21. Gjellestad Å, Oksholm T, Alvsvåg H, et al. Autonomy conquers all: a thematic analysis of nurses’ professional judgement encountering resistance to care from home-dwelling persons with dementia. *BMC Health Serv Res* 2022; 22: 1-13. DOI: https://doi.org/10.1186/s12913-022-08123-x.
22. Doyle L, McCabe C, Keogh B, et al. An overview of the qualitative descriptive design within nursing research. *J Res Nurs* 2020; 25: 443-455. 2021/08/17. DOI: 10.1177/1744987119880234.
23. Dierckx de Casterlé B, De Vliegher K, Gastmans C, et al. Complex qualitative data analysis: lessons learned from the experiences with the qualitative analysis guide of Leuven. *Qual Health Res* 2021; 31: 1083-1093.

DOI: 10.1177/1049732320966981.

24. de Jong Y, van der Willik EM, Milders J, et al. A meta-review demonstrates improved reporting quality of qualitative reviews following the publication of COREQ- and ENTREQ-checklists, regardless of modest uptake. BMC Med Res Methodol 2021; 21: 184. 2021/09/14. DOI: 10.1186/s12874-021-01363-1.
25. De Vliegher K, Paquay L, Grypdonck M, et al. A study of core interventions in home nursing. *Int J Nurs Stud* 2005; 42: 513-520. DOI: 10.1016/j.ijnurstu.2004.09.013.
26. Palinkas LA, Horwitz SM, Green CA, et al. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health* 2015; 42: 533-544. DOI: 10.1007/s10488-013-0528-y.
27. Charmaz K. Constructing grounded theory. Sage, 2014.
28. Scheepmans K, Dierck de Casterlé B, Paquay L, et al. Restraint use in older adults in home care: A systematic review. *Int J Nurs Stud* 2018; 79: 122-136. DOI: 10.1016/j.ijnurstu.2017.11.008.
29. Stahl NA and King JR. Expanding approaches for research: Understanding and using trustworthiness in qualitative research. *J Dev Educ* 2020; 44: 26-28. DOI: https://www.jstor.org/stable/45381095.
30. Guba EG and Lincoln YS. Competing paradigms in qualitative research, Handbook of qualitative research. Thousand Oaks, CA: Sage, 1994, p.105.
31. McGrath A. Dealing with dissonance: A review of cognitive dissonance reduction. Social and Personality Psychology Compass 2017; 11: e12362. DOI: doi.org/10.1111/spc3.12362.
32. Shea M. Principlism's Balancing Act: Why the Principles of Biomedical Ethics Need a Theory of the Good. *J Med Philos* 2020; 45: 441-470. 2020/07/30. DOI: 10.1093/jmp/jhaa014.
33. van der Byl Williams M and Zeilig H. Broadening and deepening the understanding of agency in dementia. *Med Humanit* 2022. Published Online. DOI: 10.1136/medhum-2022-012387.
34. Gastmans C. Dignity-enhancing nursing care: a foundational ethical framework. *Nurs Ethics* 2013; 20: 142-149. DOI: 10.1177/0969733012473772.
35. Saarnio R, Isola A and Laukkala H. The use of physical restraint in institutional care of older people in Finland: nurses’ individual, communal and alternative modes of action. *J Clinical Nurs* 2009; 18: 132-140. DOI: https://doi.org/10.1111/j.1365-2702.2008.02383.x.
36. Gastmans C and Milisen K. Use of physical restraint in nursing homes: clinical-ethical considerations. *J Med Ethics* 2006; 32: 148-152. DOI: 10.1136/jme.2005.012708.

37. Stegink J. Alternatievenbundel, Inspiratie voor vrijwillige en passende zorg, https://www.vilans.nl/actueel/nieuws/alternatievenbundel-biedt-inspiratie-voor-vrijwillige-zorg (2020, accessed 25-05-2023).
38. Backhouse T, Dudzinski E, Killett A, et al. Strategies and interventions to reduce or manage refusals in personal care in dementia: A systematic review. *Int J Nurs Stud* 2020; 109: 103640. DOI: 10.1016/j.ijnurstu.2020.103640.
39. Mohr W, Rädke A, Afi A, et al. Key intervention categories to provide person-centered dementia care: A systematic review of person-centered interventions. *J Alzheimer's Dis* 2021; 84: 343-366. DOI: 10.3233/JAD-210647.
40. Lee KH, Lee JY and Kim B. Person-centered care in persons living with dementia: A systematic review and meta-analysis. *Gerontologist* 2022; 62: e253-e264. DOI: 10.1093/geront/gnaa207.
41. Kim SK and Park M. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clin Interv Aging* 2017; 12: 381-397. DOI: 10.2147/CIA.S117637.
42. Cruise CE and Lashewicz BM. Dementia and dignity of identity: A qualitative evidence synthesis. *Dementia* 2022; 21: 1233-1249. DOI: 10.1177/14713012211072929.
43. Dyer SM, Harrison SL, Laver K, et al. An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioral and psychological symptoms of dementia. *Int psychogeriatr* 2018; 30: 295-309. DOI: 10.1017/S1041610217002344.
44. Raveesh BN, Gowda GS and Gowda M. Alternatives to use of restraint: A path toward humanistic care. *Indian J Psychiatry* 2019; 61: S693. DOI: 10.4103/psychiatry.IndianJPsychiatry_104_19.
45. Zeng J-F, Cai H-T, Li W-M, et al. Physical restraint using, autonomy, ethics among psychiatric patients in nursing practice in China. *J Integr Nurs* 2020; 2: 97.
46. Whelehan DF, Conlon KC and Ridgway PF. Medicine and heuristics: cognitive biases and medical decision-making. *Ir J of Med Sci* 2020; 189: 1477-1484.
47. Chung FF, Wang PY, Lin SC, et al. Shared clinical decision-making experiences in nursing: a qualitative study. *BMC Nurs* 2021; 20: 85. 2021/06/03. DOI: 10.1186/s12912-021-00597-0.
48. McCarthy J and Gastmans C. Moral distress: a review of the argument-based nursing ethics literature. *Nurs Ethics* 2015; 22: 131-152. DOI: 10.1177/0969733014557139.
49. Goethals S, Dierckx de Casterlé B and Gastmans C. Nurses' decision-making in cases of physical restraint: a synthesis of qualitative evidence. *J Adv Nurs* 2012; 68: 1198-1210. DOI: 10.1111/j.1365-2648.2011.05909.x.

50. Haahr A, Norlyk A, Martinsen B, et al. Nurses experiences of ethical dilemmas: A review. *Nurs Ethics* 2020; 27: 258-272. DOI: 10.1177/0969733019832941.
51. Kwame A and Petrucka PM. A literature-based study of patient-centered care and communication in nurse-patient interactions: barriers, facilitators, and the way forward. *BMC Nurs* 2021; 20: 158. 2021/09/05. DOI: 10.1186/s12912-021-00684-2.
52. Abrahams R, Liu KP, Bissett M, et al. Effectiveness of interventions for co-residing family caregivers of people with dementia: Systematic review and meta-analysis. *Aust Occup Ther J* 2018; 65: 208-224. DOI: https://doi-org.mu.idm.oclc.org/10.1111/1440-1630.12464.
53. Walter E and Pinquart M. How effective are dementia caregiver interventions? An updated comprehensive meta-analysis. *Gerontologist* 2020; 60: e609-e619. DOI: doi.org/10.1093/geront/gnz118.
54. Mengelers AM, Bleijlevens MH, Verbeek H, et al. A Quasi-experimental study on prevention and reduction of involuntary treatment at home (PRITAH) in people with dementia. *J Clin Nurs* 2021. DOI: https://doi-org.mu.idm.oclc.org/10.1111/jocn.16163.
55. Gulpers MJ, Bleijlevens MH, Ambergen T, et al. Reduction of Belt Restraint Use: Long-Term Effects of the EXBELT Intervention. *J Am Geriatr Soc* 2013; 61: 107-112. DOI: 10.1111/jgs.12057.
56. Vandervelde S, Scheepmans K, Milisen K, et al. Reducing the use of physical restraints in home care: development and feasibility testing of a multicomponent program to support the implementation of a guideline. *BMC Geriatr* 2021; 21: 1-18. DOI: 10.1186/s12877-020-01946-5.
57. Möhler R and Meyer G. Development methods of guidelines and documents with recommendations on physical restraint reduction in nursing homes: a systematic review. *BMC geriatr* 2015; 15: 1-6. DOI: doi.org/10.1186/s12877-015-0150-9.
58. Brugnolli A, Canzan F, Mortari L, et al. The effectiveness of educational training or multicomponent programs to prevent the use of physical restraints in nursing home settings: a systematic review and meta-analysis of experimental studies. *Int J Environ Res Public Health* 2020; 17: 6738. DOI: https://doi.org/10.3390/ijerph17186738.
59. Thomann S, Zwakhalen S, Siegrist-Dreier S, et al. Restraint practice in the somatic acute care hospital: A participant observation study. *J Clin Nurs* 2022. DOI: https://doi-org.mu.idm.oclc.org/10.1111/jocn.16322.
60. Jager KJ, Tripepi G, Chesnaye NC, et al. Where to look for the most frequent biases? *Nephrology (Carlton)* 2020; 25: 435-441. 2020/03/07. DOI: 10.1111/nep.13706.

CHAPTER 7

General discussion

General discussion

The aim of this dissertation was to gain insight into the use of involuntary treatment among persons living with dementia receiving professional nursing care at home. We investigated the prevalence and the associated factors of involuntary treatment use among persons with a cognitive impairment and persons with dementia, receiving professional home care. Thereafter, we explored how family caregivers of persons living with dementia deal with care dilemmas that can lead to involuntary treatment use. Furthermore, we gained insight into the attitudes and opinions of district nurses regarding involuntary treatment use and how they experience its use. In this final chapter, the main findings of this dissertation are discussed, and a reflection on methodological and theoretical considerations given. Finally, recommendations for future research and implications for practice are suggested.

Main findings

The results in this dissertation showed that involuntary treatment was applied to one out of two persons living with dementia who receive professional home care in the Netherlands and Belgium.[1, 2] Non-consensual care (83%) was the most common form of involuntary treatment, followed by psychotropic medication (41%) and physical restraints (19%).[2] The factors associated with involuntary treatment use were living alone, lower cognitive ability, higher functional dependency for activities of daily living and living in Belgium compared to living in the Netherlands. Involuntary treatment was most often applied and requested by family caregivers followed by district nurses.[2]

Family caregivers experienced the decision-making process concerning care dilemmas that can lead to involuntary treatment as complicated, stressful and exhausting. Although they considered safety and autonomy as important values, they struggled with finding the right balance.[3] Their experience was influenced by characteristics of the care triad (i.e. persons living with dementia, professional and family caregivers) such as practical and emotional support, knowledge and previous experiences.[3]

District nurses perceived involuntary treatment as a regular part of nursing care, having neither a positive nor negative attitude towards its appropriateness.[4] They considered involuntary treatment usage as moderately restrictive to persons living with dementia and felt moderately uncomfortable when using it. Having more years of experience as a district nurse and finding care for persons with dementia burdensome, were associated with having a more accepting attitude and/or opinion towards involuntary treatment use.[4]

Depending on how district nurses were involved in the decision-making process, they experienced involuntary treatment usage differently.[5] In general, they experienced its use as stressful due to cognitive dissonance regarding obverse values of safety versus autonomy. When they were involved in the decision-making process, they considered involuntary treatment use to be appropriate care despite mixed feelings. In these cases, they perceived its use as stressful. Initially, they were worried that involuntary treatment was unjust since they wished to respect the wishes of persons living with dementia. However, eventually, they found professionally that involuntary treatment use was necessary and that safety outweighed the autonomy of persons living with dementia. If district nurses were not involved in the decision-making process and found the request for involuntary treatment inappropriate dementia care, they still provided it and experienced its use as burdensome and struggled with it.[5]

Methodological considerations

Sampling

To gain a better insight into the prevalence of involuntary treatment among persons living with dementia at home, we conducted a prevalence study using a cross-sectional design in Belgium. The data collected in this study were combined in a secondary data analysis with the results from a previously conducted prevalence study in the Netherlands.[1, 6] As the sampling and setting of both studies were different, we needed to consider the issue of sampling bias. In the Dutch study, participants were recruited via dementia case managers. The case managers were asked to include every person on their caseload who lived at home and was receiving professional care.[6] For the Belgian study, the inclusion criteria were participants being 60 years or older, receiving professional nursing care at home and with a cognitive impairment, defined as being occasionally and/or constantly disoriented in place and/or time.[1] Since different inclusion strategies and criteria were used, selection bias could have occurred, undermining the internal validity. In our studies, we selected a specific group of persons living with dementia, those who received professional home care. The prevalence numbers presented in this thesis may, in general, be either an overestimation or underestimation of involuntary treatment use in persons living with dementia, living at home. For example, receiving professional support from a dementia case manager or district nurse could result in less burden experienced by family caregivers and more discussion about opportunities to avoid using involuntary treatment with family caregivers. This could result in a lower prevalence rate of involuntary treatment use.

Regarding the study concerning family caregivers' experiences of care situations that can lead to involuntary treatment and the study of the experiences of district nurses regarding involuntary treatment, we needed to also consider sampling bias. We recruited family caregivers via registered nurses that provided psychosocial support for family caregivers of persons living with dementia. Since these family caregivers needed this assistance, there could be a risk that they perceived caring for their next of kin as more burdensome, compared to family caregivers that did not need this support. Due to this, the included participants experienced dealing with situations that could lead to involuntary treatment as being more stressful, complicated and exhausting than family caregivers that did not receive this support. Furthermore, because our included family caregivers received professional support, there is a risk that they could be more aware of negative consequences and alternatives regarding involuntary treatment and therefore, could have dealt differently with care situations that could lead to involuntary treatment than family caregivers that did not receive this support.

For the study into the experiences of district nurses, we asked 296 district nurses if they were interested in participating in semi-structured interviews. Fifty-one nurses applied to participate in this study. From this group, sixteen district nurses were selected who indicated that they had experience with involuntary treatment. This sampling method, could have increased the risk that we missed the experiences of district nurses that did not use involuntary treatment, were not aware that they were applying involuntary treatment and/or found involuntary treatment use no issue. Their experiences could had given us a more nuanced and fuller picture of how district nurses experience involuntary treatment. As a result, there could be a risk that our participants experienced involuntary treatment use as more stressful than district nurses that did not participate in our study.

Assessment

To gain insight in the prevalence rate of involuntary treatment, we chose to conduct an online cross-sectional survey in which district nurses and dementia case managers completed online questionnaires. This could have led to recall/memory bias, since that case managers and district nurses could have forgotten that in certain situations involuntary treatment was applied.[7] Moreover, recent research found that measures we defined as involuntary treatment are not always visible to health-care providers; there could be a risk for under-reporting.[8] Additionally, due to a lack of knowledge regarding the negative impact of involuntary treatment and/or a more positive attitude and opinion towards its use, caregivers could be unaware that the care that they were providing was involuntary treatment.[4, 9] Therefore, we needed to consider the prevalence rate, since there could be a risk of under-reporting. However, when preparing the prevalence study, we did not find other methods that were more feasible, valid and/or reliable. In Belgium and the Netherlands, the measures we defined as involuntary treatment were not reported in a structured or uniform way in the client records of the person living with dementia.[10, 11] In addition, there were no official quality indicators regarding involuntary treatment use. As a result, analysing databases of governments and/or health-care organisations was not possible. Further, analysing individual care plans was not feasible due to time constraints and the fact that measures of involuntary treatment were not always reported. In addition, in contrast to nursing homes or hospital settings, for ethical reasons it was not feasible to observe the use of involuntary treatment at home, on a large scale.

To gain a better understanding of the experiences of district nurses regarding involuntary treatment use and the experience of family caregivers' experience in dealing with involuntary treatment, we conducted in-depth semi-structured interviews.[3, 5, 12] To ensure the quality of our findings, we used the quality framework of Guba and Lincoln.[7, 13] Guba and Lincoln suggest that there are five criteria for the development of the trustworthiness of an qualitative inquiry, namely: credibility, dependability, confirmability, transferability and authenticity.[7, 13] To ensure the trustworthiness of our results, we applied strategies including purposeful sampling, using an interview guide, providing thick descriptions, maintaining a detailed audit trail and member checking by summarising participants' responses at the end of each interview. The analysis process was frequently reviewed within the research team to establish uniformity in themes and relationships and to explore the interviewers' reflexivity, peer debriefing, thorough descriptions of the research setting, characteristics of the participants, applied measures and process. Although, we used several strategies the ensured the trustworthiness of our results, we needed to consider their credibility and dependability,[7, 13] since we could not fully exclude the risk of interview bias. Interview bias could have influenced the internal validity our study results.[14] Interview bias could have occurred due to: errors by the participants (i.e. forgetting, lying, embarrassment, misunderstanding); unintentional errors or interviewer sloppiness (i.e. misreading question, omitting questions, misunderstanding the participant); and/or the interviewer's appearance could influence the answers of the participants (i.e. tone, attitude, reactions to answers).[7, 14]

Theoretical considerations

The findings of this dissertation show that normative arguments, like protecting from harm and/or enhancing safety, influence the decision-making process of caregivers regarding involuntary treatment of persons living with dementia. Insights into these normative arguments are needed if we want to prevent involuntary treatment use. Further, our findings also have an impact on nursing and district nursing in general. Therefore, in this section, an ethical reflection and a reflection of nursing care will be discussed.

Ethical reflection on the use of involuntary treatment

This thesis indicated that caregivers perceived involuntary treatment usage as appropriate and necessary dementia care, because protecting from harm outweighed respecting the autonomy of the person living with dementia. This suggests that caregivers mostly used a principlism approach, which is a biomedical ethical approach, to rationalise why involuntary treatment was necessary.[15] However, literature suggests that biopsychosocial approaches like the ethics of care, which are more in line with a person-centred approach, could be more suitable to deal with the complexity of dementia care.[16, 17] In this section, the use of involuntary treatment will be discussed in the light of these two ethical approaches.

Principlism, a biomedical ethical approach

Principlism is a normative biomedical ethical framework designed for decision-making in health care, which is centred on the four moral principles of beneficence (i.e. obligation to act in the best interests of others), non-maleficence (i.e. do no harm), respect for autonomy (i.e. the capacity of an individual to be self-determining and to make decisions for themselves without undue pressure, coercion or other forms of persuasion) and justice (i.e. ensuring that costs and benefits are fairly distributed). The process of specification and balancing are crucial, when using this approach.[18] This ensures that in certain situations, after a cost benefit analysis, doing harm (e.g. feelings of imprisonment, due to locking in house) could be experienced as unavoidable, since the benefits (e.g. preventing a traffic accident or getting lost due to wandering) outweigh the harm. Our results show that caregivers often motivate their decision to apply involuntary treatment, by noting that preventing harm was more important than respecting the wishes of their loved one or patient. This could indicate that caregivers used a principlism approach to deal with daily care dilemmas.[19, 20] Caregivers, in most cases, refer to the principle of non-maleficence (e.g. protection from harm) and beneficence (e.g. enhancing the safety or personal well-being of the PLWD and/or family) to explain why involuntary treatment was necessary.[3, 5] By using this line of ethical reasoning, caregivers could find peace within themselves regarding why eventually, involuntary treatment was needed. However, one can question if a principlism approach is suitable in dementia care since an important focus in this approach lies in its time-limited or action-focused quality. However, when caring for persons living with dementia, caregivers must made constantly and closely interact with each other to make decisions about day-to-day care. These decisions are embedded in the life story of the care recipient and in the interactions of all involved in their care process.[3, 5, 15, 16, 21] For these reasons an approach that is focused on making isolated decisions in a single moment of time could be a too narrow approach to deal with complicated care dilemmas that are embedded in the care processes, which caregivers of persons with dementia need to deal with every day.

Ethics of care

The ethics of care is an ethical approach that is oriented on care process, considers the complexity of it and also the context.[17] Like person-centred care, this approach emphasises that all actors in the care process need to be involved in the decisions around the actual caring needs and how to meet them. Moreover, it underlines that no one should claim their own authoritative knowledge to influence these decisions. In addition, this approach emphasises that when caregivers make care decisions, they must understand the complexity of the care process and be aware of the ‘full story’ of it.[17, 22] Further, this approach points out that the care process is fraught with conflicts, that this is inherent in care and that there are more needs for care than can be met.[17] In our findings we identified similar conflicting situations regarding safety and respecting the wishes of loved ones or patients.[3, 5] These conflicts were situated within and between the four phases of caregiving (i.e. attentiveness, responsibility, competence and responsiveness) and in the context of care.[3, 5, 17] For example, we found that when a person living with dementia resisted their care or were agitated, caregivers were insufficiently attentive and/or responsive that this could be an expression of their bodily autonomy. Further, caregivers indicated that they were sometimes not competent to tailor their hygienic care and communication to the world of experience of the person living with dementia. Moreover, when decisions were made regarding involuntary treatment use, the interprofessional dialogue was often missing and the family caregiver was the sole decision maker. This contributed to family caregivers and district nurses experiencing caring for persons living with dementia as stressful to burdensome. As a result, involuntary treatment use altered the care situation and produced new caring needs for persons living with dementia and their caregivers, making the caring process became a full and dynamic circle.[17]

When caregivers are aware of these four phases of caregiving and could identify possible conflicting situations, it could help them to gain insight in the complex picture of what 'good caring' could be.[17] However, in reality due the conflicting situations in the context of caregiving, between and within the four phases of caregiving, this process rarely occurs in a perfect way. This could mean that involuntary treatment use could be a result of conflicts within the care process. Therefore, we need to be aware of the phases of caregiving and the possible conflicts, and find resolutions for them with all who are involved, in order to improve the caregiving process and prevent involuntary treatment. These insights show that the framework of ethics of care could be more helpful to support caregivers of persons living with dementia in making minor and major daily care decisions in a more person-centred manner than biomedical approaches. The framework of ethics of care helps caregivers to analyse, identify possible conflicts and understand care processes better. Based on these insights, steps can be undertaken to find more person-centred solutions and prevent involuntary treatment use. To achieve this, we need to improve the attentiveness, responsibility, competence and responsiveness skills of all caregivers involved and foster interdisciplinary dialogue. When in dialogue with each other, all involved must be aware that when dealing with these daily care dilemmas, it is normal that they cause discomfort and stressful feelings. If caregivers confronted themselves with these feelings and enter into an open dialogue about them, they can find a better balance between their own needs and those of others.[17]

Involuntary treatment in the light of nursing care at home

To improve dementia nursing care at home, a critical reflection is given on the meaning of involuntary treatment in the light of nursing and district nursing.

Involuntary treatment conflicts with nursing theory

When nurses apply care without the consent and/or where the patient resists, it is in conflict with respecting the human dignity of their patients, one of the core values of nursing.[23-25] Dignity encompasses respect, autonomy, holism, empowerment, communication of information and person-centredness.[23] This value is embedded in several definitions of nursing like that of Henderson, the rights of persons with disabilities and nursing theories like those of Orlando.[26-28] The definition of nursing of Henderson, states that nurses are responsible for assisting their patients in receiving dignified care, if their patients do not have the necessary strength for it. When nurses apply involuntary treatment, they do not take up their responsibility to go in dialogue with the patient and their caregivers and/or assist them in it, in order to receive dignified care.[29-32] The Rights of Persons with Disabilities emphasises that caregivers like nurses must be their patients' advocates, if their patients do not have the abilities to stand up for their rights for receiving dignified care.[19, 26] Further, the 'Deliberative Theory of Nursing Process Theory' of Orlando states that effective interaction with the care recipient is needed to reach a positive outcome. Care recipients have their own meanings and interpretations of situations and therefore, nurses must validate their inferences and analyses with patients before concluding.[28] In this way, nurses can provide nursing care that is tailored to the needs of persons living with dementia.[28] When nurses deliver care without the consent and/or where the person receiving it resists, it is in disagreement with this theory. These insights could indicate that when nurses apply involuntary treatment, they lack the necessary knowledge and skills to provide dignified care, a core value of nursing.

The role of district nurses in involuntary treatment use

District nurses have a pivotal role in dementia care at home and therefore, in the prevention of involuntary treatment. Through their trust and professional relationship with their patients and their families, they can detect timely practical problems and proactively advise on how to manage these problems. Further, they can have a coordinating and facilitating role within the care triad and be the patient's advocat.[33, 34] Moreover, through shared decision-making and advanced care planning, district nurses can gain a timely and thorough insight into the care needs of their patients and families and discuss them within the care triad.[35, 36] In this way, the risk for involuntary treatment use can be reduced and prevented. The results in this dissertation show that, in many cases, district nurses could not take up their key role in the prevention of involuntary treatment, as they were often insufficiently attentive and/or responsive to the moral needs of their patients, their own and other involved caregivers. Further, district nurses were, in most cases, not involved in the decisions made by others, due a lack of interdisciplinary dialogue. Moreover, they did not always succeed in creating a dialogue with the family caregiver about care requests they perceived as inappropriate. As result, they applied the requested involuntary treatment, which they perceived as inappropriate. Further, family caregivers also indicated that professional caregivers often underestimated their care needs and that they wanted more timely and tailor-made support. These findings show that more and timely care planning is needed in order to better align each other's needs and expectations and so, reduce the risk of involuntary treatment.[35] In Belgium, general practitioners with the support of district nurses could play a crucial role in the coordination of advanced care planning.[37, 38] However, our results show that the district nurse and/or general practitioner were not involved in the majority of cases.[3, 5] We found that there was often great diversity in who was involved in making decisions about the care of persons with dementia. The district nurse was often the executor instead of the pivot of the care of persons living with dementia.[5] These situations can cause nurses to feel like 'task-oriented technicians' rather than the 'caring professionals' they would like to be.[39] These insights could help us understand why district nurses experienced involuntary treatment as stressful, due to cognitive dissonance,[5] as district nurses experienced a gap between what they would like to do and what they were expected to in practice.[39] Therefore, professional home nurse care organisations should invest in increasing and supporting the interdisciplinary dialogue about involuntary treatment.

Moreover, professional nurse home care organisations need to have a clear policy regarding involuntary treatment, stating what the expectations and responsibilities of district nurses are. When developing this policy, it is crucial that all stakeholders are involved (interest groups of patients, family caregivers, general practitioners, district nurses etc.), as each stakeholder plays a key role in the organisation and provision of care for persons living with dementia.

The results of this dissertation indicate that district nurses often provide involuntary treatment at home due to the identified barriers. However, on the other hand, if we address these barriers, they could also be seen as opportunities to increase the quality of dementia nursing care at home.

Implications for research and practice

The results of this dissertation show that involuntary treatment is a common practice in dementia care at home and there should be more emphasis on preventing it. Further, we found that the decision-making process regarding care dilemmas that lead to involuntary treatment is complicated. Often caregivers lack the necessary knowledge and skills to go into dialogue with each other about involuntary treatment in a timely and tailored manner. Increasing knowledge and skills regarding person-centred care could help in reducing and/or preventing involuntary treatment. These insights have several implications for future research and practice.

Research

Prevalence of involuntary treatment

If we want to generalise the results of this dissertation to other settings and gain more insight into involuntary treatment use among persons living with dementia, studies are needed into the prevalence rates of caregivers in other health-care settings like home care settings where no professional caregivers are involved or residential care.

Additionally, research is needed regarding the development of universal quality indicators concerning involuntary treatment. These quality indicators are needed to evaluate the prevalence of involuntary treatment use and effect of multicomponent programmes that are aimed to prevent its use. Based on these quality indicators, policymakers on organisational and governmental levels can monitor the use of involuntary treatment and plan more tailored interventions to prevent and reduce it usage.

Prevention of involuntary treatment

More knowledge is needed concerning intervention programmes that prevent and/or reduce involuntary treatment usage. The first steps towards the development of these multicomponent programmes have been made recently, like PRITAH, EIT-4-BPSD.[40-45] Therefore, we advise that further research focus on evaluation of these multicomponent programmes, by conducting process and effect studies. We suggest that a mixed method pre-post-test study should be conducted to evaluate the implementation and impact of these programmes in organisations that provide nursing care at home.

In addition, we recommend that research focus on how the insights of this dissertation can be integrated into previously developed multicomponent programmes like increasing the knowledge of caregivers about the sensitivity and awareness of the negative consequences and misconceptions of involuntary treatment use.

Decision-making process

Our research focused on the experiences of district nurses and family caregivers, separately. To get a thorough insight into the decision-making process around involuntary treatment use, a case-study of several ecosystems (PLWD, family, family caregivers, general practitioner, domestic carer, district nurses, etc.) is required.

Further research is needed regarding how the knowledge and skills of caregivers can be increased concerning the diminishing decision-making capacity of persons living with dementia. These interventions must focus on increasing their skills in adequately supporting and assisting persons living with dementia in the decisions concerning their care in a tailored manner.[35] Additionally, we need to investigate which interventions are needed to foster the ethical reflection skills of all caregivers involved in dealing with minor and major dilemmas in dementia care, in a timely and tailored way.[39, 46, 47]

Increasing person-centred care

More research is needed concerning how we can integrate components in multicomponent programmes that increase the knowledge and skills of caregivers: 1) about person-centred care and person-centred alternatives for involuntary treatment (i.e. interventions involving music, approaching, bathing techniques, ability focused approach or distraction approach); [48-51] 2) regarding the needs of persons living with dementia in light of person-centred care and how they can support these needs; and 3) so that they can provide timely emotional and social support for persons living with dementia (i.e. information, training activities of daily living, walking and environmental adaptations) and their family caregivers (information, psycho-education, respite, skills training and coping strategies).

Practice

Prevalence of involuntary treatment

Since involuntary treatment is a common practice in home care, it is important that health-care organisations and governments develop systems to monitor the use of involuntary treatment and openly rapport over its use on a frequent basis. Based on these results, health-care organisations and governments can measure the use of involuntary treatment in their organisation or country, implement intervention to prevent its use and monitor its progression.

Prevention of involuntary treatment

Home care organisations need to develop a clear policy regarding how to deal with complex care situations that could result in involuntary treatment and prevent its use. Studies indicate that multicomponent programmes like PRITAH show promising results in training and supporting district nurses to gain sufficient skills and knowledge to bring this policy into practice.[42, 43] To successful implement and sustain these policies, home care organisations must involve all stakeholders in their development, implementation and evaluation.

Our findings point out the need for clear unambiguous legislation to prevent involuntary treatment in Belgium and Flanders. In Belgium and Flanders, in contrast to the Netherlands or Norway, there is in no specific legislation that regulates the rights of persons with a psychogeriatric disorders in the case of involuntary treatment or forced treatment use.[52, 53] Accordingly, under Dutch law 'Care and Coercion' involuntary treatment should only be used if, after thoroughly multidisciplinary consultation including experts and/or specialists, there are no alternatives to prevent a risk of serious harm. A weakness of this law is that it only applies to professional caregivers, so relatives and caregivers can still use involuntary treatment. The multicomponent programmes can facilitate the implementation of this law in daily practice.[42, 43] Studies indicate that legislation and related regulatory mandates together with multicomponent programmes are both crucial elements to reduce and/or prevent involuntary treatment.[44, 54, 55] The insights of this dissertation into the complexity of involuntary treatment use could help governmental policymakers develop legislation that is practical, clear and feasible to implement in home care practice.

Decision-making process

This dissertation shows that district nurses need to be involved in timely dialogue and assist persons living with dementia in making decisions and formulating wishes about their daily care together with their next of kin and all other involved caregivers. To guarantee this, health-care organisations need to integrate the concepts of shared decision-making into their policies and actively promote this, train their employees in it, and monitor and frequently evaluate its use.[35, 36]

As nurses often lack the necessary skills to go into dialogue about involuntary treatment, it is important that nurse education curricula make it a priority to strengthen the critical ethical reflection and dialogue skills of nursing students.

Government policymakers need to redesign financial reimbursement systems, through targeted financing of key elements like shared decision-making, interprofessional collaboration, consultation when involuntary care is considered and individualised care plans that are based on shared decision-making. In this manner, governments can intervene in a targeted way to prevent involuntary care.

Increasing person-centred care

Professional nurse home care organisations need to invest in increasing the knowledge and skills of their employees regarding biopsychosocial approaches like the ethics of care in order to be able to critically reflect in a person-centred manner on the daily dilemmas of dementia care at home. In addition, it is strongly recommended that professional nurse home care organisations invest in creating a value-supportive context and value-based leadership to continuously support, stimulate and improve the ethical skills of district nurses.[46, 56]

Our results point out that nurse education curricula need to implement programmes to increase the knowledge and practical skills of nurse students in providing person-centred care. Therefore, it is important that nursing students gain insight into ethical frameworks like biomedical or biopsychosocial approaches, which are currently predominant, and that they be able to interpret, discuss and use them in a person-centred manner.[19, 39, 57] In this way, nurses would have the skills to go into dialogue with all involved actors to find person-centred alternatives for involuntary care.

References

1. Moermans VR, Bleijlevens MH, Verbeek H, et al. The use of involuntary treatment among older adults with cognitive impairment receiving nursing care at home: A cross-sectional study. *Int J Nurs Stud* 2018; 88: 135-142. DOI: 10.1016/j.ijnurstu.2018.09.004.
2. Mengelers AM, Moermans VR, Bleijlevens MH, et al. Involuntary treatment in dementia care at home: Results from the Netherlands and Belgium. *J Clin Nurs* 2022; 31: 1998-2007. DOI: 10.1111/jocn.15457.
3. Moermans VR, Mengelers AM, Bleijlevens MH, et al. Caregiver decision-making concerning involuntary treatment in dementia care at home. *Nurs Ethics* 2021; 29: 330-343. DOI: 10.1177/09697330211041742.
4. Moermans VR, Bleijlevens MH, Verbeek H, et al. District nurses' attitudes towards involuntary treatment in dementia care at home: A cross-sectional study. *Geriatr Nurs* 2022; 47: 107-115. DOI: 10.1016/j.gerinurse.2022.07.009.
5. Moermans VR, Bleijlevens MH, Verbeek H, et al. District Nurses' Experiences with Involuntary Treatment in Dementia Care at Home: A qualitative descriptive study.; Submitted for publication.
6. Hamers JP, Bleijlevens MH, Gulpers MJ, et al. Behind Closed Doors: Involuntary Treatment in Care of Persons with Cognitive Impairment at Home in the Netherlands. *J Am Geriatr Soc* 2016; 64: 354-358. DOI: 10.1111/jgs.13946.
7. Polit DF and Beck CT. *Nursing research: Generating and assessing evidence for nursing practice.* Lippincott Williams & Wilkins, 2012.
8. Häikiö K, Sagbakken M and Rugkåsa J. Dementia and patient safety in the community: a qualitative study of family carers' protective practices and implications for services. *BMC Health Serv Res* 2019; 19: 1-13. DOI: 10.1186/s12913-019-4478-2.
9. Kurata S and Ojima T. Knowledge, perceptions, and experiences of family caregivers and home care providers of physical restraint use with home-dwelling elders: a cross-sectional study in Japan. *BMC Geriatr* 2014; 14: 1-11. DOI: 10.1186/1471-2318-14-39.
10. Scheepmans K, Dierckx de Casterlé B, Paquay L, et al. *Streven naar een fixatiearme thuiszorg, praktijkrichtlijn.* Leuven: Acco, 2016.
11. Wet van 24 januari 2018, houdende regels voor het kunnen verlenen van verplichte zorg aan een persoon met een psychische stoornis (Wet verplichte geestelijke gezondheidszorg). 2018.
12. Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001; 358: 483-488. DOI: https://doi.org/10.1016/S0140-6736(01)05627-6.
13. Guba EG and Lincoln YS. *Competing paradigms in qualitative research, Handbook of qualitative research.* Thousand Oaks, CA: Sage, 1994, p.105.

14. Neuman WL. Social research methods, qualitative and quantitative approaches - 7th ed. Pearson, 2011.
15. Beauchamps TL and Childress JF. *Principles of Biomedical Ethics.* 8th edition ed. New York, NY: Oxford University Press Inc, 2019.
16. Gastmans C. Dignity-enhancing nursing care: a foundational ethical framework. *Nurs Ethics* 2013; 20: 142-149. DOI: 10.1177/0969733012473772.
17. Tronto JC. An ethic of care. *J Am Soc Aging* 1998; 22: 15-20. DOI: https://www.jstor.org/stable/44875693.
18. Shea M. Principlism's balancing act: why the principles of biomedical ethics need a theory of the good. In: *J Med Philos* 2020, pp.441-470. Oxford University Press US.
19. Vandenbulcke M, Dröes R-M and Schokkaert E. *Dementia and Society.* Cambridge University Press, 2022.
20. Cruise CE and Lashewicz BM. Dementia and dignity of identity: A qualitative evidence synthesis. *Dementia* 2022; 21: 1233-1249. DOI: 10.1177/14713012211072929.
21. Gastmans C. *Kwetsbare waardigheid, Ethiek aan het begin en einde van het leven.* Kalmthout: Pelckmans, 2021.
22. Brummel-Smith K, Butler D, Frieder M, et al. Person-centered care: A definition and essential elements. *J Am Geriatr Soc* 2016; 64: 15-18. DOI: 10.1111/jgs.13866.
23. Schmidt BJ and McArthur EC. Professional nursing values: A concept analysis. In: *Nursing forum* 2018, pp.69-75. Wiley Online Library.
24. Fahrenwald NL, Bassett SD, Tschetter L, et al. Teaching core nursing values. *J Prof Nurs* 2005; 21: 46-51. DOI: https://doi.org/10.1016/j.profnurs.2004.11.001.
25. Kangasniemi M, Pakkanen P and Korhonen A. Professional ethics in nursing: an integrative review. *J Adv Nurs* 2015; 71: 1744-1757. DOI: https://doi-org.mu.idm.oclc.org/10.1111/jan.12619.
26. Nations U. Convention on the rights of persons with disabilities., http://www.un.org/disabilities/convention/conventionfull.shtml (2006).
27. International Council of Nurses. Nursing Definitions, https://www.icn.ch/nursing-policy/nursing-definitions (2022, accessed 08-12-2022).
28. May BA. Orlando's nursing process theory in nursing practice. *MR Alligood (Ed), Nursing theory: Utilization and practice* 2013: 285-302.
29. Beerens HC, Sutcliffe C, Renom-Guiteras A, et al. Quality of life and quality of care for people with dementia receiving long term institutional care or professional home care: the European RightTimePlaceCare study. *JAMA* 2014; 15: 54-61. DOI: https://doi.org/10.1016/j.jamda.2013.09.010.

30. Gastmans C and Milisen K. Use of physical restraint in nursing homes: clinical-ethical considerations. *J Med Ethics* 2006; 32: 148-152. DOI: 10.1136/jme.2005.012708.
31. Hofmann H and Hahn S. Characteristics of nursing home residents and physical restraint: a systematic literature review. *J Clin Nurs* 2014; 23: 3012-3024. DOI: 10.1111/jocn.12384.
32. Voyer P, Cohen D, Lauzon S, et al. Factors associated with psychotropic drug use among community-dwelling older persons: A review of empirical studies. *BMC Nurs* 2004; 3: 1-13. DOI: 10.1186/1472-6955-3-3.
33. Wit-Gele Kruis Vlaanderen. *Wegwijs in de thuisverpleging.* Antwerpen: Standaard Uitgeverij, 2011.
34. Thoma-Lürken T, Bleijlevens MH, Lexis MA, et al. Facilitating aging in place: A qualitative study of practical problems preventing people with dementia from living at home. *Geriatr Nurs* 2018; 39: 29-38. DOI: 10.1016/j.gerinurse.2017.05.003.
35. Wendrich-van Dael A, Bunn F, Lynch J, et al. Advance care planning for people living with dementia: an umbrella review of effectiveness and experiences. *Int J Nurs Stud* 2020; 107: 103576. DOI: 10.1016/j.ijnurstu.2020.103576.
36. Miller LM, Whitlatch CJ and Lyons KS. Shared decision-making in dementia: a review of patient and family carer involvement. *Dementia* 2016; 15: 1141-1157. DOI: 10.1177/1471301214555542.
37. Rijksinstituut voor ziekte- en invaliditeitsverzekering. Advance Care Planning: anticiperen op een betere zorg voor uw palliatieve patiënten, https://www.riziv.fgov.be/nl/professionals/individuelezorgverleners/artsen/verzorging/Paginas/advanc-care-planning-anticiperen-betere-zorg-patient-palliatief.aspx (2022, accessed 30-12-2022).
38. Federale overheid volksgezondheid veiligheid van de voedselketen en leefmilieu. Praat tijdig over je oude dag, het zijn levens belangrijke onderwerpen., https://mijnoudedag.be/burger/ (2022, accessed 30-12-2022).
39. Goethals S, Gastmans C and de Casterlé BD. Nurses' ethical reasoning and behaviour: A literature review. *Int J Nurs Stud* 2010; 47: 635-650. DOI: 10.1016/j.ijnurstu.2009.12.010.
40. Resnick B, Van Haitsma K, Kolanowski A, et al. Implementation of the Evidence Integration Triangle for behavioral and psychological symptoms of dementia (EIT-4-BPSD) in care communities. *Nurs outlook* 2021; 69: 1058-1071. DOI: 10.1016/j.outlook.2021.06.004.
41. Vandervelde S, Scheepmans K, Milisen K, et al. Reducing the use of physical restraints in home care: development and feasibility testing of a multicom-

ponent program to support the implementation of a guideline. *BMC Geriatr* 2021; 21: 1-18. DOI: 10.1186/s12877-020-01946-5.

42. Mengelers AM, Bleijlevens MH, Verbeek H, et al. A Quasi-experimental study on prevention and reduction of involuntary treatment at home (PRITAH) in people with dementia. *J Clin Nurs* 2021 2021/12/09. DOI: 10.1111/jocn.16163.
43. Mengelers AM, Bleijlevens MHC, Verbeek H, et al. Prevention and reduction of involuntary treatment at home: A feasibility study of the PRITAH intervention. *Geriatr Nurs* 2020; 41: 536-543. DOI: 10.1016/j.gerinurse.2020.02.001.
44. Gulpers MJ, Bleijlevens MH, Ambergen T, et al. Reduction of Belt Restraint Use: Long-Term Effects of the EXBELT Intervention. *J Am Geriatr Soc* 2013; 61: 107-112. DOI: 10.1111/jgs.12057.
45. Resnick B, Kolanowski A, Van Haitsma K, et al. Pilot Testing of the EIT-4-BPSD Intervention. *Am J Alzheimers Dis Other Demen* 2016; 31: 570-579. DOI: 10.1177/1533317516662337.
46. Vanlaere L and Gastmans C. Ethics in nursing education: learning to reflect on care practices. *Nurs Ethic* 2007; 14: 758-766. DOI: https://doi.org/10.1177/0969733007082116.
47. Doane G, Pauly B, Brown H, et al. Exploring the Heart Ofethical Nursing Practice: implications for ethics education. *Nurs Ethic* 2004; 11: 240-253. DOI: doi.org/10.1191/0969733004ne692oa.
48. Mohr W, Rädke A, Afi A, et al. Key intervention categories to provide person-centered dementia care: A systematic review of person-centered interventions. *J Alzheimer's Dis* 2021; 84: 343-366. DOI: 10.3233/JAD-210647.
49. Backhouse T, Dudzinski E, Killett A, et al. Strategies and interventions to reduce or manage refusals in personal care in dementia: A systematic review. *Int J Nurs Stud* 2020; 109: 103640. DOI: 10.1016/j.ijnurstu.2020.103640.
50. Sefcik JS, Boltz M, Dellapina M, et al. Are Interventions for Formal Caregivers Effective for Improving Dementia Care? A Systematic Review of Systematic Reviews. *Innov Aging* 2022; 6: 1-16. DOI: 10.1093/geroni/igac005.
51. Kim SK and Park M. Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis. *Clin Interv Aging* 2017; 12: 381-397. DOI: 10.2147/CIA.S117637.
52. Wet zorg en dwang voor personen met een psychogeriatrische aandoening of een verstandelijke handicap 2018.
53. Gjellestad Å, Oksholm T and Bruvik F. Forced treatment and care in home-dwelling persons with dementia. *Nurs Ethics* 2020; 28: 372-386.

DOI: 10.1177/0969733020948107.

54. Hamers J and Huizing AR. Why do we use physical restraints in the elderly? *Z Gerontol Geriatr* 2005; 38: 19-25. DOI: https://doi.org/10.1007/s00391-005-0286-x.
55. Köpke S, Mühlhauser I, Gerlach A, et al. Effect of a guideline-based multi-component intervention on use of physical restraints in nursing homes: a randomized controlled trial. *JAMA* 2012; 307: 2177-2184. DOI: 10.1001/jama.2012.4517.
56. Denier Y, Dhaene L and Gastmans C. 'You can give them wings to fly': a qualitative study on values-based leadership in health care. *BMC Med Ethics* 2019; 20: 35. DOI: 10.1186/s12910-019-0374-x.
57. Gastmans C. Care as a moral attitude in nursing. *Nurs ethics* 1999; 6: 214-223. DOI: https://doi-org.mu.idm.oclc.org/10.1177/096973309900600303.

ADDENDA

—

Summary

Summary

Persons living with dementia wish, like all other persons, to be involved in the decisions about their care. When dementia further evolves, persons living with dementia experience more problems with this, and eventually, they lose (part of) their decision-making capacity. As a result, caregivers and next of kin gradually take over these decisions. When the person living with dementia is not involved in these decisions or does not agree with them, it can lead to involuntary treatment. Involuntary treatment is defined as care provided without the consent of the person receiving it and/or to which this person resists. Involuntary treatment has a negative impact on the quality of life of persons living with dementia and their caregivers. Moreover, more effective and person-centred alternatives exist than involuntary treatment usage such as interventions involving music, approaching persons living with dementia bathing techniques, ability-focused approach, and distraction approach. Therefore, we must prevent the use of involuntary treatment. Since scientific literature regarding this topic is scarce, we need more insights into its use among persons living with dementia receiving professional home care. These insights are needed to successfully develop interventions or adapt existing interventions to prevent its use. Therefore, this thesis aims to: 1) gain insight into the prevalence and the associated factors of involuntary treatment use among persons living with dementia at home, who receive professional home care; 2) describe how family caregivers experience the decision-making process of care dilemma situations that can lead to involuntary treatment use; and 3) investigate the attitudes and opinions of district nurses towards the use of involuntary treatment in dementia care at home and to describe their experiences with it.

Chapter 1 contains a general introduction to this dissertation, addressing dementia, person-centred care, family caregiving, professional home care nursing and involuntary treatment use. Finally, the aims of the study are presented and an outline of this dissertation provided.

To investigate the prevalence of involuntary treatment, associated factors and who requests and applies its use among older adults with cognitive impairment receiving nursing care at home, a cross-sectional survey was conducted (**Chapter 2**). Data from 1194 randomly selected older adults with cognitive impairments receiving nursing care at home in Belgium were analysed. District nurses completed a questionnaire based on their knowledge. The application of involuntary treatment, who requests and applies it, and associated factors were assessed. Data were analysed using descriptive analyses and

random intercept logistic regression. We identified that involuntary treatment was used with half of the older adults with cognitive impairments receiving nursing care at home. Non-consensual care was most often used (73%), followed by psychotropic drugs (43%) and physical restraints (38%). The use of involuntary treatment was associated with dependency in activities of daily living (ADL), cognitive impairment, informal caregiver burden and age. Informal caregivers (71%), followed by general practitioners (47%) most frequently requested the use of involuntary treatment, and nurses (81%) mostly applied it. We found that among persons with a diagnosis of dementia, significantly more involuntary treatment was used than persons without the diagnosis of dementia. Therefore, the following step is to gain insight into involuntary treatment use among persons living with dementia at home receiving professional home care.

To gain insight into the request, use and associated factors of involuntary treatment in persons living with dementia receiving professional home care in the Netherlands and Belgium, a secondary data analysis of two cross-sectional surveys was conducted (**Chapter 3**). Dementia case managers and district nurses completed a questionnaire for each person living with dementia on their caseload. This study included data from 627 persons living with dementia 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. Our results showed that more than half of those living with dementia (50.7%) at home received involuntary treatment (Belgium 68.2% and the Netherlands 44.7%). Non-consensual 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. Family caregivers played a crucial role in the request for and use by family caregivers of involuntary treatment. For this reason, insights are needed into the experiences of family caregivers regarding care decisions that can lead to involuntary treatment use.

To identify and describe family caregivers’ experiences regarding care decisions in situations that can lead to involuntary treatment use in persons living with dementia at home, a qualitative descriptive study was performed (**Chapter 4**). Data were analysed using the Qualitative Analysis Guide of Leuven.[1] The results of 10 in-depth semi-structured interviews among family caregivers of 13 persons living with dementia revealed that they experienced the decision-making process concerning care dilemmas that can lead to involuntary treatment as complicated, stressful and exhausting. Although they considered safety and autonomy as important values, they struggled with finding the right balance between them. Due to the progressive and unpredictable nature of dementia, they were constantly seeking new solutions while they were still adapting to the current situation. Family caregivers felt responsible, and experienced social pressure for the safety of the person living with dementia. They may be blamed if something adverse happens to their loved one, which increased an already stressful situation. Their experience was influenced by characteristics of the care triad such as practical and emotional support, knowledge and previous experiences. To prevent involuntary treatment, professionals need to support family caregivers in dementia care in a timely manner, especially regarding behavioural symptoms concerning safety. Since district nurses play a key role in dementia nursing care at home, they can support family caregivers in dealing with these care situations. However, district nurses are often involved in the use of involuntary treatment. Therefore, we need to gain more insights into attitudes and opinions of district nurses regarding involuntary treatment use in dementia care at home.

To explore district nurses' attitudes towards the use of involuntary treatment in dementia care at home, its determinants and their opinions about the restrictiveness and discomfort, a cross-sectional study was conducted (**Chapter 5**). Data were collected from 296 Belgian district nurses with experience in dementia care. They completed an online version of the Maastricht Attitude Questionnaire Home Care.[2] Data were analysed using descriptive analyses, multiple linear regression and multinomial logistic models. We identified that district nurses perceived involuntary treatment as a regular part of nursing care, having a neither positive nor negative attitude toward its appropriateness. They considered its usage as moderately restrictive to persons living with dementia and felt moderately uncomfortable when using it. District nurses experienced physical restraint measures that were closely attached to the body (e.g. belts) or non-consensual care measures restricting freedom of living (e.g. withholding walking aids, telephone or mail) as more restrictive for persons living with dementia and felt more uncomfortable using them when compared to more covert measures, such as camera surveillance, sensor mats or hiding medication. When years of experience as a district nurse in dementia care at home increased, district nurses had a lower educational background or the care for persons with dementia was perceived as burdensome, they tended to consider the use of involuntary treatment as: 1) a more appropriate clinical practice; 2) less restrictive for the person living with dementia; and 3) less uncomfortable to use. These findings underscore the need to train and support them in a timely manner, in critically reflecting and discussing how to deal with care situations that (can) result in the use of involuntary treatment in a more person-centred manner. To gain further insights into how district nurses can be supported in dealing with involuntary treatment use in a person-centred manner, qualitative research is needed that identifies and describes the experiences of district nurses regarding the use of involuntary treatment in dementia care at home.

To describe the experiences of district nurses who use involuntary treatment for persons living with dementia at home, a qualitative descriptive study was conducted (**Chapter 6**). Using in-depth semi-structured interviews, data were collected from 16 district nurses with experience in involuntary treatment usage, who were recruited through purposive sampling. Data were analysed using the Qualitative Analysis Guide of Leuven.[1] Our results showed that the experiences of district nurses with involuntary treatment were influenced by their involvement in the decision-making process. When they were involved, they considered involuntary treatment use to be appropriate care. However, in the beginning, they were worried that involuntary treatment was unjust since they wished to respect the wishes of persons living with dementia. However, as more safety incidents occurred, they eventually felt, from a professional perspective, that involuntary treatment use was necessary, as the safety of those living with dementia outweighed respecting their wishes. District nurses indicated that they experienced dealing with the dilemma of safety versus autonomy as stressful, as they were trying to fulfil two opposing values at the same time, namely protecting their patients from harm and respecting their opinions and/or having to provide care that conflicted with their values such as locking persons living with dementia in their homes. If district nurses were not involved in the decision-making process regarding the use of involuntary treatment, family caregivers generally decided on the use. Often district nurses perceived this request as inappropriate dementia care and they first tried to create a dialogue with them to reach a compromise. However, in most cases, family caregivers stood by their request and the district nurse still provided involuntary treatment and found this difficult to tolerate. To prevent involuntary treatment use and obverse values regarding safety versus autonomy, we need to increase their ethical awareness, communication skills, knowledge and skills with person-centred care.

Chapter 7 comprises a summary of the main findings of this dissertation. Further, reflection is given on the main findings of this dissertation from a methodological and theoretical perspective. This resulted in recommendations for future research and practice. The findings of this dissertation were that biomedical ethical normative arguments, like protecting from harm and/or enhancing safety, influence the decision-making process of caregivers regarding involuntary treatment of persons living with dementia and were used to rationalise why involuntary treatment was needed. However, this dissertation suggests that biopsychosocial approaches, which are more in line with a person-centred approach, are more suitable to dealing with the complexity of dementia care. Further, our findings also have an impact on nursing and district nursing in general. When nurses apply care without the consent and/or where the patient resists, it is in conflict with respecting the human dignity of their patients, one of the core values of nursing. Therefore, it is crucial that involuntary treatment is prevented. Since district nurses have a pivotal role in the care of persons living with dementia, they have an important role in the prevention of involuntary treatment use. Through their trust and professional relationship with their patients and their families, they can detect practical problems in a timely manner and proactively advise on how to manage these problems using a person-centred approach and be a true patient advocate. Therefore, this dissertation emphasises the need to increase the knowledge and skills of professional caregivers regarding undertaking dialogue with each other about involuntary treatment in a more timely and tailored manner. Further, we need to increase their knowledge and skills regarding the negative effects of involuntary treatment, alternatives to involuntary treatment, how persons living with dementia with a diminishing decision-making capacity can be involved in their care for as long as possible and person-centred care. For these reasons, this thesis recommends that more research is needed on how these insights can be integrated into multicomponent interventions, in co-creation with professional home care organisations. Further, we recommend that home care organisations integrate these interventions into their organisation, monitor and openly report on involuntary treatment usage.

References

1. Dierckx de Casterlé B, Gastmans C, Bryon E, et al. QUAGOL: a guide for qualitative data analysis. *Int J Nurs Stud* 2012; 49: 360-371. DOI: 10.1016/j.ijnurstu.2011.09.012.
2. Mengelers AM, Bleijlevens MH, Verbeek H, et al. Professional and family caregivers' attitudes towards involuntary treatment in community-dwelling people with dementia. *J Adv Nurs* 2018; 75: 96-107. DOI: 10.1111/jan.13839.

ADDENDA

—

Samenvatting

Samenvatting

Personen met dementie willen, net als iedereen, betrokken worden bij de beslissingen over hun zorg. Wanneer de symptomen van dementie toenemen, beginnen personen met dementie meer en meer problemen te ervaren met het nemen van beslissingen en verliezen ze uiteindelijk (een deel van) hun beslissingsvermogen. Hierdoor nemen mantelzorgers en naaste familieleden geleidelijk aan deze beslissingen over. Wanneer personen met dementie niet betrokken worden bij deze beslissingen of het er niet mee eens zijn, kan dit leiden tot onvrijwillige zorg. Onder onvrijwillige zorg wordt zorg verstaan die wordt verleend zonder toestemming van degene die deze ontvangt en/of waartegen deze persoon zich verzet. Onvrijwillige zorg heeft een negatieve invloed op de kwaliteit van leven van personen met dementie en hun mantelzorgers. Bovendien bestaan er effectievere en persoonsgerichte alternatieven voor onvrijwillige zorg zoals interventies met muziek, het op een gepaste wijze benaderen van personen met dementie, aangepaste hygiënische verzorgingstechnieken, focussen op wat de persoon met dementie nog wel kan en het afleiden van de persoon met dementie. Om deze redenen dienen we het gebruik van onvrijwillige zorg te voorkomen. Omdat wetenschappelijke literatuur over dit onderwerp beperkt is, hebben we meer inzicht nodig in het gebruik van onvrijwillige zorg bij mensen met dementie die thuiszorg ontvangen. Deze inzichten zijn nodig om nieuwe interventies te ontwikkelen of bestaande interventies aan te passen om het gebruik van onvrijwillige zorg te voorkomen. Daarom heeft dit proefschrift tot doel 1) inzicht te verwerven in de prevalentie en de bijbehorende factoren van onvrijwillig zorg bij thuiswonende personen met dementie die thuiszorg ontvangen; 2) het beschrijven hoe mantelzorgers het besluitvormingsproces ervaren van zorgdilemma's die kunnen leiden tot onvrijwillig zorg; en 3) het onderzoeken van de houding en mening van wijkverpleegkundigen ten aanzien van het gebruik van onvrijwillige zorg bij thuiswonende ouderen met dementie en het beschrijven van hun ervaringen.

Hoofdstuk 1 is de algemene inleiding van dit proefschrift; hierin wordt dieper ingegaan op dementie, persoonsgerichte zorg, mantelzorg en professionele thuisverpleging en onvrijwillige zorg. Ten slotte worden de doelstellingen van het onderzoek geformuleerd en wordt een overzicht van dit proefschrift gegeven.

Om de prevalentie van onvrijwillige zorg bij thuiswonende ouderen met cognitieve stoornissen die thuiszorg ontvangen te onderzoeken, alsook de bijbehorende factoren en wie het gebruik ervan aanvraagt en toepast, werd een cross-sectioneel onderzoek uitgevoerd (**hoofdstuk 2**). Gegevens van 1194 willekeurig geselecteerde thuiswonende ouderen met een cognitieve stoornis die thuiszorg ontvingen in België werden geanalyseerd. Een wijkverpleegkundige vulde een vragenlijst in op basis van zijn of haar kennis. De toepassing van onvrijwillige zorg, wie deze aanvraagt en toepast, en bijbehorende factoren werden bevraagd. Deze gegevens werden geanalyseerd met behulp van beschrijvende analyses en een willekeurige logistische interceptie regressieanalyse. We stelden vast dat bij de helft van de participanten onvrijwillige zorg werd toegepast. Gedwongen zorg werd het vaakst toegepast (73%), gevolgd door psychofarmaca (43%) en fysieke vrijheidsbeperkende maatregelen (38%). Het gebruik van onvrijwillige zorg werd geassocieerd met een grotere afhankelijkheid voor activiteiten van het dagelijks leven (ADL), een lager cognitief vermogen, een hogere mantelzorgbelasting en het hebben van een hogere leeftijd. Mantelzorgers (71%), gevolgd door huisartsen (47%), vroegen het vaakst onvrijwillige zorg aan en verpleegkundigen (81%) pasten dit het vaakst toe. We stelden vast dat bij personen met een diagnose van dementie significant meer onvrijwillige zorg werd toegepast dan bij personen zonder deze diagnose. Om deze reden is het belangrijk dat we inzicht verwerven in de toepassing van onvrijwillige zorg bij thuiswonende personen met dementie die professionele thuiszorg ontvangen.

Om inzicht te krijgen in de vraag, het gebruik en de bijbehorende factoren van onvrijwillige zorg bij personen met dementie die thuiszorg ontvangen in Nederland en België, werd een secundaire data-analyse uitgevoerd van twee cross-sectionele onderzoeken (**hoofdstuk 3**). Casemanagers dementie en wijkverpleegkundigen vulden voor elke persoon met dementie in hun caseload een vragenlijst in. Deze studie omvatte gegevens van 627 personen met dementie die professionele thuiszorg ontvingen in Nederland en 217 in België. In beide steekproeven werd dezelfde methodologie (vragenlijst en variabelen) gebruikt. Beschrijvende statistiek en logistische regressieanalyses op meerdere niveaus werden toegepast om de gegevens te analyseren. Onze resultaten toonden aan dat bij meer dan de helft van de participanten (50,7%) onvrijwillige zorg werd toegepast (België 68,2% en Nederland 44,7%). Gedwongen zorg (82,7%) kwam het meest voor, gevolgd door psychofarmaca (40,7%) en fysieke vrijheidsbeperkende maatregelen (18,5%). Onvrijwillige zorg werd geassocieerd met alleen wonen, een grotere ADL-afhankelijkheid, een lager cognitief vermogen, een hogere belasting van de mantelzorger en het ontvangen van thuiszorg in België versus Nederland. Omdat mantelzorgers een cruciale rol hebben in de aanvraag en toepassing van onvrijwillige zorg, hebben we meer inzicht nodig in hoe ze de zorgbeslissingen ervaren die kunnen leiden tot onvrijwillig zorg.

Om de ervaringen te beschrijven van mantelzorgers van personen met dementie met betrekking tot het besluitvormingsproces van zorgdilemma's die kunnen leiden tot onvrijwillige zorg, werd een kwalitatief beschrijvend onderzoek uitgevoerd (**hoofdstuk 4**). Gegevens werden geanalyseerd met behulp van de Kwalitatieve Analysegids van Leuven.[1] Uit de resultaten van de 10 semigestructureerde diepte-interviews van mantelzorgers die voor 13 personen met dementie zorgden, bleek dat zij het besluitvormingsproces van zorgdilemma's die kunnen leiden tot onvrijwillige zorg als gecompliceerd, stressvol en uitputtend ervaarden. Hoewel ze veiligheid en het respecteren van de mening van hun naaste als belangrijk waarden ervaarden, worstelden ze met het vinden van de juiste balans hierin. Door het progressieve en onvoorspelbare karakter van dementie waren ze voortdurend op zoek naar nieuwe oplossingen terwijl ze zich nog aan het aanpassen waren aan de bestaande situatie. Mantelzorgers voelden zich verantwoordelijk voor de veiligheid van hun naaste en bijkomend werd deze druk nog eens verhoogd door hun omgeving, die de mantelzorg verantwoordelijk stelde, mocht er iets gebeuren. Hierdoor konden zij beschuldigd worden als de persoon met dementie iets overkwam, wat een reeds stressvolle situatie nog zwaarder maakte. Hun ervaring werd beïnvloed door de achtergrondkenmerken van de zorgtriade, zoals praktische en emotionele steun, kennis en eerdere ervaringen. Om onvrijwillige zorg te voorkomen, moeten professionele zorgverleners mantelzorgers van personen met dementie tijdig ondersteunen, vooral wanneer er gedragssymptomen met veiligheidsimplicaties zijn. Omdat wijkverpleegkundigen een sleutelrol spelen in de thuiszorg bij personen met dementie, kunnen zij mantelzorgers ondersteunen bij het omgaan met deze situaties. Daarom is het nodig om meer inzicht te krijgen in de houding en mening van wijkverpleegkundigen ten aanzien van onvrijwillig zorg bij thuiswonende personen met dementie.

Om de houding van wijkverpleegkundigen ten aanzien van het gebruik van onvrijwillige zorg bij thuiswonende ouderen met dementie die thuiszorg ontvangen, de determinanten ervan en hun mening over de restrictiviteit en het ongemak ervan te onderzoeken, werd een cross-sectioneel onderzoek uitgevoerd (**hoofdstuk 5**). Er werden gegevens verzameld van 296 Belgische wijkverpleegkundigen met ervaring in de zorg voor thuiswonende ouderen met dementie. Zij vulden hiervoor de online Maastricht Attitude Thuiszorg vragenlijst in.[2] Gegevens werden geanalyseerd met behulp van beschrijvende analyse, meervoudige lineaire regressie en multinomiale logistieke modellen. We stelden vast dat wijkverpleegkundigen onvrijwillige zorg beschouwden als reguliere zorg bij thuiswonende personen met dementie. Zij hadden noch een positieve noch een negatieve houding ten aanzien ervan. Zij gaven aan dat zij onvrijwillige zorg als matig beperkend ervaarden voor personen met dementie en zich er matig ongemakkelijk bij voelden als ze het toepasten. De resultaten toonden aan dat zichtbare maatregelen zoals fysieke fixatie (bijvoorbeeld het gebruik van banden) of maatregelen die vrijheid van leven beperkten (bijvoorbeeld het afnemen van mobiliteitshulpmiddelen) als meer beperkend werden ervaren voor personen met dementie en zij zich er ongemakkelijker bij voelden dan onopvallende maatregelen (bijvoorbeeld camerabewaking, medicatie verbergen). Wijkverpleegkundigen met meer jaren ervaring in de zorg voor personen met dementie, wijkverpleegkundigen met een lagere opleiding of wijkverpleegkundigen die de zorg voor mensen met dementie als meer belastend ervaren, waren eerder geneigd om het gebruik van onvrijwillige zorg te beschouwen als: 1) een meer geschikte klinische praktijk; 2) minder beperkend voor de personen met dementie; en 3) voelden zich minder oncomfortabel bij het gebruik ervan. Deze bevindingen onderstrepen het belang om wijkverpleegkundigen tijdig te trainen en te ondersteunen in het kritisch reflecteren en bespreken van hoe om te gaan met zorgsituaties die (kunnen) leiden tot onvrijwillige zorg, op een meer persoonsgerichte wijze. Om meer inzicht te krijgen in hoe wijkverpleegkundigen hierin kunnen worden ondersteund, dienen we inzicht te verwerven in de ervaringen van wijkverpleegkundigen met de toepassing van onvrijwillige zorg bij thuiswonende ouderen met dementie.

Om de ervaringen te beschrijven van wijkverpleegkundigen met de toepassing van onvrijwillige zorg bij thuiswonende ouderen met dementie, werd een kwalitatief beschrijvend onderzoek uitgevoerd (**hoofdstuk 6**). Aan de hand van semigestructureerd diepte-interviews werden gegevens verzameld van 16 wijkverpleegkundigen die ervaring hadden met onvrijwillige zorg bij thuiswonende ouderen met dementie. De wijkverpleegkundigen werden gerekruteerd door middel van een doelgerichte steekproef. De gegevens werden geanalyseerd met behulp van de Kwalitatieve Analysegids van Leuven.[1] Onze resultaten toonden aan dat hoe wijkverpleegkundigen onvrijwillige zorg ervaarden, beïnvloed werd door hun betrokkenheid bij het besluitvormingsproces. Wanneer zij er van dichtbij bij betrokken waren, beschouwden zij onvrijwillig zorg als gepaste zorg. In het begin waren ze echter bang dat onvrijwillige zorg onrechtvaardig was, omdat ze de wensen van de persoon met dementie wilden respecteren. Echter, als zich meer veiligheidsincidenten voordeden, vonden ze uiteindelijk dat vanuit een professioneel perspectief onvrijwillig zorg noodzakelijk was, gezien de veiligheid van de persoon met dementie zwaarder doorwoog dan het respecteren van zijn of haar mening. Wijkverpleegkundigen gaven aan dat zij het omgaan met het dilemma veiligheid versus autonomie als stressvol ervaarden, omdat ze tegelijkertijd aan twee tegengestelde waarden probeerden te voldoen, namelijk het beschermen van hun patiënt tegen letsels en het respecteren van zijn of haar mening en/of zorg moesten verlenen die in strijd was met hun waarden, zoals het opsluiten van thuiswonende ouderen in hun woning. Als wijkverpleegkundigen niet betrokken waren bij de besluitvorming over het gebruik van onvrijwillige zorg, beslisten meestal de mantelzorgers hierover. Wijkverpleegkundigen ervaarden dit verzoek vaak als ongepaste zorg en probeerden eerst me de mantelzorgers in dialoog te gaan, om zo tot gepaste zorg te komen. De mantelzorgers bleven echter meestal bij hun verzoek en de wijkverpleegkundigen verleenden de gevraagde onvrijwillige zorg. Wijkverpleegkundigen ervaarden een innerlijke strijd bij de uitvoering van deze zorg, wat als zeer belastend werd ervaren. Om onvrijwillig zorg en tegengestelde waarden met betrekking tot veiligheid versus autonomie te voorkomen, is het belangrijk om het ethisch bewustzijn van wijkverpleegkundigen, hun communicatieve vaardigheden, kennis en vaardigheden met persoonsgerichte zorg te vergroten.

Hoofdstuk 7 is een samenvatting van de belangrijkste bevindingen van dit proefschrift. Verder wordt er gereflecteerd op de belangrijkste bevindingen van dit proefschrift vanuit een methodologisch en theoretisch standpunt. Deze reflecties resulteerden in aanbevelingen voor toekomstig onderzoek en praktijk. De bevindingen van dit proefschrift laten zien dat biomedisch-ethische argumenten, zoals bescherming tegen lichamelijke letsels en/of het bewaken van de veiligheid, het besluitvormingsproces rondom onvrijwillige zorg bij zorgverleners van personen met dementie beïnvloedden en dat deze argumenten gebruikt werden om het gebruik ervan te rationaliseren. Dit proefschrift beschrijft dat bio-psychosociale benaderingen die meer aansluiten bij een persoonsgerichte benadering, geschikter zijn voor het omgaan met de complexiteit van de zorg voor thuiswonende ouderen met dementie. Verder hebben onze bevindingen ook impact op de (wijk)verpleging, aangezien het verlenen van verpleegkundige zorg zonder de toestemming van diegenen die deze zorg ontvangt en/of zich ertegen verzet in strijd is met het respecteren van zijn of haar menselijke waardigheid; een van de kernwaarden van verpleging. Om deze reden is het van cruciaal belang dat onvrijwillige zorg wordt voorkomen. Omdat wijkverpleegkundigen een centrale rol hebben in de zorg voor personen met dementie, kunnen zij een belangrijke rol spelen bij de preventie ervan. Door hun vertrouwens- en professionele relatie met hun patiënten en hun familieleden kunnen ze tijdig praktische problemen opsporen en proactief advies geven over hoe met deze problemen om te gaan en een echte belangenbehartiger van hun patiënt zijn. Daarom benadrukt dit proefschrift de noodzaak om de kennis en vaardigheden van professionele zorgverleners te vergroten, zodat ze tijdig en op een gerichte wijze met elkaar in dialoog kunnen gaan rondom onvrijwillige zorg.

Bijkomend is het nodig om de kennis en vaardigheden te vergroten met betrekking tot de negatieve effecten van onvrijwillige zorg, alternatieven voor onvrijwillige zorg, persoonsgerichte zorg, alsook hoe personen met dementie die een afnemend beslissingsvermogen hebben zo lang mogelijk betrokken kunnen worden bij de beslissingen rondom hun zorg. Om deze redenen raadt dit proefschrift aan om te onderzoeken hoe deze inzichten kunnen worden geïntegreerd in multi-componenten en dit in co-creatie met professionele thuiszorgorganisaties. Verder bevelen we aan dat thuiszorgorganisaties deze interventies integreren in hun organisatie, de vooruitgang ervan monitoren en openlijk rapporteren over het gebruik van onvrijwillig zorg.

Referenties

1. Dierckx de Casterlé B, Gastmans C, Bryon E, et al. QUAGOL: a guide for qualitative data analysis. *Int J Nurs Stud* 2012; 49: 360-371. DOI: 10.1016/j.ijnurstu.2011.09.012.
2. Mengelers AM, Bleijlevens MH, Verbeek H, et al. Professional and family caregivers' attitudes towards involuntary treatment in community-dwelling people with dementia. *J Adv Nurs* 2018; 75: 96-107. DOI: 10.1111/jan.13839.

ADDENDA

—

Impact

Impact

The aim of this dissertation was to gain insight into the use of involuntary treatment among persons living with dementia receiving professional nursing care at home. Therefore, studies were conducted to: 1) gain insight into the prevalence and associated factors of involuntary treatment use among older adults with cognitive impairment and persons living with dementia receiving professional home care; 2) describe how family caregivers experience the decision-making process within care dilemmas that can lead to involuntary treatment use; and 3) investigate the attitudes and opinions of district nurses towards the use of involuntary treatment and to describe their experiences with involuntary treatment use among persons living with dementia at home.

Main results

Involuntary treatment was applied to one out of two persons living with dementia who receive professional home care in the Netherlands and Belgium. Non-consensual care (83%) was the most common form of involuntary treatment, followed by psychotropic medication (41%) and physical restraints (19%). The following characteristics increased the risk for involuntary treatment: living alone, cognitive impairment, higher functional dependency for activities of daily living and living in Belgium compared to living in the Netherlands. Involuntary treatment was most often applied and requested by family caregivers followed by district nurses. Family caregivers experienced the decision-making process concerning care dilemmas that can lead to involuntary treatment as complicated, stressful and exhausting. Although they considered safety and autonomy as important values, they struggled with finding the right balance between them. Their experience was influenced by the background characteristics of the care triad (i.e. persons living with dementia, family caregivers, professional caregivers) such as practical and emotional support, knowledge and previous experiences. District nurses perceived involuntary treatment as a regular part of nursing care, having neither positive nor negative attitudes towards its appropriateness. Having more years of experience as a district nurse and finding care for persons with dementia burdensome, were associated with having a more accepting attitude and/or opinion towards involuntary treatment use. Depending on how district nurses were involved in the decision-making process, they experienced involuntary treatment usage differently. In general, they experienced its use as stressful since they tried to meet opposing demands at the same time like preventing harm and respecting the wishes of the persons living with dementia and/or needed to provide care that conflicted with their values like locking up persons living with dementia.

Main conclusions

The results of this dissertation show that involuntary treatment is commonly used in professional dementia care at home. Therefore, interventions are needed to prevent it. These interventions need to focus on how professional caregivers like district nurses can, in a timely manner, tailor support for family caregivers regarding complex care situations that can lead to involuntary treatment and engage in dialogue with them about these situations. Further, our results point out that district nurses have a pivotal role in involuntary treatment use. Therefore, we need to increase their awareness regarding the negative consequences of involuntary treatment use and increase their knowledge and skills to deal with situations that can evolve into involuntary treatment use in a person-centred manner.

Scientific impact

The scientific impact of this dissertation can be demonstrated in different ways.

First, this thesis provides more insights into involuntary treatment, a relatively new concept in dementia nursing care at home. The fact that we have revealed that involuntary treatment is a common practice among persons with a cognitive impairment and persons living with dementia at home, confirmed earlier research. Based on these results, there is an urgent need to develop interventions to prevent it use.

This dissertation was part of a larger project on involuntary treatment of the Living Lab in Ageing and Long-Term Care Limburg. Simultaneously with this research project, other researchers conducted studies related to the development of multicomponent intervention in order to prevent involuntary treatment (PRITAH).[1, 2] The results of the studies in this thesis provided input for the development of this multicomponent intervention. For example, the insights that district nurses together with family caregivers were often involved in the request and application of it, were used in the development of PRITAH. The assumption was made that district nurses were the most suitable to educate and support family caregivers in the decision-making process to avoid involuntary treatment; being the constant factor in caring for care dependent persons living with dementia, having the most direct knowledge of the person living with dementia, their family caregiver(s) and home situation, being able to estimate their needs, wishes and challenges. Subsequently, the findings from the studies surrounding the development and evaluation of the PRITAH intervention led us to conduct research into the attitudes and opinions of community nurses towards involuntary treatment, as well as their experiences with its use.

Next, the results that district nurses had no outspoken attitudes and opinions towards it were important findings for scientific nursing and dementia literature. This confirmed that having no outspoken attitudes is a barrier for the implementation of multicomponent interventions towards the prevention of involuntary treatment. Therefore, our results pointed out that it is necessary that district nurses develop a more critical and negative attitude towards involuntary treatment usage.

Furthermore, our results confirm scientific findings in nursing settings that family caregivers and nurses wished to provide ‘good’ care, which is safe and respects the wishes of the care recipient, in order to age in place. Our results contributed to the wider scientific community, since we provided new insights into why caregivers often provide care that is in conflict with the wishes of persons living with dementia. These insights were that caregivers, due a lack of support and/or knowledge regarding person-centred alternatives, were not always aware that they were applying involuntary treatment or did not know person-centred alternatives for it. Moreover, often they experienced involuntary treatment as necessary dementia care. These findings are scientifically valuable, as they provide more insights into why multicomponent intervention does not always influence the intention of caregivers. This stressed the requirement that researchers need to gain more insight, into how: 1) district nurses and family caregivers can be supported and trained in dealing with situations that could evolve into involuntary treatment in a timely and person-centred manner; and 2) district nurses can support family caregivers and engage in dialogue with them in delivering this care.

Finally, our studies contributed to a greater openness in the scientific community regarding involuntary treatment use in dementia care at home. At the start of this project, we experienced resistance several times from international editors and reviewers to publish our articles or discuss them during international congresses. They argued that involuntary treatment use was appropriate dementia care and necessary to age in place. However, over the years, we experienced more openness regarding involuntary treatment in the scientific community. Studies were published and submissions to national and international congresses were accepted. Additionally, the results and insights in this dissertation were used in other international studies, like we used their knowledge to further develop our insights into involuntary treatment use. Consequently, the results of these studies have led to further research being conducted regarding involuntary treatment use in nursing homes, how to implement knowledge about involuntary treatment in both home care and nursing home care, to investigate how this implementation is best achieved and to introduce the knowledge and methodology from PRITAH in vocational education for carers and nurses.

Societal impact

Professional home care organisations

The results of this dissertation contributed to professional home care organisations gaining more awareness that involuntary treatment usage was often conducted among persons living with dementia, whom they are responsible for. This resulted in the development and implementation of interventions to prevent involuntary treatment usage. In the Netherlands, in 2018–2020, the multicomponent intervention PRITAH was developed in co-creation between home care organisations and researchers.[2] The findings of this dissertation that family caregivers and nurses were often involved in the application and requests, resulted in the interventions being focused to increase their knowledge and skills. These interventions increased knowledge about involuntary treatment and how to prevent it, resulting in a behavioural change. The study of Mengelers et al. confirmed that the PRITAH intervention had a positive effect on professional caregivers' subjective norms and perceived behavioural control regarding the prevention of involuntary treatment.[1] At this moment, in the Netherlands, several home care organisations are using the PRITAH intervention. In Belgium, home care organisations are developing interventions based on the insights of this thesis.

In addition, based on the findings of this thesis, researchers of the Living Lab in Ageing and Long-Term Care Limburg developed a fact sheet to increase the knowledge of professional caregivers regarding involuntary treatment and the PRITAH intervention.

Furthermore, the identified barriers like: not having an outspoken attitude towards involuntary treatment, finding involuntary treatment necessary care to prevent harm and/or that nurses do not always succeed in being the patient's advocate, confirmed earlier findings that interventions to prevent measures we defined as involuntary treatment were not always successful. These insights were used to adapt previously developed interventions like focusing more on increasing knowledge regarding the negative and ethical consequences of involuntary treatment and increasing dialogue skills. As a result, district nurses became more aware of the negative outcomes of involuntary treatment, increased their skills and knowledge of how to prevent its use, engaged more effectively in dialogue about involuntary treatment and/or could be their patients' advocates. This resulted in experiencing caring for persons living with dementia as less burdensome.

Persons living with dementia and family caregivers

This dissertation revealed that persons living with dementia are not always involved in decisions about their care and that family caregivers often decide in their place. Furthermore, family caregivers played a pivotal role in the request for and application of involuntary treatment. They indicated that they experienced caring for their next of kin as exhausting, complicated and stressful, and that it needed to be more timely and socially supported. These insights led to a better understanding of the decision-making process regarding involuntary treatment. Based on these findings, previously developed multicomponent interventions to prevent involuntary treatment could be more practically adapted, so that professional caregivers could, in a timely manner, target support to family caregivers in dealing with daily care dilemmas that could evolve into involuntary treatment. This contributes to a better quality of life for persons living with dementia and their family caregivers.

Government and legislation

The findings of this dissertation have increased policymakers' awareness of the use of involuntary treatment among persons living with dementia at home. In this way, the studies in this thesis have contributed to the implementation of the Care and Coercion Act in the Netherlands. The Care and Coercion Act regulates the rights of people with an intellectual disability and people with a psychogeriatric disorder like dementia, against involuntary treatment or involuntary admission.

Dissemination of findings

Throughout this project attention was paid to dissemination of the findings.

The findings of this dissertation and publications were shared on social media and with all the home care organisations that are embedded within the

Living Lab in Ageing and Long-Term Care Limburg and White and Yellow Cross Limburg.

The study results were presented during oral presentations, symposia and poster presentations at national and international congresses in Belgium, the Netherlands, Denmark, Sweden and the United States. During these conferences, connections were made for collaboration and further research in Belgium, the Netherlands and Norway.

All studies included in this dissertation were submitted to international peer-reviewed journals and four studies were published. Additionally, the results of two studies from this thesis were published in two newsletters from the International Psychogeriatric Association.

Furthermore, since research about involuntary treatment is a research line embedded in the Living Lab in Ageing and Long-Term Care Limburg, regular updates were given to the 'involuntary treatment' working group, to policy makers, experts and client councils of the home care organisations in the Netherlands. In addition to previous research lines that focussed on involuntary treatment in home care, a new research line has been established that focusses on involuntary treatment use in nursing homes. Moreover, this dissertation will be shared among the participating Belgian and Dutch home care organisations. This thesis will also be freely available as an e-book on the website of the Living Lab in Ageing and Long-Term Care Limburg (http://www.academischewerkplaatsouderenzorg.nl) and the Belgian home nursing care organization (http://www.witgelekruis.be).

References

1. Mengelers AM, Bleijlevens MH, Verbeek H, et al. A quasi-experimental study on prevention and reduction of involuntary treatment at home (PRITAH) in people with dementia. *J Clin Nurs* 2021 2021/12/09. DOI: 10.1111/jocn.16163.
2. Mengelers AM, Bleijlevens MH, Verbeek H, et al. Prevention and reduction of involuntary treatment at home: A feasibility study of the PRITAH intervention. *Geriatr Nurs* 2020; 41: 536–543. DOI: 10.1016/j.gerinurse.2020.02.001.

ADDENDA

—

Dankwoord

Dankwoord

Zeven jaar geleden begon ik aan dit avontuur. Vanaf het allereerste moment tot nu, kan ik zeggen, het was een geweldige reis. Het was even mooi als het zwaar was. Ik heb genoten van elk moment, zowel van de successen als de worstelingen *“Carpe Diem”*. Ik heb veel geleerd en zoals Deepak Chopra zegt over onze levensreis: *“Ontwaken is niet veranderen wie je bent, maar weggooien wie je niet bent.”*

Zoals bij elke reis, zijn het de ontmoetingen die ik onderweg tegenkwam, die me bijblijven. Ze hielpen me met het overwinnen van de obstakels op mijn weg en lieten me beseffen dat je niet alles kunt veranderen of overwinnen. Soms moet je ze gewoon accepteren om zo je standpunt te kunnen veranderen en de oplossingen te zien. Bedankt voor jullie aanwezigheid, steun en inzichten.

Zonder de steun van collega’s, vrienden en familie was ik nooit tot op dit punt gekomen.

Daarom wil ik allereerst Karen, mijn echtgenote bedanken voor al haar geduld en ondersteuning. Marit en Tijmen, mijn dochter en zoon, wil ik graag bedanken voor al de pauzes en afleidingen die ze mij bezorgden tijdens het schrijven van dit proefschrift en de artikels.

Tijdens mijn promotietraject werd ik begeleid door prof. dr. Jan Hamers, dr. Michel Bleijlevens, prof. dr. Hilde Verbeek en prof. dr. Koen Milisen. Graag wil ik jullie bedanken om in me te geloven, me te begeleiden, het delen van jullie inzichten en discussies. Ik kijk ook met veel plezier en dankbaarheid terug, op alle reizen die ik met jullie heb mogen maken. Deze reizen hebben mijn horizon verbreed.

Tijdens mijn eerste onderzoeksjaren kon ik terugvallen op de steun en inzichten van dr. Angela Mengelers, die een jaar eerder voor mij was gestart met haar onderzoek rondom onvrijwillige zorg. Samen hebben we twee studies gedaan en artikels geschreven. Bedankt voor je discussies, inzichten en ondersteuning.

Naast mijn promotieteam, wil ik ook graag mijn coauteurs prof. dr. Frans Tan, prof. dr. Bernadette Dierickx de Casterlé, prof. dr. Elizabeth Capezuti en dr. Valeria Lima Passos bedanken. Ze hebben me bijgestaan en begeleidt tijdens de verschillende studies. Graag wil ik ook nog mijn collega-onderzoekers Jules

Willems, Maud Hamers en Audrey Beaulen, bedanken voor het mee analyseren van de interviews van de twee kwalitatieve studies.

Zonder deelnemers geen onderzoek. Graag had ik daarom alle deelnemers willen bedanken voor het invullen van de vele vragenlijsten en deelname aan de interviews. Jullie ervaringen en openheid hebben ertoe geleid dat we vandaag een beter zicht hebben op onvrijwillige zorg en zo de kwaliteit van onze zorg hebben verbeterd.

Ook wil ik de leden van de werkgroep onvrijwillige zorg bedanken, voor hun praktische inzichten rondom de onderzoeksvoorstellen en hun feedback over de studieresultaten. Math Gulpers, Ine Smeets, Leontine Smeets, Jos Stevens, Nicole Thomas Maddy Mohrmans en Lisette Ars, bedankt voor jullie inzichten en fijne samenwerking.

Graag wil ik de beoordelingscommissie, bestaande uit prof. dr. M. E. de Vugt, prof. dr. S.M.G. Zwakhalen, prof. dr. J. W.M. Muris, prof. dr. C. Gastmans en prof. dr. S. Köpke, bedanken voor hun interesse in het proefschrift en de tijd die ze hebben genomen voor de beoordeling ervan.

Tijdens mijn promotietraject kon ik steeds terugvallen op het secretariaat van de Academische Werkplaats Ouderenzorg Limburg voor raad, advies en het declareren van mijn onkosten. Bedankt voor jullie ondersteuning.

Vervolgens wil ik al mijn collega's, reisgenoten van HSR en kamergenoten van kamer 00.36 en later de flexkamer 00.44 bedanken voor hun steun en luisterende oor. Ik keek elke donderdag ernaar uit om al jullie verhalen en inzichten te horen. Kamer 00.36 en 00.44 waren echt smeltkroezen van culturen over de ganse wereld. Graag had ik jullie allemaal willen bedanken, maar tijdens mijn zeven jaar ben ik zoveel fijne mensen tegengekomen en gesprekken gehad dat het teveel zijn om op te noemen.

Verder wil ik al mijn collega's van het Wit- Gele Kruis Limburg (WGKL) bedanken om me de gelegenheid te geven om deze reis te kunnen maken. Solange Indenkleef (directeur zorg WGKL) bedankt om me te stimuleren om dit avontuur aan te gaan, de tijd te geven om onderzoek te voeren en studies te schrijven en voor je steun doorheen de voorbije zeven jaren. Bedankt voormalig algemeen directeur WGKL Luc Bijnens om dit traject goed te keuren en huidig algemeen directeur WGKL Nadja Vananroye om mij de kans te geven om dit traject te mogen afronden. Graag wil ik ook nog Joël Neelen bedanken voor de geslaagde lay-out, mooie indeling en ondersteuning bij het drukproces van dit proefschrift. Verder wil ook nog al mijn collega-regioverantwoordelijken, referentiespecialisten, referentieverpleegkundigen Locomotorische, Neurologische Zorg, Geestelijke Gezondheidszorg, collega's communicatiedienst en afdelingsleidinggevenden bedanken voor hun inzet en steun. Zonder jullie was er geen proefschrift geweest.

Tot slot wil ik mijn naasten bedanken, die niet meer bij ons zijn. Bedankt voor jullie steun en ervaringen. Jullie waren steeds bij me.

Bedankt, iedereen! En tot de volgende en tot dan…

Moge de weg je tegemoet komen.
Moge de wind altijd in je rug zijn.
Moge de zon warm op je gezicht schijnen,
de regen zachtjes op je velden vallen.

Moge de zon je dagen verwarmen,
de sterren je nachten verlichten.
Moge de bloemen bloeien langs je pad.

En tot we elkaar weer ontmoeten,
moge God je dragen in de palm van Zijn hand.

(Oude Ierse wens)

ADDENDA

—

About the author

About the author

Vincent Roger Albert Moermans was born in Hasselt, Belgium on November 4, 1975.

He completed secondary school at Sint-Jozef institute in Genk and obtained a bachelor's degree in Occupational Therapy in 1999 at PXL in Hasselt and a bachelor's degree in Nursing in 2005 at KHLIM in Hasselt. In 2007 and 2011 he acquired several certificates in health and safety.

In 2008, he started to work at the White and Yellow Cross Limburg, within the nursing department as a specialist nurse, nursing coach and health and safety officer. The With and Yellow Cross Limburg is an organization that provides professional nursing care at home in Belgium Limburg. As a specialist nurse he was involved in topics like transfer techniques, prevention of falls, prevention of physical, restraints and locomotor and neurological care. He was also involved in the development of the practical guideline for the prevention of physical restraint in home care in Flanders. Since November 2021, he works their as a regional manager for several nursing department in South-eastern part of Belgium Limburg.

In 2015, Vincent received his Master's degree in Healthcare Policy, Innovation and Management at Maastricht University.

In September 2016, he started as an external PhD-student at Maastricht University. He worked within the Living Lab in Ageing and Long Term care. The Living Lab in Ageing and Long-Term Care, is a formal and structural multidisciplinary network consisting of Maastricht University and nine long-term care organizations, all located in the southern part of the Netherlands. Vincent combined this with his work within the White and Yellow Cross Limburg. His research focuses on the prevention and reduction of involuntary treatment (including the use of physical restraints, psychotropic medication, and nonconsensual care). Together with his team, he provided insight into the prevalence, associated factors, and decision-making process of involuntary treatment among people living with dementia, and the role of district nurses. Vincent presented his work at different national and international conferences.

Since April 2021, Vincent is also been affiliated as a voluntary scientific employee at the Department of Public Health and Primary Care, Academic Centre for Nursing and Midwifery, KU Leuven, Leuven, Belgium.

ADDENDA

—

List of publications

List of publications

SCIENTIFIC PUBLICATIONS

- Claes N., Storms H. & Moermans V.R.A. (2016). *Care, communication and educational needs of primary care nurses to treat disabled patients.* Journal of Nursing Education and Practice, 6 (7), 109-115. DOI: 10.5430/jnep.v6n7p109.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Tan F.E.S, Milisen K. & Hamers J.P.H (2018). *The Use of Involuntary Treatment among Older Adults with Cognitive Impairment Receiving Nursing Care at Home: A Cross-sectional Study.* International Journal of Nursing Studies, 88, 135-142. DOI: 10.1016/j.ijnurstu.2018.09.004.

- Mengelers A.M.H.J., Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Capezuti E., Milisen K. & Hamers J.P.H. (2019). *The use of involuntary treatment in people with cognitive impairment living at home.* IPA Bulletin, 36 (1).

- Mengelers A.M.H.J., Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Capezuti E., Tan F.E.S. Milisen K. & Hamers J.P.H. (2020). *Involuntary treatment in dementia care at home: Results from the Netherlands and Belgium.* Journal of Clinical Nursing. DOI: 10.1111/jocn.15457.

- Mengelers A.M.H.J., Bleijlevens M.H.C, Verbeek H, Moermans V.R.A., Capezuti E. & Hamers J.P.H. (2020). *Prevention and Reduction of Care Against Someone's Will in Cognitively Impaired People at Home: A Feasibility Study.* Geriatric Nursing, 41 (5), 536-543. DOI: 10.1016/j.gerinurse.2020.02.001.

- Moermans V.R.A., Mengelers A.M.H.J., Bleijlevens M.H.C., Verbeek H., Dierckx de Casterlé B., Milisen K., Capezuti E., & Hamers J.P.H. (2021). *Caregiver decision-making concerning involuntary treatment in dementia care at home.* Nursing Ethics, 29, 330-343. DOI: 10.1177/09697330211041742.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Lima Passos V., Milisen K. & Hamers J.P.H. (2022). *District nurses' attitudes towards involuntary treatment in dementia care at home: a cross-sectional study.* Geriatric Nursing 2022; 47: 107-115. DOI: 10.1016/j.gerinurse.2022.07.009.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Lima Passos V., Milisen K. & Hamers J.P.H. (2022). *District nurses' attitudes towards involuntary treatment in dementia care at home: a cross-sectional study.* IPA Bulletin, December 2022.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Dierckx de Casterlé B., Milisen K. & Hamers J.P.H. (2022). District Nurses Experiences in Dealing with Involuntary Treatment in Dementia Care at Home, A qualitative descriptive study. Submitted for publication.

PRESENTATIONS

Scientific presentations

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Tan F.E.S, Milisen K. & Hamers J.P.H., *The Use of Involuntary Treatment among Older Adults with Cognitive Impairment Receiving Nursing Care at Home: A Cross-sectional Study.* European Doctoral Conference in Nursing, Maastricht, The Netherlands, June 22-2,3 2018.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Tan F.E.S, Milisen K. & Hamers J.P.H., *The Use of Involuntary Treatment among Older Adults with Cognitive Impairment Receiving Nursing Care at Home: A Cross-sectional Study.* Care 4 – International Scientific Nursing and Midwifery Congress, Leuven, Belgium, February 4-6, 2019.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Tan F.E.S, Milisen K. & Hamers J.P.H., *Het gebruik van onvrijwillige zorg bij ouderen met een cognitieve beperking, die thuisverpleging ontvangen, een cross-sectionele studie.* Geriatriedagen, Den Bosch, The Netherlands, February 7-8, 2019.

- Moermans V.R.A., Mengelers A.M.H.J., Bleijlevens M.H.C., Verbeek H., Capezuti E., Tan F.E.S. Milisen K. & Hamers J.P.H., *Comparison of Involuntary Care Use in People with Dementia receiving Home Care in the Netherlands and Belgium.* International Association of Gerontology and Geriatrics – European Region Congress, Göteborg, Sweden, May 23-25, 2019.

- Moermans V.R.A., Mengelers A.M.H.J., Bleijlevens M.H.C., Verbeek H., Capezuti E., Tan F.E.S. Milisen K. & Hamers J.P.H., *Involuntary treatment in dementia care at home: Results from the Netherlands and Belgium.* Geriatric Society of Amerika Annual Meeting 2020, Philadelphia, Pennsylvania, United States of Amerika – Online Congress, November 4-7, 2020. Innovation in Aging 4 (supplement_1): 664-665. DOI: 10.1093/geroni/igaa057.2299.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Lima Passos V., Milisen K. & Hamers J.P.H., *District Nurses' Attitudes Towards Involuntary Treatment in*

Dementia Care at Home: a Cross-sectional Study. Nordic Congress Gerontology – Odense, Denmark, June 8-10, 2022.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Lima Passos V., Milisen K. & Hamers J.P.H., *Attitudes and Opinions of Belgian District Nurses Towards Involuntary Treatment Use in Dementia Care.* European Nursing Congress, Rotterdam, The Netherlands - Online Congress, October 4-7, 2022.

Poster presentations

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Tan F.E.S, Milisen K. & Hamers J.P.H., *The Use of Involuntary Treatment among Older Adults with Cognitive Impairment Receiving Nursing Care at Home: A Cross-sectional Study.* Caphri Research Day, Valkenborg, The Netherlands, November 6, 2018.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Tan F.E.S, Milisen K. & Hamers J.P.H., *The Use of Involuntary Treatment among Older Adults with Cognitive Impairment Receiving Nursing Care at Home: A Cross-sectional Study.* Geriatric Society of Amerika Annual Meeting 2018, Boston, Massachusetts, United States of Amerika, November 14-18, 2018.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Dierckx de Casterlé B., Milisen K. & Hamers J.P.H., *Safety or Autonomy in Dementia Care at Home, a Qualitative Study on Family Caregivers' Experiences.* Geriatric Society of Amerika Annual Meeting 2020, Philadelphia, Pennsylvania, United States of Amerika – Online Congress, November 4-7, 2020. Innovation in Aging 4 (supplement_1): 435-435. DOI: 10.1093/geroni/igaa057.1406.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Lima Passos V., Milisen K. & Hamers J.P.H., *District Nurses' Attitudes Towards Involuntary Treatment in Dementia Care at Home: a Cross-sectional Study.* Geriatric Society of Amerika Annual Meeting 2022, Indianapolis, Indiana, United States of Amerika, November 2-6, 2022. Innovation in Aging 6 (supplement_1): 643-644. DOI: 10.1093/geroni/igac059.

- Moermans V.R.A., Bleijlevens M.H.C., Verbeek H., Dierckx de Casterlé B., Milisen K. & Hamers J.P.H., *District Nurses' Experiences with Involuntary Treatment in Dementia Care, A Qualitative Study.* Geriatric Society of Amerika Annual Meeting 2022, Indianapolis, Indiana, United States of Amerika, November 2-6, 2022. Innovation in Aging 6 (supplement_1): 644. DOI: 10.1093/geroni/igac059.

ADDENDA

—

Living Lab in Ageing and Long-Term Care

Living lab in ageing and long-term care

This thesis is part of the Living Lab in Ageing and Long-Term Care, a formal and structural multidisciplinary network consisting of Maastricht University, nine long-term care organizations (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Intermediate Vocational Training Institutes Gilde and VISTA college and Zuyd University of Applied Sciences, all located in the southern part of the Netherlands. In the Living Lab we aim to improve quality of care and life of older people and quality of work for staff employed in long-term care via a structural multidisciplinary collaboration between research, policy, education and practice. Practitioners (such as nurses, physicians, psychologists, physio- and occupational therapists), work together with managers, researchers, students, teachers and older people themselves to develop and test innovations in long-term care.

Academische werkplaats ouderenzorg limburg

Dit proefschrift is onderdeel van de Academische Werkplaats Ouderenzorg Limburg, een structureel, multidisciplinair samenwerkingsverband tussen de Universiteit Maastricht, negen zorgorganisaties (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Gilde Zorgcollege, VISTA college en Zuyd Hogeschool. In de werkplaats draait het om het verbeteren van de kwaliteit van leven en zorg voor ouderen en de kwaliteit van werk voor iedereen die in de ouderenzorg werkt. Zorgverleners (zoals verpleegkundigen, verzorgenden, artsen, psychologen, fysio- en ergotherapeuten), beleidsmakers, onderzoekers, studenten en ouderen zelf wisselen kennis en ervaring uit. Daarnaast evalueren we vernieuwingen in de dagelijkse zorg. Praktijk, beleid, onderzoek en onderwijs gaan hierbij hand in hand.

Phd-theses living lab in ageing and long-term care/ proefschriften academische werkplaats ouderenzorg limburg

Vincent Moermans. Struggling with daily care dilemmas. Insights in involuntary treatment use among persons living with dementia receiving professional home care. 2023

Ron Warnier. Frailty screening in older hospitalized patients. 2023

Amal Fakha. Improving the implementation of transitional care innovtions. 2023

Megan Davies. Tri-national ethnographic multi-case study of person-centred care and quality of life in long-term residential care. 2023

Christoph Golz. Technostress among health professionals: The blame game between health professionals and technology. 2023

Teuni Rooijackers. Supporting older adults to STAY ACTIVE AT HOME. Process, effect and economic evaluation of a reablement training program for homecare staff. 2022

Anne van den Bulck. Differences that matter: Understanding case-mix and quality for prospective payment of home care. 2022

Marlot Kruisbrink. Towards enhanced management of fear of falling in older people. Unravelling interventions and measuring related avoidance of activity. 2022

Ruth Vogel. Nurses in the Lead: empowering community nurse leaders to implement evidence into practice. 2022

Fabian Groven. The bed bath with or without water? It’s a wash! Experiences with the washing without water intervention used for the bed bath. 2021

Roy Haex. Take a look through my eyes: The development of an experienced quality measure with clients, informal, and formal caregivers in Dutch home care. 2021

Sascha Bolt. The fundamentals of a DEDICATED palliative approach to care for people with dementia. 2021

Angela Mengelers. To risk or to restrain? Involuntary treatment use in people with dementia living at home. 2021

Katya Sion. Connecting Conversations. Experienced quality of care from the resident's perspective: a narrative method for nursing homes. 2021

Linda Hoek. Change begins with choice. Supporting the autonomy of nursing home residents with dementia through partnership. 2020

Mirre den Ouden. Every step counts. Daily activities of nursing home residents and the role of nursing staff. 2018

Theresa Thoma-Lürken. Innovating long-term care for older people. Development and evaluation of a decision support app for formal caregivers in community-based dementia care. 2018
Eveline van Velthuijsen. Delirium in older hospitalised patients: diagnosis and management in daily practice. 2018

Bram de Boer. Living at a green care farm. An innovative alternative for regular care in nursing homes for people with dementia. 2017

Nienke Kuk. Moving forward in nursing home practice. Supporting nursing staff in implementing innovations. 2017

Irma Everink. Geriatric rehabilitation. Development, implementation and evaluation of an integrated care pathway for older patients with complex health problems. 2017

Ramona Backhaus. Thinking beyond numbers. Nursing staff and quality of care in nursing homes. 2017

Martin Van Leen. Prevention of pressure ulcers in nursing homes, a big challenge. 2017

Mariëlle Daamen-Van der Velden. Heart failure in nursing home residents. Prevalence, diagnosis and treatment. 2016

Armand Rondas. Prevalence and assessment of (infected) chronic wounds. 2016

Hanneke Beerens. Adding life to years. Quality of life of people with dementia receiving long-term care. 2016 (Cum Laude)

Donja Mijnarends. Sarcopenia: a rising geriatric giant. Health and economic outcomes of community-dwelling older adults with sarcopenia. 2016

Tanja Dorresteijn. A home-based program to manage concerns about falls. Feasibility, effects and costs of a cognitive behavioral approach in community-dwelling, frail older people. 2016

Basema Afram. From home towards the nursing home in dementia. Informal caregivers' perspectives on why admission happens and what they need. 2015

Noemi Van Nie-Visser. Malnutrition in nursing home residents in the Netherlands, Germany and Austria. Exploring and comparing influencing factors. 2014

Silke Metzelthin. An interdisciplinary primary care approach for frail older people. Feasability, effects and costs. 2014

Jill Bindels. Caring for community-dwelling frail older people: a responsive evaluation. 2014

Esther Meesterberends. Pressure ulcer care in the Netherlands versus Germany 0-1. What makes the difference? 2013

Math Gulpers. EXBELT: expelling belt restraints from psychogeriatric nursing homes. 2013

Hilde Verbeek. Redesigning dementia care. An evaluation of small-scale homelike care environments. 2011

Judith Meijers. Awareness of malnutrition in health care, the Dutch perspective. 2009

Ans Bouman. A home visiting program for older people with poor health. 2009

Monique Du Moulin. Urinary incontinence in primary care, diagnosis and interventions. 2008
Anna Huizing. Towards restraint free care for psychogeriatric nursing home residents. 2008

Pascalle Van Bilsen. Care for the elderly, an exploration of perceived needs, demands and service use. 2008

Rixt Zijlstra. Managing concerns about falls. Fear of falling and avoidance of activity in older people. 2007

Sandra Zwakhalen. Pain assessment in nursing home residents with dementia. 2007