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To risk or to restrain?

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TO RISK OR TO RESTRAIN?

Involuntary treatment use in
people with dementia
living at home

Angela M.H.J. Mengelers

To risk or to restrain?

Involuntary treatment use in people with dementia living at home

Angela Maria Herma Jozefina Mengelers

The research presented in this thesis was conducted at CAPHRI Care and Public Health Research Institute, Department of Health Services Research, of Maastricht University. CAPHRI participates in the Netherlands School of Public Health and Care Research CaRe. This research was conducted within the Living Lab in Ageing and Long-Term Care and funded by Maastricht University.

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Voor oma, door jouw afwezigheid ben je er juist bij.

CONTENTS

CHAPTER 1

General introduction

INTRODUCTION

Providing care for people with dementia (PwD) can be complex when caregivers are faced with difficult dilemmas: Should you lock the door to prevent someone from leaving the house, or accept someone's freedom and risk that someone gets lost or injured? Dilemmas like this one can lead to involuntary treatment, which is defined as any type of care provided without the person's consent and/or to which the person resists. This thesis examines the use of involuntary treatment in community-dwelling PwD. Several aspects will be discussed, including professional and family caregivers' attitudes towards involuntary treatment use, the prevalence of involuntary treatment use in PwD receiving home care in the Netherlands and Belgium, the development and evaluation of an intervention for professional caregivers to prevent and reduce involuntary treatment use at home, and family caregivers' experiences with involuntary treatment use in PwD. This chapter starts with a general background on aging and dementia, followed by an overview of the organization of family and professional caregiving for PwD in the Netherlands. The challenges in providing home care for PwD are discussed and at the end we describe the main objectives and outline of this thesis.

AGING & DEMENTIA

In the Netherlands, over 3.2 million people (19%) are aged 65 years or older and this amount will only increase the next years [1]. Older age is often characterized by the emergence of several health challenges, including hearing loss, back and neck pain, osteoarthritis, diabetes and (mild) cognitive impairment. With the aging population, dementia forms a significant public health problem worldwide [2]. Dementia is a neurodegenerative syndrome characterized by cognitive and functional decline over time [2]. Every hour 5 people in the Netherlands get a type of dementia [1]. Currently more than 270.000 people living in the Netherlands are diagnosed with dementia, of which more than 95% is 65 years or older. Almost 75% of PwD still live at home [1]. The Dutch government actively supports aging in place and most people also prefer to remain at home as long as possible, in an environment that feels safe and familiar for them [3, 4]. However, maintaining PwD to live at home requires assistance from family caregivers, social support and professional home care, which can be quite challenging [5].

FAMILY & PROFESSIONAL CAREGIVING FOR PEOPLE WITH DEMENTIA IN THE NETHERLANDS

Dementia is often associated with memory loss, disorientation in time and place, and behavioral changes [6]. Performing activities of daily living (ADL) such as showering or getting dressed and household tasks become difficult for PwD and they gradually need more assistance. Due to this, many people in need of care depend on support from family caregivers and their social network. Family caregiving for PwD can be experienced as positive, for example due to a sense of personal accomplishment, growth and gratification [7]. Some family caregivers also report feelings of mutuality and reciprocity, and an increase of family cohesion and functionality. However, most family caregivers experience providing care for PwD as challenging and burdensome [8] and the process is often described as demanding, stressful and frustrating [9]. Changes in behavior and functional dependency can be experienced as frustrating and stressful not only for the person with dementia, but also for their caregivers and loves ones [10, 11]. Two out of three family caregivers indicate to feel distressed during caregiving activities [12]. It can lead to higher levels of anxiety, depression, use of psychotropic medication, sleep problems and chronic fatigue for family caregivers [13]. If family caregiving no longer meets the needs and wishes of PwD or their family caregivers, they can receive professional support and home care.

In the Netherlands several options for professional care and support are available to facilitate aging in place for PwD. PwD can receive professional home care from a district team, consisting of a district nurse, registered nurses with a bachelor's degree in nursing, licensed vocational nurses and certified nursing assistants. A district team supports clients in ADL such as toileting, dressing and bathing. The district nurse functions as the supervisor of the team and is responsible for performing the formal needs assessment, taking into account the client's care needs and opportunities for self-reliance [14]. PwD can also receive support from domestic workers in performing household tasks and instrumental activities of daily living such as house cleaning, laundry and grocery shopping. In addition, PwD have the right to be supported by a dementia case manager. The general practitioner usually refers PwD to a dementia case manager to stimulate aging in place. A dementia case manager is a professional, often with a nursing background, who provides long-term support and guidance for both PwD and their family caregivers. It can be considered as person-centered care since their support is based on the individual needs of the PwD and family caregivers [15]. Their tasks include support in the diagnostic phase, coordination of care and an advisory and counseling function [15].

CHALLENGES IN CARE FOR PEOPLE WITH DEMENTIA

The needs and wishes (for care) can differ between PwD and their caregiver: PwD may still want to do their own groceries, while caregivers are concerned about the risks involved and no longer consider it safe [16]. Making sure that PwD take their (prescribed) medication and eat and drink enough may be considered as necessary or the “right” type of care, but what are caregivers supposed to do if PwD refuse or resist? Caregivers have to balance providing quality of care and safety while maintaining the autonomy of PwD, which can lead to complex ethical dilemmas. Should we lock the door to prevent people from going outside, or respect their freedom with the risk that they get lost? Caregivers may feel the necessity to find an acute solution although this might be against the will of the PwD and not appear to be the most optimal option in the long term. Several terms are used to describe actions or care provided against someone’s will, including restraints [17, 18], coercive care [19-21], resistiveness to care [22-24] and involuntary treatment [25-27]. Restraints can broadly be defined as all devices and other actions that restrict an individual’s freedom in some way, for example the use of belts or a restraint vest but also forced administration of (psychotropic) medication and locking a door [28]. Coercion involves acting against an individual’s autonomy and can be described as an activity in which someone exerts his or her will upon another person [29] or imposes an action against the other persons’ expressed wishes [30]. Coercion includes for example the use of physical force [31] and protest behavior [32] and is commonly described in mental healthcare literature. Resistiveness to care can be described as a set of behaviors signaling an opposition to the care provided during a caregiving encounter between a caregiver and care recipient [33]. The terms resistiveness to care and involuntary treatment are often used in care for older people and/or people with a cognitive impairment (e.g. dementia). In this thesis we use the term involuntary treatment, which is defined as treatment provided by a family and/or professional caregiver without the client’s consent and/or to which the client resists [25, 26].

INVOLUNTARY TREATMENT

Involuntary treatment can be divided in three types including (1) physical restraints, (2) psychotropic medication, and (3) nonconsensual care [25]. Physical restraints are 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” [34]. Examples of physical restraints include waist belts, wrist and ankle restraints, chairs with a locked tray table, deep or overturned chairs, locked chairs, (bilateral) bedrails and sleep suits. The use of sensors (including GPS) or electronic monitoring can also be seen as restrictive measures. Psychotropic medication are drugs that act directly on the central nervous system, affecting the person's mood, cognition and behavior [26, 35]. According to the Anatomical Therapeutic Chemical classification, psychotropic medications were classified as antipsychotics, anxiolytics, hyponotic-sedatives, and antidepressants [36]. Nonconsensual care includes measures that restrict the client's freedom of living, such as restricting communication (e.g. removing access to the telephone, withholding mail, shutting off internet access), confining the person by for example locking a door, shutting off gas, restricting transportation by for example hiding car keys or removing aids so that the person is unable to walk. In addition, forced or hidden administration of medication, food or fluid and forced hygiene (e.g. washing or bathing against one's will), are considered non-consensual care.

Studies conducted in recent years mainly focused on physical restraint use in care settings like hospitals and nursing homes. Prevalence rates vary greatly between countries and care settings. The prevalence of physical restraints in nursing homes varies from 6% to 83% in several European countries [37], and from 9% in the United States to 20% in Hong Kong [38]. Many of those being physically restrained also receive psychotropic drugs [39]. Prevalence rates of psychotropic drugs range from 60% to as high as 90% in several European countries [37]. Literature on non-consensual care such as forced ADL care are more scarce, but studies show that it is regularly applied in nursing homes, especially in PwD [20]. About 40% of nursing home residents are subject to some type of non-consensual care over the course of a week [40].

Nowadays it is especially important to investigate the use of involuntary treatment in home care, since most PwD live at home and involuntary treatment presents a broad concept including all types of care provided against one's will. Although research on involuntary treatment use in home care is still scarce, recent studies have indicated that involuntary treatment is used in 40-52% of people with a cognitive impairment receiving home care [25, 26]. Non-consensual care is the most common type of involuntary treatment (73-79%). Psychotropic medication is used in 41-43% of the people, followed by physical restraints (7-38%). In most cases, involuntary treatment was requested by a family caregiver, followed by home care professionals and GPs. It is expected that involuntary treatment is even more often used in PwD, since its use is associated with greater ADL dependency and poorer cognitive ability [25, 26]. Caregivers may use involuntary treatment because they believe it can prevent or postpone nursing home admission [18] or to respite from other caregiving activities and offer (temporary) rest for the caregivers (e.g. when the caregiver needs to shower and puts the PwD in a locked chair). A common reason for professional or family caregivers to use involuntary treatment is safety, for example to prevent wandering or to control aggressive or restless behavior of PwD [41]. However, it is debatable whether the use of involuntary treatment is necessary and justified for these reasons, since (physical) restraints, psychotropic medication and non-consensual care are often used incorrectly, for too long or have shown to be ineffective [42]. In addition, involuntary treatment can have several negative effects on PwD. Physical restraints can lead to negative psychological and physical effects such as incontinence, pressure ulcers, aggression and depression [43-45]. People were injured as a result of physical restraint use, and it even caused death [43, 46, 47]. The use of psychotropic medication, especially in older people, is associated with adverse effects including dizziness, ataxia and impaired psychomotor functioning [48]. Besides, the use of force or coercive measures may cause feelings of stress, humiliation, fear and eventually anger and frustration [41, 49].

PREVENTION (AND REDUCTION) OF INVOLUNTARY TREATMENT

Because of the negative consequences of involuntary treatment use, it is necessary to investigate ways to prevent and/or reduce involuntary treatment use in PwD living at home. Since both professional and family caregivers are involved in the care for PwD, they can learn from and support each other. Professional caregivers often have the knowledge, experience and expertise regarding dementia and providing care for PwD, whereas family caregivers often have known the PwD for a long time and thus know their wishes and needs. Previous studies on reduction of physical restraints in nursing home residents indicated that knowledge and education alone is not sufficient to realize behavioral change in caregivers [50-52]. A culture change is needed to affect participants' attitudes: involuntary treatment can no longer be regarded as good quality and necessary care. Involuntary treatment conflicts with providing client-centered care, which embraces the interpersonal relationship and autonomy. Alternatives and a more client-centered care approach are needed to prevent involuntary treatment as much as possible. In addition to education, the following factors seem important to realize this culture change and behavioral change in caregivers [52-55]: 1) awareness, 2) a multidisciplinary approach in which professional and family caregivers support each other, 3) a clear policy, 4) guidance and coaching to support professional and family caregivers, and 5) availability of alternatives. Assessing caregivers' understanding of involuntary treatment use and increasing their awareness and knowledge regarding the consequences and alternatives is necessary to uphold good quality of care whilst maintaining PwD's dignity and liberty. In the Netherlands a new law "Care and Coercion" went into effect in January 2020. This law set a standard in which involuntary treatment should not be applied, unless there is no other option to prevent serious harm. This thesis offers insight, knowledge and possibilities that contribute to the overall aim to prevent and reduce involuntary treatment.

OBJECTIVES

The two main objectives of this thesis are:

1. To gain insight into involuntary treatment use in PwD living at home, specifically the prevalence and associated factors, professional and family caregivers' attitudes towards involuntary treatment use and family caregivers' experiences with managing care situations that can lead to involuntary treatment.
2. To develop and evaluate an intervention aimed at the reduction and/or prevention of involuntary treatment use in people with dementia living at home.

OUTLINE

Chapter 2 describes the development of the Maastricht Attitude Questionnaire-Home Care (MAQ-HC) and provides insight into professional and family caregivers' attitudes regarding involuntary treatment in community-dwelling people with dementia.
Chapter 3 reports on involuntary treatment use and associated factors in people with dementia receiving professional home care in the Netherlands and Belgium.
Chapter 4 contains a qualitative study on the experiences of family caregivers with managing care dilemmas that can lead to involuntary treatment in people with dementia living at home.
Chapter 5 presents the results of a feasibility study of the PRITAH intervention which aims to prevent and reduce involuntary treatment at home.
Chapter 6 reports the findings of the implementation, working mechanisms and contextual factors of the PRITAH intervention.
Chapter 7 provides an overview of the main findings and the general discussion, ending with some suggestions regarding the implications and challenges for future research and clinical practice.

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CHAPTER 2

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

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ABSTRACT

Aim: To gain insight into professional and family caregivers' attitudes towards involuntary treatment in community-dwelling people with dementia (PwD).
Background: The number of PwD with complex care needs living at home is increasing rapidly. In some situations, caregivers provide care against the will of PwD, referred to as involuntary treatment, which includes non-consensual care, psychotropic medication and physical restraints.
Design: A cross-sectional study.
Methods: A total of 228 professional (nursing staff, general practitioners (GPs) and other health care professionals such as physical therapists and psychologists) and 77 family caregivers of PwD completed the Maastricht Attitude Questionnaire – Home Care. This questionnaire measures attitudes towards involuntary treatment and perceived restrictiveness of and experienced discomfort in using involuntary treatment. Data were collected in the Netherlands between June – November 2016.
Results: Family caregivers and GPs had more positive attitudes towards involuntary treatment than nursing staff and other health care professionals, indicating that they are more accepting of involuntary treatment. A more positive attitude was associated with higher perceived caregiver burden and being a family caregiver. Family caregivers and GPs found the use of involuntary treatment less restrictive and indicated feeling more comfortable when using these measures.
Conclusion: It is important to account for the differences in attitudes and foster dialogue among professional and family caregivers to find common ground regarding alternatives to involuntary treatment. These results will inform the development of an intervention that aims to prevent involuntary treatment in home care.

INTRODUCTION

Dementia is a growing problem: over 230.000 people with dementia (PwD) currently live in the Netherlands, which is expected to double by 2040. Most people with dementia age in place (70%) and require extensive assistance from family caregivers, social support and professional home care [1]. In addition to professional home care, PwD and their informal caregivers can receive support from models of dementia case management in the Netherlands [2]. Dementia case managers provide long-term support and guidance for both community-dwelling PwD and their family caregivers based on their individual needs [3]. PwD are usually referred to a dementia case manager by their general practitioner (GP) to stimulate aging in place for as long as possible.

Everyday dementia care at home is becoming increasingly complex and more than half of the informal caregivers perceive the care for their loved one as being difficult and burdensome [1]. It can be quite challenging for caregivers to deal with the changes in behavior and cognition of PwD and to provide the right, desired care. High caregiver burden can lead to the inability to deal with difficult situations and family caregivers often feel the necessity to find an acute solution, although this might not always appear to be the most optimal option in the long term. The care for PwD involves several ethical and legal dilemmas. How do we create a balance between providing quality of care and safety while maintaining the dignity and autonomy of people living with dementia? Should we lock the door to prevent people from going outside, or respect their freedom with the risk that they get lost? These dilemmas can lead to difficult situations where caregivers provide care against the will of PwD. Forcing people to eat, using physical restraints and administering psychotropic medication to reduce agitation are examples of involuntary treatment [4] or coercive care [5].

In this article these types of treatment will be referred to as involuntary treatment. Involuntary treatment is defined as treatment provided by professional or family caregivers without the consent of the client and/or to which the client opposes and can be divided into (1) non-consensual care, (2) psychotropic medication and (3) physical restraints [4]. Non-consensual care includes all types of care used against the wishes of the client, such as imposing restrictions on daily life choices and activities. Examples of non-consensual care are forced administration of medication, food and fluid, washing or bathing against one's will and restricting communication or transportation. Psychotropic medication is medicine capable of affecting the mind, emotions and behavior and is often used in PwD to treat neuropsychiatric symptoms [6]. Antidepressants, antipsychotics and benzodiazepines are psychotropic medications commonly prescribed to PwD [7, 8]. Physical restraints are 'actions or procedures that prevent a person's free body movement to a position of choice and/or normal access to his/her body by the use of any method, attached or adjacent to a person's body that he/she cannot control or remove easily' [9]. Examples of physical restraints include waist belts, a (wheel) chair with a locked tray table, special sheets and full-enclosure bedrails [10].

Most studies reporting on (types of) involuntary treatment focus on physical restraints and/or the use of psychotropic medication and were conducted in the nursing home setting. Literature regarding the use of involuntary treatment in home care is scarce, especially regarding non-consensual care, its effects and the attitudes of professional and family caregivers towards the use of involuntary treatment and non-consensual care [4, 11, 12]. The first study assessing the prevalence of all types of involuntary treatment in PwD living at home showed that 39% of older people with cognitive impairment experience at least one type of involuntary treatment [4]. In case of involuntary treatment use, non-consensual care was most commonly used (80%), followed by psychotropic medication (41%) and physical restraints (7%). In 74% of the cases, involuntary treatment was used by family caregivers. General practitioners and other health care professionals were less likely to use involuntary treatment [4]. Important factors associated with involuntary treatment use were living alone, caregiver burden, ADL dependency, cognitive status and a diagnosis of dementia [4]. Another study indicated that restraints were used in 24.7% of older adults receiving home care [11]; however, in this study restraints included both physical restraints and non-consensual care. Like the findings of the first study [4], restraints were most often used by family caregivers.

BACKGROUND

Dilemmas encountered in dementia care are often associated with behavioral symptoms such as verbal and physical agitation, apathy and depression [13]. These behavioral symptoms can be challenging for caregivers to deal with, causing distress that can threaten the safety and comfort of PwD and their caregivers by leading to resistance to care and the use of non-consensual care. Resistance to care includes any behavior with which PwD resist or oppose caregiving efforts and puts PwD at risk of involuntary treatment use [13, 14]. The most common reasons for involuntary treatment are preserving safety, increasing the time a PwD can live at home and providing caregiver respite [11]. However, involuntary treatment can sometimes be an unsafe practice and can even be harmful. To inhibit behavioral symptoms in PwD psychotropic medication are often prescribed, although the intended effects of these medications have not been supported and they are associated with several adverse effects such as drowsiness, dizziness, ataxia and impaired psychomotor functioning

[8]. Physical restraints are often used in PwD to prevent falls, even though studies have shown that these measures do not lower the risk of falls or fall-related injuries [10, 15, 16]. In addition, physical restraints may lead to immobility, incontinence, agitation and even death [17, 18]. These potential negative effects clearly indicate that involuntary treatment should be prevented, and alternatives are needed.

Most studies describing the use of involuntary treatment, especially physical restraints and psychotropic medication, in nursing homes settings. It is important, however, to gain more insight into involuntary treatment in the client's home since dementia care is shifting from institutional settings to home care. To prevent and eliminate the current use of involuntary treatment in home care, it is important to understand the attitudes of professional and family caregivers involved in home care for PwD. Attitudes regarding the necessity of involuntary treatment will likely differ since they are influenced by perceptions, experiences and how we value one's safety, autonomy and freedom. Professional and family caregivers hold contrasting views on issues such as non-consensual care and the need for medication of PwD [19]. These differences may be attributed to family caregivers seeking to reduce their own burden while not fully understanding the negative implications for the PwD. Moreover, professional and family caregivers have different views on what is considered a physical restraint or other types of involuntary treatment [20, 21]. In some cases caregivers may not be aware or realize that the care they provide constitutes involuntary treatment. Although a fixation belt may be considered by caregivers as restrictive, other actions such as hiding medication may not be considered involuntary treatment. To support future efforts to eliminate and prevent involuntary treatment use it is necessary to first gain insight into attitudes towards these practices from both professional and family caregivers of PwD living at home.

AIMS

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

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

- What are the perceptions of professional and family caregivers regarding how uncomfortable they would feel when using non-consensual care, psychotropic medication and physical restraints and do perceptions differ between caregivers?

METHODS

Design

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

Participants

Both professional and family caregivers were included if they were involved in the care for PwD living at home. A family caregiver could be a spouse, relative, neighbor or friend. Professional caregivers were divided into GPs, nursing staff and other health care professionals. Nursing staff included care assistants, (district- and specialized) nurses and dementia case managers. Other health care professionals included among others physical therapists, psychologists, social workers, physician assistants and professionals with management roles. When we refer to professional caregivers, GPs, nursing staff and other health care professionals are all included. Forty-three dementia case managers distributed questionnaires for this study. Dementia case managers coordinate the care for PwD and their family caregivers with a network of other professional caregivers [22]. Dementia case managers provided the work addresses of all GPs (*N =310)* in their network and questionnaires were sent to GPs' offices. Questionnaires for nursing staff and other health care professionals (*N* =366) and family caregivers (*N* =292) were distributed in-person by dementia case managers. In total, 968 questionnaires were distributed. An overview of the distribution of questionnaires is provided in Figure 1.

Data collection

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

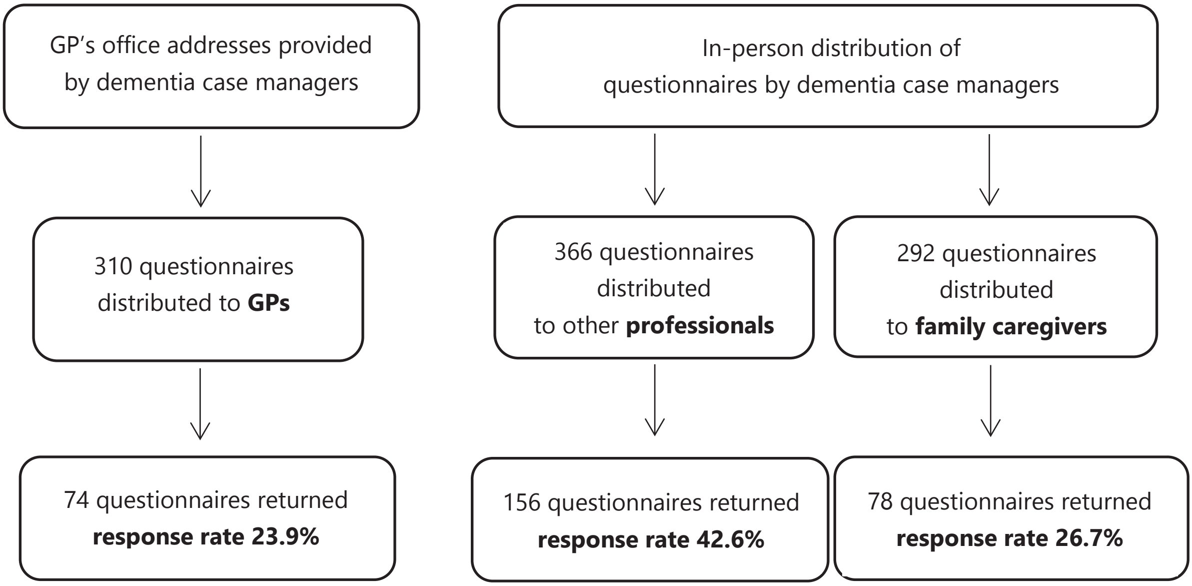

Figure 1. Flowchart describing the distribution of questionnaires

The Maastricht Attitude Questionnaire – Home Care

The MAQ-HC was developed for this study, based on the Maastricht Attitude Questionnaire (MAQ) on restraint use in nursing homes [23-25]. The first part of the MAQ-HC consists of 60 statements to measure attitudes towards the use of involuntary treatment. The items are grouped into four subscales based on pre-defined constructs [4]: involuntary treatment in general (20 items), non-consensual care (15 items), psychotropic medication (13 items) and physical restraints (12 items). Examples of statements are 'The safety of people with dementia is more important than the freedom of people with dementia' and 'Physical restraints reduce the quality of life of people with dementia'. Each item has to be rated on a 5-point Likert scale ranging from 'totally disagree' to 'totally agree'. Some items have to be recoded so that for every item a higher score represents a more positive attitude towards involuntary treatment. A more positive attitude towards involuntary treatment can be interpreted as being more accepting of involuntary treatment. The subscale scores are calculated by adding up all scores of the items in that subscale divided by the number of items in that subscale. The total subscale scores range from 1-5, with a higher score indicating a more positive attitude towards involuntary treatment. Conversely, a lower score indicates a more negative attitude towards involuntary treatment. The second part of the MAQ-HC measures caregivers' perceptions on how restrictive (not restrictive, moderately restrictive or very restrictive) they find involuntary treatment for PwD and how uncomfortable (not uncomfortable, moderately uncomfortable or very uncomfortable) they would feel when using involuntary treatment with PwD. The items are grouped into three subscales: non-consensual care (11 items), psychotropic medication (1 item) and physical restraints (13 items). Table 4 provides an overview of all types of involuntary treatment included in the second part of the MAQ-HC. We collected socio-demographic variables (age, gender, hours of care per week for PwD and perceived caregiver burden). For family caregivers, we additionally collected data regarding their relationship with the PwD and the living situation; for professional caregivers' data on years of working experience and current role were collected.

Ethical considerations

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

Data analyses

Prior to analyses, negative items (N =27) were reverse coded so that for every item a higher score represents a more positive attitude towards involuntary treatment. Missing items were substituted by the participant's mean on that scale if the total number of missing items for that person were no greater than 20%. If more than 20% of the items were left blank, no scores were imputed for that scale. Descriptive statistics including means, standard deviations, percentages and frequencies were used to provide an overview of demographic characteristics and to summarize attitudes towards involuntary treatment and perceptions on how restrictive the caregivers view involuntary treatment for PwD and how uncomfortable caregivers feel when using involuntary treatment. One-way ANOVAs were conducted to investigate differences between the four groups of caregivers in attitudes towards involuntary treatment in general, non-consensual care, psychotropic medication and physical restraints. One-way ANOVAs were also conducted to examine differences in perceived restrictiveness of and experienced discomfort in using involuntary treatment among the four groups of caregivers. If statistically significant differences in attitudes were found, post hoc analyses with correction for multiple testing were conducted to identify which groups differed from each other. Independent samples t-test analyses were conducted to investigate whether family caregivers not living with PwD had different attitudes towards involuntary treatment than family caregivers living with PwD. Multiple regression analyses were conducted to investigate the relationship between caregivers' characteristics and attitudes towards involuntary treatment use. The dependent variable was attitude towards involuntary treatment. Independent variables were age, gender, hours of care per week for people with dementia, perceived burden and professional (GP, nursing staff or other health care professional) versus family caregiver. All analyses were conducted using the Statistical Package for the Social Sciences (SPSS version 23; IBM, Chicago, IL, USA). A P-value of ≤ 0.05 was considered statistically significant, unless stated otherwise.

Validity, reliability and rigour of the MAQ-HC

The first version of the MAQ-HC consisted of two parts: 1) 67 statements to measure attitudes towards involuntary treatment and 2) 25 items to measure attitudes towards restrictiveness and discomfort of involuntary treatment. This version was pilot tested by 15 professional and family caregivers. Based on pilot testing some changes were made in the first part of the questionnaire: eight statements were deleted because of overlap with other items or because the items were not appropriate, four statements were rewritten because they were unclear, and one statement was added. No adjustments were made to the second part of the MAQ-HC. The second version of the MAQ-HC, as described in the methods section and used for distribution, consisted of 60 items in the first part and 25 items in the second part. Completing the MAQ-HC was feasible (within 25 minutes) and face validity was good.

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

RESULTS

Sample characteristics

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

Attitudes of professional and family caregivers towards involuntary treatment

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

Table 1. Sample characteristics

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

Table 2. Attitudes towards involuntary treatment

	Nursing staff	General practitioners	Other care professionals	Family caregivers	P-value (ANOVA)
Involuntary treatment	2.88 (0.43) [‡, ¶]	3.27 (0.39) [†, §]	2.97 (0.44) [‡, ¶]	3.28 (0.33) [†, §]	<0.001
Non-consensual care	2.97 (0.44) [‡, ¶]	3.25 (0.42) [†]	3.04 (0.43) [¶]	3.44 (0.46) [†, §]	<0.001
Psychotropic medication	2.88 (0.44) [‡, ¶]	3.19 (0.54) [†]	2.94 (0.48)	3.17 (0.39) [†]	<0.001
Physical restraints	2.37 (0.53) [‡, ¶]	2.83 (0.42) [†]	2.55 (0.53) [¶]	3.02 (0.54) [†, §]	<0.001

Items were rated on a 5-point Likert scale indicating 1 as a negative attitude and 5 as a positive attitude. Reported scores are mean scores and standard deviations. Corrected alpha ≤ 0.002.

[†] Significantly different from nursing staff

[‡] Significantly different from GPs

[§] Significantly different from other health care professionals

[¶] Significantly different from family caregivers

Relation between caregivers' characteristics and their attitudes towards involuntary treatment

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

Caregivers' perceptions regarding restrictiveness of and experienced discomfort in using involuntary treatment

Table 4 provides an overview of mean item scores regarding perceived restrictiveness and experienced discomfort in using non-consensual care, psychotropic medication and physical restraints. In general, the mean scores of all caregivers regarding perceived restrictiveness of non-consensual care, psychotropic medication and physical restraints varied between 1.87 and 2.50, indicating that overall these types of involuntary treatment are considered moderately restrictive. Similar results were found regarding feeling uncomfortable when using involuntary treatment, with mean scores varying between 1.84 and 2.40, indicating that all caregivers feel moderately uncomfortable when using involuntary treatment.

Table 5 summarizes the results of the ANOVA analyses of the mean subscale scores regarding perceived restrictiveness of and experienced discomfort in using non-consensual care, psychotropic medication and physical restraints. Family caregivers and GPs perceived non-consensual care and physical restraints less restrictive for PwD and indicated feeling more comfortable when using these measures than nursing staff. Results also indicated some differences between family caregivers and other health care professionals: family caregivers perceived non-consensual care and physical restraints less restrictive and indicated feeling more comfortable in using non-consensual care compared with other health care professionals. Finally, GPs indicated feeling less uncomfortable in using non-consensual care compared with other health care professionals. No differences were found regarding perceived restrictiveness of and discomfort in using psychotropic medication between the four groups.

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

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

† reference = male (coded as 0), female (coded as 1)

‡ reference = <10 hours (coded as 0), at least 10 hours (coded as 1)

§ reference = never/rarely (coded as 0), sometimes/often/always (coded as 1)

Table 4. Opinions regarding degree of restrictiveness and discomfort to involuntary treatment (descriptives)

Restrictiveness	**Nursing staff**	**General practitioners**	**Other care professional**	**Family caregivers**
Non-consensual care				
1. Withholding aids, e.g. walking aid	2.93 (0.26)	2.73 (0.48)	2.89 (0.32)	2.41 (0.79)
2. Withholding the telephone	2.72 (0.49)	2.26 (0.66)	2.58 (0.58)	2.33 (0.72)
3. Forced administration of food/fluids	2.59 (0.58)	2.54 (0.55)	2.41 (0.62)	1.91 (0.70)
4. Forced hygiene	2.52 (0.55)	1.99 (0.67)	2.43 (0.63)	1.87 (0.62)
5. Forced administration of medication	2.45 (0.63)	2.12 (0.60)	2.34 (0.57)	1.84 (0.59)
6. Withholding car(keys)	2.32 (0.73)	2.20 (0.76)	2.22 (0.80)	1.89 (0.85)
7. Withholding the mail	2.24 (0.71)	2.11 (0.73)	2.16 (0.74)	1.93 (0.76)
8. Hidden administration of medication, for example in food	1.94 (0.74)	1.70 (0.68)	1.75 (0.72)	1.56 (0.66)
9. Shutting off gas	1.94 (0.64)	1.76 (0.74)	1.89 (0.75)	1.75 (0.77)
10. Hiding away medication (painkillers)	1.72 (0.65)	1.61 (0.62)	1.80 (0.66)	1.63 (0.71)
11. Hiding away prescribed medication	1.60 (0.64)	1.57 (0.60)	1.60 (0.69)	1.47 (0.70)
Psychotropic medication				
12. Use of psychotropic medication	2.17 (0.58)	2.01 (0.67)	2.29 (0.63)	1.99 (0.63)

Physical restraints				
13. Fixation belt	2.94 (0.25)	2.86 (0.38)	2.84 (0.37)	2.67 (0.99)
14. Vest with fixation belt	2.89 (0.31)	2.80 (0.41)	2.76 (0.52)	2.44 (0.69)
15. Wrist belt	2.87 (0.39)	2.66 (0.53)	2.80 (0.55)	2.77 (0.59)
16. Ankle belt	2.87 (0.41)	2.62 (0.68)	2.78 (0.56)	2.75 (0.62)
17. Tightly tucked sheet	2.84 (0.39)	2.66 (0.65)	2.82 (0.39)	2.55 (0.69)
18. Special sheet	2.72 (0.51)	2.41 (0.66)	2.47 (0.63)	2.08 (0.80)
19. Deep/overturned chair	2.52 (0.55)	2.24 (0.59)	2.36 (0.61)	1.99 (0.72)
20. (Wheel)chair on a board	2.50 (0.65)	1.91 (0.71)	2.27 (0.72)	1.86 (0.71)
21. (Wheel)chair with locked tray table	2.50 (0.62)	1.99 (0.61)	2.18 (0.68)	1.67 (0.71)
22. Bilateral bedrails	2.49 (0.65)	2.27 (0.58)	2.53 (0.55)	2.11 (0.70)
23. Sleep suit	2.42 (0.67)	2.34 (0.67)	2.36 (0.61)	2.11 (0.76)
24. Camera surveillance	1.72 (0.68)	1.76 (0.72)	1.73 (0.72)	1.67 (0.69)
25. Sensor mat	1.28 (0.49)	1.32 (0.53)	1.44 (0.55)	1.37 (0.54)

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

Discomfort	**Nursing staff**	**General practitioners**	**Other care professional**	**Family caregivers**
Non-consensual care				
1. Withholding aids, e.g. walking aid	2.84 (0.36)	2.55 (0.65)	2.87 (0.41)	2.53 (0.99)
2. Withholding the telephone	2.73 (0.52)	2.15 (0.70)	2.64 (0.61)	2.32 (0.83)
3. Forced administration of food/fluids	2.64 (0.48)	2.57 (0.58)	2.66 (0.57)	2.01 (0.81)
4. Forced hygiene	2.59 (0.51)	2.07 (0.73)	2.77 (0.42)	2.00 (0.74)
5. Forced administration of medication	2.51 (0.60)	2.20 (0.68)	2.57 (0.59)	1.95 (0.73)
6. Withholding the mail	2.30 (0.74)	1.92 (0.81)	2.09 (0.79)	2.04 (0.85)
7. Withholding car(keys)	2.09 (0.81)	1.74 (0.73)	2.00 (0.83)	1.77 (0.85)
8. Hidden administration of medication, for example in food	2.06 (0.79)	1.84 (0.76)	1.93 (0.76)	1.59 (0.76)
9. Hiding away medication (painkillers)	1.53 (0.72)	1.41 (0.62)	1.67 (0.71)	1.53 (0.72)
10. Shutting off gas	1.60 (0.70)	1.44 (0.60)	1.71 (0.76)	1.61 (0.79)
11. Hiding away prescribed medication	1.59 (0.68)	1.34 (0.56)	1.56 (0.73)	1.37 (0.63)
Psychotropic medication				
12. Use of psychotropic medication	2.06 (0.68)	1.84 (0.69)	2.29 (0.63)	1.91 (0.77)

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

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

Table 5. Opinions regarding degree of restrictiveness and discomfort to involuntary treatment (ANOVA)

	Nursing staff	**General practitioners**	**Other care professional**	**Family caregivers**	**P-value**
Restrictiveness					
Non-consensual care	2.27 (0.33) ‡, ¶	2.05 (0.35) †	2.20 (0.32) ¶	1.87 (0.39) †, §	<0.001
Psychotropic medication	2.17 (0.58)	2.01 (0.67)	2.29 (0.63)	1.99 (0.63)	0.023
Physical restraints	2.50 (0.28) ‡, ¶	2.30 (0.32) †	2.41 (0.30) ¶	2.16 (0.42) †, §	<0.001
Discomfort					
Non-consensual care	2.23 (0.36) ‡, ¶	1.93 (0.41) †, §	2.23 (0.38) ‡, ¶	1.88 (0.51) †, §	<0.001
Psychotropic medication	2.06 (0.68)	1.84 (0.69)	2.29 (0.63)	1.91 (0.77)	0.004
Physical restraints	2.40 (0.33) ‡, ¶	2.16 (0.38) †	2.31 (0.35)	2.13 (0.46) †	<0.001

Items were rated on a 3-point Likert-scale indicating 1 as not restrictive/no discomfort and 3 as very restrictive and very discomforting.
Reported scores are means (standard deviation).
Corrected alpha ≤ 0.003.
† Significantly different from nursing staff
‡ Significantly different from GPs
§ Significantly different from other health care professionals
¶ Significantly different from family caregivers

DISCUSSION

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

The finding that family caregivers are more accepting of involuntary treatment than nursing staff and other health care professionals is similar to previous findings that involuntary treatment is most often used and requested by family caregivers [4]. It is reasonable to assume that those with more positive attitudes towards involuntary treatment are more likely to use involuntary treatment in complex situations. These differences can be explained by different ethical perspectives and views of how to balance the best interests of PwD with practices such as coercion and the need for medication [19]. Family caregivers experience that they have to restrict the activities of PwD for the sake of safety, not only because of their duties towards the PwD but also because this “safety first” is expected by other family members [19]. Another possible explanation for the differences in attitudes is perceived caregiver burden. Caregiver burden is positively associated with the use of involuntary treatment [4] and our study also indicates an association between higher caregiver burden and a positive attitude towards the use of involuntary treatment. In our study, 32% of the family caregivers indicated that they often or always find the care for PwD burdensome, whereas for nursing staff and other health care professionals only 12% and 22%, respectively, indicated that they often find the care for PwD burdensome. Finally, family caregivers perceived non-consensual care and physical restraints less restrictive to PwD and indicated feeling less discomfort when using these types of involuntary treatment compared with nursing staff and other health care professionals. All these factors may explain why family caregivers have a more positive attitude towards involuntary treatment and more often use involuntary treatment. Although the attitudes and perceptions towards the use of involuntary treatment differed, results also indicated some similarities between professional and family caregivers: all caregivers considered physical restraints the most restrictive type of involuntary treatment and indicated feeling the most discomfort when using physical restraints. In addition, the order of restrictiveness of involuntary treatment use and feelings of discomfort when using involuntary treatment are more or less similar between the four groups: withholding aids and the telephone were considered the most restrictive types of non-consensual care and fixation belts, wrist- and ankle belts are considered the most restrictive types of physical restraints by all caregivers. These types of involuntary treatment are the least requested and applied [4, 11].

There are no previously published studies to compare the results of this study concerning professional and family caregivers' attitudes towards involuntary treatment use in PwD living at home. Differences in attitudes between nursing staff and other health care professionals versus family caregivers may be explained by knowledge of the negative effects since poor knowledge about physical restraints is related to more positive attitudes towards restraint use [26]. Almost 42% of family caregivers believed that the use of physical restraints is unavoidable, and the majority of family caregivers consider physical restraints as appropriate and is willing to use them with a relative [27]. Family caregivers are often not aware of regulations to prohibit or minimize involuntary treatment and the harmful physical and psychological effects [27, 28].

The consequences and effects of physical restraint use in nursing homes are well known, including immobility, depression, aggression and even death [10, 16]. These effects are probably similar in home care, however little is known about the use and effects of other types of involuntary treatment, especially non-consensual care. This might explain why the use of physical restraints is regulated heavily in institutional settings, while legislation regarding the use of (other types of) involuntary treatment in home care is currently lacking in the Netherlands. When new clients are being referred for home care an individual care plan accounts for their needs and wishes, including advanced directives. Providing client-centered care is a common discussion. However, the use of involuntary treatment, its effects and possible alternative interventions are not common subjects of discussion between professional and family caregivers and clients beforehand. Usually this is only discussed when problems arise, or clients show resistance to care; then a solution is usually sought on the spot, if necessary with external expertise. Some caregivers might not be aware that they provide involuntary treatment, such as locking a door when leaving the house or hiding medication. Also, some types of involuntary treatment such as providing medication, assisting with feeding and hiding car keys might be considered as necessary interventions and there is a lack of consensus regarding what constitutes “good” care. Future studies should focus on the frequency, outcomes, related issues and health impacts of involuntary treatment in home care, especially regarding non-consensual care. More research is needed on whether there are differences in negative consequences of involuntary treatment in the home environment versus the nursing home environment and how these differences are expressed. Understanding the potential hazards, dilemmas and alternatives to involuntary treatment is therefore warranted and should be the primary step in developing interventions to prevent involuntary treatment. It is important to foster dialogue between professional and family caregivers regarding the use of involuntary treatment and the decision-making process. The ethical challenges involved in involuntary treatment at home need to be considered when developing policy concerning involuntary treatment use in home care. Finally, it is important to monitor the well-being of family caregivers and identify ways to reduce caregiver burden, since this is associated with the use of involuntary treatment.

Limitations

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

Conclusion

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

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CHAPTER 3

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

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ABSTRACT

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

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

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

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

Results: More than half of the PwD (50.7%) living at home received involuntary treatment (Belgium 68.2% and the Netherlands 44.7%). 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 PwD, which is in line with previous findings indicating dementia as a risk factor for involuntary treatment use. More research is needed to gain insight into variations in prevalence across other countries, which factors influence these differences and what countries can learn from each other regarding prevention of involuntary treatment.

Relevance to clinical practice: To provide person-centered care, it is important to study ways to prevent involuntary treatment in PwD 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 people with dementia (PwD) experience at least one of the following neuropsychiatric symptoms: agitation (eg. aggression, irritability, restlessness), psychosis (eg. hallucinations, delusions) and mood disorders (eg. depression, anxiety, apathy) [2-4]. As a result, PwD experience difficulties expressing their needs and wishes, which can lead to restless behavior or restiveness to care [5]. Dealing with these symptoms and changes can be very challenging for PwD and their caregivers [3, 6]. The majority (70%) of PwD 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 PwD to live at home is challenging due to an increasing complexity of care as well and the need for extensive assistance from family caregivers, social support and professional home care [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 PwD and their caregivers, which can lead to situations in which caregivers provide care against the will of the client and/or to which the client resists.

Caregivers may choose "quick but potentially harmful solutions", such as physical restraints or other measures that can negatively affect the PwDs' quality of life [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 behavior" [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 behavior [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-centered 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 PwD and the increased risk of involuntary treatment due to increasing complexity and care demands, it is urgent to gain more insight into involuntary treatment among PwD.

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

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 PwD since this group is especially at risk for involuntary treatment use. In contrast to the original studies, this study only included people with a formal diagnosis of dementia as determined by a physician (e.g. GP, geriatric specialist, psychiatrist or neurologist), living at home and receiving professional home care. A formal diagnosis of dementia was determined by a physician, often a general practitioner (GP), geriatric specialist or neurologist. To gain insight into the client's cognitive functioning (e.g. memory, orientation, language) a GP usually uses the Mini-Mental State Examination, where a score below 24 (range 0-

30) indicates cognitive impairment [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 PwD. In Belgium eligible participants were included if they received professional nursing care at home from and had a Weckx score of at least two on the items disorientation in time and place [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 [31-33]. Table 1 provides an overview of the involuntary treatments included in our questionnaire. Dementia case managers and district nurses filled in the questionnaire for every selected PwD in their caseload [11, 12]. No incentives were provided for participating in this study.

Data collection

Besides the use of involuntary treatments, the person who requested and applied involuntary treatment was recorded (family caregiver, nurse, GP, psychologist or social worker). Sociodemographic factors including age, sex and living situation (alone or together) were collected of PwD. To assess functional and cognitive ability, two subscales (Activity of Daily Living Hierarchy (ADLH)) and Cognitive Performance Scale (CPS)) from the Resident Assessment Instrument Minimum Data Set (RAI-MDS) in the Netherlands [34] and the Inter Resident Assessment Instrument Home Care Belgium (InterRAI HC) In Belgium [35]. 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) [36]. 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 [37]. 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 [38].

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 PwD 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.

Involuntary treatment

Table 1 presents all involuntary treatments used. In total, 889 individual measures of some type of involuntary treatment were used in 428 (50.7%) PwD. The majority of PwD received one (n=200), two (n=99) or three (n=69) involuntary treatments. In two PwD, 10 involuntary treatments were used. A total of 126 physical restraints were used in 79 people. One hundred and seventy-four people received psychotropic medication and 589 measures of 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 car keys or deactivate 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.

Table 1. Involuntary treatments used

	The Netherlands (n=627)	Belgium (n=217)	Total (n=844)
Types of involuntary treatment †,‡ *Number of measures (number of PwD receiving the measure, percentage in relation to PwD who receive involuntary treatment*	*511 (n=280,* ***44.7%****)*	*378 (n=148,* ***68.2%****)*	*889 (n=428,* ***50.7%****)*
Physical restraints	*34 (n=20,* ***7.1%****)*	*92 (n=59,* ***39.9%****)*	*126 (n=79,* ***18.5%****)*
1. Waist belt in (wheel)chair	1	9	10
2. Waist belt in bed	0	3	3
3. Wrist or ankle ties	0	1	1
4. Chair with fixed tray table	5	6	11
5. Deep, overturned or reclined chair[a]	13	6	19
6. Chair on a board	0	0	0
7. Locked (wheel)chair	8	15	23
8. Bilateral fully enclosed bedrails[b]	6	48	54
9. Special sheet[c]	0	3	3
10. Sleep suit[d]	1	1	2

Psychotropic medication	*(n =113, **40.4%**)*	*(n=61, **41.2%**)*	*(n= 174, **40.7%**)*
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 PwD receiving the measure and percentages are calculated in relation to people who received involuntary treatment)

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

[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.

Table 2. Sample characteristics

Variable	**The Netherlands** n = 627	**Belgium** n = 217	**Total** n=844	**P-value**
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)	3.2 (1.3)	4.0 (1.4)	3.4 (1.3)	<0.001
median (25th, 75th percentile)	3 (2, 4)	5 (3, 5)	3 (2, 5)	
ADL ‡, mean (SD)	1.8 (1.3)	3.2 (1.3)	2.1 (1.5)	<0.001
median (25th, 75th percentile)	2 (1,3)	3 (3, 4)	2 (1, 3)	
Caregiver burden §, mean (SD)	6.1 (2.6)	5.0 (3.2)	5.8 (2.8)	<0.001
median (25th, 75th percentile)	7 (4, 8)	5 (2, 8)	6 (4, 8)	

Categorical variables were analyzed using chi-square tests; continuous variables were analyzed 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.

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-erceived informal caregiver burden, country.
Dependent variable is involuntary treatment: no (0) and yes (1).
† 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).

Request and use of involuntary treatment

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

Table 4. Request and use of involuntary treatment

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

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

DISCUSSION

Involuntary treatment is common practice in PwD receiving professional home care. In one out of two PwD at least one measure of involuntary treatment was used. In both the Netherlands and Belgium 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 PwD seems to be higher compared to studies focusing on older people and/or people with cognitive impairment in general, reporting prevalence rates ranging from 24% to 52% in Belgium [12, 21] and 39% in the Netherlands [11]. This clearly indicates that PwD are particularly at risk for involuntary treatment use, which may be related to their higher functional dependency and impaired cognitive functioning. The finding that involuntary treatment use is associated with lower cognitive functioning, higher functional dependency and higher perceived family caregiver burden is in line with previous studies in home care [11, 12, 21]. Due to impaired cognitive and functional ability the neuropsychiatric symptoms of dementia [3], caring for a PwD 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-centered care is effective in decreasing neuropsychiatric symptoms in PwD, 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 PwD 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 PwD 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-centered care approach, along with continuous training and education [23, 39]. Other key elements to support PwD and their caregivers are a trusting relationship, one single point of contact (e.g. dementia case manager) and a tailored care plan [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 PwD 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 characteristics. In the Netherlands anyone with (a suspicion of) dementia can receive support from a dementia case manager, who coordinates the care for PwD and their family caregiver and provides emotional guidance and support [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 PwD in the Netherlands and Belgium should be comparable. In addition, in the analyses we controlled for confounding factors such as differences in background characteristics. Finally, the use of restraints has received a lot of attention in (the south of) the Netherlands in recent years and a national policy that will go into effect in January 2020 aims to prevent involuntary treatment use. National differences in involuntary treatment use and possible causes and explanations for these differences should be studied further.

Limitations

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. Strengths 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 PwD within their caseload. The same definitions and measures were used to collect data on involuntary treatment use. Another strength of this study is that it presents results from a large sample of PwD (n = 844), who are particularly at risk for involuntary treatment use [45].

Conclusions

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

Relevance to clinical practice

Involuntary treatment is commonly used in PwD receiving professional home care in the Netherlands and Belgium. This manuscript is especially valuable for professional caregivers such as nurses and GPs who focus on providing person-centered dementia care. Involuntary treatment is not only common in home care for PwD, 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-centered 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.

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CHAPTER 4

Family caregivers' experiences in dealing with involuntary treatment in dementia care at home: a qualitative study

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CHAPTER 5

Prevention and reduction of involuntary treatment at home: A feasibility study of the PRITAH intervention

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ABSTRACT

Sometimes care is provided to a cognitively impaired person against the person's will, referred to as involuntary treatment. We developed the PRITAH intervention, aimed at prevention and reduction of involuntary treatment at home. PRITAH consists of a policy discouraging involuntary treatment, workshops, coaching by a specialized nurse and alternative interventions. A feasibility study was conducted including 30 professional caregivers. Feasibility was assessed by attendance lists (reach), evaluation questionnaires, a logbook and focus group interviews (delivery of and interaction with the intervention, satisfaction & barriers). The workshops and coach were positively evaluated and the average attendance rate was 73%. Participants gained more awareness and knowledge and received practical tips and advice to prevent involuntary treatment. Implementation of the intervention was feasible with minor deviations from protocol. Recommendations for improvement included more emphasis on involvement of family caregivers and general practitioners and development of a guideline to comply with the policy.

INTRODUCTION

Due to most older persons' preference to live at home as long as possible and government policy supporting aging in place, an increasing number of people with cognitive impairment require support from family caregivers and professional home care [1]. The care for people with cognitive impairments is often experienced as challenging [2]. People with cognitive impairments can experience difficulties in understanding what they are being asked, requests might not match their preferences and they sometimes struggle with (verbally) expressing their wishes and needs [3]. Almost 70% of family caregivers experience their caregiving situation as stressful, especially when the care recipient is resistant to assistance with activities of daily living (ADL) [4, 5]. People with cognitive impairment may experience the care provided by the caregiver as unnecessary or undesirable, which may be expressed by behaviors such as resisting the efforts of a caregiver or preventing the caregiver to perform or assist with ADL such as bathing, dressing and toileting [6]. This can lead to stress, agitation and aggression for both the care recipient and the caregiver [7], and places the caregiver in a complex dilemma. Should the caregiver force hygiene or respect the person's autonomy to refuse care? It is difficult for caregivers to find a balance in providing quality care and safety, while accepting the person's autonomy [8]. Distressed by these complex situations, caregivers often feel the necessity to find an immediate solution, which can lead to care provided without the consent of the client and/or to which the client resists; this is referred to in the literature as restraints [9], coercive care [10], resistiveness to care [6, 11] and involuntary treatment [8, 12, 13]. In this study, we use the term involuntary treatment that is commonly used in home care [12] and includes the use of physical restraints [14], psychotropic medication and non-consensual care [8, 12, 13].

Previous studies indicate that 25% to 51% of people with cognitive impairment living in the Netherlands and Belgium receive at least one type of involuntary treatment [9, 12, 13]. Non-consensual care is the most common type of involuntary treatment (73-79%), followed by psychotropic medication (41-43%) and physical restraints (7-38%) [12, 13]. Common reasons for the use of involuntary treatment are preserving safety (e.g. preventing falls or wandering), managing aggressive behavior [15, 16] or lack of awareness of alternative interventions [17]. In addition, involuntary treatment can be used to provide caregivers respite and to extend the time someone can live at home [9]. However, various studies concluded that the use of these involuntary treatment measures are often ineffective and can even be unsafe and harmful [18-21]. Physical restraints are associated with several physical, psychological and social consequences including incontinence, pressure ulcers, depression, aggression and discomfort [22, 23]. Psychotropic medication are often prescribed to older people to inhibit behavioral symptoms, although the intended effects of these medications have not been supported and the use of these medications are often associated with adverse effects including drowsiness, dizziness, ataxia and impaired psychomotor functioning [24]. Non-consensual care includes the use of force or coercive measures, which may cause feelings of distress, humiliation, fear, aggression or agitation for the client receiving the care, as well as the caregiver itself [25]. In addition, the use of involuntary treatment contradicts the basic principle of caregiving: providing care based on the patient's consent [26] and is in conflict with the values of person-centered care, which focus on the individual's needs and providing high-quality interpersonal care that implies recognition, respect and trust [27]. A multidisciplinary approach is needed to support professional and family caregivers in finding alternative interventions to these measures.

We developed the PRITAH intervention (Prevention and Reduction of Involuntary Treatment At Home), a multidisciplinary approach that aims to support both professional and family caregivers by providing them with knowledge and tools to prevent and reduce involuntary treatment at home. The intervention consists of four main components: 1) implementation of a policy within the home care organization that discourages involuntary treatment use, 2) an information meeting and three 2.5-hour workshops for professional caregivers including practical assignments and discussion of case studies, 3) consultation by a specialized nurse during the workshop and coaching on the job and 4) availability of alternative interventions. This study aims to assess the feasibility of the PRITAH intervention using Saunders' process evaluation framework [28]. This framework provides a comprehensive and systematic approach for developing a process-evaluation plan. Process indicators used within this framework include dose delivered, fidelity, dose received, satisfaction, reach and barriers.

METHODS

Design

An exploratory mixed-methods study was performed including qualitative and quantitative measures. The study was conducted between October 2018 and January 2019. Figure 1 provides an overview of the study.

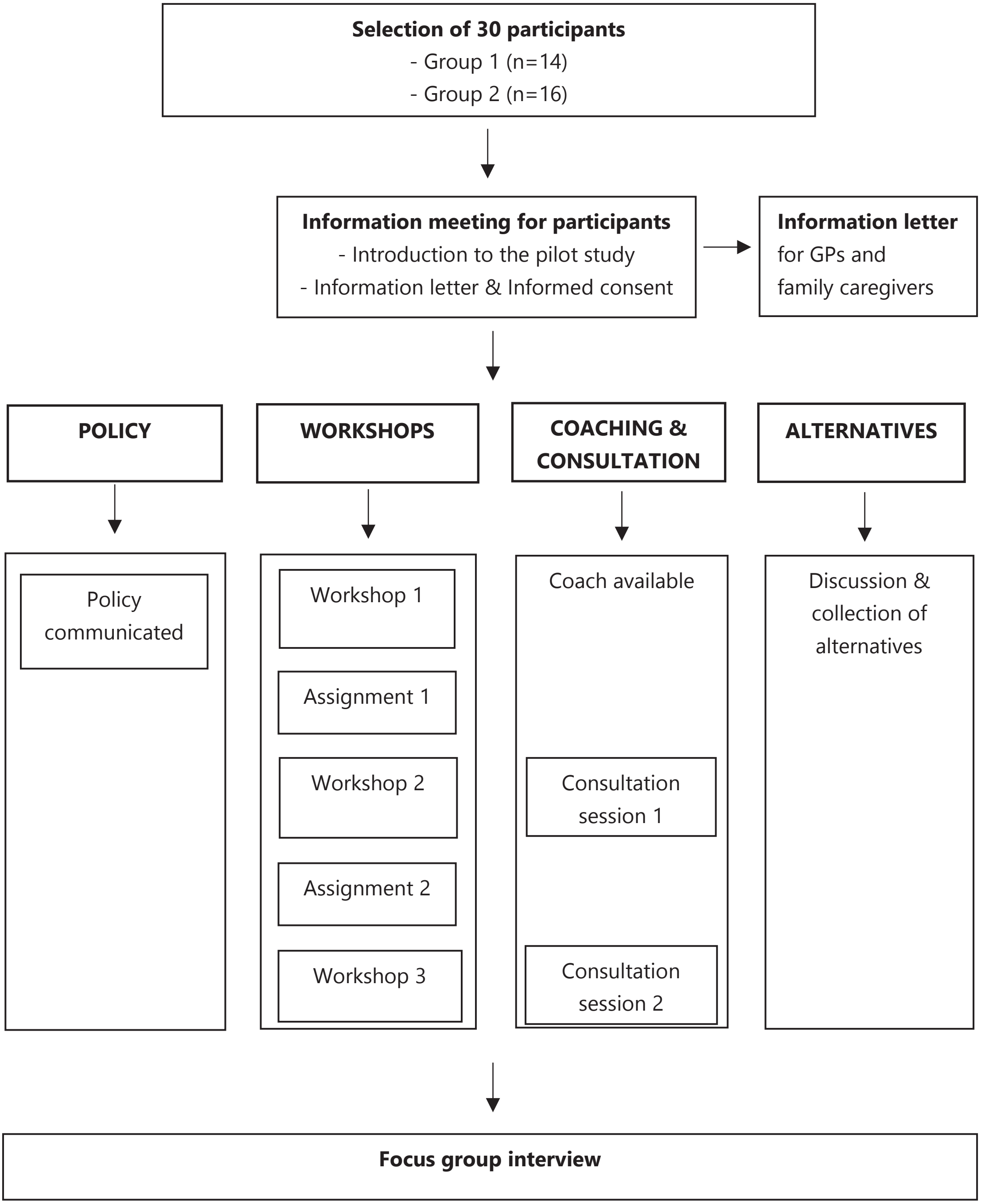

Figure 1. Overview of the study

Setting

The study was conducted within a large healthcare organization in the south of the Netherlands, providing among others nursing services, domestic support and personal guidance for people with dementia (PwD). The organization is divided into district teams, including a district nurse (a bachelor educated registered nurse, supervisor of the district team), registered nurses with a bachelor's degree in nursing, licensed vocational nurses and certified nursing assistants. This district team supports clients in ADL such as toileting, dressing and bathing. The district nurse is responsible for performing the formal needs assessment, taking into account the client's care needs and opportunities for self-reliance [29]. Domestic workers support clients in performing household tasks and instrumental activities of daily living (iADL) such as house cleaning, laundry and grocery shopping. A dementia case manager is a professional, often with a nursing background, whose tasks include support in the diagnostic phase, coordination of care and an advisory function for PwD and their family caregivers [30].

Participants

For the current study, we aimed to include a total of 30 professional caregivers. Professional caregivers were eligible if they 1) were employed at the start of the study and 2) if they provide care for people with a cognitive impairment living at home. First of all, two district nurse teams were selected by the participating home care organization. A district team usually comprises about 10 professional caregivers, including a district nurse (a bachelor educated registered nurse, supervisor of the district team), registered nurses with a bachelor's degree in nursing, licensed vocational nurses and certified nursing assistants. In addition, we included dementia case managers and domestic workers who were involved in the care for clients with a cognitive impairment within the participating districts until 30 professional caregivers were included.

Workshop provider

The workshops and consultation sessions were provided by a specialized nurse (a bachelor educated registered nurse), who had over 20 years of experience in elder care and providing education regarding involuntary treatment. An instructor's manual was develop with a detailed description of the themes (and time indication) for the workshops. The performance and suggestions for improvement were discussed in process evaluation meetings between the workshop provider and the principal researcher (AM) after each workshop.

Design of the PRITAH intervention

The PRITAH intervention was developed using the Medical Research Committee (MRC) Framework [31]. The MRC framework describes four phases including development, feasibility and piloting, evaluation and implementation. Empirical and theoretical data from previous studies and input from an expert group were used to further refine the intervention [8, 12, 13, 32, 33]. The expert group consists of professional caregivers, policy makers, a care advisor, the manager of a nursing home facility and the manager of the participating dementia case managers. EXBELT, an effective intervention to prevent and decrease physical restraints in nursing homes was used as the basis for the PRITAH intervention [34, 35]. The PRITAH intervention consists of four components, including policy, education, consultation and coaching-on-the-job and alternatives. Then, the intervention was further refined to match home care practice. First, the role of the family caregivers and GPs was emphasized in preventing and/or reducing involuntary treatment since the former are most likely to request/apply and the latter are most likely to recommend involuntary treatments [8, 12, 13]. Second, we matched the content of the workshops with the different roles and responsibilities of the participants and added 30 minutes of interactive consultation in which case studies were discussed. Finally, the implications of the Care and Compulsion Act, which went into effect in the Netherlands in January 2020, were discussed during the workshops. This act aims to protect people with intellectual disabilities or a psychogeriatric disease (such as dementia) from involuntary treatment by providing criteria for the use of involuntary treatment and its documentation in the care plan.

The policy discouraged the use of involuntary treatment and underscored the importance of person-centered care and individualized alternative interventions. The expert group developed the main content of a policy template, which was then tailored by the home care organizations' management team to their specific context. This policy was communicated to all participants and general practitioners (GPs) via an information letter. The policy was further explained during the workshops. The educational component consists of three 2.5-hour workshops, facilitated by a specialized nurse. The workshops aimed to increase participants' awareness regarding involuntary treatment use and provided them with the knowledge and tools to prevent or decrease these measures. The specialized nurse also provided guidance on how to prevent involuntary treatment during 30-minute consultation sessions in which participants discussed case studies. In addition, the specialized nurse was available for coaching-on-the-job if participants needed advice. Finally, alternative interventions were discussed during the consultation sessions and participants received a comprehensive list of alternatives and a link to a website with an overview of alternatives to involuntary treatment. A detailed description of the content of the PRITAH intervention can be found in Table 1.

Table 1. Content of the PRITAH intervention program

Policy	The policy included information regarding: - the importance of a policy regarding involuntary treatment use at home - a definition of involuntary treatment, consisting of physical restraints, psychotropic medication and non-consensual care - the vision and mission of the home care organization - preconditions to the policy such as creating awareness, a multidisciplinary approach, communication with GPs and family caregivers and providing alternatives
Education	Workshop 1: Increasing knowledge & awareness - Discussing statements about involuntary treatment, such as "freedom of persons with dementia (PwD) is more important than safety of PwD" - Explaining the home care organization's policy regarding involuntary treatment - Providing an overview of the current literature on involuntary treatment use, such as prevalence, risk factors and consequences of involuntary treatment Workshop 2: Conducting a problem analysis & communicating with stakeholders - Tips and tricks on how to communicate with people with cognitive impairment and their family caregivers - Role play to practice communicating with different stakeholders - Using a 6-step plan to conduct a problem analysis that aims to stimulate critical appraisal of the cause, risks and effects of involuntary treatment and to recommend alternatives to involuntary treatment.

	The problem analysis included the following steps: STEP 1: Identify the problem or risky behavior STEP 2: Identify the cause of the problem STEP 3: Estimate the risks and consequences STEP 4: Describe your aim(s): what do you want to achieve? STEP 5: Find the best possible solution or alternative (least restrictive, most effective, most person-centered) STEP 6: Evaluate the effects of the solution or alternative Workshop 3: Reporting & evaluating involuntary treatment - Case studies to practice with finding possible alternatives - Development and adjustment of clients' individualized care plans with regards to involuntary treatment Practical assignments Between each of the workshops, participants had to perform a practical assignment by evaluating cases in their own practice based on the content presented at each workshop (case study). Practical assignment 1: describe one experience you had with a client involving involuntary treatment - describe the specific context (e.g. client characteristics, living situation) - describe the behaviors or risks that occurred (e.g. resistiveness to care, aggressive behavior, miscommunication, safety issues) - describe the effects the use of involuntary treatment had or could have had on the client, the

	professional caregiver and the family caregiver Practical assignment 2: conduct a problem analysis Participants had to apply the 6-step plan on one of their own case studies.
Consultation & coaching on the job	Consultation 30-minute consultation sessions were part of the second and third workshop, in which participants' cases were discussed and participants exchanged their experiences. The specialized nurse provided guidance on how to prevent involuntary treatment Coaching on the job In addition, the district nurse and specialized nurse were available for consultation if participants needed advice or had any questions regarding involuntary treatment. The district nurse was the first point of contact who would communicate to the specialized nurse during consultation sessions.
Alternative interventions	Alternative interventions were discussed during the consultation sessions. A comprehensive list of alternatives and a link to a website with an overview of possible alternatives were provided and discussed.

Measures

Characteristics of the professional caregivers were collected including age, gender, level of education, current role, years of working experience in the care for older people and home care, hours of working in home care per week and experienced burden in their jobs (“How stressful do you find your job?”, rated on a 10-point scale ranging from 0 (not stressful at all) to 10 (very stressful)).

Process indicators

We collected data on several process indicators on Saunders’ framework, including dose delivered, fidelity, dose received, satisfaction, reach and barriers [28]. Table 2 provides an overview of the process indicators and instruments used.

Dose delivered, fidelity and dose received were continuously monitored by keeping a logbook by the principal researcher (AM). Dose delivered was considered complete if 1) the upcoming policy change was communicated to all participants, including GPs and family caregivers, 2) the information meeting and three workshops were organized for the participants, 3) the consultation sessions with the specialized nurse were organized and the specialized nurse and district nurses were available for coaching, and 4) alternative interventions were collected and discussed during the workshops and consultation sessions. To ensure fidelity of the workshops and consultation sessions an instructor’s manual was developed with a time schedule and detailed description of all topics that should be addressed. Dose received was assessed by completion of the practical assignments, usefulness of the content of the workshops in daily practice and the number of requested consultations with the specialized nurse. Participants’ satisfaction was assessed during the focus group interview and using an evaluation questionnaire including statements which could be rated on a 5-point Likert scale (ranging from totally disagree (1) to totally agree (5)), and open-ended questions regarding the strengths and weaknesses of the workshops and suggestions for improvement. Participants were asked to what extent they were satisfied with the expertise and teaching skills of the workshop provider, whether they had acquired new knowledge and tools to prevent involuntary and whether they would recommend the intervention to colleagues. Reach was measured using attendance lists for the workshops and consultation meetings maintained by the principal researcher (AM). Barriers were assessed by means of evaluation questionnaires, focus group interviews and evaluation meetings between the specialized nurse and principal researcher.

Table 2. Measurement instruments

Component	**Measurement Instrument**				
Operationalization	**AL**	**L**	**Q**	**M**	**FI**
Dose delivered Extent to which all components are actually delivered to participants		X		X	
Fidelity Extent to which the intervention was implemented as planned		X			X
Dose received Extent to which participants interacted, were receptive to, or used materials or recommended resources		X	X	X	X
Participants' satisfaction Satisfaction of the participants regarding the intervention program			X		X
Reach Proportion of the intended target population who participated and attended the workshops	X				
Barriers Problems encountered during implementation of the intervention		X		X	X

AL = attendance list
L = logbook
Q = evaluation questionnaire
M = evaluation meetings between workshop provider and principal researcher
FI = focus group interview

Focus group interviews

One focus group interview was planned with domestic workers since they only attended the first workshop, and one with the other participants. Participation in the focus group interviews was on a voluntary basis, with a minimum amount of two domestic workers for the first focus group and at least two nurse assistant(s), one (district) nurse and one dementia case manager for the second focus group. Alongside the principal researcher, VM was present during the focus group interviews to support the discussion and make field notes. During the focus groups interviews, the experiences of the professional caregivers with the intervention were discussed. Data from open-ended questions in the evaluation questionnaires were summarized by the principal researcher (AM) and formed the basis for the topic list for the focus group interviews. These topics included 1) communication regarding the policy change, 2) content and organization of the workshops, 3) practical assignment(s), 4) experiences with involuntary treatment, and 5) role and involvement of the different stakeholders (both professional and family caregivers). Questions were for example whether participants felt supported by their colleagues and the organization in adhering to the new policy regarding involuntary treatment, what participants thought about the multidisciplinary approach of the workshops and to what extent the practical assignments contributed to (more) awareness regarding involuntary treatment use.

Data analyses

Quantitative data was analyzed using SPSS version 25 (SPSS, Inc, Chicago, IL). Descriptive statistics were used to analyze quantitative data from the evaluation questionnaires and background characteristics of the participants. The focus group interviews were audio-taped and transcribed by the principal researcher (AM). An iterative process was conducted and transcripts were analyzed multiple times to find emerging themes. A codebook was created via conventional content analyses, in which the data were coded into themes deriving straight from the data at hand instead of using preconceived categories [36]. These themes were then discussed with a second assessor (MB) until consensus was reached. A summary was written presenting the most important findings of the participants per theme for each topic.

Ethical considerations

The design and protocol for this pilot study were reviewed and approved by the Medical Ethics Committee of Zuyderland Hospital (Z20180101) in August 2018. The home care director provided permission to conduct the feasibility study. Before the start of the intervention an information meeting was organized by the principal researcher to inform all professional caregivers about the study. All participants received an information letter and signed an informed consent.

RESULTS

Participants

Two district teams including 2 district nurses, 3 registered nurses, 5 certified nursing assistants and 9 licensed vocational nurses were approached to participate in this study. Of these, all 19 agreed to participate. They provide home care for about 140 clients, of which 24 persons with cognitive impairments. In addition, all dementia case managers (n=4) and seven domestic workers (including their manager) were invited to participate and provided informed consent, leading to a total of 30 professional caregivers. One registered nurse dropped out before the start of the intervention due to pregnancy leave and one dementia case manager did not attend any of the workshops due to other obligations. Background characteristics of the participants are shown in Table 3. No statistically significant differences were found between background characteristics of participants in the two groups.

Table 3. Background characteristics of the participants

	Group 1	**Group 2**	**Total**
Participants (n)	13	15	28
Age (years, SD)	50 (9.1)	48 (7.4)	49 (8.2)
Female (%)	100	100	100
Working experience (years, SD)			
Elderly care	17 (9.2)	18 (8.8)	17 (8.8)
Home care setting	13 (6.7)	13 (5.6)	13 (6.1)
Working hours per week (mean, SD)	24 (6.4)	21 (4.8)	23 (5.9)
Experienced caregiver burden[1]	5.4 (2.6)	5.4 (1.8)	5.4 (2.2)
Current function			
Manager domestic workers	1	0	1
Domestic workers	2	4	6
Certified nursing assistants	3	2	5
Licensed vocational nurses	4	5	9
Registered nurses (bachelor)	1	1	2
District nurses	1	1	2
Dementia case managers	1	2	3

[1] Scores range from 1-10, a higher score indicating higher experienced burden.

Process indicators

Dose delivered & fidelity

All four components (policy change, education, consultation, and alternatives) of the PRITAH intervention were delivered. The evaluation questionnaires and focus group interviews indicated that the policy change was communicated to the participants during the information meeting, workshops and via an information letter. However, it deviated from protocol because the letter was not signed by the organization's management. GPs were informed by an information letter sent to their work address. The family caregivers were not informed because due to privacy issues with receiving the contact details and the professional caregivers were not instructed to inform the family caregivers themselves. The logbook revealed that all themes described in the instructor's manual were addressed during the workshops. However, some themes took a bit shorter (participants introducing themselves, explanation of the policy change) or longer (discussing statements) than expected. Alternative interventions were discussed using case studies during workshop 3. Finally, registration of the consultation sessions indicated that consultation and coaching was available. Overall, 2.5 hour was sufficient for each workshop, although the last consultation session (workshop 3) took 50 minutes instead of 30 minutes in one team. We aimed to deliver the workshops in a period of 7 weeks, with 3 weeks between each workshop. For workshop 3 we received many cancellations due to illness and short staffing and it was rescheduled for both teams, with a time span of 7 weeks between workshops 2 and 3.

Dose received

At the first consultation session 15 of 16 attendees handed in their practical assignment, at the second consultation session 5 of 12 attendees did so. On average it took participants about 20 minutes to complete the practical assignment. Common cases discussed in the practical assignments included resistiveness to care when assisting clients with ADL (e.g. bathing, dressing), issues with medication such as hiding or taking away medication (for example in a locker) or forced administration of medication, and the risk of wandering and locking a door. The specialized nurse was consulted two times for advice regarding resistiveness to care. Alterative interventions that were discussed in order to avoid involuntary treatment included a GPS tracking system, music and alternative ways of providing hygiene (e.g. washing without water). Although the key message of the new policy was clear ('prevention and reduction of involuntary treatment'), participants found it difficult to translate this to daily practice; it was unclear what was expected of them when they face situations with a risk of involuntary treatment or when different stakeholders have different opinions. Participants indicated that the content of the workshops were suitable for implementation in daily practice: they learned about the risk factors for involuntary treatment and are more aware of the consequences of involuntary treatment use. Participants received practical tips and skills how to start a dialogue with PwD and other stakeholders, can apply a problem analysis to gain more insight into PwD's behavior and needs and know how and where to search for alternative interventions. Finally, participants indicated that involuntary treatment is now more often discussed with colleagues during team meetings. Some professional caregivers informed family caregivers about the new policy to stress the importance of prevention of involuntary treatment.

Participants' satisfaction

Overall, the workshops and workshop provider were positively evaluated with an average score of 8.1 and 8.7 out of 10 respectively. All participants would recommend the workshops to colleagues, the content was considered of added value because the topics discussed were interesting, it increased their awareness regarding involuntary treatment use and provided new insight into its risk factors and effects. The workshops also offered the opportunity to discuss this topic in a multidisciplinary setting and learn from each other's experiences. Participants appreciated the advice and practical tips they could use in their daily work, including the 6-step plan to conduct a problem analysis and the list of alternatives. The consultation sessions and practical assignments led to more awareness of involuntary treatment use, stimulated them to critically think about involuntary treatment use among their own clients and was a positive way of putting their knowledge into practice. Suggestions for improvement included adding video material with practical examples, more assignments during workshops 1 and 2, and a more multidisciplinary approach, for example by inviting GPs and family caregivers as well. Finally, participants would prefer domestic workers to attend all workshops, which was also indicated by the domestic workers themselves.

Reach

All eligible participants (n=30) provided informed consent to participate in the study. The overall attendance rate for the first workshop was 93%, 70% for workshop 2 and 52% for workshop 3. More information regarding attendance per team can be found in Table 4. All domestic workers (n=7) participated in workshop 1. Of all participants, 48% attended all three workshops, 82% attended at least 2 workshops, 2 attended only one workshop and 2 did not attend any workshop. Reasons for absence were mainly illness and work-related activities (e.g. client visit, multidisciplinary meeting). The evaluation questionnaires were filled in by all attendees after workshop 1 and 2 (n=28 and n=15 respectively). The evaluation questionnaire after workshop 3 was completed by 10 of the 12 attendees. Two focus group interviews were held: one focus group with two domestic workers and the second focus group with two district nurses, one dementia case manager and three licensed vocational nurses.

Table 4. Overview of participants' attendance at the workshops

	Workshop 1	**Workshop 2**	**Workshop 3**
Team 1	13/14 (93%)	7/11 (64%)	6/11 (55%)
Manager domestic workers	1/1	-	-
Domestic workers	2/2	-	-
Certified nursing assistants	3/3	1/3	1/3
Licensed vocational nurses	4/4	4/4	3/4
Registered nurses (bachelor)	1/1	1/1	0/1
District nurses	1/1	0/1	1/1
Dementia case managers	1/2	1/2	1/2
Team 2	15/16 (94%)	10/12 (83%)	6/12 (50%)
Domestic workers	4/4	-	-
Certified nursing assistants	2/2	2/2	1/2
Licensed vocational nurses	5/5	4/5	3/5
Registered nurses (bachelor)	1/2	1/2	0/2
District nurses	1/1	1/1	1/1
Dementia case managers	2/2	2/2	1/2

Barriers

Several barriers were identified. First, for participants it was unclear how they could implement the new policy regarding involuntary treatment use in their daily work. They voiced their preference for more guidance while retaining their flexibility in the decision-making process. Second, it was difficult to offer the same workshop for all different disciplines because they have different educations, roles and responsibilities. Some of the domestic workers mentioned that the content of workshop 1 could be more in line with their care tasks and less focused on nursing-related tasks. In addition, it was difficult to have the same group of participants at workshops 1, 2 and 3. Some participants of team 1 joined team 2, and vice versa, because it better fit their work schedule. Finally, although workshop 3 was rescheduled, the attendance rate was low (52%). In case of absence, participants missed the knowledge and explanation for the practical assignment they had to prepare for the following workshop.

Recommendations for improvement

There was no formal announcement from the organization's management indicating when the policy would go into effect, which led to confusion among the participants as to what was expected of them. Participants expressed the need for a guideline or checklist to guide them what to do if involuntary treatment cannot be (easily) prevented and where, how and what to document in the care plan in case of involuntary treatment use. They also need more advice and tools on how to start a conversation with family caregivers about involuntary treatment use, since family caregivers often feel burdened and it can be a difficult and emotional topic to discuss. In case the family caregiver does not live together with the client, the professional caregivers do not often have the opportunity to meet with the family caregiver. For these family caregivers, it may be necessary to organize information meetings to inform them about (prevention of) involuntary treatment use. Finally, to increase reach, online workshops or a web-based webinar could be considered.

DISCUSSION

This study indicated that the four components of the PRITAH intervention (policy, workshops, coaching and consultation, and alternatives) can be implemented in home care practice. Delivery of the four components was high: professional caregivers were informed on the policy change, three workshops were provided, the specialized nurse was available as a workshop facilitator and coached the participants during the consultation sessions and the use of alternatives to prevent involuntary treatment were discussed throughout the intervention. This study indicated that involuntary treatment is now more often discussed during team meetings and with colleagues, participants practiced with applying their (new) knowledge and skills on one of their clients during practical assignments, and some participants consulted the specialized nurse for more advice regarding dealing with resistiveness to care. Also, alternatives for involuntary treatment were discussed and participants were informed on the organization's policy towards involuntary treatment (delivery of the intervention). Nevertheless, the intervention was not fully implemented according to protocol and some barriers and recommendations for improvement were identified:

First, it is important that the policy is announced by the management board before the start of the intervention, as previous studies indicated that this creates an environment in which employees feel supported [35, 37, 38]. Discussion of the organization's practices and guidelines concerning involuntary treatment by the management and staff members makes them feel supported [39] and can contribute to the reduction or prevention of involuntary treatment. In addition, this policy must be clearly translated into practice. For example, it should require clear documentation of involuntary treatment use, approval of the responsible nurse and review of its effectiveness [40].

Second, although the specialized nurse was present during the consultation sessions and was available for individual coaching, only two participants asked for advice. Embedding the available consultants in a more proactive way would facilitate staff members in their decision making regarding the use of alternative resources [41], for example by assigning “champions” or “nurse change agents” to provide coaching-on-the-job to the participants, next to the role of the specialized nurse as a consultant [37, 42-44]. This “champion” could motivate and mentor the professional caregivers by providing positive reinforcement for documenting involuntary treatment or using alternative interventions, supporting staff by integrating certain activities into routine care and team meetings (e.g. multidisciplinary discussion about involuntary treatment and alternatives) [42]. Within the PRITAH intervention the district nurse could be assigned the role of “champion”, as the district nurse is responsible for coordinating the care for their clients.

Third, discussion of case studies during the consultation sessions was well-received, however this did not necessarily lead to the use of alternatives in practice. Not all alternative interventions were immediately available during this study. A list of possible alternatives was provided however there is no limitative list of alternatives since they should be individualized and discussed through multidisciplinary consultation. When facing difficult dilemma’s in home care practice, caregivers tend to focus on finding an immediate solution, but they must critically reflect on these situations: is there a problem, and if so, what is the cause of it? The intervention does not aim to provide caregivers with alternatives but to provide knowledge and tools so that caregivers themselves can critically analyze on the situation, and then look for possible solutions [45]. For the specialized nurse it would be helpful to gain input from an independent group of professionals in which they could dialogue about alternative interventions. In addition, financing the use of alternative interventions is an important point: the client and his/her family caregiver(s) are responsible for the purchase of any alternatives or aids; the government or home care organization (often) does not reimburse these costs. Equipment costs can be a barrier for the family caregivers, in contrast to nursing homes where alternatives often are available from the organizations themselves [46]. It needs to be further explored how burdensome these possible costs are for family caregivers.

Fourth, although involuntary treatment is commonly used in home care, some caregivers might not be aware that they provide involuntary treatment [8]. As a result, involuntary treatment is often not discussed, while multidisciplinary discussion regarding this topic can help to prevent the use of these measures [35, 47]. It is important that caregivers know the risk factors associated with involuntary treatment and that they can identify situations in which clients are at risk for involuntary treatment use. For this reason, interventions should focus on creating awareness: caregivers need to know what involuntary treatment is and how to prevent it [8].

In addition, reach should be increased to create more impact on professional caregivers' daily practice. Other stakeholders such as GPs and family caregivers should also be involved in this process: they need to be informed, as family caregivers are often not aware of the harmful physical and psychological effects of involuntary treatments and regulations to prohibit or minimize involuntary treatment [48, 49]. Understanding the potential hazards of involuntary treatment, fostering dialogue between professional and family caregivers and supporting them in the decision-making process about involuntary treatment are therefore important components of the intervention. Previous studies also stressed the importance of informing and involving the family caregivers and other stakeholders to raise awareness [35, 37].

Finally, the district nurse has an important role in the establishment of person-centered care plans. Supporting and motivating the district nurse in evaluating residents' personal preferences, using appropriate communication techniques and facilitating participation in care-related activities may help in preventing behavioral and psychological symptoms of dementia BPSD such as aggression and agitation [44]. It is critical to actively discussed person-centered care plans during team meetings, since education itself is not sufficient to change the behavior of professional caregivers [44, 50, 51].

Limitations

There are several limitations. The delivery and fidelity of the implementation of the PRITAH intervention were mainly based on data collected by the specialized nurse and/or the principal researcher. No measurements were available to collect this data in another way. Although the consultation sessions and available coaching were evaluated positively, it was difficult to evaluate this more in depth. This was mainly due to the fact that consultation and coaching was not continued during the period after the workshops and we did not collect data extensively after the workshops. However, the data collected during this study provided useful suggestions to improve the PRITAH intervention and its feasibility in daily practice. This study also provided insight into the development and content of the four components of the PRITAH intervention, which is needed to understand the possible effects of an intervention.

In the Netherlands the 'Care and Coercion' law has been developed and went into effect in January 2020. This law aims to protect clients with an intellectual disability or psychogeriatric disorder against involuntary treatment use. However, involuntary treatment use is not only common in the Netherlands: other studies indicated that involuntary treatment measures are common throughout Europe [52], Australia [53] and the United States [53]. A multidisciplinary approach in which all stakeholders discuss whether alternative, voluntary interventions are available is needed to prevent and reduce involuntary treatment use. Many approaches have been developed internationally to prevent the use of involuntary treatment measures, especially restraints [47, 54]. Future studies are needed to test the effectiveness of these approaches as well as the PRITAH intervention and to provide more insight into the mechanisms of impact and treatment fidelity.

Conclusions

This study indicated that the PRITAH intervention can be implemented in professional home care, but also indicated some adjustments to improve its feasibility. All components of the PRITAH intervention, consisting of policy, education, coaching and consultation and alternatives, were delivered. Overall the intervention was positively evaluated by the participants. Suggestions for improvement included development of a clear policy and guideline regarding involuntary treatment use, more emphasis on the role of GPs and family caregivers and advice on how to include these stakeholders in the prevention/reduction of involuntary treatment, and assigning a pro-active coach who is responsible for guiding and consulting his/her team.

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CHAPTER 6

Prevention and reduction of involuntary treatment at home (PRITAH): A quasi-experimental study on the implementation, mechanisms of impact and context

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CHAPTER 7

General discussion

Care against someone's will or to which a person resists, also referred to as involuntary treatment, is a complex topic of which relatively little is known, especially in home care practice. The main objectives of this thesis were to gain insight into involuntary treatment use and to develop and test an intervention to prevent and reduce involuntary treatment use in people with dementia (PwD) living at home. First, this thesis provided insight into professional and family caregivers' attitudes towards involuntary treatment use in PwD and the prevalence of involuntary treatment use in PwD receiving professional home care in the Netherlands and Belgium. Furthermore, family caregivers' experiences with care situations that can lead to involuntary treatment use were explored. These insights were used to develop the multi-component PRITAH ('Prevention and Reduction of Involuntary Treatment at Home') intervention, which was tested for its feasibility in a pilot study. A process evaluation of the PRITAH intervention was conducted to evaluate the implementation, mechanisms of impact and contextual factors.

This final chapter provides an overview of the main findings of the studies presented in this thesis. Furthermore, the methodological and theoretical considerations are discussed. The end of this chapter concludes with recommendations and implications for future research and practice.

MAIN FINDINGS

Studies presented in this thesis showed that involuntary treatment is commonly used in PwD receiving professional home care in the Netherlands (45%) and Belgium (68%). Involuntary treatment use is associated with living alone, higher functional dependency, impaired cognitive functioning and greater family caregiver burden. In both countries involuntary treatment was most often requested by family caregivers, which stresses the important role of family caregivers in providing involuntary treatment 'behind closed doors', and the need to focus on both professional and family caregivers in an approach to prevent and reduce involuntary treatment. Family caregivers and GPs had more positive attitudes towards involuntary treatment, indicating they are more accepting of involuntary treatment use in PwD than nursing staff and other health care professionals. In addition, family caregivers and GPs perceived non-consensual care and physical restraints as less restrictive and indicated feeling more comfortable using these measures compared with nursing staff. Family caregivers experience the decision-making process concerning care dilemmas that can lead to involuntary treatment as complicated, stressful and exhausting. They consider both safety and autonomy as important values and struggle with finding the right balance between them. Due to the progressive and unpredictable nature of dementia, they are constantly seeking solutions while adapting to new situations. In addition, family caregivers feel responsible and experience social pressure for the safety of PwD: they may be blamed if something adverse happens to the PwD, which increases an already stressful situation.

To prevent and reduce involuntary treatment at home, we developed the PRITAH intervention (Prevention and Reduction of Involuntary Treatment At Home), which aims to support professional caregivers by providing them with knowledge, skills and tools to prevent and reduce involuntary treatment use at home. PRITAH consists of 1) policy discouraging involuntary treatment use, 2) three workshops with practical assignments, 3) consultation and coaching by a specialized nurse and 4) alternative measures for involuntary treatment. We were able to deliver all four components and found that the PRITAH intervention is feasible in home care practice. However, the intervention was not fully implemented according to the original protocol and several revisions were necessary. In the second phase, these revisions were integrated in the intervention. Results showed that PRITAH contributes to changing professional caregivers' subjective norms and perceived behavioral control towards involuntary treatment use, both prerequisites for behavioral change in professional caregivers. No evidence was found for an effect on participants' attitude and intention. These results legitimize the need for a large follow-up study on the effectiveness of PRITAH on behavioral change and actual prevention and reduction of involuntary treatment use in PwD receiving home care.

METHODOLOGICAL CONSIDERATIONS

This section addresses the methodological considerations of the studies conducted in this thesis. Considerations that are discussed are related to the: 1) sample/participants, 2) measurement of involuntary treatment use and 3) the (lack of) standardization of a complex multi-component intervention.

Sample/participants

The aim of this thesis was to gain insight into involuntary treatment in people with a cognitive impairment or dementia living at home and receiving professional care. For both the attitude and prevalence study, participants were recruited via professional caregivers (e.g. dementia casemanagers and/or district nurses). This could have resulted in a selection bias, as these studies specifically focus on PwD receiving professional home care. Therefore, the studies presented in this thesis do not present the results of involuntary treatment use in the average PwD, but specifically for PwD receiving professional home care. Since not all PwD living at home receive professional care, this may undermine the internal validity of the study. Family caregivers who receive professional support from a casemanager dementia may feel more relieved and less burdened and therefore have a more negative attitude regarding involuntary treatment use (indicating they are less accepting of involuntary treatment). In addition, the prevalence of involuntary treament use in PwD who receive professional support may be lower due to the support family caregivers receive and the possibility to discuss alternative measures to prevent involuntary treatment use. Therefore the results of involuntary treatment use presented in this thesis may be an underestimation of involuntary treatment use in PwD in general.

In addition, the studies in this thesis were conducted in the south of the Netherlands among dementia casemanagers of whom some may have already heard of or participated in prior projects regarding (prevention and reduction of) physical restraints, which may have influenced their attitude and the way they provide care. Because they are aware of the negative consequences of and alternatives for physical restraints, they may also be more cautious regarding any form of involuntary treatment. There is a large proportion of PwD and family caregivers by whom professional support is not accepted or considered necessary. To gain insight into involuntary treatment use in PwD living at home without receiving professional care, other family caregivers need to be included as well. Since care burden is positively related to both family caregivers' attitude [1] and the prevalence of involuntary treatment use [2], family caregivers providing care for PwD without professional support may be more accepting of involuntary treatment and thus more inclined to use it.

Measurement of involuntary treatment

Involuntary treatment use is difficult to assess in a valid, reliable manner. To gain insight into its prevalence, we administered questionnaires by dementia case managers and nurses, which includes several possible limitations. First, caregivers may lack the knowledge or awareness regarding involuntary treatment use, which could lead to an underestimation of the actual prevalence of involuntary treatment. Second, professional caregivers may not be aware or informed of all measures that are applied in PwD by other professionals and especially family caregivers, who most often use involuntary treatment. Third, caregivers may provide socially desirable answers which could lead to an underestimation.

In addition to using a questionnaire, the research team also discussed the use of interviews, observations and data from client records as a source of information. Conducting interviews is very time-consuming and involuntary treatment is a sensitive subject that needs to be introduced well. We conducted 10 additional interviews with family caregivers to explore whether they can provide insight into involuntary treatment use in PwD. These interviews indicated that PwD are capable and willing to provide information regarding involuntary treatment use in PwD. However, it is unknown whether they are aware of all measures that are considered “involuntary” and are willing to disclose all relevant information. Therefore conducting interviews on a larger scale would not be feasible. Observations by a blinded rater multiple times during a 24-hour period [3] was not considered feasible due to 1) practical constraints in home care (care is provided behind closed doors; it is difficult to reach family caregivers) and limited time (visiting each PwD at home is very time consuming), 2) ethical issues, privacy and informed consent procedures (e.g. allowing external visitors in your private home environment), and 3) the possibility that caregivers’ behavior changes when someone is watching. Although the use of a body camera by professional caregivers would solve the first issue [4], the other issues still remain. Besides, although physical restraints are relatively easy to observe, non-consensual care and the use of psychotropic medication are more difficult to observe and would take multiple, long-term observations.

Finally, client records were considered. As a pilot test we collected anonymous client records during our last study to investigate whether client records provide insight into involuntary treatment use. It turned out there was a lack of reporting of involuntary treatment use. Whereas studies [5, 6] indicate that involuntary treatment is used in 4 out of 10 people with a cognitive impairment and even more prevalent in PwD, it was rarely reported in client records. Therefore questionnaires were considered the most feasible and reliable measurement. To gain more complete and reliable prevalence rates of involuntary treatment, it would be suggested to adminster the questionnaire in two or more professional caregivers, for example the dementia casemanager, district nurse and first responsible nurse. This way of data collection can also be used in future studies aimed at testing the effectiveness of PRITAH or other studies on involuntary treatment use.

Standardization of a complex multi-component intervention

PRITAH is a complex, multi-component intervention comprising 1) policy, 2) education, 3) coaching and consultation and 4) the availability of alternative measures to prevent and reduce involuntary treatment use. Standardization of a multi-component intervention is complex, since there are many variables that can affect the study. The PRITAH intervention cannot be standardized like, for example, studies on medication effectiveness. In cases when a study is not completely standardized, this may lead to bias due to external influences such as background characteristics of the persons delivering and receiving the intervention. PRITAH was implemented by specialized nurses with different backgrounds and experience in caring for PwD. It was important that the PRITAH intervention meets the needs of the participants and matches their knowledge and experiences regarding involuntary treatment use, which may have influenced the standardization of the PRITAH intervention across the organizations and teams. Also, it was essential that PRITAH takes place in a multidisciplinary context, directly in home care practice, with real-life case studies. These factors may lead to a decrease or lack of standardization, which in turn may affect the implementation and fidelity (e.g. some parts were offered in a different way, in more detail, shorter or even skipped due to a lack of time), and ultimately the working mechanisms of the intervention. However, several steps were taken to reduce this by 1) providing training and a training manual for the specialized nurses, 2) presence of research assistants to check whether the workshops and consultation sessions deviated from protocol and 3) regular contact between researcher and specialized nurses to adapt the protocol if needed. For PRITAH it was important to resemble daily practice as much as possible since it must be feasible and implemented in daily home care.

A strength of this practice-oriented approach is that, if necessary, the intervention could be (slightly) adapted to the specific context and needs of the participants. Our assumption is that this ‘lack of standardization’ and more ‘ tailored’ approach actually contributed to the succesfull implementation of PRITAH. The content of the workshop and coaching were slightly adapted based on caregivers’ experiences, which integrates acquired knowledge directly into practice. In addition, the mechanisms of impact indicated that PRITAH had a positive effect on participants’ subjective norm and perceived behavioral control. A change in subjective norm and perceived behavioral control are considered prerequisites for behavioral chage and thus necessary for prevention and reduction of involuntary treatment use.

THEORETICAL CONSIDERATIONS

To study (prevention and reduction of) involuntary treatment use in home care, several things are important. First of all, there needs to be a clear definition and conceptualization of involuntary treatment. Second, stigmatization towards (people with) dementia needs to be reduced and a different approach towards dementia (care) is needed. Finally, awareness regarding the physical, psychological and social impact of involuntary treatment, and especially non-consensual care, needs to increase. These three points will be discussed in this section.

Defining involuntary treatment

Several concepts are used to describe care provided against a person’s will or to which someone resists. Restraints [7-9], coercion/coercive care [10-13] and resistiveness to care [14-17] are commonly used terms in scientific literature. However, a single, clear definition of these concepts is often lacking. Restraints can be defined as “any device or action professional or family caregivers perform that restricts the individual’s freedom in some way” [18, 19], and can be divided into physical [20], chemical and environmental restraints [21]. Coercive care can include compulsion (the use of force) or threats ("if you refuse to take medication, you have to be admitted to a nursing home") [22]. Resistiveness to care can be defined as 1) "the repertoire of behaviors with which PwD withstand or oppose the efforts of a caregiver" [17], 2) a rejection of care [23], or 3) behavior that prevents or interferes with caregivers' performing or assisting activities of daily living [24]. In this thesis, the term involuntary treatment is used, which is broadly defined as any type of care provided without the person's consent and/or to which the person resists [5]. Although there is a definition and involuntary treatment can be divided in three types (physical restraints, psychotropic medication and non-consensual care), a clear consensus and operationalization is missing. Involuntary treatment is broadly defined, and the examples that can be regarded as such are endless. The most important similarities between involuntary treatment and the other concepts and definitions include 1) restriction of freedom, 2) rejection or resistance and 3) the use of force. These three characteristics are important to develop a clear, international definition and operationalization of involuntary treatment. However, it can be quite difficult to determine whether some type of care or activity should be considered involuntary (treatment), for example if the person receiving it does not resist and is not capable of providing (verbal or written) consent. This can also lead to the discussion whether or not involuntary treatment is acceptable or justified, and whether involuntary treatment use actually exists and is a problem in (dementia) care.

Stigmatization and a different approach towards (care for) people with dementia

The ultimate aim is prevention and reduction of involuntary treatment by changing professional and family caregivers' behavior. Behavioral change is a complex and lengthy process in which several factors play an important role including knowledge and attitudes [25]. In addition, this requires a new, innovative approach towards (people with) dementia in general. Both lay public and professional caregivers hold stigmatized attitudes regarding (people with) dementia. Stigma can be manifested as beliefs (stereotype), emotion (prejudice) and behavior (discrimination) [26]. Common perceived stereotypes regarding PwD include dangerousness, loss of self-esteem and lower competence. Dementia is also associated with negative emotional reactions such as fear, anxiety, shame, pity and disgust. Discrimation commonly manifests in forms of social distance, avoidance and coercion, which can lead to exclusion of PwD in healthcare decisions [27], avoidance of family caregivers [28] and may form a potential barrier to adequate care and support [29]. For example the level of inclusion of PwD by GPs in care planning and the concern with loss of autonomy varies greatly [29]. In addition, there may be the lay perception that seeking help is useless because dementia is untreatable or that it is not possible to communicate with PwD about their needs and wishes. Popular media (e.g. films) may contribute to existing stigma by presenting misleading messages about dementia [30]. By focusing on what is lost in dementia rather than what is preserved, we frame both caregivers and PwD in a negative light. Stigmatization may also influence the way care is provided. In home care, activities of daily living that PwD can still perform (under supervision) are regularly taken over by care professionals [31, 32], because they think the PwD can no longer perform the activity or it takes more time for the PwD to do it themself. Although dementia is characterized by cognitive decline, it is important to focus on people's abilities rather than their disabilities. Knowledge of and experience with PwD can reduce stigma. Since the majority of PwD live at home and (almost) everyone will come into contact with a PwD during their life, it is important to develop and maintain a dementia-friendly society: a society that minimizes social stigma and empowers PwD to maintain their competences [33]. In addition, more understanding about the holistic needs of PwD is needed to facilitate a human-rights based approach towards (care for) PwD, encompassing values such as particiation, accountability, non-discrimination and empowerment (World Health Organization, 2015). PwD need to be recognized as people with the right to choose the support or care they need or require. Their ability to still participate in the decision-making process regarding their care, such as what to eat and when to shower or shop for groceries are expressions of autonomy that should be preserved and supported as much as possible. To realize this, an attitudinal and behavioral change in caregivers is needed, for which the PRITAH intervention provides practical and feasible possibilities.

Involuntary treatment: a big issue?

Studies throughout this thesis indicated that caregivers' attitudes regarding involuntary treatment vary considerably. For some, involuntary treatment is a necessary measure to assure safety and to protect PwD. The use of physical restraints and psychotropic medication can have negative physical and psychological consequences, are often ineffective and can even be unsafe and harmful [34-37] [38]. However, less is known about the effects of non-consensual care. This may explain why both professional and family caregivers are more accepting of non-consensual care than the other types of involuntary treatment, and why non-consensual care is most commonly used in PwD.

There seems to be a continuum of involuntary treatment, in which non-consensual care appears to be the least restrictive and most accepted type of involuntary treatment. About twenty years ago the use of physical restraints such as fixation belts were considered necessary and adequate care, whereas nowadays this type of involuntary treatment is rarely used and considered to be the most restrictive. A change in awareness of the negative consequences, coupled with alternative measures and coaching dramatically reduced restraint use. A similar culture change is needed for the use of non-consensual care, since we know that the use of force or coercion can cause feelings of distress, humiliation, fear and agitation [39].

In the recent months people worldwide have experienced the effects of imposing restrictions on our freedom and interpersonal interactions due to COVID-19. These restrictions include social and physical distancing, staying at home as much as possible, not being able to visit family or friends, travel, or go to the gym. Experience with these restrictions showed us the serious adverse effects it can have on our social, mental and cognitive well-being [40]. It can lead to loneliness and an increased risk of anxiety, depression, cognitive dysfunction and even mortality [41]. For PwD and their caregivers, the reduction of social support and care such as respite care, day care and support groups due to COVID-19 contributed to reduced well-being and increased anxiety [42]. After a visistors ban of several weeks or months in nursing homes, professional and family caregivers and nursing home residents supported allowing visitors back into the nursing home. Being able to receive visitors and professional care is highly valued, experienced as pleasant and has a positive impact on well-being [43]. When it comes to health, safety and prevention of injury and infection are often considered important aspects, however psychological and social effects play an equally or even more important role and are sometimes overlooked. Although a common first response to (potential) danger is to protect PwD from (physical) harm and 'save' their lives, we also need to protect PwD from the social, mental and cognitive adverse effects of involuntary treatment. Restricting people's freedom and autonomy can lead to resistance and irritable or aggressive behavior. Some people consider freedom more important than safety, even if that includes the risk of injury or even death. PwD's capacity to function in the society, manage their life despite their disease and participate in social activities are important for their social health [44]. Therefore care for PwD should focus on supporting their capabilities and personhood, which implies recognition, respect, trust, autonomy, relationships, and moral solidarity [45, 46].

RECOMMENDATIONS AND IMPLICATIONS

Future research

Although several studies have recently been published on involuntary treatment in PwD living at home, literature remains relatively scarce. This thesis indicated several suggestions for future research.

First, consensus needs to be reached regarding a clear, international definition of the concept of providing care against a person's will and/or to which the persons resists, which we refer to as 'involuntary treatment' [5]. In current literature, several terms and definitions are used to refer to measures used against someone's will, such as restraints, coercion and resistiveness to care, which makes it difficult to compare results from different studies to each other.

Second, more research is needed to document the effects of non-consensual care on PwD. Multiple studies demonstrated the consequences of physical restraints and psyhchotropic medication in older PwD, however less is known about the effects of non-consensual care in PwD. Resistance demonstrates a sense of autonomy that cannot be ignored, and more research is needed into the adverse effects of measures leading to resistance. Negative consequences are often measured in mortality or physical discomfort such as pain, however especially for non-consensual care it is essential to study the psychological and social consequences and impact on PwD's mental well-being as well.

Third, research is needed to further investigate the working mechanisms of PRITAH and its effectiveness on professionals' actual behavior and involuntary treatment use. This thesis already demonstrated that PRITAH is feasible in home care practice and has a positive effect on professionals' subjective norms and perceived behavioral control regarding (prevention and reduction of) involuntary treatment. Future studies should focus on working mechanisms needed to realize behavioral change in professional and family caregivers, such as attitude and intention.

Fourth, research is needed to investigate involuntary treatment use in other settings, such as nursing home care. Although most PwD live at home, this thesis showed that people with lower cognitive ability and greater ADL dependency are more at risk for involuntary treatment use. Cognitive and functional ability are usually more impaired in PwD in nursing homes, and insight into the potential hazards and dilemmas can help to develop an approach to support nursing home professionals in dealing with these challenges. In addition, it would be valuable to investigate involuntary treatment use in PwD who do not receive professional care or support, and in other populations such as people with an intellectual disability or a mental disorder.

Implications for home care practice

This thesis indicated that involuntary treatment is highly prevalent in dementia care at home and to prevent and reduce this, professional and family caregivers need to be supported in dealing with complex care situations that can lead to involuntary treatment use.

First of all, it is important that home care organizations develop a clear policy supporting person-centered care and prevention and reduction of involuntary treatment use. This policy needs to be umabiguous and feasible in home care practice. Professionals need to feel supported in implementing this policy, and it should be clearly stated who is responsible for the decision to (not) use involuntary treatment and any consequences, as this can be a major concern for professional caregivers. Although a general step-by-step plan that professionals can follow is needed, professionals need (to be able) to tailor this plan based on the situation and client. This thesis indicated that implementing such a step-by-step plan to prevent and reduce involuntary treatment is feasible and supports professionals in the decision-making process. However, this is a time consuming process and requires a change in professionals' daily routine and approach. Consultation should be routinely available for evaluating the most challenging cases. Most GPs indicate that they do not have time or interest in this, however, further work is needed how to engage GPs in the decision-making process. This policy needs to be communicated to all stakeholders, including the home care teams, domestic workers, dementia casemanagers, GPs and family caregivers. During the start of care and interim evaluations, it is necessary to discuss this subject with family caregivers and report and/or adjust agreements regarding involuntary treatment use in the client's care plan. In addition, the organization needs to provide the time and (financial) resources (e.g. a physician, nurse specialist or psychologist) for consultation and coaching. Finally, perhaps the most important factors: creativity and out-of-the box thinking are necessary to avoid involuntary treatment. Traditionally, home care services focus on doing things for older people rather than with them [32] and it is important to stimulate one's capacities which can contribute to greater health and well-being. Knowledge of the PwD as a person including their interests and preferences can inform care processes instead of strictly following professional guidelines focusing on safety. Alternatives for involuntary treatment are often relatively easy and simple adjustments in for example the (physical) environment or the daily activities of the PwD.

Second, collaboration among various professionals and between professional and family caregivers needs to be emphasized. Professionals involved in dementia home care included the home care team, domestic workers, dementia case manager and GPs, who all have different roles. Although domestic workers usually are not the ones requesting or applying involuntary treatment, they often spend multiple hours a week at the PwD's home and therefore have an important role in noticing behavioral changes in the PwD. If domestic workers notice something that might indicate a risk of involuntary treatment, they have to report this, for example to their manager or other professionals involved. However, this thesis indicated that communication between professionals (especially domestic workers and the home care team) is limited. In case something is reported, they sometimes do not receive feedback. Thus, this is a missed opportunity for further dialogue that can inform the care plan. In addition to this professional viewpoint, it is also important to take into account the social, psychological and environmental characteristics of a PwD. This information can only be provided by the family (caregiver), which highlights the importance of communication between professional and family caregivers. Professional and family caregivers must continue to engage in the conversation regarding innovative ways to provide the best person-centered care as possible.

Third, it is advised to carefully report the use and decision-making process regarding involuntary treatment use. One of the studies presented in this thesis included a review of client records and revealed that reporting on involuntary treatment use and resistance to care in PwD is not consistently documented in the client's care plan or record. There is lack of 'rules' on how to report involuntary treatment use and/or resistance to care. In case a colleague is taking over the care for a client or new professionals are joining the team, it is desirable that they can understand the client's behaviors and the decision-making process underlying the choice of care approaces, including involuntary treatment use. In this way, professionals can learn from each other and are stimulated to be aware of (the effects of) involuntary treatment use, and to how to prevent and/or reduce usage. Consistently reporting on involuntary treatment use can also be used to monitor the prevalence of involuntary treatment use and to evaluate whether the policy is actually effective.

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Summary

Providing care for people with dementia (PwD) living at home is challenging and can lead to difficult dilemmas. Involuntary treatment, defined as any type of care provided without the person's consent and/or to which the person resists, is commonly used in PwD living at home. However, scientific literature regarding this topic is still relatively scarce. This thesis aims to 1) gain insight into involuntary treatment use in people with dementia living at home (e.g. professional and family caregivers' attitudes, prevalence and associated factors and family caregivers' experiences with managing care dilemmas that can lead to involuntary treatment) and 2) develop and evaluate an intervention aimed at reduction and/or prevention of involuntary treatment use in PwD living at home.

Chapter 1 provides a general introduction, describing how professional and family caregiving for PwD living at home is organized in the Netherlands, the challenges in providing care for PwD and involuntary treatment use. This chapter ends with the overall aim and outline of this thesis.

Chapter 2 presents the results of a cross-sectional study on professional and family caregivers' attitudes towards involuntary treatment use in PwD. A total of 109 nursing staff, 74 general practitioners (GPs), 45 other health care professionals and 77 family caregivers completed a questionnaire assessing their attitude towards involuntary treatment in general, non-consensual care, psychotropic medication and physical restraints. Overall, scores on all four subscales indicated rather neutral attitudes of both professional and family caregivers towards involuntary treatment use. Family caregivers and GPs had more positive attitudes towards involuntary treatment in general and the three types compared to nursing staff. This indicates that involuntary treatment is more accepted by family caregivers and GPs. In addition, family caregivers had more positive attitudes towards involuntary treatment in general, non-consensual care and physical restraints compared to other healthcare professionals. Attitude towards involuntary treatment was positively associated with perceived caregiver burden. Attitudes of family caregivers living with PwD did not differ from attitudes of those not living with PwD. Participants also had to rate the restrictiveness and experienced discomfort in using 25 types of non-consensual care, psychotropic medication and physical restraints. Family caregivers' and GPs perceived non-consensual care and physical restraints less restrictive for PwD and indicated feeling more comfortable when using these measures than nursing staff. No differences were found regarding perceived restrictiveness of and discomfort in using psychotropic medication between the four groups. In order to prevent involuntary treatment in PwD, it is important to account for the differences in attitudes and foster dialogue among professional and family caregivers to find common ground regarding alternatives to involuntary treatment.

Chapter 3 provides insight into the use, request and associated factors of

involuntary treatment use in PwD living in the Netherlands and Belgium. Secondary data analyses of two cross-sectional survey studies were conducted. Dementia case managers and district nurses filled in questionnaires for PwD receiving professional home care in the Netherlands (n=627) or Belgium (n=217). More than half of the PwD (51%) living at home received involuntary treatment (Belgium 68% and the Netherlands 45%). Non-consensual care was the most commonly used (83%), followed by psychotropic medication (41%) and physical restraints (19%). Involuntary treatment use was associated with living alone, greater ADL dependency, lower cognitive ability, higher family caregiver burden and living in Belgium versus the Netherlands. There was no evidence supporting that PwD’s age and gender were associated with involuntary treatment use. In the sample of both the Netherlands and Belgium involuntary treatment was most often requested by family caregivers (78% and 80% respectively). Family caregivers have a crucial role in the request and use of involuntary treatment 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 and experiences regarding involuntary treatment is the next step needed for the development of an intervention to prevent or reduce involuntary treatment.

Chapter 4 describes how family caregivers experience dealing with care situations that can lead to involuntary treatment in dementia care at home. We conducted a qualitative study including 10 semi-structured interviews with family caregivers of 13 PwD receiving professional home care. Interviews were audio-recorded and analyzed using the Qualitative Analysis Guide of Leuven (QUAGOL). Results indicated that family caregivers experience the decision-making process concerning care dilemmas that can lead to involuntary treatment use as complicated, stressful and exhausting. First, they consider both safety and autonomy important values and struggle with finding the right balance between them. Second, due to the progressive and unpredictable nature of dementia, they are constantly seeking solutions and adapting to new situations. Third, family caregivers experience social pressure and feel responsible for the safety of PwD. They may be blamed if something adverse happens to the PwD, which increases an already stressful situation. Family caregivers’ experiences are influenced by characteristics of the care triad (PwD, professional and family caregivers) such as practical and emotional support, knowledge and previous experiences. To prevent involuntary treatment use, professionals need to proactively inform and support family caregivers in dealing with complex care situations that could lead to involuntary treatment.

Chapter 5 presents the results of a pilot study to assess the feasibility of the PRITAH (Prevention and Reduction of Involuntary Treatment At Home) intervention. PRITAH consists of 1) a policy discouraging involuntary treatment use, 2) workshops,

3) coaching by a specialized nurse and 4) alternatives. Two district teams including 30 professional caregivers participated in this study. Based on Saunders' framework for process evaluations, we used attendance lists (reach), a logbook (dose delivered and fidelity), evaluation questionnaires and focus group interviews (dose received, satisfaction and barriers) to evaluate the feasibility of PRITAH. Implementation of the PRITAH intervention was feasible in home care practice, with minor deviations from protocol. The average attendance rate was 73%. The workshops and specialized nurse were positively evaluated with an 8.1 and 8.7 out of 10 respectively. Participants gained more awareness and knowledge and received practical tips and advice regarding prevention and reduction of involuntary treatment. Recommendations for improving the PRITAH intervention included a more multidisciplinary approach with emphasis on the involvement of family caregivers and GPs, development of an extensive guideline to comply with the policy and assigning a more pro-active role to the specialized nurse who is responsible for guiding and consulting the professional caregivers. Future studies are needed to gain insight into the mechanisms of impact of the PRITAH intervention.

Chapter 6 describes a quasi-experimental study on the implementation, mechanisms of impact and context of the PRITAH intervention, based on the Medical Research Council (MRC) framework. The implementation and context were assessed by means of questionnaires, attendance lists, focus groups and logbooks. The mechanisms of impact of the PRITAH intervention were assessed by means of questionnaires measuring participants' attitude, subjective norm, perceived behavioral control and intention regarding (prevention and reduction of) involuntary treatment use. Eight home care teams from two home care organizations participated (n=124), of which 70 professional caregivers followed the intervention and 54 provided care as usual (control group). The PRITAH intervention showed positive effects on professional caregivers' subjective norms and perceived behavioral control regarding involuntary treatment use. Both are prerequisites for behavioral change in order to prevent and reduce involuntary treatment. No effects were found for participants' attitudes and intention. This study confirmed that the adapted PRITAH intervention is feasible in home care and all four components were delivered to the intervention group with minor deviations from protocol. Future studies are needed to investigate the effectives of the PRITAH intervention on professional caregivers' behavior change and actual prevention and reduction of involuntary treatment.

Chapter 7 includes the general discussion. The main findings of this thesis are discussed, including a critical reflection on the methodological and theoretical considerations. Methodological considerations discussed in this chapter include the participants in the studies described in this thesis, measuring involuntary treatment and standardization of a complex multi-component intervention. Theoretical considerations discussed in this chapter include defining involuntary treatment, stigmatization and a different approach towards (care for) people with dementia, and positioning involuntary treatment as a ‘big issue’. Finally, implications and recommendations for future research and practice are provided.

Samenvatting

Zorg leveren aan mensen met dementie die thuis wonen kent veel uitdagingen en dilemma's. Onvrijwillige zorg, gedefinieerd als zorg waar de persoon die het ontvangt geen toestemming voor geeft en/of zich tegen verzet, komt vaak voor bij mensen met dementie die thuis wonen. Desondanks is de wetenschappelijk literatuur rondom dit onderwerp nog vrij schaars. Het doel van dit proefschrift is om 1) inzicht te krijgen in onvrijwillige zorg bij mensen met dementie die thuis wonen (o.a. attituden van professionele zorgverleners en mantelzorgers, prevalentie, geassocieerde factoren en ervaringen van mantelzorgers in het omgaan met zorgsituaties rondom veiligheid en vrijheid die kunnen leiden tot onvrijwillige zorg), en 2) het ontwikkelen en evalueren van een interventie gericht op het voorkomen en verminderen van onvrijwillige zorg bij mensen met dementie die thuis wonen.

Hoofdstuk 1 bevat een algemene introductie, waarin wordt omschreven hoe professionele zorgverlening en mantelzorg voor mensen met dementie die thuis wonen is georganiseerd in Nederland, de uitdagingen die komen kijken bij de zorg voor mensen met dementie, en onvrijwillige zorg. Dit hoofdstuk eindigt met het doel en de opzet van dit proefschrift.

Hoofdstuk 2 presenteert de resultaten van een cross-sectionele studie naar de attituden van professionele zorgverleners en mantelzorgers ten aanzien van het gebruik van onvrijwillige zorg bij mensen met dementie. In totaal hebben 109 verpleegkundig personeel, 74 huisartsen, 45 overige zorgprofessionals en 77 mantelzorgers een vragenlijst ingevuld om inzicht te krijgen in hun attituden ten aanzien van onvrijwillige zorg in het algemeen, gedwongen zorg, psychotrope medicatie en fysieke vrijheidsbeperkende maatregelen. Over het algemeen tonen de scores op alle vier de subschalen aan dat zowel professionele zorgverleners als mantelzorgers een neutrale attitude hebben ten aanzien van (de verschillende vormen van) onvrijwillige zorg. Mantelzorgers en huisartsen hadden een positievere attitude ten aanzien van onvrijwillige zorg in het algemeen en de drie verschillende vormen van onvrijwillige zorg, vergeleken met verpleegkundig personeel. Dit houdt in dat onvrijwillige zorg meer wordt geaccepteerd door mantelzorgers en huisartsen. Ook hadden mantelzorgers een positievere attitude ten aanzien van onvrijwillige zorg in het algemeen, gedwongen zorg en fysieke vrijheidsbeperkende maatregelen vergeleken met overige zorgprofessionals. Attitude ten aanzien van onvrijwillige zorg was positief geassocieerd met ervaren zorgbelasting. Attituden van mantelzorgers die samenwonen met hun naaste met dementie verschilden niet van attituden van mantelzorgers die niet samenwonen met hun naaste met dementie. Deelnemers hebben ook aangegeven in hoeverre zij 25 voorbeelden van gedwongen zorg, psychotrope medicatie en fysieke vrijheidsbeperkende maatregelen beperkend vinden voor iemand met dementie en het gebruik hiervan als ongemakkelijk ervaren. Mantelzorgers en huisartsen vonden het gebruik van gedwongen zorg en fysieke vrijheidsbeperkende maatregelen minder beperkend en ervaren minder ongemak bij het gebruik hiervan dan verpleegkundig personeel. Er werd geen verschil gevonden voor de mate van beperking en ervaren ongemak bij het gebruik van psychotrope medicatie tussen de vier groepen. Om onvrijwillige zorg bij mensen met dementie te voorkomen is het belangrijk om rekening te houden met de verschillende attituden en professionele zorgverleners en mantelzorgers te ondersteunen het dialoog aan te gaan en gezamenlijk op zoek te gaan naar alternatieven voor onvrijwillige zorg.

Hoofdstuk 3 geeft inzicht in het gebruik, de aanvraag en de geassocieerde factoren van onvrijwillige zorg bij mensen met dementie woonachtig in Nederland of België. Hiervoor is gebruik gemaakt van secondaire data analyse van twee cross-sectionele vragenlijstonderzoeken. Casemanagers dementie en wijkverpleegkundigen vulden een vragenlijst in voor mensen met dementie die professionele thuiszorg ontvangen in Nederland (n=627) of België (n=217). Meer dan de helft (51%) van de mensen met dementie die thuis woont ontving onvrijwillige zorg (68% in België en 45% in Nederland). Gedwongen zorg was de meest voorkomende vorm van onvrijwillige zorg (83%), gevolgd door psychotrope medicatie (41%) en fysieke vrijheidsbeperkende maatregelen (19%). Onvrijwillige zorg was geassocieerd met alleen wonen, hogere ADL afhankelijkheid (meer ondersteuning nodig bij het uitvoeren van activiteiten in het dagelijks leven), lager cognitief functioneren, hogere ervaren zorgbelasting door mantelzorgers en woonachtig zijn in België versus Nederland. Er was geen bewijs dat leeftijd en geslacht van de persoon met dementie geassocieerd zijn met het gebruik van onvrijwillige zorg. In de onderzoekspopulatie van zowel Nederland als België werd onvrijwillige zorg het vaakst aangevraagd door de mantelzorger (respectievelijk 78% en 80%). Mantelzorgers spelen een cruciale rol in de aanvraag en toepassing van onvrijwillige zorg in de thuissituatie. Professionele zorgverleners dienen het gesprek met mantelzorgers aan te gaan om mogelijke alternatieven te vinden. Inzicht in de besluitvorming en ervaringen met onvrijwillige zorg is de eerstvolgende stap die nodig is om een interventie te ontwikkelen om onvrijwillige zorg te voorkomen en verminderen.

Hoofdstuk 4 omschrijft de ervaringen van mantelzorgers in het omgaan met zorgsituaties die kunnen leiden tot onvrijwillige zorg bij mensen met dementie die thuis wonen. We hebben een kwalitatieve studie uitgevoerd waarbij 10 semi-gestructureerde interviews zijn afgenomen met mantelzorgers die zorg verlenen aan 13 mensen met dementie die professionele thuiszorg ontvangen. Interviews werden opgenomen en geanalyseerd met behulp van de Qualitative Analysis Guide of Leuven (QUAGOL). De resultaten tonen aan dat mantelzorgers het besluitvormingsproces rondom zorgdilemma's die kunnen leiden tot het toepassen van onvrijwillige zorg als ingewikkeld, stressvol en vermoeiend ervaren. Ten eerste vinden zij zowel veiligheid als autonomie belangrijke waarden in de zorg voor mensen met dementie en hebben zij moeite met het vinden van de juiste balans hiertussen. Ten tweede zijn mantelzorgers door het progressieve en onvoorspelbare karakter van dementie continu op zoek naar oplossingen terwijl zij zich aanpassen aan nieuwe situaties. Ten derde voelen mantelzorgers zich verantwoordelijk voor en ervaren zij sociale druk rondom de veiligheid van mensen met dementie. Zij kunnen de schuld krijgen als de persoon met dementie iets overkomt, wat deze stressvolle situatie nog lastiger maakt. De ervaringen van mantelzorgers worden beïnvloedt door achtergrondkenmerken van de zorg triade (persoon met dementie, professionele zorgverlener en mantelzorger) zoals praktische en emotionele steun, kennis en eerdere ervaringen. Om onvrijwillige zorg te voorkomen moeten professionele zorgverleners mantelzorgers proactief informeren over en ondersteunen bij het omgaan met deze complexe zorgsituaties die kunnen leiden tot onvrijwillige zorg.

Hoofdstuk 5 presenteert de resultaten van een pilot studie om de praktische uitvoerbaarheid van PRITAH (Prevention and Reduction of Involuntary Treatment At Home) te testen. PRITAH bestaat uit 1) beleid dat het gebruik van onvrijwillige zorg ontmoedigt, 2) workshops, 3) coaching door een gespecialiseerd verpleegkundige en 4) alternatieven. Twee wijkteams bestaand uit 30 professionele zorgverleners hebben deelgenomen aan deze studie. Gebaseerd op het framework van Saunders voor proces evaluaties hebben we gebruik gemaakt van aanwezigheidslijsten (reach), een logboek (dose delivered en fidelity), evaluatievragenlijsten en focus groep interviews (dose received, satisfaction en barriers) om de praktische uitvoerbaarheid van de PRITAH interventie te evalueren. Implementatie van de PRITAH interventie was haalbaar en uitvoerbaar in de thuiszorg, met enkele kleine afwijkingen van het protocol. De gemiddelde aanwezigheid was 73%. De workshops en de gespecialiseerd verpleegkundige werden positief geëvalueerd met respectievelijk een 8.1 en 8.7 van de 10. Deelnemers hebben bewustzijn en kennis opgedaan en praktische tips en advies ontvangen over het voorkomen en verminderen van onvrijwillige zorg. Aanbevelingen voor het verbeteren van de PRITAH interventie omvatte een meer multidisciplinaire aanpak met nadruk op de betrokkenheid van mantelzorgers en huisartsen, de ontwikkeling van een uitgebreide richtlijn om te voldoen aan het beleid, en het toekennen van een meer proactieve rol aan de gespecialiseerd verpleegkundige die verantwoordelijk is voor het begeleiden en adviseren van de professionele zorgverleners. Verder onderzoek is nodig om inzicht te krijgen in de werkingsmechanismen van de PRITAH interventie.

Hoofdstuk 6 omschrijft een quasi-experimentele studie om de implementatie, werkingsmechanismen en context van de PRITAH interventie te onderzoeken volgens het Medical Research Council (MRC) framework. De implementatie en context werden gemeten met behulp van vragenlijsten, aanwezigheidslijsten, focus groepen en logboeken. De werkingsmechanismen van de

PRITAH interventie werden gemeten aan de hand van vragenlijsten die de attituden, subjectieve normen, zelf-effectiviteit en intentie van deelnemers ten aanzien van (preventie en reductie van) onvrijwillige zorg meten. Acht wijkteams van twee thuiszorgorganisaties hebben deelgenomen (n=124), waarvan 70 professionele zorgverleners de interventie volgden en 54 zorg zoals gewoonlijk leverden (controlegroep). De PRITAH interventie heeft een positief effect op de subjectieve normen en zelfeffectiviteit van professionele zorgverleners. Beiden zijn voorwaarden voor gedragsverandering om onvrijwillige zorg te voorkomen en verminderen. Er werd geen effect gevonden op de attitude en intentie van deelnemers. Deze studie bevestigt dat de aangepaste PRITAH interventie uitvoerbaar is in de thuiszorg en alle vier de componenten zijn aangereikt aan de interventie groep, met kleine afwijkingen van het protocol. Vervolgonderzoek is nodig om de effectiviteit van de PRITAH interventie op gedragsverandering bij professionele zorgverleners en daadwerkelijke reductie en preventie van onvrijwillige zorg te onderzoeken.

Hoofdstuk 7 is de algemene discussie. De voornaamste bevindingen van dit proefschrift worden besproken, inclusief een kritische reflectie op de methodologische en theoretische overwegingen. Methodologische overwegingen die in dit hoofdstuk worden besproken zijn de deelnemers aan de studies beschreven in dit proefschrift, het meten van onvrijwillige zorg en de standaardisatie van complexe interventies bestaande uit meerdere componenten. Theoretische overwegingen die worden besproken zijn de definitie van onvrijwillige zorg, stigmatisatie en een andere aanpak ten aanzien van (de zorg voor) mensen met dementie en de positionering van onvrijwillige zorg als een ‘big issue’. Tenslotte worden implicaties en aanbevelingen voor toekomstig onderzoek en de dagelijkse praktijk gegeven.

Impact

The aim of this thesis was to 1) provide insight into the use of involuntary treatment in people with dementia (PwD) living at home and 2) develop and evaluate an intervention to provide professional caregivers with knowledge, skills and tools to prevent and reduce involuntary treatment use in PwD. The results of this thesis provide new insights into professional and family caregivers' attitudes towards and their role in involuntary treatment use, and the development, implementation and evaluation of a multi-component intervention to decrease and prevent involuntary treatment use in PwD living at home. Knowledge is only of value when shared; therefore this chapter addresses the societal and scientific impact of this thesis. It also elaborates on the efforts made and needed to disseminate the findings.

SOCIETAL IMPACT

Providing person-centered care focuses on the autonomy, needs and wishes of the client and the relationship between the client and caregiver [1]. Involuntary treatment is in conflict with the principles of person-centered care and caregivers should look for alternatives to prevent involuntary treatment. This thesis presents results that are relevant to home care practice and all caregivers involved. The development of the PRITAH intervention was a co-creative and iterative process in which professional caregivers and policy makers were regularly consulted to provide input. Their involvement was considered of great importance to develop an intervention that would fit the complex home care context.

Societal impact through co-creation between research and practice

A good way to create and optimize societal impact and truly embed research meaningfully within the health care system, is to actively involve the target group or end users in your research, also known as co-creation [2]. All studies in this thesis were developed, conducted and interpreted by co-creation between researchers and home care practitioners. The studies in this thesis were initiated based on the needs of professional caregivers and care organizations to gain more insight into involuntary treatment use in home care. Researchers and professional caregivers together formulated scientific research questions. The results of the studies presented in this thesis were discussed and translated into guidelines for home care practice. Before the start of this project, a work group, focusing on involuntary treatment in PwD, was established including nurses, managers and policy advisors from several care organizations. This work group met multiple times a year to discuss the purpose, design, outcome measures and results of the studies. People with dementia, general practitioners and family caregivers were also consulted to share their ideas and/or feedback. Involving the end users from the beginning of a project facilitates motivation to change and the match between the needs of daily practice and scientific research.

People with a cognitive impairment or dementia

Although they did not directly participate in the studies of this thesis, people with a cognitive impairment or dementia are the ultimate target group. The ultimate aim of this research was to develop an intervention to prevent and reduce involuntary treatment in PwD. The underlying idea is that in this way, we contribute to the quality of care for PwD and their general well-being and quality of life. PwD can experience difficulty expressing their feelings and needs, but resistance to care or refusal to cooperate or comply indicate signs of autonomy that should not be ignored. Although these behaviors may be interpreted as defiant or aggressive, it is important to investigate the cause of this behavior, which can provide insight into the needs and wishes of PwD. They should be involved in their own care and decision-making process as much as possible. Therefore professional and family caregivers have a duty to carefully and critically reflect on the care they provide and whether this is the most optimal for the client's well-being, now and in the long-term.

Professional and family caregivers

Professional caregivers were the main participants of the research presented in this thesis. They were involved in the development and implementation of the PRITAH intervention and indicated the challenges regarding involuntary treatment use in home care practice. The intervention is therefore practice-oriented with direct implications for home care practice and all caregivers involved. Professional and family caregivers are the ones who can implement a change (in care) for PwD, but they have to be willing and supported to do so. The increased knowledge and awareness regarding involuntary treatment use enables professional and family caregivers to work together in identifying alternative, person-centered ways to prevent involuntary treatment. A multidisciplinary approach, involving other disciplines such as an occupational therapist or physical therapist further enhances the process. Caregivers must remain critical, share knowledge and feedback with each other and involve PwD as much as possible throughout the care process. The resulting solutions to prevent involuntary treatment include both assessment of the underlying cause of the behavior as well as changing interpersonal approaches and care practices.

(Home) care organizations

This thesis provides implications for home care practice such as implementation of a policy and availability of education, coaching and alternative measures aimed at prevention and reduction of involuntary treatment. First, the policy must be clear and practically feasible, in which professional caregivers have a guideline that provides the freedom to tailor the intervention to the individual situation since there is no 'one size fits all'. This policy must be communicated to all stakeholders: employees of the organization as well as the clients, family caregivers and general practitioners (GPs). For new clients, this policy must be discussed during the intake and (if needed) continuously throughout the care process. A multidisciplinary approach is required and the organization should encourage good communication between the home care team, dementia case managers and domestic workers. In addition to the policy, it is important to offer education, coaching and alternatives to prevent involuntary treatment use. The workshops of PRITAH consist of topics relevant for various professionals (nursing staff, domestic workers, dementia case managers and GPs), such as the consequences associated with involuntary treatment. During the workshops, awareness increased and multiple alternative measures to prevent involuntary treatment were described using case studies. Although this thesis specifically focusses on PwD living at home, these results may also be valuable for other care settings and/or target groups. Insights derived from this thesis may also help professional caregivers working with people with an intellectual disability or a mental illness, in nursing home or hospital care, on how to change daily practice and avoid involuntary treatment.

Policy advisors

Evidence-based practice in health care practice and policy development is increasingly important. Throughout the research presented in this thesis policy advisors and the management of the (home) care organizations were involved in the decision-making process with the researcher(s). The studies presented in this thesis reveal that caregivers need 1) a clear policy including a step-by-step guideline how to implement this in daily practice, 2) clear communication to and between all stakeholders (including PwD and their family caregivers) and 3) to feel supported by their organization and management. A combination of both top-down (e.g. clear mission and vision, being supportive and providing resources such as time or expertise) and bottom-up processes (e.g. having input in the development of policy, being solicited for advice/feedback) are needed.

Government and national legislation

This thesis also offers new insights for further development and implementation of the Dutch law 'Care and Compulsion'. In the Netherlands, the law 'Care and Compulsion' (Wet Zorg en Dwang) went into effect in January 2020. This law regulates the rights in case of involuntary treatment use in people with a psychogeriatric disorder (such as dementia) or intellectual disabilities. According to this law, involuntary treatment should only be used if there are no alternatives to prevent a risk of (serious) danger.

This applies for all care settings: nursing home, hospital and at home. Implementation of new legislation is very time-consuming for care organizations and care providers. Time that, according to professional caregivers, sometimes is not available or comes at the expense of daily care activities. This also requires experts, such as a specialized nurse or GP, with detailed knowledge to coach other professional caregivers during their daily work. Whereas the law provides a framework to prevent involuntary treatment, the PRITAH intervention offers a feasible way on how to implement this in daily care practice and realize societal impact: PRITAH provides the knowledge and tools needed that can be directly applied in home care practice.

SCIENTIFIC IMPACT

In addition to societal impact, the studies presented in this thesis also have scientific impact for several reasons.

First of all, this thesis describes and elaborates on a relatively new concept: involuntary treatment. Whereas previous studies mainly focused on specific measures such as physical restraints, and residential settings like the nursing home and hospital, this thesis focuses on all forms of involuntary treatment. Involuntary treatment is defined as any type of care to which someone resists and/or does not provide consent for [3], and includes physical restraints, psychotropic medication and non-consensual care.

Second, a great amount of knowledge, insight and awareness regarding involuntary treatment has been acquired. Although literature on involuntary treatment use in home care is still relatively scarce, this thesis provides valuable, new insight into involuntary treatment in home care. Since the majority of PwD live at home, it was necessary to gain insight 'behind closed doors'. The studies presented in this thesis are the first indicating the high prevalence of involuntary treatment use specifically in PwD living at home. In addition, this thesis provided insight into the role of both professional and family caregivers in the request and use of involuntary treatment, their attitudes regarding involuntary treatment use and family caregivers' experiences with care situations that may lead to involuntary treatment use.

Third, the findings presented in this thesis led to multiple discussions with editors and reviewers of scientific journals and peer researchers about involuntary treatment use, the scarcity of studies on this topic and the need for new insights. Results were (inter)nationally presented and published which had an impact on the awareness of involuntary treatment among the scientific community. Although researchers and caregivers may not be aware, disabling a stair lift or hiding medication are also considered involuntary treatment. The findings presented in this thesis may encourage peer researchers to investigate innovative ways of providing care without involuntary treatment use.

Fourth, this thesis contributes to the scientific literature on person-centered care, autonomy and personhood in PwD. The insights gained throughout the studies underline the importance of these concepts in dementia care and create awareness among editors, reviewers and peer researchers of the impact involuntary treatment can have on PwD and their caregivers. Without this thesis, it remained unknown how prevalent involuntary treatment is among PwD and how necessary it is to conduct further research on this topic.

Finally, this thesis provides insight into the development, implementation, working mechanisms and evaluation of a multi-component intervention aimed at prevention and reduction of involuntary treatment at home. The PRITAH intervention consisted of policy, education, coaching and alternative measures and proved to be feasible in home care practice. The intervention has a multidisciplinary approach and was designed and developed in close collaboration with professionals. The findings presented in this thesis point to the need to further investigate the effectiveness of the PRITAH intervention. This thesis provides practical recommendations for future research, including proactive involvement of both GPs and family caregivers, as well as how to measure involuntary treatment use (e.g. administer a questionnaire in multiple professional caregivers or adequately report in client records to get a more reliable result).

DISSEMINATION OF FINDINGS

Throughout this project attention was paid to dissemination of the findings. Professional caregivers and people working in the field were involved in developing, conducting and interpreting the studies. The results of the studies were communicated to the participants, policy makers and the management board of the participating home care organizations. In addition, the findings of these studies were and will be distributed via various channels to professional and family caregivers, care organizations, researchers, students and other stakeholders.

All studies included in this thesis were submitted and/or published to international peer-reviewed journals. Results were also presented and discussed at (inter)national congresses focusing on gerontology, dementia and/or nursing. In addition, symposia and workshops were organized in- and outside Europe on involuntary treatment use. In 2019 we organized a Dutch congress on ‘involuntary treatment use’, which was visited by over 100 researchers, nurses, dementia case managers, policy advisors, directors, management staff and domestic workers. These meetings, discussions and publications contributed to raising awareness about involuntary treatment. In addition, discussions were held with editors and reviewers of (inter)national peer-reviewed papers about the definition and impact of involuntary treatment. The findings presented in this thesis were also integrated in educational programs. Lectures on involuntary treatment use and alternatives for PwD in home care were discussed during interactive lectures for students of the health sciences bachelor program at Maastricht University. In addition, students conducted literature reviews and wrote theses about involuntary treatment use and interventions to prevent and reduce its use. Finally, a workshop for dementia nurses and case managers was provided for the Beroepsvereniging Verzorgenden en Verpleegkundigen (V&VN) on how to deal with involuntary treatment at home.

The studies discussed in this thesis are part of a research line embedded in the Living Lab that started in 1999, focusing on restraint use in nursing home residents. Over the years this research line has evolved and now studies mainly focus on involuntary treatment use in home care. Studies on involuntary treatment will continue, for example a process- and effect evaluation of the PRITAH intervention and a prevalence study on involuntary treatment use in nursing home residents will be conducted in 2021. Besides, this dissertation will be shared with the care organizations and will be freely available as an e-book on the website of the Living Lab.

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About the author

Angela Maria Herma Jozefina Mengelers was born on May 3, 1992 in Geleen. After completing secondary school at Trevianum Sittard in 2010, she studied Psychology at Maastricht University. She obtained her Bachelor's degree in 2013 after completing her minor abroad in Nicosia, Cyprus. In 2015 she received her Master's degree in Neuropsychology at Maastricht University. During and after her studies she worked as a research assistant and tutor at the faculty of Psychology and Neuroscience. Angela completed her research and clinical internship at the memory clinic at the Maastricht University Medical Centre MUMC+ and acquired her diagnostic registration (BAPD) in 2015. In November 2015 she started as a PhD candidate within the Living Lab in Ageing and Long-Term Care, part of the Health Services Research department at Maastricht University. Her PhD focused on involuntary treatment use in people with dementia living at home. Alongside her research activities, she was one of the PhD representatives for the Care and Public Health Research Institute (CAPHRI) for 2 years and was involved in the organization of the European Doctoral Conference in Nursing Science (EDCNS) in Maastricht 2018. She also was involved in several educational activities such as supervising bachelor theses, tutoring and lecturing students of the Health Sciences studies. In March 2020 Angela started working as a lecturer in general and clinical psychology at the Open University in Heerlen.

Scientific publications

ARTICLES

Mengelers, A. M. H. J., Bleijlevens, M. H. C., Verbeek, H., Capezuti, E., Tan, F. E. S., & Hamers, J. P. H. (2019). Professional and family caregivers' attitudes towards involuntary treatment in community-dwelling people with dementia. *Journal of Advanced Nursing*, *75*(1), 96-107.

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Moermans, V.R.A., Mengelers, A.M.H.J., Bleijlevens, M.H.C., Verbeek, H., Dierckx de Casterle, B., Milisen, K., Capezuti, E. & Hamers, J.P.H. Family caregivers' experiences in dealing with involuntary treatment in dementia care at home: a qualitative study. *Submitted for pulication*

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 involuntary treatment at home: A feasibility study of the PRITAH intervention. *Geriatric Nursing, 41*(5), 536-543.

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ABSTRACTS, POSTERS AND PRESENTATIONS

Mengelers AMHJ, Bleijlevens, M, Verbeek H, Capezuti L & Hamers JPH. Attituden en meningen van professionele zorgverleners en mantelzorgers ten aanzien van onvrijwillige zorg bij mensen met dementia die thuis wonen. 14e Nationaal Gertontologiecongres, Ede, Nederland, 3 November 2017.

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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 for 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.

PROEFSCHRIFTEN ACADEMISCHE WERKPLAATS OUDERENZORG LIMBURG

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

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