

To risk or to restrain?

Citation for published version (APA):

Mengelters, A. M. H. J. (2021). *To risk or to restrain? Involuntary treatment use in people with dementia living at home*. [Doctoral Thesis, Maastricht University]. Gildeprint Drukkerijen.
<https://doi.org/10.26481/dis.20210614am>

Document status and date:

Published: 01/01/2021

DOI:

[10.26481/dis.20210614am](https://doi.org/10.26481/dis.20210614am)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

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.

REFERENCES

1. Fazio, S., et al., *The Fundamentals of Person-Centered Care for Individuals With Dementia*. Gerontologist, 2018. **58**(suppl_1): p. S10-S19.
2. Jull, J., A. Giles, and I.D. Graham, *Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge*. Implement Sci, 2017. **12**(1): p. 150.
3. Hamers, J.P., et al., *Behind Closed Doors: Involuntary Treatment in Care of Persons with Cognitive Impairment at Home in the Netherlands*. J Am Geriatr Soc, 2016. **64**(2): p. 354-8.

