

CAPHRI School for Public Health and Primary Care

Prevalence and associated factors of involuntary treatment in dementia home care in the Netherlands

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- Case managers dementia

- Persons with dementia and their family-caregivers

Proposition

- We should prevent harm and the use of involuntary treatment in one of the most vulnerable patient groups:
Persons with cognitive impairment living in their own homes

Background

- Ageing in place currently guides healthcare policy in most Western countries
- Persons with cognitive impairments are expected to live in their own homes as long as possible
 - Emphasis on informal care, social support and professional home care
- Increase of complexity of care in the community
 - Wandering, falls, agitation, problem behavior, etc.
- Risk of involuntary treatment

Involuntary treatment

- Involuntary treatment = treatment provided by professional and/or family caregivers without the consent of the person with cognitive impairments who is receiving the treatment

- Physical restraints
 - E.g. waist belts, chair with fixed tray tables

- Psychotropic medications
 - E.g., antipsychotics, hypnotics

- Nonconsensual care
 - E.g., forced hygiene, hidden application of medication

Government of the Netherlands: involuntary admission and the use of compulsion in the care sector, 2015.

Research questions

- What is prevalence of involuntary treatment (physical restraints, psychotropic medication, nonconsensual care) in home care?
- What factors are associated with involuntary treatment?
- Who decides and starts the use of involuntary treatment?

Methods

➤ Cross-sectional survey

➤ Sample

- Persons with cognitive impairments receiving home care
- Inclusion via case managers specialized in dementia care
 - Case load: 20-75
 - Estimation: maximum of 1050 subjects eligible

➤ Data collection

- Questionnaire
 - Involuntary treatment used during previous 30 days
 - Associated factors
 - Age, gender, living situation, functional status, cognitive status, formal diagnosis of dementia, and caregiver burden
 - Information about person who decided to use involuntary treatment

Involuntary treatment (Y/N)

- Physical restraints
 - Waist belts, wrist and/or ankle restraints, chairs with a locked tray table, deep or overturned chairs, locked (wheel)chairs, bilateral full-enclosure bedrails
- Psychotropic medication
 - Prescription of psychotropic medication yes/no after reviewing patient records
- Nonconsensual care
 - Forced application of medication, hiding away medication, forced fluid/food intake, forced hygiene, restricting communication, locking person in, cutting off gas, restricting transportation, removing aids, electronic supervision

Results

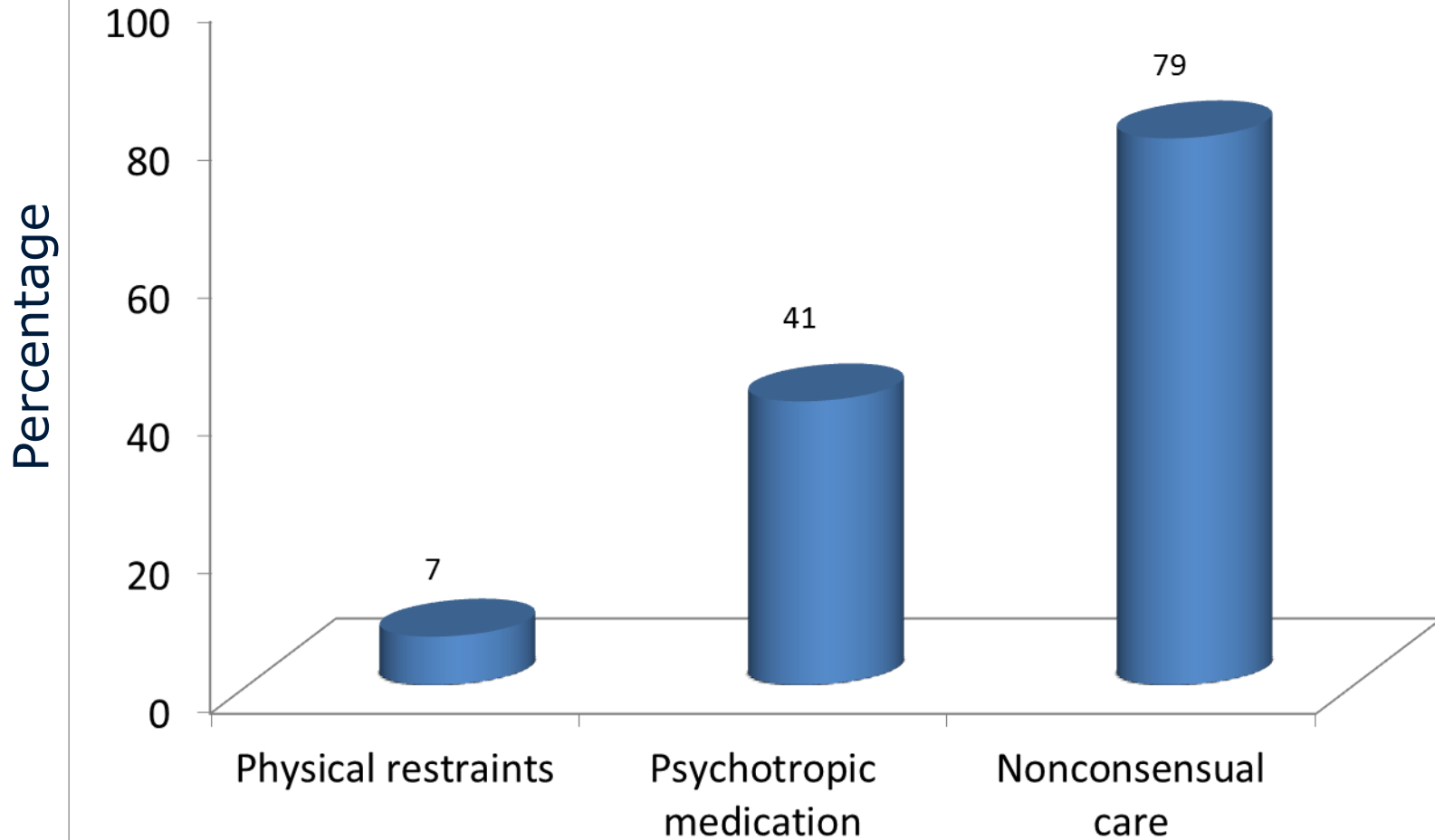
➤ Sample

- 837 persons with cognitive impairments
- Mean age: 82 year (SD=6.7)
- 60% women
- Living situation
 - 49% living alone
 - 46% living with a partner
 - 5% other

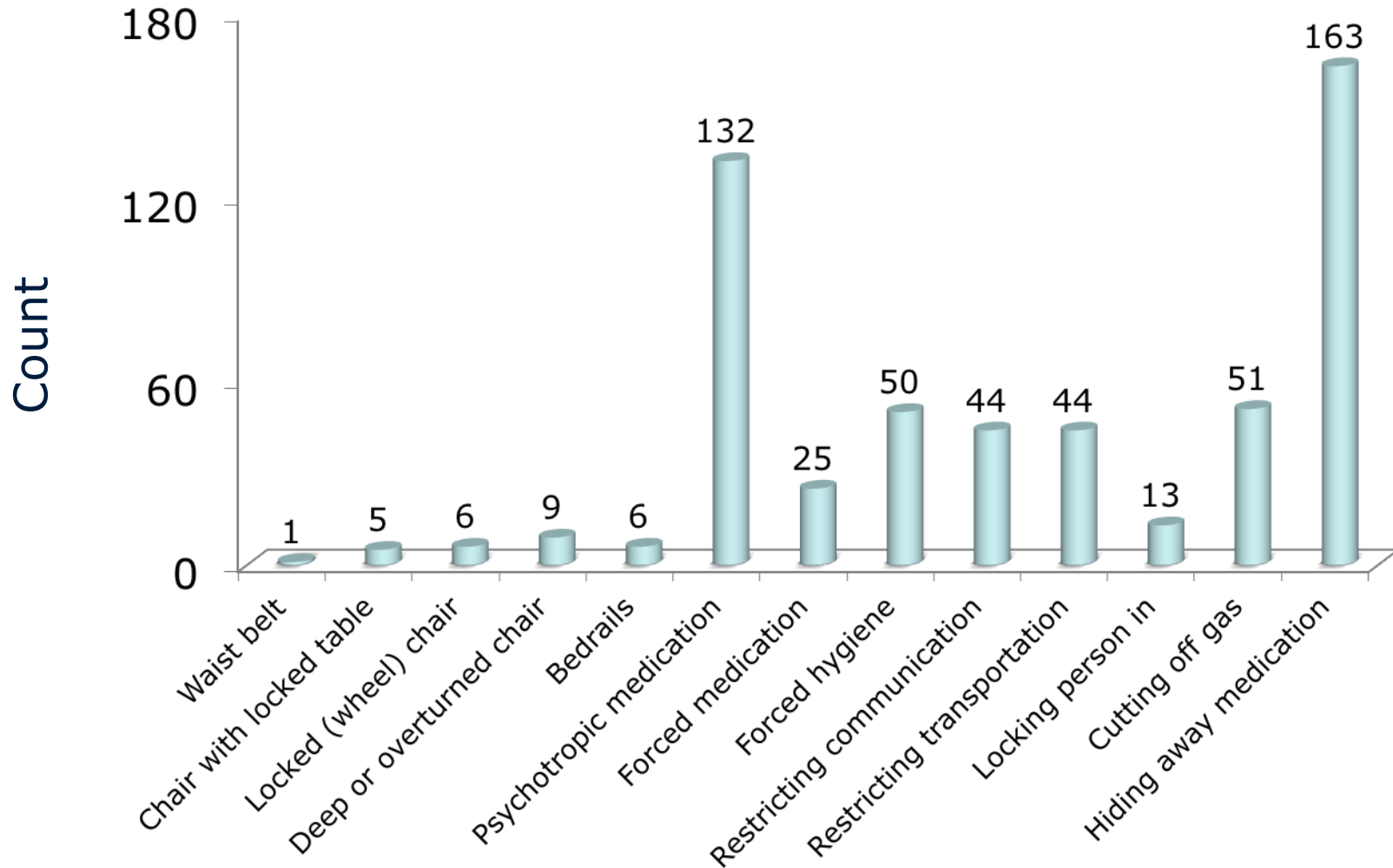
Results

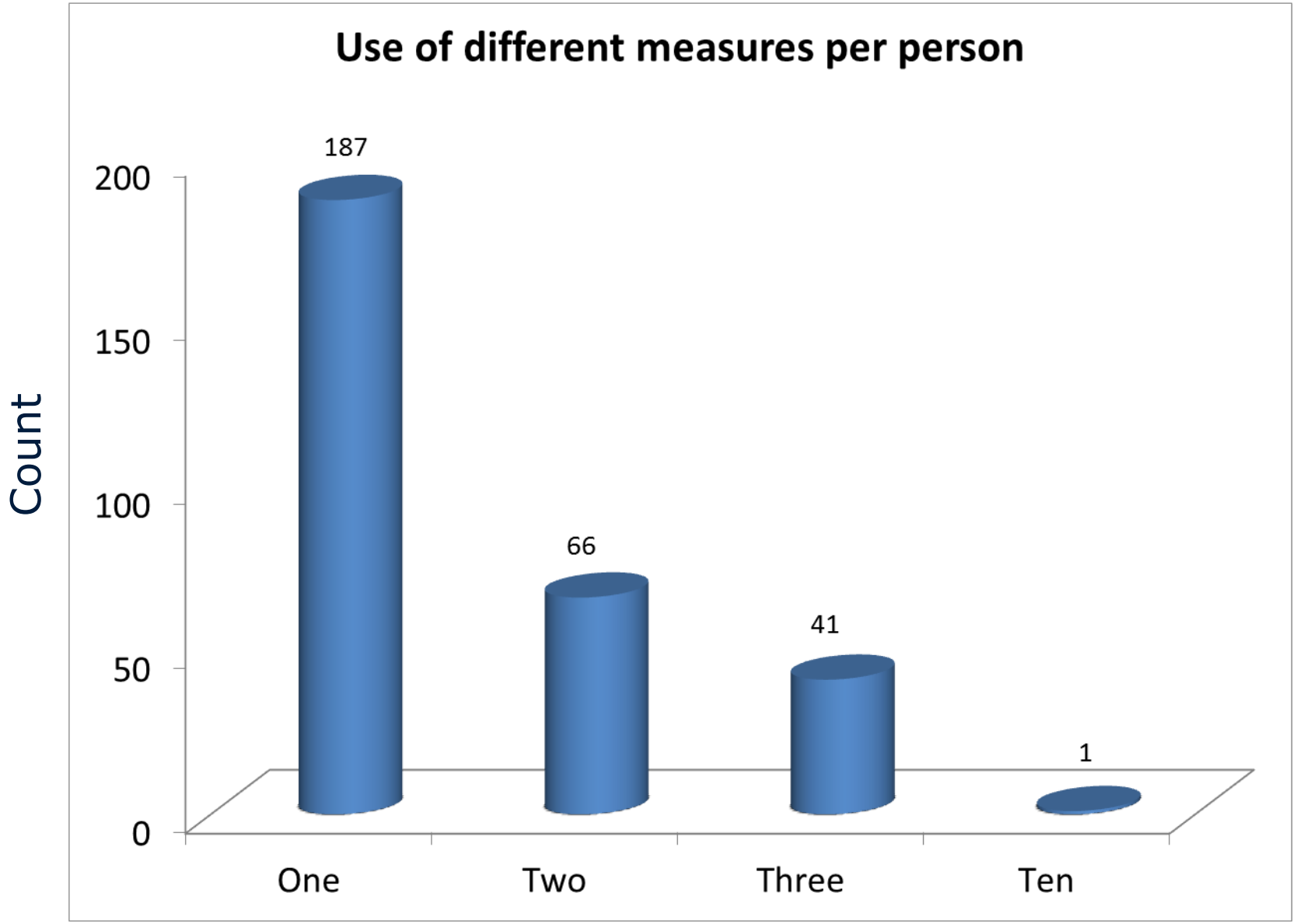
- Involuntary treatment: 39% (321 persons)
 - 95% CI: 0.35-0.42

Involuntary treatment



Prevalence of different measures



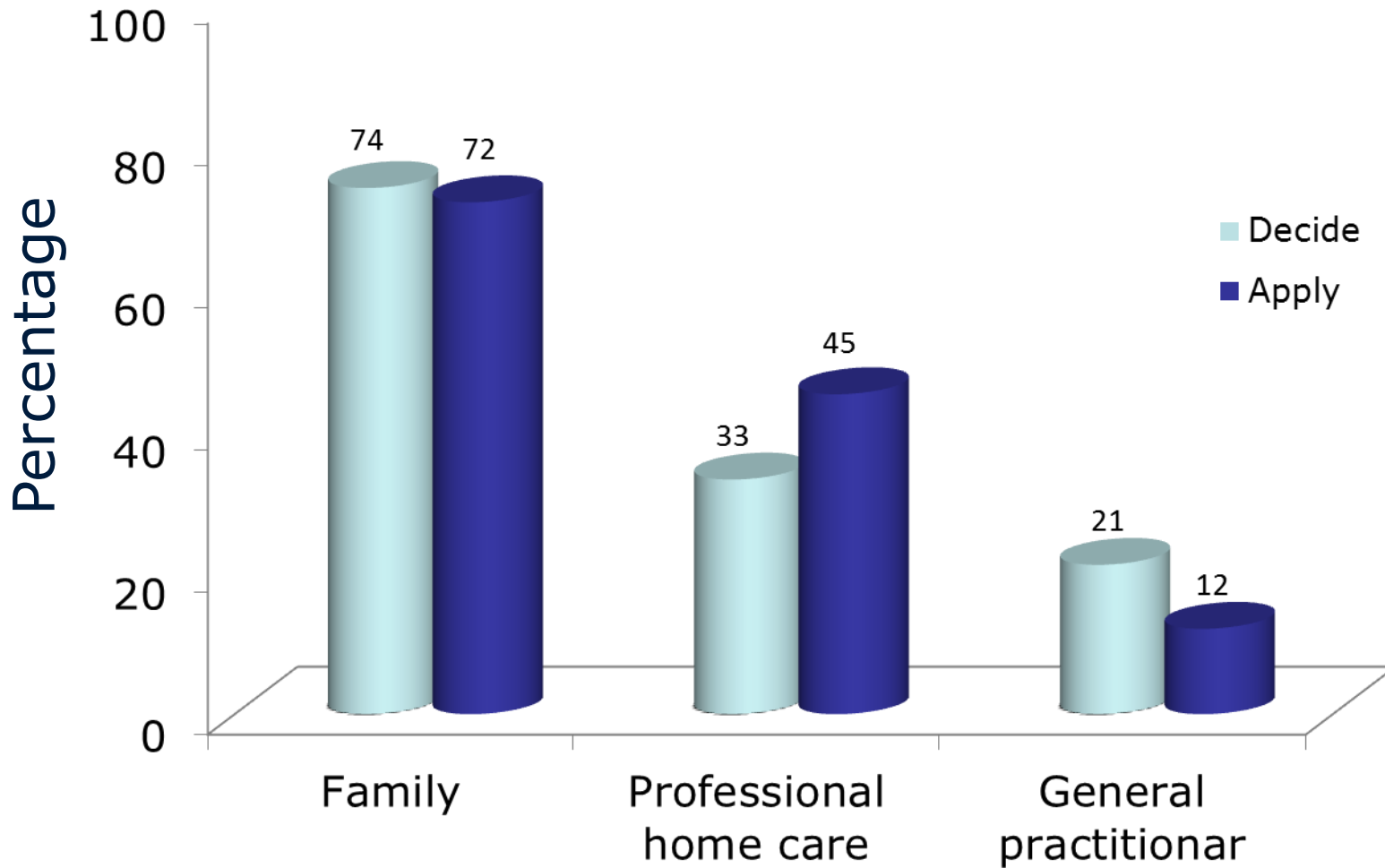


Factors associated with involuntary treatment

- Cognitive status
- ADL dependency

- Caregiver burden
- Living alone

Decision and use of measures



Conclusion

- Involuntary treatment is frequently used in home care
 - Most frequent: medication and nonconsensual care
- Associated factors specific at home
 - Caregiver burden and living situation
- Decision often made by family
 - They want to minimize risk of harm and injury
 - They perceive involuntary treatment (nonconsensual care) as the only way to prevent injuries, and/or to control inappropriate behaviors

Understandable, but

- Involuntary treatment can have reverse effects
 - Persons with cognitive impairment don't understand why a measure is used
 - Some measures even can increase the risks on injuries
- Overestimate the risks of injuries
- The use of involuntary treatment in an individual case may be no legitimation for the general application of it

Recommendations

- Prevent unnecessary use of involuntary treatment
 - More insight into reason for using involuntary treatment
 - More insight into opinions of family and professional caregivers
 - Learn from best practices and complex cases

- Focus at development of programs aiming to support family and professional caregivers
 - Education, alternatives and policy changes



Behind Closed Doors: Involuntary Treatment in Care of Persons with Cognitive Impairment at Home in the Netherlands

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OBJECTIVES: To explore the prevalence and associated factors of involuntary treatment (physical restraints, psychotropic medication, nonconsensual care) in persons with cognitive impairment receiving home care.

DESIGN: Cross-sectional survey using association analyses.

SETTING: Professional home care in the southern part of the Netherlands.

PARTICIPANTS: Data were collected on 837 persons with cognitive impairment (mean age 81.6; 60% female).

MEASUREMENTS: Involuntary treatment was measured using a tool to identify physical restraints, psychotropic medication, and nonconsensual care. Activities of daily living (ADLs) were measured using the ADL. Hierarchy sub-

Key words: involuntary treatment; physical restraints; psychotropic medication; nonconsensual care; cognitive impairment; dementia; home care

In the Netherlands, like most Western countries, the government is supporting aging in place, resulting in emphasis on informal care, services, and social support at home (under the responsibility of and covered by municipalities) and professional home care provided by district nurses (covered by healthcare insurance). People who require constant care or supervision are entitled to a place in a resi-



Thank you for your attention

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