

Ethics of technology and restraints in residential care for elderly with dementia and people with intellectual disabilities: development of a multidisciplinary direction for safe care

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The goal of this research project is to develop a multidisciplinary guideline for the responsible and restrictive treatment of freedom restriction in the care for elderly with dementia and people with intellectual disabilities. In this guideline the...

Ethical review	Approved WMO
Status	Recruiting
Health condition type	Other condition
Study type	Observational non invasive

Summary

ID

NL-OMON35336

Source

ToetsingOnline

Brief title

RESIDENT ID Restrictions & Electr. Surveillance In DEmeNTia & Intel. Disab.

Condition

- Other condition
- Dementia and amnestic conditions
- Legal issues

Synonym

dementia, intellectual disabilities

Health condition

verstandelijke beperkingen

Research involving

Human

Sponsors and support

Primary sponsor: Vrije Universiteit Medisch Centrum

Source(s) of monetary or material Support: RVVZ; NUTS OHRA; VERENIGING HET ZONNEHUIS; STICHTING REGIONALE ZORGVERLENING ZEELAND; DIORAPHTE; VERSTANDELIJK GEHANDICAPTENZORG NEDERLAND; ACTIZ

Intervention

Keyword: Freedom restriction, intellectual impairment, surveillance technology

Outcome measures

Primary outcome

-difference in policy (in the way of guidelines, appliances, explicated care outlook and other) that care facilities carry out for people with dementia and people with intellectual disabilities with regard to the application of freedom restrictions

-difference in domotics that are being implemented in these institutions, whether or not as result of the policy with regard to freedom restrictions

-the sumtotal of care content related and normative (legal and ethical) demands that a policy should satisfy in order to be regarded as paradigm of 'good care', this also on the basis of views or experiences of care facilitators (nurses, care workers, doctors, psychologists, orthopedics) clients and their representatives.

-determining the normative status of various means and techniques in the domain of domotics in light of good care (especially considering aspects such as safety and autonomy) on the one hand, and in light of the legal norms in the matter of (the application of) freedom restrictions on the other hand.

Secondary outcome

n/a

Study description

Background summary

In recent years various research * among which the second evaluation of the Special Admission to Psychiatric Hospitals Act (BOPZ) * has endorsed that the current judicial framework for freedom restriction in the care for elderly with dementia and people with intellectual disabilities does not offer the necessary legal protection to patients/clients that are faced with freedom restrictions. The current judicial framework also fails to correspond with concepts of good care as they have been developed from within the field. Moreover, traditional institutionalised care is increasingly shifting towards small scale living arrangements where new care supportive -and safety enhancing technology (domotics) is becoming increasingly important.

Taking this in consideration, there is need for a clear normative framework for the localization and application of freedom restricting measures in the care for people with dementia and people with intellectual disabilities. This framework should offer the necessary legal protection to those who are subjected to freedom restrictions, but should also correspond with concepts of good care as they have been developed from within the field, in particular when it comes to alternatives for (traditional) freedom restrictions. Special attention should be given to the place of new care supporting -and safety enhancing technology (domotics) that is being increasingly applied in the field. This technology has on the one hand as its aim to increase safety and quality of life and serves on the other hand as an alternative to the more traditional *hard* freedom restrictions.

Study objective

The goal of this research project is to develop a multidisciplinary guideline for the responsible and restrictive treatment of freedom restriction in the

care for elderly with dementia and people with intellectual disabilities. In this guideline the emphasis will lie in the prevention of freedom restriction, the application of alternatives for freedom restriction and the role of electronic surveillance (domotica). The research project will combine a normative approach with an empirical approach, whereby, on the basis of concept mapping *best practices* will be selected for additional empirical research. Next to all the developments in the field to decrease all applications of freedom restriction, there is also a law proposal for freedom restriction in preparation in order to replace the current Special Admission to Psychiatric Hospitals Act (BOPZ). The results of this research project could contribute to the further consolidation of the law proposal and a better implementation of new regulation.

Study design

There will be chosen for a combination of literature research and empirical research. The empirical research will combine qualitative and quantitative methods. Firstly, use will be made of the methodology of concept mapping. This is a structured conceptualization process developed by the sociologist Trochim, whereby qualitative and quantitative methods are combined, bringing together the views of the participants of the process in a conceptual framework (Trochim & Kane, 2005; Trochim, 1989; Burke et al, 2005).

The findings of the concept mapping will form the basis for the development of a questionnaire. Questions will be drawn on the institution's policy in relation to freedom restrictions, the used definition of freedom restriction, the specific measures that are being applied, the application of other freedom restricting means, the use of domotics and nature of this use, the decision-making and involvement of the clients and their representatives, the manner in which awareness is being raised or not, etc. The present/used directive or guideline(s) will also be requested.

On the basis of a comparison between the answers to the questionnaire and the 'normpolicy freedom restrictions' three institutions will be selected of each sector that will be subsequently be approached to participate in the second qualitative part of the research project. If it emerges that per sector more than 3 institutions satisfy the criteria, a decision will be made by the projectgroup in correspondance with the assisting committee.

The researcher will subsequently perform ethnographic fieldstudy in the form of participatory observation in two of the selected institutions, one of each sector. For practical reasons only short observation will be done in the remaining intitutions, with additional interviews that will take place chiefly there. Besides the conversations held with care helpers and representatives of the management these interviews will also entail conversations with clients.

Study burden and risks

n/a

Contacts

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Trial sites

Listed location countries

Netherlands

Eligibility criteria

Age

Adults (18-64 years)

Elderly (65 years and older)

Inclusion criteria

patients with dementia or intellectual disabilities who are faced with assistive technology in a care facility

Exclusion criteria

no assistive technology or electronic surveillance present;
not capable of holding a conversation (with regard to the interviews)

Study design

Design

Study type: Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Other

Recruitment

NL

Recruitment status: Recruiting

Start date (anticipated): 09-08-2010

Enrollment: 25

Type: Actual

Ethics review

Approved WMO

Date: 03-08-2010

Application type: First submission

Review commission: METC Amsterdam UMC

Study registrations

Followed up by the following (possibly more current) registration

No registrations found.

Other (possibly less up-to-date) registrations in this register

No registrations found.

In other registers

Register

CCMO

ID

NL21623.029.08