# **Empowerment** and Technology An ethical-empirical exploration of technology-assisted dementia care

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## 1. Background

- *Empowerment* is a major goal of current healthcare policy<sup>1</sup>. \*\*
  - It remains unclear what *Empowerment* exactly is and how it can be assessed<sup>2</sup>.
- Intelligent Assistive Technology (IAT) is considered an innovative way to empower people with \*\* dementia, e.g. by increasing their independence and safety<sup>3,4</sup>.
  - Empirical data regarding the use of IAT in dementia care is lacking.
- It is unclear how the use of IAT impacts the *Empowerment* of people with dementia.

## 2. Aims

- Specifying Empowerment for technology-assisted dementia care. \*
- **Exploring** attitudes of German academic experts and professional caregivers regarding IAT in dementia care.
- **Reflecting** preconditions, chances and risks of IAT in dementia care from an *Empowerment*-perspective.

## 3. Methods

- Conceptual analysis of *Empowerment* 
  - In mental health, long-term care, and healthcare policy.
  - Identifying target groups, procedural dimensions, and normative dimensions.
- Qualitative Content Analysis<sup>5</sup> of semi-structured interviews
  - **41 participants:** 20 academic experts in key roles in technology development/ research, healthcare politics and professional associations and 21 professional caregivers as experts in *practice* - in-patient as well as out-patient care.

• 17 items regarding the social, economic and legal preconditions (only for academic experts), the chances and risks, and the criteria of IAT in dementia care.

## 4. Findings

#### **Empowerment** in technology-assisted dementia care

- *Empowerment* as an ethos
- Enablement and partnership
- Opposite to paternalistic caregiving
- *Empowerment* as a set of practices
- Education, enabling to critical thinking, enforcement of one's own interests
- Reduction of asymmetric relationships, focus on participatory design and decision making-processes
- Institutional change

#### *Empowerment* as an ethical concept

- **Target groups**: people with dementia, family caregivers, professional caregivers
- Procedural dimensions: with regard to the use of IAT, by the use of IAT
- Normative dimensions: equal access, self-determination, participation

## Theme 1: Preconditions impacting IAT in dementia care

- (only academic experts)
- Sub-theme 1.1 Accelerators
- Societal Digitization
- Demographic Change
- Change in family structures
- Shortage of professional caregivers
- Change in mentalities
- Growing wealth

#### **Sub-theme 1.2 Inhibitors**

- Lack of technology literacy
- Deficient digital infrastructure
- Ressentiments against technology
- Economic considerations
- Uncluttered economic market
- Open (re-)financing
- Data security

### Theme 2: Opportunities of IAT in dementia care

#### Sub-theme 2.1 For people with dementia

- Prolonged living in one's own home
- Independence
- Increased safety
- Enhanced outdoor mobility
- Enhanced social participation
- Enhanced quality of care
- Enhanced prediction
- Sub-theme 2.2 For family caregivers
- Relief of caregiver burden
- Physically
- Psychologically
- In terms of time
- Independence
- Caring on a distance
- Enhanced possibility for employment (only by experts)

- Enhanced polity and policy
  - Enhanced legislation
  - Enhanced research funding
- Technical progress and increased customizability
- COVID19-pandemic
- Technically
- Legally
- Dementia-specific issues
- Symptoms
- Stigmatization
- Non dementia-specific technologies
- Theme 3: Risks of IAT in dementia care
- Sub-theme 3.1 For people with dementia
- Invasion of privacy
- Continuous surveillance
- Misuse of data
- Disregard of self-determination
- Regarding the implementation
- By the usage
- Dependence on technology
- Rise of new normativity (only by experts)
- Dehumanization
- Isolation
- Objectification
- Technology as source of fear

- Sub-theme 3.2 For family caregivers
- Rise of new burdens
  - Technology education/ training
  - New tasks regarding technologies
  - Psychologically
  - Financially (only by experts)
- Big Brother-effect
- Deceptive feelings of safety
- Manipulation by technology companies (only by experts)
- Frustration
- Sub-theme 3.3 For professional caregivers
- Rise of new burdens
- Technology education/ training
- New tasks regarding technologies Psychologically

- Enhanced rehabilitation and activation • Enhanced tele-medical supply (only by experts)
- Enhanced leisure activities
- Enhanced quality of life
- Enhanced privacy (only by two experts)
- Reduction of custodial measures (only by one *expert*)
  - Sub-theme 2.4 For the healthcare system (only by experts)
  - Enhanced quality of care
  - Relief of skilled caregiver shortage
  - Financial efficiency

- Enhanced quality of life
- Enhanced participation in care network

#### **Sub-theme 2.3 For professional caregivers**

- Relief of caregiver burden
  - Physically
- Psychologically
- In terms of time
- Independence
- Enhanced working conditions
- Interdisciplinary communication
- Salary
- Legal reassurance
- Enhanced data-basis

## 5. Conclusions

- **Empowerment** as an ethos, a set of practices, and an ethical concept.
- Academic experts' assessments of **preconditions** of IAT in dementia care ambivalent.
  - Equal access to IAT is not ensured due to unequal technology literacy, lack of (re-)financing possibilities and deficient digital infrastructure. - Education and information programs have to be installed; public (re-)funding has to be ensured; digital infrastructure has to be enhanced, esp. in rural areas.
  - Participation of people with dementia in development processes is challenging due to dementia-specific

Sub-theme 3.4 For the healthcare system (only experts)

• Dehumanized care

• Financing gaps

- Change of caregiving ideal and practice
- Surveillance by employers (only by experts)

Substitution

- Concealing of responsibilities
- Technology breakdown (only by experts)

symptoms as well as stigmatization. -> Participatory design approaches have to be modified in dementiasensitive ways.

- Academic experts' and professional caregivers' assessments of chances and risks of IAT in dementia care largely converge.
  - By enabling people with dementia to live longer at home, IAT can contribute to the evident wish of many elderly and their independence. It must be ensured that decisions about staying in one's own home and to therefore use IAT is self-determined and not unduly forced, e.g. by economic or caregiver-related considerations.
  - IAT can contribute to social participation of people with dementia, e.g. by enabling them to safe outdoormobility as well as a media of social interaction. It must be ensured that IAT does not exacerbate social isolation of people with dementia nor substitute human caregivers.
  - IAT can relieve caregivers' burden by assisting in physically challenging or recurrent administrative tasks. It must be ensured that this contribution is not contradicted by rise of new tasks regarding technologies, esp. when caregivers are not trained.

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