

Autonomy restricting medical procedures in people with dementia – German older people’s and Betreuers’ perspectives on the decision-making-process

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Introduction

People with dementia may experience behavioural and psychological symptoms (e.g. agitation, aggression, and sleep or appetite changes); frequently leading to distress in patients and carers. The percutaneous endoscopic gastrostomy (PEG), the use of physical restrains (PR), and the prescription of antipsychotic drugs (AP) are supposed to enhance quality of care.

The evidence for the anticipated benefits is limited. The interventions are potentially harmful and important threats to autonomy. However, their prevalence remains high possibly due to decision-makers’ attitudes and beliefs.

Objective To explore the processes of decision-making, experiences and preferences of older people and legal guardians regarding PEG, PR, and AP.

Methods

In a qualitative approach, personal interviews were conducted in Hamburg, Germany.

(1) Professional and voluntary Betreuer were eligible. In problem-centered interviews their experiences of decisions about PEG, PR and AP were explored.

(2) Older people were eligible if they had no cognitive impairment and resided comparable to people with dementia. In episodic interviews their attitudes regarding PEG, PR and AP and their wishes for surrogate decision-making were explored.

Interview guides were pilot tested and optimized. The interviews were audio recorded, transcribed, and analyzed according to the *Grounded Theory* and the principle of conceptualizing data [1]. A category system with dimensions and characteristics was developed.

Results

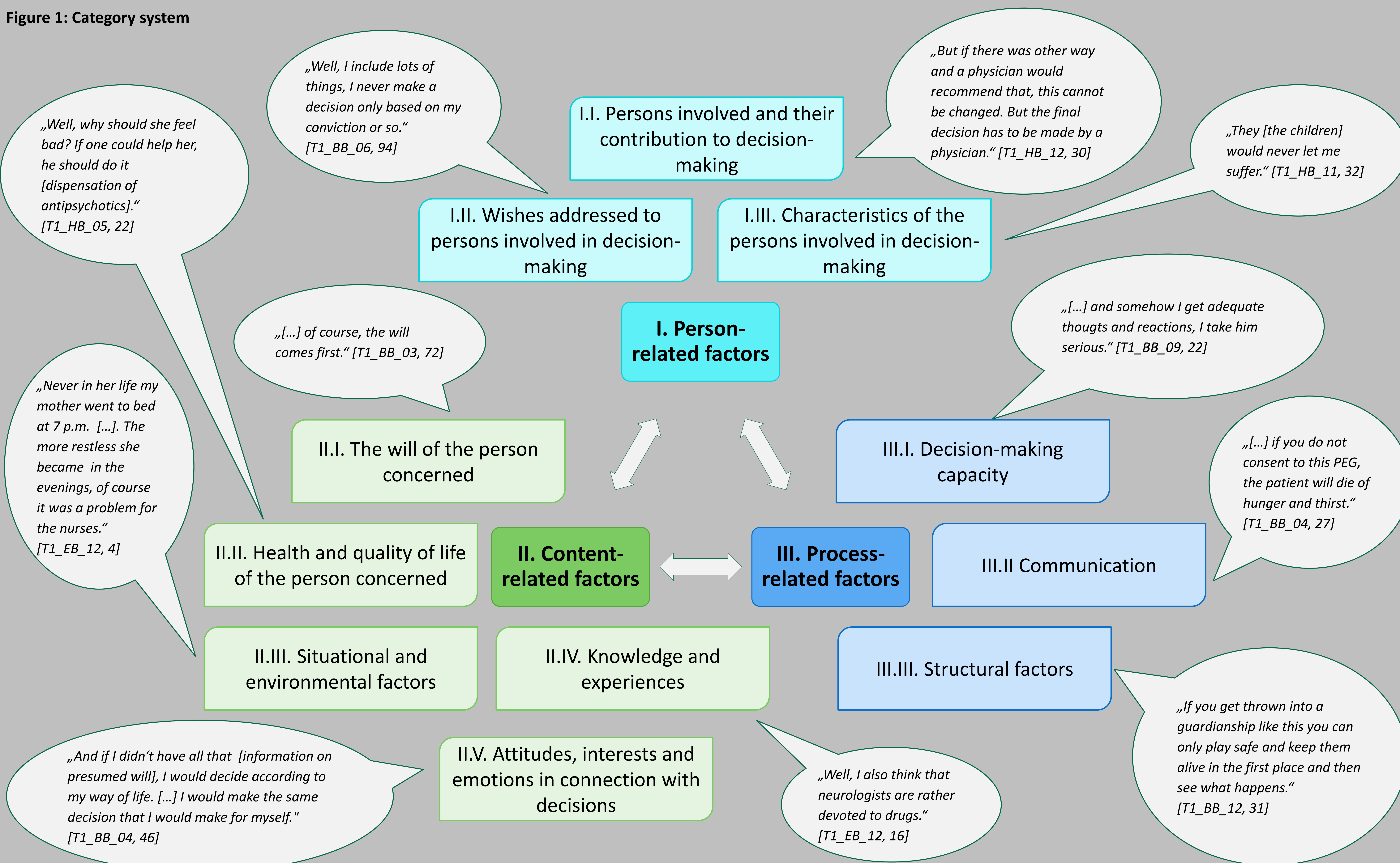
38 interviews were conducted (professional (n=12) and voluntary (n=12) Betreuer, older people (n=14)). The number of interviews was added to the theoretic sampling (Table 1).

→ 11 categories were identified and assigned to three main categories (Figure 1). These categories were found in all groups. Subcategories and the degree of characteristics influencing the decision-making process differed [2].

Tabelle 1- Sampling of Betreuer and older people

	Betreuer		Older people	
	Professional (n=12)	Voluntary (n=12)	(n=14)	
Age in years			Age in years	
< 30	-	-	< 65	2
30 – 50	6	-	65 - 80	6
> 50	6	12	> 80	6
Female	9	6	Female	11
Family member	not applicable	3	Under legal supervision	9
Degree in social education, medicine, nursing science; health professionals	4	not applicable	Level of care	
			0-1	11
			≥ 2	3

Figure 1: Category system



Conclusion

Preferences, attitudes and wishes regarding PEG, PR, AP and the process of decision-making were heterogeneous.

In the group of older people trust in the physician was predominant, especially regarding the prescription of (antipsychotic) drugs. Delegating decisions was highly related to personal and emotional relationships.

The will and the wishes of the person concerned were highly relevant. If they were unknown, Betreuer would base their decisions mainly on their own attitudes and beliefs. Evidence seemed to be less important. The communication with health professional needs to be improved. A structural approach to make decisions is lacking.

Betreuer have to ensure the right of informed decision-making of persons concerned. Required competencies cannot be presupposed. To enhance these competencies may result in less inappropriate and autonomy restricting interventions. Therefore a education programme was developed and tested for feasibility [2]. The evaluation is being planned.

Referenzen:

- [1] Strauss A, Corbin J. Grounded Theory: Grundlagen Qualitativer Sozialforschung. Weinheim: Beltz, Psychologie Verlags Union; 1996.
[2] Richter T, Lühnen J. Entwicklung und Pilotierung eines Schulungsprogramms zur Gesundheitsversorgung für ehrenamtliche BetreuerInnen und BerufsbetreuerInnen von Menschen mit Demenz – Proxy-decision-making (PRODECIDE). Hamburg, 2015. <https://www.deutsche-alzheimer.de/die-krankheit/forschung/forschungsfoerderung-der-dalzg.html> (Zugriff am 27.04.2016).

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