Supportive Interactions in Decision Making: Exploring the Subjective Experience of People with Dementia

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Aim

To evaluate how PwD perceive supportive interactions in decision-making processes.

Research questions

1. How do PwD experience enhanced consent procedures?
2. Which factors do PwD evaluate in the process of the enhanced consent?
3. How do PwD perceive the interaction with professionals in the process of the enhanced consent?

Theory

Symbolic Interactionism

• “(...) human beings act toward things on the basis of the meanings that the things have for them.”
• “(...) the meaning of such things is derived from, or arises out of, the social interaction that one has with one’s fellows.”
• “(...) these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he encounters.” (Blumer, 1986, p. 2)

Person-Centred Care

• Paradigm shift: need for a changing focus in research and treatment, focusing the PERSON-with-dementia, instead of person-with-DEMENTIA
• Recommendations how to implement authoritative and respectful interactions in the handling of PwD regardless of the setting (Kitwood, 1997)

Method

• Implementation of developed tools in real informed consent processes (Figure 1).
• Evaluation of tools with PwD and their relatives, who attended the informed consent process (Figure 2 and 3)
• Problem-Centered Interviews (Witzel, 2000)
• Interview guide with three gradations of questions: main question, deepening questions, inimmanent questions

Background

• The lives of PwD are strongly influenced by the quality of social interactions, unmet social needs could have various reasons (e.g. von Kutzleben et al., 2012).
• To develop need-oriented support strategies, views, perceptions and experiences of PwD must be included.

Aims of Subproject Gerontology (Goethe University Frankfurt)

• Identification of dementia and country-specific demands and needs, and actual conditions governing informed consent procedures in clinical dementia research
• Development, implementation, and evaluation of tools to enhance the informed consent process in CDR

Subordinate research questions

• How could PwD be supported without being patronized or stigmatized?
• How could supportive interactions in decision-making be established?