

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

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Ensure

Background

- 2006: United Nations Assembly adopt the Convention on the Rights of Persons with Disabilities (UN-CRPD)
- “(...) States parties have (...) to provide persons with disabilities with access to support in the exercise of their legal capacity. States (...) must (...) enable them to make decisions that have legal effect.” (Article 12 (3) of the UN-CRPD) (Committee on the Rights of Persons with Disabilities 2014, p. 4)
- Article 12 involves a paradigm shift in the concept of legal capacity, it stresses autonomy and ensures respect for the person with dementia’s (PWD) rights, will and preferences

Aim of the overall Ensure Project

- Provision of interdisciplinary recommendations to support the development of an action model of an informed consent process in clinical dementia research (CDR)

Subproject Gerontology

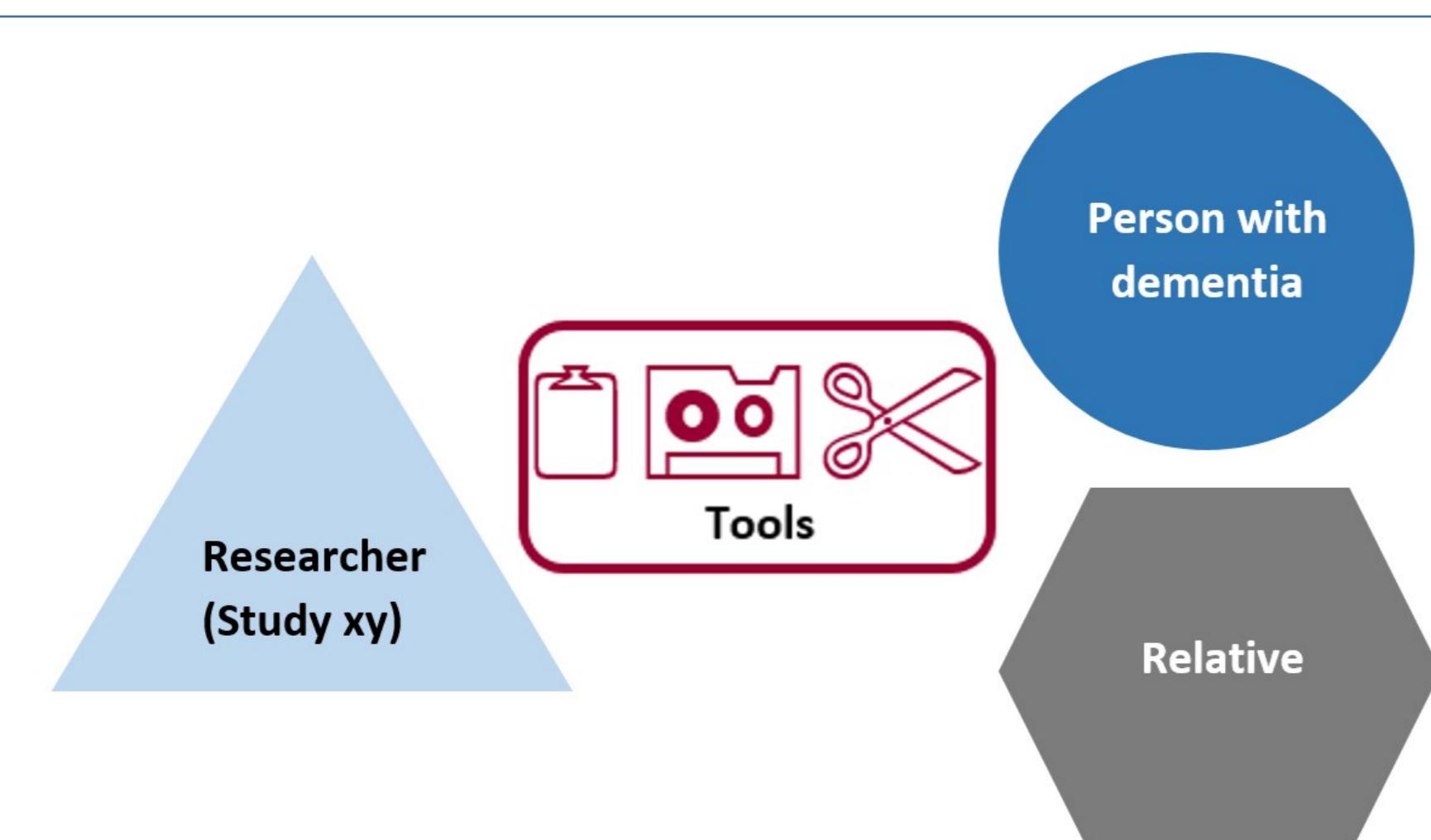


Figure 1: Enhanced consent procedure

Background

- The lives of PwD are strongly influenced by the quality of social interactions, unmet social needs could have various negative impacts on PwD (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?

Doctoral thesis

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 appreciative 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-Centred Interviews (Witzel, 2000)
 - Interview guide with three gradations of questions: main question, deepening questions, immanent questions

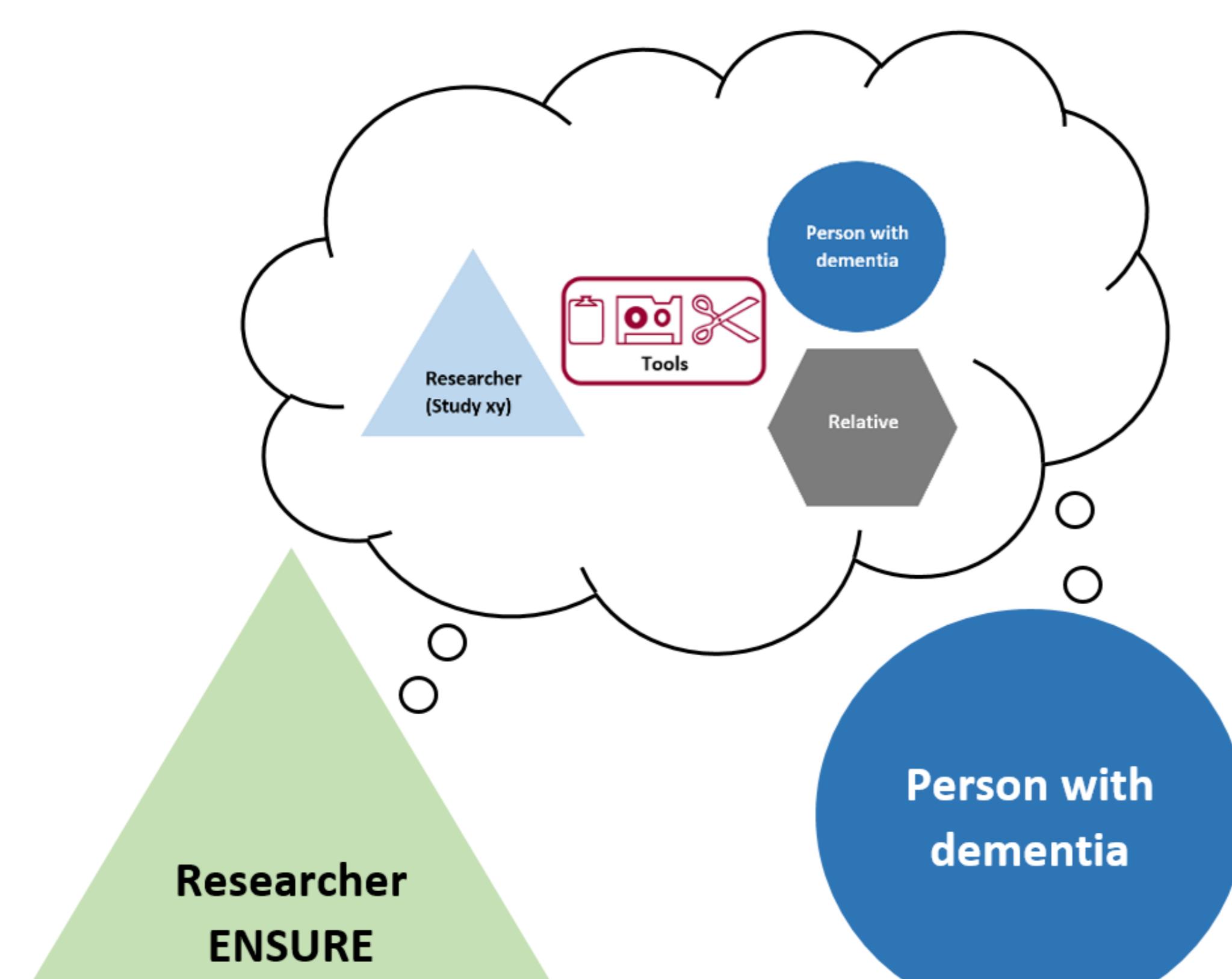


Figure 2: Problem-Centred Interviews with PwD

General contextual focus

- Experience of the enhanced informed consent process where the developed tools were applied

Specific contextual focus

- Perception of the support by the clinical researcher
- Experience of the interaction with the clinical researcher and social needs
- Personal preferences regarding decision-making

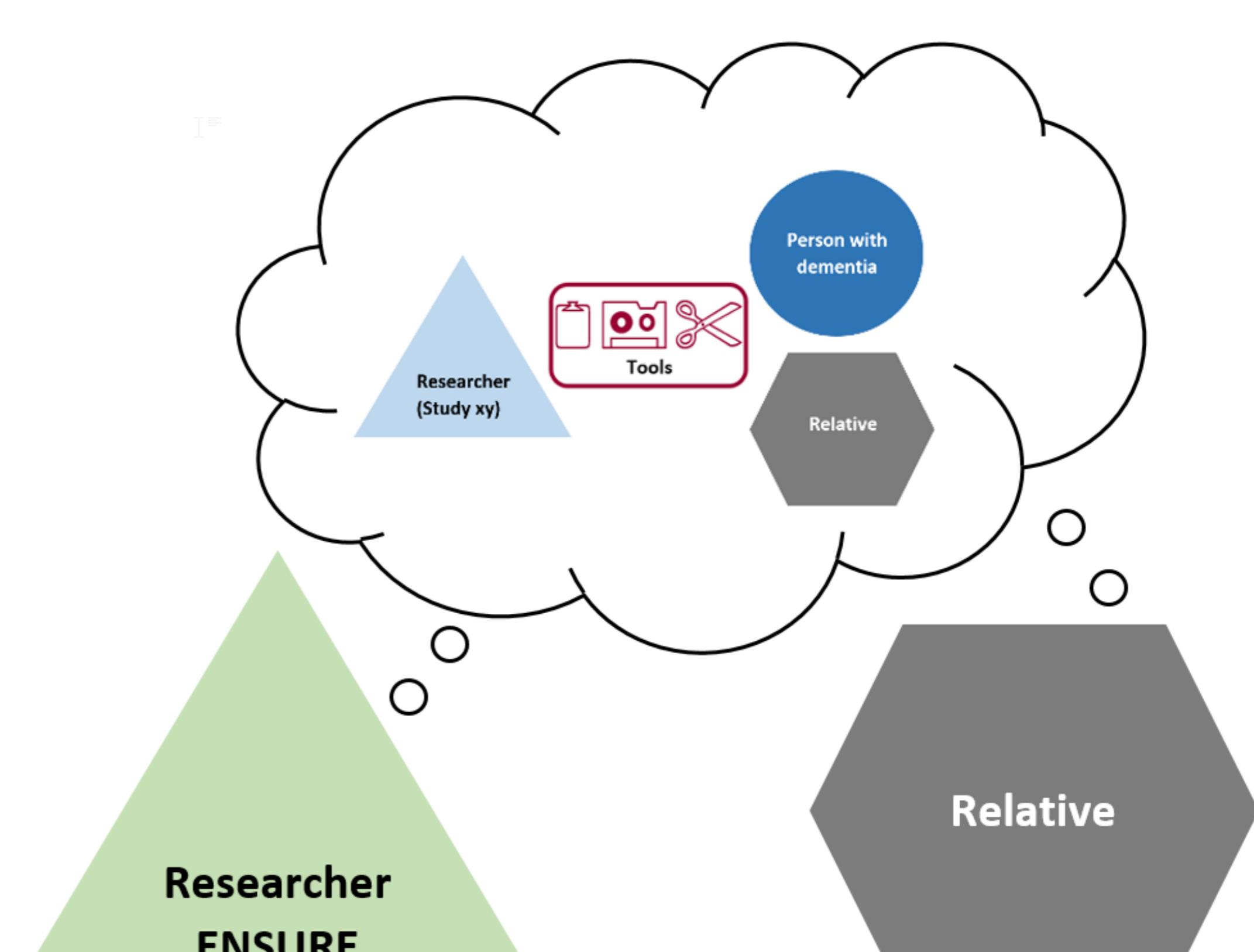


Figure 3: Problem-Centred Interviews with relatives

General contextual focus

- Experience of the enhanced informed consent process where the developed tools were applied

Specific contextual focus

- Perception of the interaction between the clinical researcher and the PwD
- Perception of the PwD's condition within the enhanced informed consent process
- Biographic information about decision-making and social needs of the PwD

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