

INVOLVING PEOPLE WITH EARLY-STAGE DEMENTIA IN QUALITATIVE RESEARCH ABOUT THEIR LIFEWORLD PERSPECTIVES: DEVELOPMENT OF A PARTICIPATORY RESEARCH MODEL

Presentation:

Oral presentation

Researcher presentation:

Senior lecturer, MnSc, RN, joint degree PhD student Diana Schack Thoft is employed at University College of Northern Denmark. She is interested in giving people with dementia a voice in research with the purpose to involve them as equal partners and co-producers in participatory research. E-mail: Dst@ucn.dk

The aim of the study was to develop a participatory research model drawing from qualitative research about the lifeworld perspectives of people with early-stage dementia. Twelve participants with dementia were recruited from a compensatory adult school in Denmark. They were trained to enable them to conduct a participatory research project in collaboration with the researcher.

A combination of participant observations, interviews and focus groups were used with observations and interviews being conducted before the research skills' training to enable the researcher to plan the training and the participatory project in accordance with the participants' competencies. Data were analysed from a hermeneutic phenomenological perspective. The focus groups were used during the training and the research project and video data from these were analysed by a thematic analysis.

The participatory research model illustrates the importance of recruiting and gaining consent from people with dementia which takes into consideration their needs. It is necessary to adjust the recruitment strategy and the consent form. In order to allow them to be involved as active participants, it is essential to plan and establish a research project which reflects their individual cognitive challenges. To simplify the project and establish small project groups can be supportive. Also role agreements are vital. It is essential to support them throughout the research process and, among other strategies; it is useful to have an errorless inspired learning environment with a structure that is repeated. Furthermore, it is important to evaluate continually to ensure a constructive process. The participants also need support and structure provided by the researcher in any dissemination phase.

Furthermore, the researcher needs to invest in the interaction to establish trusting committed constructive research collaboration. It is also important that the researcher balances the roles of being a researcher and a supporter together with being a teacher and a learner when collaborating with people with dementia. Furthermore, the researcher has to support the participants own peer-learning and -support together with creating a relaxed atmosphere. The participatory research model *Engaging people with dementia in*

research can ensure more people with early-stage dementia are involved in future qualitative participatory research.

References:

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