Improving demeNtia care Through Self-Experience- INTenSE

Output Title 1 E-booklet on self-experience practices for dementia care

T1.2 – FOCUS GROUPS FOR SELF-EXPERIENCE PRACTICES AWARENESS_Study protocol

Rationale

Self-experience or simulation practices are widely used in education and training for health care professionals, but rarely for spezialized care for people with dementa. Examples of self-experience or simulation practices are Virtual Dementia Tours (VDT), role-playing games or theatre laboratories. The INTenSE project aims to develop and implement an integrated, technology-based self-experience intervention. This intervention should enhance empathy and understanding of health care professionals and informal carers for the lived experience of dementia and improve the quality of dementia care.

The aim of the focus group interviews is to explore self-experience practices and to enhance the understanding of developing, implementation, conducting and evaluation of self-experience/simulation practice in dementia care. Information about country specific health and social care structures of education and training in dementia care are required to appropriately interpret research findings, and to derive suitable context-specific recommendations.

Method

Focus groups are characterized as active discussions between participants, guided by a moderator. Group interaction and building on group dynamics are the core elements of the method (Flick, 2014; Freeman, 2006; Jayasekara, 2012). Self-disclosure may be enhanced and group interaction may contribute to clarifying own views and attitudes (Jayasekara, 2012; Krueger and Casey, 2015). Furthermore, certain attitudes may be challenged by the other participants, and hence require deeper explanation which finally contributes to a better understanding of peoples thoughts and values (Jayasekara, 2012). This method is further suitable to explore beliefs, attitudes and feelings, while similarities and differences in perspectives become apparent (Freeman, 2006; Krueger and Casey, 2015). The *interpretive paradigm* can be regarded as the theoretical underpinning of focus groups. By generating new information from the perspectives of the participants, valuing their perceptions and subjectivity, the meaning of a certain experience for the people concerned is explored (Jayasekara, 2012).

Qualitative data reporting personal experiences, attitudes and values of people concerned are of major importance. According to the participatory design, which is the core methodology of the project, we aim to include people with (mild) dementia, informal carers and professionals working in different fields of arts or education learning through methods of self-experience into the focus groups.

Participants

Participants with experience in the field will be recruited from different national organizations (e.g. dementia self-help groups and advocacy groups or local dementia networks) and via personal contact.

Each focus group will comprise 5-8 participants. This size is recommended in order to ensure a rich discussion and enable all participants to get a word in edgeways (Freeman, 2006, Jayasekara, 2012, Krueger and Casey, 2015). Groups with people with dementia will be smaller and may consist of approximately 4 participants. Alternatively, single interviews with persons with dementia can be conducted. Oversampling of two participants is recommended, since some people with demenita, informal carers or professionals may not show up (Jayasekara, 2012), possibly due to deteriorated health condition (Barrett and Kirk, 2000).

We aim at exploring experiences and views on self experience of the disturbances which originate from cognitive impairment. Thus, participants must have made such experiences and are interested to share them.

The target people are:

- people with (mild) dementia
- informal carers/next of kin
- professionals working in the field of simulation/learnig through self-experience or care for people with dementia

The aim is to have different focus groups where each capture a different perspective.

Further characteristics

(1) People with dementia: We will include people with dementia who are willing and capable to participate in focus groups. Mainly people with mild dementia will be included, but also people with middle stage of dementia might be eligible. If wished (e.g. because they may feel more comfortable or secure), a person with dementia can participate together with his/her next of kin. As an alternativ interview format to a focus group, an individual interview might be an option.

(2) Informal carers: We will further approach informal carers of people with dementia. Informal carers shall cover a wide range of care giving situations (according to different stages of dementia). Furthermore, carers should be of different ages and have different relationships to the people with dementia (e.g. spouse, child). They should have contact to the person with dementia at least once a week.

Carers of a person with dementia who passed away no longer than 9-12 months might also be eligible.

(3) Health and nursing care professionals working in the field of simulation/learning through self-experience:

We aim to include professionals who are active in both areas: simulation/learning through self-experience and dementia care, e.g. teachers of nurses with skills lab experience using simulation techniques.

Targeted professionals have to be:

- in personal contact with people with dementia and their carers and;
- involved in the development, implementation, conducting or evaluation of methods of learning through self-experience or simulation;
- used to these methods to develop their own competences as professionals in dementia care.

To provide a range of different perspectives, they shall further have various professional backgrounds that are of importance in the respective country.

Sampling approach

We will purposively select the participants of the focus groups according to the above described criteria (purposive sampling). Different sampling strategies may be used to approach eligible participants. The national working groups must consider the promising approaches which might work in the respective country. Each partner will document the applied sampling procedure in detail (see appendix 1).

The sampling procedure might last several weeks (planned start in December 2020 and end in February 2021). After eligible participants have been identified (e.g. by relevant contact persons), oral and written information about the general aim of the INTenSE study and the focus groups will be provided. In case eligible participants (or group of participants) agreed to take part, their contact details are documented by a researcher in charge. After having collected a sufficient number of participants, the date of the group will be scheduled.

Subsequently, written information about the focus group will be provided too (e.g. date, time, (web)location). According to recommendations in the literature, participants will be contacted one or two days in advance of the focus group (Krueger and Casey, 2015; Lamnek, 2005).

Group composition

Homogeneous groups vs. diverse groups: in general, homogeneity in the composition of the focus group is recommended because common background and areas of identification are supposed to increase the openness of communication (Freeman, 2006; Hyde et al., 2005; Jayasekara, 2012; Krueger and Casey, 2015; Stevens, 1996). Homogeneity is understood as having something in common with regard to the aim of the research (Krueger and Casey, 2015). Furthermore, it is recommended to avoid mixing people who may feel they have a different level of expertise or power related to the investigated issue (Jayasekara, 2012; Krueger and Casey, 2015). Hence, we will perform separate groups with people with dementia, informal carers and healthcare professionals.

Natural groups vs. arranged groups: With regard to the research question, it might be possible (and feasible) to perform focus group discussions with pre-existing groups, for example a team of dementia care professionals who have jointly participated in a training course with self-experience or the team of an organisation working in the field of simulation/learning through self-experience. In natural groups people know each other and have a trustful relationship, which facilitates an open exchange of their thoughts. However, certain challenges are described with regard to natural groups. Such groups may have a formal or informal hierarchy or pre-existing dynamics (known or unknown to the moderator) that might hamper a free and open discussion (Freeman, 2006; Krueger and Casey, 2015). Hierarchies may be of special importance with regard to the professionals. Moreover, natural groups usually share similar knowledge and experiences, and take certain things for granted. Hence, it may be not necessary to explain ideas, attitudes and perceptions in depths to the other participants, which might hamper the understanding (Flick, 2014; Lamnek, 2005).

To sum up, natural groups may be practical but tend to be more challenging for the moderator and more difficult to analyse. Against this background, we recommend to carefully consider the composition of the group. At least, it should be reported whether the interview has been conducted with a natural group or a newly arranged (see appendix 1).

Number of focus groups

The number of focus groups is basically determined by the complexity of the research question (Krueger and Casey, 2015). However, the aim must be weighed up against the given resources and time. Therefore, 2-3 focus groups per country are recommended: one focus group will include professionals and another informal caregivers. A third focus group will include people with dementia.

Questioning route

The IO1 team (Germany) will develop a questioning route together with the partners which will be used in all countries. According to the participatory design of the study, producing the interview guide is a joint activity. In a first step of the development of the interview guide, all questions that seem relevant to the focus groups will be collected from researchers of all countries. As a result 3 different interview guides will be used for: people with dementia, informal carers/next of kin and professionals.

From the collection of questions the German team will develop the guidelines (Helfferich, 2011; Krueger and Casey, 2015). The overall Consortium will discuss and agree on the final interview guide which remains then to be translated to national languages.

The interview guide will be piloted by the German team with professionals. Modifications will be suggested if necessary.

Moderators

It is assumed that the impact of the moderator is less important in focus groups compared to individual interviews (Jayasekara, 2012). The moderator must be a neutral person, and should not have a pre-existing connection with the participants which might impede the openness of the discussion (Lehoux et al., 2006). A moderator will serve as a facilitator of the discussion, but has to avoid interfering discussion (Jayasekara, 2012). Less structured group discussion – without losing the focus – offer better opportunity to unveil topics with specific importannce to participants (Stevens, 1996). However, the influence of the moderator cannot be completely ruled out – it can be rather considered as a part of the method (Lehoux et al., 2006). Hence, the person who moderates the focus group will be carefully prepared and described with the report (see appendix 1).

The focus group will probably be conducted by two experienced and trained researchers; one researcher will serve as a moderator, and one as an assistant moderator supporting the moderator and taking notes. Involving external moderators might also be possible. The moderators are well prepared to react to possible problems during or after the focus groups, particularly with regard to the people with dementia.

Procedure

Focus groups will be conducted in each participating country.

In the context of the Covid-19 pandemia focus groups might be conducted as online groups. However, this might not be feasible for people with dementia. Therefore, single interviews can be offerened as an alternative.

The focus groups are estimated to last no longer than 2 hours. When focus groups with older people are performed, the discussion should last no longer than 1.5 hours, including a refreshment break because the ability to sustain attention might be lower (Barrett and Kirk, 2000). These aspects get even more important in cognitively impaired older people.

The first 15 minutes should be used as informal welcoming. During this time, the questionnaire on socio-demographic characteristics (see appendix 2a, b, c) might be completed, and the informed consent sheet to be signed (if not yet done).

Focus groups with people with dementia

Overall, conducting focus groups with older (and cognitively impaired) people might be more difficult due different reasons. Barrett & Kirk (2000) provide an overview about their experiences in running focus groups with older people and propose a number clues and strategies how to deal with certain challenges. Their description might be used as practical guide for the focus groups with people with dementia. However, even if focus groups with older people are particularly challenging, group discussions also have advantages. No participant must feel pressured to answer a particular question, and each person may only speak when she or he has a definite feeling or opinion about a certain question (Stevens, 1996). Furthermore, the group may be perceived as supportive, and the discussion may be even less exhausting than single interviews because a participant is not urged to answer.

Location

The focus groups will be conducted online using a secure and easy-to-understand method of communication, such as Webex or Bigbluebutton meetings. Each person should be located in a protected and quiet place without distractions. In general, barriers to reach the locations shall be low and people should feel comfortable (Krueger and Casey, 2015). In principle, the online format should make it easier to reach such a place in a private or institutional environment.

Documentation

Reporting is a precondition for assessing the trustworthiness of the study (Rolfe, 2006; Tong et al., 2007). Hence, a concise and precise description of the process of recruiting, data collection and analysis is required.

(1) Information about participants
A short questionnaire asking for some socio-demographic information will be filled in by the participants (see appendix 2a, b, c). Please report the collected information on a table (template provided, see appendix 3).

(2) Documentation of the discussion
During the discussion, the assistant moderator will take notes on non-verbal communication and emotional reactions (e.g. when the other participants nod or shake their heads). Any disturbances or distractions that might affect the group discussion will also be noted (e.g. someone enters the room by mistake). Furthermore, we recommend noting the initial words of each contribution (“*Well, I do not agree ...*”). That was perceived as particularly helpful when writing the transcripts. A template for the notes is provided (see appendix 4).

(3) Information about the moderators
A brief description of the moderator will be provided including age, gender, profession, and whether an external professional moderator was engaged or whether a member of the research team performed the focus groups. Please indicate whether the moderator had any pre-existing relationship to the participants, and if so, please describe whether this relationship could have influenced the discussion (see appendix 1).

(4) Information about the researchers analysing the data
The researcher who performed the analysis should be described: age, gender, profession, and whether they have also performed the focus group and/or had any connection with the participants (see appendix 1). Moreover, researchers reflections on their own action and observations and also their impressions and feelings will be part of the interpretation (Flick, 2014). Personal assumptions and pre-existing opinions may be helpful, but could also bias the analysis and impede the openness of the researcher (Krueger and Casey, 2015). Hence, each member of the research team contributing to the analysis shall reflect on and note down their ideas and presumptions with regard to the research question. Making aware of own presumptions may enhance the reflexibility and openness. This information may support the analysis but does not need be forwarded to the IO1 team.

Analysis

So far, few studies have analysed cross-national, qualitative data, and if so, mainly by using joint categories applying a consented coding system (Bastiaens et al., 2007; Moretti et al., 2011). Stephan et al. (2018) developed a stepwise procedure with an independent country analysis before the cross-national findings were synthesised. We will use this procedure for analysing our focus group interviews.

1) Analysis of national focus groups:
The focus groups will be transcribed verbatim. In each country, the transcripts will be independently analysed using thematic analysis (Braun & Clarke, 2006) according to a defined procedure.

Presumptions
Researchers contributing to the analysis shall reflect on and note down their presumptions with regard to the research questions (e.g. „The experiences of people with dementia will be different during the trajectory of the dementia." or „The use of self-experience practices require reflective abilities of professionals or informal carers."). That step can enhance the awareness of researchers for their own presumptions to improve the reflexivity and openess.

Since the group interaction is a special characteristic of focus groups, group dynamics should be considered within the analysis (Reed and Payton, 1997; Webb and Kevern, 2001). A set of *analytic questions* taking group dynamics into account is proposed in the literature (Stevens, 1996). Those questions contribute to a better understanding of the group interaction, and provide insight into how the meaning at the group level can be understood rather than focusing on individual answers of certain participants.
Thus, as a first step of the analysis, each working group will concisely answer the analytic questions for each focus group (see appendix 1). Consecutively, an inductive content analysis will be applied that means using open coding and deriving categories directly from the material (Elo and Kyngas, 2008; Graneheim and Lundman, 2004; Hsieh and Shannon, 2005). When applying an open coding procedure, we follow the assumption that dialogue among researchers is highly valuable and promotes the most likely interpretation of the data (Graneheim and Lundman, 2004).
Hence, the analysis should be performed by at least two researchers (Researcher A and Researcher B, see Figure 1). Both shall develop independently initial codes, and first categories shall be developed jointly during a meeting. Deviations, divergent interpretations and variants of meanings within the transcripts shall be discussed until agreement is reached. We follow the assumption that dialogue among researchers is highly valuable and promotes most likely the interpretation of the data (Graneheim and Lundman, 2004).
The transcripts of the focus groups will be read line by line to identify meaning units (such as words, sentences or paragraphs that relate to the same meaning), aiming to condense the material. To abstract the content, meaning units will be labelled with codes. Codes are described *as tools to think with* because labelling a meaning unit with a code presents a new way of thinking about the data (Graneheim and Lundman, 2004). Based on the codes, categories and sub-categories will be developed that are considered as the manifest content of the transcript (Graneheim and Lundman, 2004; Hsieh and Shannon, 2005). During the process of analysing and interpreting the data, researchers shall reflect their presumptions, feelings and impressions (Flick, 2014). Each (sub-) category will be described in its meaning, and so called *anchor examples* have to be selected from the transcripts. *Anchor examples* are chosen to clearly illustrate the meaning of each category. If necessary, sequences of the discussion could be chosen to point out how the interaction between the participants contributed to the result. In a final step, derived categories shall be introduced to researchers not involved within the analysis (e.g. discussed within the research team) in ordert o check ist plausibility.
The findings should be reported in a narrative and comprehensive way. A thick description of each category (and sub-categories if necessary) shall be given, explaining its content, meaning, reach (or relation to other categories, if applicable), and appropriate anchor examples shall be added. For each (sub-) category, one or two citations or anchor examples are to be chosen that illustrate clearly the

meaning of the category. Sequences of the discussion could also be chosen to underline how the interpretation between the participants contributed to the result.
For validation purposes, the results (categories, descriptions and anchor examples) of each country will be carefully translated into English. Translation of qualitative data is described as challenging and has to be carefully conducted (Twinn, 1997). To establish trustworthiness of the translation, the same translator will be involved. The wording and phrasing might vary between different translators which impedes interpretation. Moreover, it is more likely that one translator gets familiar with the data and reaches more reliable translations (Twinn, 1997). The translation shall be checked bay a second person (or the research team) to avoid deviations in meaning or misinterpretations (Al-Amer et al., 2014).

2) Cross-national analysis: Translated country results will be forwarded to the IO1 leader, who will summarise and synthesise the findings. The IO1 team will review the results of all countries. The aim is to develop joint categories representing the country-specific findings on an interpretative level (Graneheim and Lundman, 2004).

3) Evaluation of the synthesis:
As a final step, the synthesis of the cross-national analysis will be evaluated and discussed by the whole Consortium. This process requires closed collaboration between the partners to ensure that interpretations reflect and capture the meaning of each country's results (in personal meetings or using video conferencing).

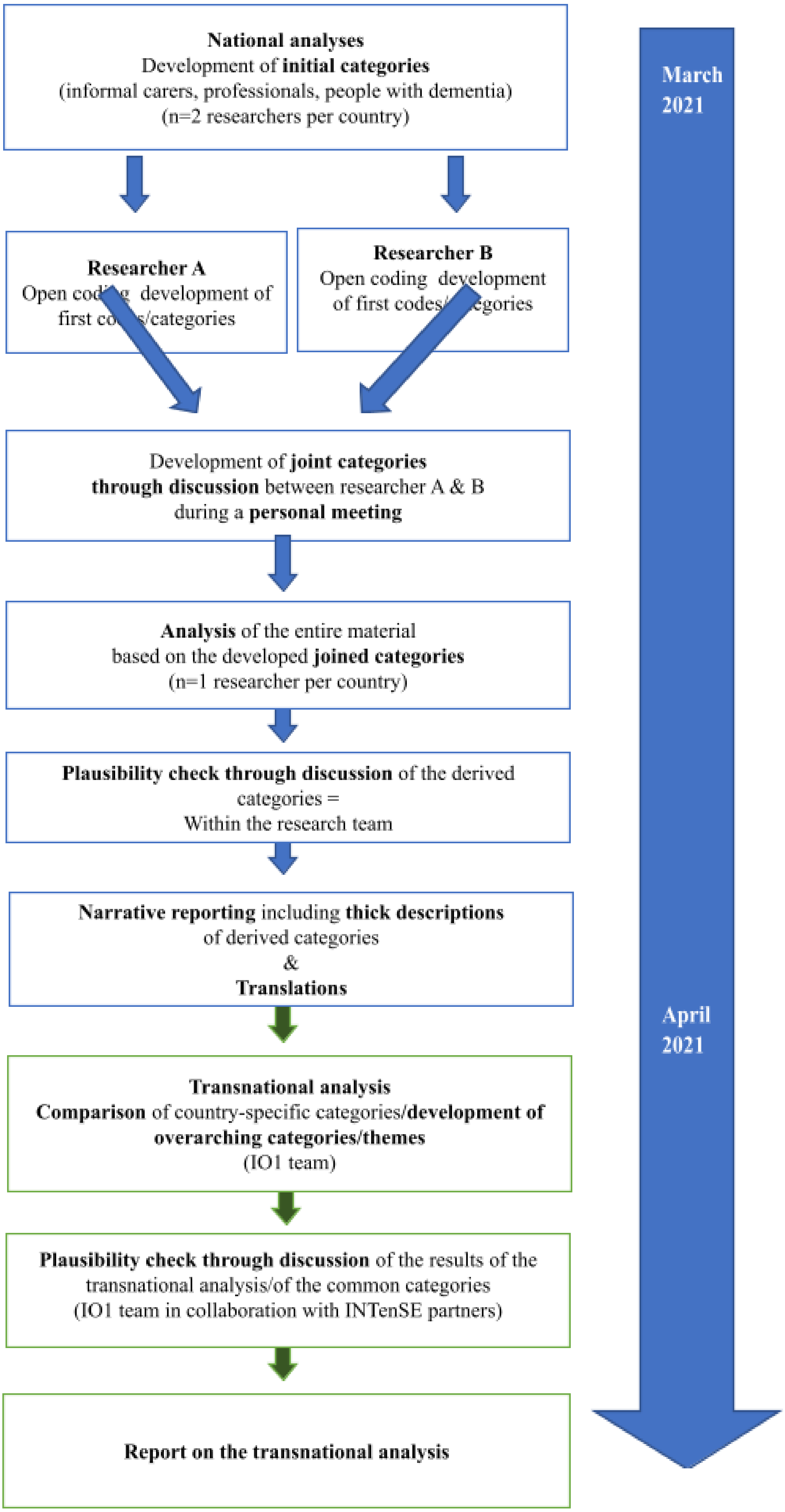
Ethical considerations

Each country will apply for ethical approval with their responsible national or local authorities. Focus groups will be taped or video recorded (according to country specific regulations) and consecutively transcribed verbatim. National regulations in assessing informed consent, in particular with regard to the informed consent of people with dementia are followed. Appropriate informed consent forms, information letters and invitations will be developed by the respective working group of each country. Data protection will be ensured by each country and no personal data of participants will be made accessible to other people outside the local research team.

Schedule

The focus groups will be conducted between February and March 2021. First, a pilot focus group will be performed by the IO1 leader (planned in early February 2021). Procedures and questionning route will be piloted and adjusted if necessary. A brief report about the pilot focus group, the encountered problems and necessary adjustments will be circulated by the German team. The data of the pilot focus group will be provided as soon as possible. Afterwards, the focus groups will be performed in all countries. The country analysis must be performed between March and April 2021, while the cross-national analysis will be contucted between April and May 2021. A joint web-conference in February 2021 will be used as preparatory session. A second session will be used to prepare the analysis procedure in March 2021. In May 2021, a third session will take place to discuss the synthesis of the cross-country analysis. Figure 1 shows the flow-chart of the analysis procedure steps.

Figure1: Flow-chart displaying the national and transnational analysis including time schedule.



Appendices

- annex_1_template_process&context
- annex_2a_questionnaire_carer
- annex_2b_questionnaire_pwd
- annex_2c_questionnaire_professionals
- annex_3_tables
- annex_4_template_notes
- annex_5_analytic_questions

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