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Supplementary Material – 2

Guiding questionnaire for focus group discussion or interviews with caregivers and early-diagnosed persons (to be translated in German and Hebrew)

1. Starting Round (max. 10-15 minutes):

Please introduce yourself very briefly in 1-2 sentences and tell us, what interests you about the topic of prediction and early diagnosis of dementia and what has motivated you to participate in the focus group discussion / interview.

2. Experience, knowledge and assessment of the prognosis and early diagnosis (15 minutes):

Some of you might have already experiences or knowledge about the procedures in memory clinics/dementia diagnostics:

(a) What do you know about the technical possibilities of predicting the probability of being affected by dementia, for example by means of imaging techniques of the brain or the examination of the spinal fluid?

(b) Which advantages and disadvantages do you foresee in being able to predict some years ahead that someone will suffer from dementia with a statistical probability, but not with a 100% certainty?

3. Evaluation of specific situations in which affected people are told the results of the examinations mentioned earlier (30 minutes)

Firstly, imagine the following scenario: Ms. Wagner is in her early 60s and notices that she occasionally forgets certain things. She visits a memory clinic to be examined. After a few tests – both physical as well as neuro-psychological tests, such as repeating word lists – she is

told that there would be a higher risk of her developing Alzheimer's disease in the years to come.

(a) In which sense could this diagnosis have an impact on Ms. Wagner's life positively or negatively? (Do you think Ms. Wegner would have to make changes in her life style (by means of nutrition, sports, housing, etc.) after having been informed on the risk of developing the disease in the coming years?)

(b) If you were in Ms. Wagner's shoes, what kind of information would you need in order to be able to deal with such a diagnosis?

Additional questions (only if they haven't been mentioned previously or to facilitate a more in-depth conversation)

- Do you think Ms. Wagner should share her diagnosis with others? Should she inform her family members or other relatives? In your opinion, to whom should she most certainly not talk about this? Who should be present when the results of the tests are told?
- What do you think, how would relatives/the family response to this diagnosis? (What would they feel or think about her? Would they change their behavior towards Ms. Wagner?)
- What do you think, how the social environment (neighbors, colleagues, friends) react to Mrs. Wagner after they heard about the diagnosis?
- What do you think, what the social environment would think about Ms. Wagner's **family**?
- When is the best moment to seek help and undergo such tests from your point of view? Sooner or rather later?

Thank you so far!

4. Impact of such knowledge/information on the individual/family life (10 minutes)

Imagine you are one of Ms. Wagner's friends and she tells you about her diagnosis and ask you for advice what to do in general. To what extend would you advise her to change certain things in her life, and, if so, why would you advise her to do so in the first place?

- Should she change things such as reconsidering finances and investment, living arrangements, nutrition and fitness, advance directives, patient wills, etc.) – (Mention one after the other, do not mention all at once and consider addressing or linking back to points mentioned previously!).

Thank you so far!

5. Impact of dementia diagnosis/prediction for assessing the tool of advance directives for care/treatment and for research (20 – 30 minutes)

Imagine the following scenario: a teacher is in his late 60s years old and decides to write/compose an advance care directive because of the prognosis that he probably would suffer from dementia later. In this advance directive, he specifies that he will object any medical treatment when suffering from severely advanced dementia.

(a) What is your general opinion about advance care directives? Would you get one? Or do you have one in place already?

(b) What do you think: Should one really follow such an advance care directive, which would mean in this case, not to treat any illness, neither whether it is reversible (e.g. pneumonia) or of irreversible (e.g. stroke, with irreversible damage of brain parts, incl. paralysis of body parts)

(c) In the field of medical research about dementia and its potential treatment, relatives as care givers or legally appointed proxies/power of attorneys currently decide in the patient's place if he/she is no longer able to do so for him/herself. There are new suggestions to allow those affected to draw up an advance research directive outlining their intent to participate in future research studies or not. This directive would come into effect as soon as the patient is no longer able to express clearly his/her will – comparable to an advance care directive.

How do you feel about this? What would you prefer: let relatives and legal power of attorneys decide or rather the patient decides about him/herself in advance?

- *Which problems do you foresee?*
- *As to the benefits of the medical and behavioural research about dementia: does it matter to you if there is a slight chance for the person diagnosed with dementia to*

benefit from the research herself or would it be sufficient that only the future patient generations would benefit?

- *Would you make a difference for such a research directive what type of research is considered? Some studies with people with dementia include solely the observation of their behavior in a care institution (e.g. which sort of care influences the well-being and activity pattern of patients positively?). Other studies include the testing of new medication or diagnostic techniques. If so, could you kindly elaborate on your reasoning?*

Thank you so far!

6. Conclusion (max. 10 minutes)

Thank you. It was an enlightening discussion. As we now come to the end of this focus group, we would be happy to welcome any final contributions at this point.

Is there anything we haven't mentioned or asked about, but what you think is very important for us researcher to consider?

Thank you very much for your participation. We wish you a safe way home.