

# Supplementary Material

## Dyadic Discrete Choice Experiments Enable Persons with Dementia and Informal Caregivers to Participate in Health Care Decision Making: A Mixed Methods Study

### Supplementary Material 1

**Table 5.** A Checklist for MMR Manuscript Preparation and Review.

Rational and description of MMR design	<ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> Provide a clear statement of the study purpose</li> <li><input checked="" type="checkbox"/> Explicitly describe the MMR design in accordance with Creswell's (2015) typology and use a diagram to illustrate the relationship and sequence of qualitative and quantitative research components</li> </ul>
Transparency in describing method details	<ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> Justify why the MMR design is appropriate for meeting the study purpose</li> <li><input checked="" type="checkbox"/> Describe the study population(s) and sample(s; e.g., who, what, how many)</li> <li><input checked="" type="checkbox"/> Describe the sampling procedures (including inclusion and exclusion criteria, recruitment)</li> <li><input checked="" type="checkbox"/> Describe qualitative data collection processes (how often data were collected, who collected the data, what kind of data collection instruments were used, how data were recorded—e.g., notes, transcripts)</li> <li><input checked="" type="checkbox"/> Describe quantitative data collection processes (how often data were collected, who collected the data, what kind of data collection instruments were used measurements, validity/reliability)</li> <li><input checked="" type="checkbox"/> Describe qualitative data analysis processes (coding, single or multiple coders, replication logic, credibility)</li> <li><input checked="" type="checkbox"/> Describe quantitative data analysis procedures (missing data and how they are handled, statistical tests used)</li> </ul>
Integration of qualitative and quantitative research components	<ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> Interpret qualitative analysis results with appropriate quotes if necessary</li> <li><input checked="" type="checkbox"/> Interpret quantitative analysis results in consideration of statistical significance, selection bias, and threats to validity</li> <li><input checked="" type="checkbox"/> Compare qualitative and quantitative results</li> <li><input checked="" type="checkbox"/> Address divergencies and inconsistencies between qualitative and quantitative results</li> </ul>

Table 5. A Checklist for MMR Manuscript Preparation and Review.

## Supplementary Material 2

### COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

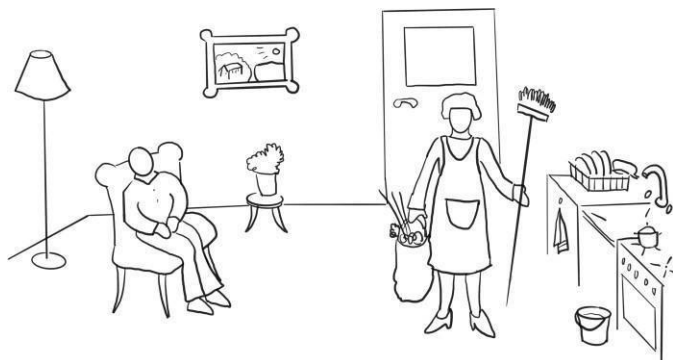
Topic	Item No.	Guide Questions/Description	Reported on Page No.
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
<b>Domain 2: Study design</b>			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
<b>Domain 3: analysis and findings</b>			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

**Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.**

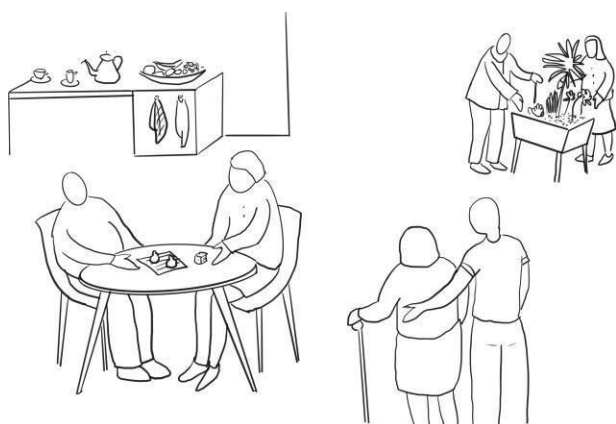
### Supplementary Material 3



I can get assistance with household tasks such as cleaning, doing groceries, and cooking.



I can get assistance with personal care such as washing, bathing, dressing, and medication.



I can participate in activities that I like and socialize with other people.



I can talk to someone if I want to share my worries or concerns.



I can get information about having memory loss or dementia.

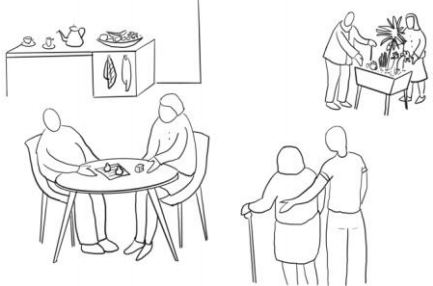



I can receive home adaptations such as a stairlift or grab bars for the toilet and shower.



I can get assistance with organizing care such as applying for in-home care or help with insurance.

**Supplementary Material 4**

	Package A	Package B
 <p>I can participate in activities that I like and socialize with other people</p>	<p><b>Once per week</b> activities are organized <b>at a daycare center</b></p>	<p><b>Multiple times per week</b> there is someone <b>coming to my house</b> to do activities together</p>
 <p>I can talk to someone if I want to share my worries or concerns.</p>	<p>I can talk to a <b>peer support group</b></p>	<p>I can talk to my <b>case manager</b></p>
<p>Select your preference</p>	<p><input type="checkbox"/></p>	<p><input type="checkbox"/></p>

## Supplementary Material 5

	Explanation	Example quotes
Individual DCE person with dementia		
Understanding the choice task <ul style="list-style-type: none"> <li>- Understand choice task</li> <li>- Learning curve</li> <li>- Need for reminders</li> <li>- Decision making strategy</li> </ul>	<ul style="list-style-type: none"> <li>- Understand what is expected making the choice task and able to make trade-offs</li> <li>- Participants understand choice task after the practice round or multiple choice tasks</li> <li>- Participants needed a reminder of what was expected at every new choice task or during a single choice task</li> <li>- How did people start making choices. Starting point on top of choice task or from most attractive attribute/level</li> </ul>	<p><b>Person with dementia:</b> So what do I need to do? I have to choose between A and B right?</p> <p><b>Interviewer:</b> Yes that's right.</p> <p><b>Person with dementia:</b> Why can't I choose for this care A and for this B, I don't get it.</p> <p><b>Person with dementia:</b> You want the best options from the package. This is not possible because they are in both A and B. Both packages have their advantageous, which makes it difficult to choose.</p> <p><b>Person with dementia:</b> I think I'll go for package A, in home care at a fixed time, peer group for emotional support. Even though I prefer the case manager, I don't think this is most important, so peer support is sufficient. For Information about dementia; I think the phone helpline is not that good. Also for organizing care I can go to her (case manager) in package A. So A, I choose for A.</p>
Attribute perception <ul style="list-style-type: none"> <li>- Screening</li> </ul>	<ul style="list-style-type: none"> <li>- Attributes were not taken into consideration</li> </ul>	<p><b>Person with dementia:</b> This (emotional support) is very</p>



<ul style="list-style-type: none"> <li>- Understanding attribute</li> <li>- Attribute preference</li> <li>- Recognizing attributes</li> </ul>	<ul style="list-style-type: none"> <li>- Could provide description of attribute</li> <li>- Strong preference for single attributes</li> <li>- Recognizing after few choice tasks</li> </ul>	<p>important. Sometimes the tension builds up. It also has to do with the disease, I have dementia. Therefore many things are changing in my life, that is hard to deal with.</p> <p><b>Person with dementia:</b> I think personal in-home care becomes more important than help with daily activities. You can ask your children to do groceries and those sort of things, however you cannot expect them to come to shower you every morning and things like that.</p>
<p>Attribute level perception</p> <ul style="list-style-type: none"> <li>- Understanding levels</li> <li>- Single level preference</li> <li>- Difficulties with same level used multiple attributes</li> </ul>	<ul style="list-style-type: none"> <li>- Understood meaning level yes/no</li> <li>- Strong preference for only 1 attribute of the choice task</li> <li>- E.g. case manager in multiple attributes in 1 choice task</li> </ul>	<p><b>Person with dementia:</b> At the day care center you are out for a day and there are other people you can talk to. That is different from somebody coming to my home, then everything stays the same. At the day care people know you, it is an outing.</p>
<p>Option attractiveness evaluation</p> <ul style="list-style-type: none"> <li>- Process all options</li> <li>- Trade-off over all options full DCE</li> <li>- Visual overload</li> </ul>	<ul style="list-style-type: none"> <li>- Able to understand all information from the options given in the choice task</li> <li>- Could make tradeoffs across all aspects of the choice task presented</li> <li>- Too much info presented, unable to process all information</li> </ul>	<p><b>Person with dementia:</b> I do not know; it is a lot. Yes, combining the cards [attributes and levels]. I try to do it card by card. Then if I read the next, this one was B, the other I had A, then I do not know what to do.</p> <p><b>Person with dementia:</b> So far I have B, B, A, and A. And now I have to choose where I place</p>

		the weight on so I can choose between package A or package B
<p>Decision rule selection</p> <ul style="list-style-type: none"> <li>- No motivation (random choice)</li> <li>- Denying present situation</li> <li>- Refer to present situation/care use</li> <li>- Outside choice task</li> <li>- Simplified choice</li> <li>- Proxy</li> <li>- Future needs</li> </ul>	<ul style="list-style-type: none"> <li>- Making a decision without any consideration</li> <li>- Deny they have dementia/care needs</li> <li>- E.g. use of home care, day care centre</li> <li>- Refer to motivation outside the boundaries of choice task</li> <li>- Counting preferred attributes/levels (e.g.3 versus 1 attributes) instead of making trade-offs,</li> <li>- Motivate decision from other persons view (e.g. my caregiver thinks this is important</li> <li>- difficult to think what might be needed in the future</li> </ul>	<p><b>Person with dementia:</b> Well I think I choose for ... let see, one, two, three for this package. That is three out of four, so I choice that one</p> <p><b>Person with dementia:</b> I try to take into account that in the future I might be doing worse. It is a shame, at this moment I'm doing quite ok, however it will become less and less. At a given point I can have a major setback, then things become more difficult. Now I have to think about what I still might be able to in the future and what not, that is very difficult.</p> <p><b>Person with dementia:</b> So for sharing my worries (emotional support) with the case manager, that is in package B. The case manager is also in package A for information about dementia. For info the telephone helpline is in B. Well, if in the end I choose for package B, and let's say I want to ask her for information, I can just ask her because I will see her anyway.</p>
Joint Dyadic DCE		

<p>Informal caregiver assisting with choice task</p> <ul style="list-style-type: none"> <li>- Help understand choice task</li> <li>- Provide decision making strategy</li> <li>- Provide contextual considerations</li> </ul>	<ul style="list-style-type: none"> <li>- Informal caregivers explained what is expected in making the choice task</li> <li>- Informal caregivers provide the person with dementia strategies to make trade-offs</li> <li>- Informal caregiver provides context to persons with dementia reminding them what happens in reality, or what a person with dementia can or can't do</li> </ul>	<p><b>Informal Caregiver:</b> You also must consider the other cards.</p> <p><b>Person with dementia:</b> You mean I cannot pick both?</p> <p><b>Informal care Caregiver:</b> No, you must choose between package A or B. So, if you prefer to have the home adaptations reimbursed, you can only contact the telephone helpline for assistance with organizing care and not the case manager.</p> <p><b>Person with dementia:</b> Ok, now I remember. I cannot take both, I must choose between these two.</p> <p><b>Person with dementia:</b> I do not need help with doing groceries. This is something I can still do myself.</p> <p><b>Caregiver:</b> No, you cannot do this by yourself.</p> <p><b>Person with dementia:</b> Why not?</p> <p><b>Caregiver:</b> How? You have not done this for years.</p> <p><b>Person with dementia:</b> I just go there by bike.</p> <p><b>Caregiver:</b> I do not think that is a good idea, sometimes we ask our children to do that.</p>
<p>Preference adaptations</p> <ul style="list-style-type: none"> <li>- Letting the person with dementia choose first</li> <li>- Ask for confirmation</li> </ul>	<ul style="list-style-type: none"> <li>- Informal caregivers asking for the preference of the person with dementia before revealing their own preference</li> </ul>	<p><b>Person with dementia:</b> what is your choice?</p> <p><b>Informal caregiver:</b> you go first, I want to hear your opinion first</p>

<ul style="list-style-type: none"><li>- Letting the informal caregiver choose</li></ul>	<ul style="list-style-type: none"><li>- Person with dementia asking if the informal caregiver agrees with his decision/motivation</li><li>- Persons with dementia refraining from choosing if they find the choice task too difficult</li></ul>	<p><b>Person with dementia:</b> what do you think? <b>Informal caregiver:</b> I'm going to say option B <b>Person with dementia:</b> Ok, we will take B. I don't know.</p>
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