

Patient Relevant Criteria of Person-Centered Care for Community-Dwelling People with Dementia: A Formative Qualitative Study to Design a Quantitative Preference Study

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Background

- To provide **Person-Centered Care (PCC)** patient preferences must be known¹
- Data on stated preferences for care are scarce among People living with Dementia** and Mild Cognitive Impairment (hereafter commonly 'PlwD')²
- Elicitation of **stated preferences requires a priori information** about **patient relevant criteria**^{3, 4}
- Poorly identified criteria** can have **negative implications** for the design and conduct of stated preference-surveys⁵
- A combination of methods**, e.g. **literature reviews**, expert opinion reviews, professional recommendations, and **qualitative research with patients**, has been recommended, to ensure patient relevance⁶

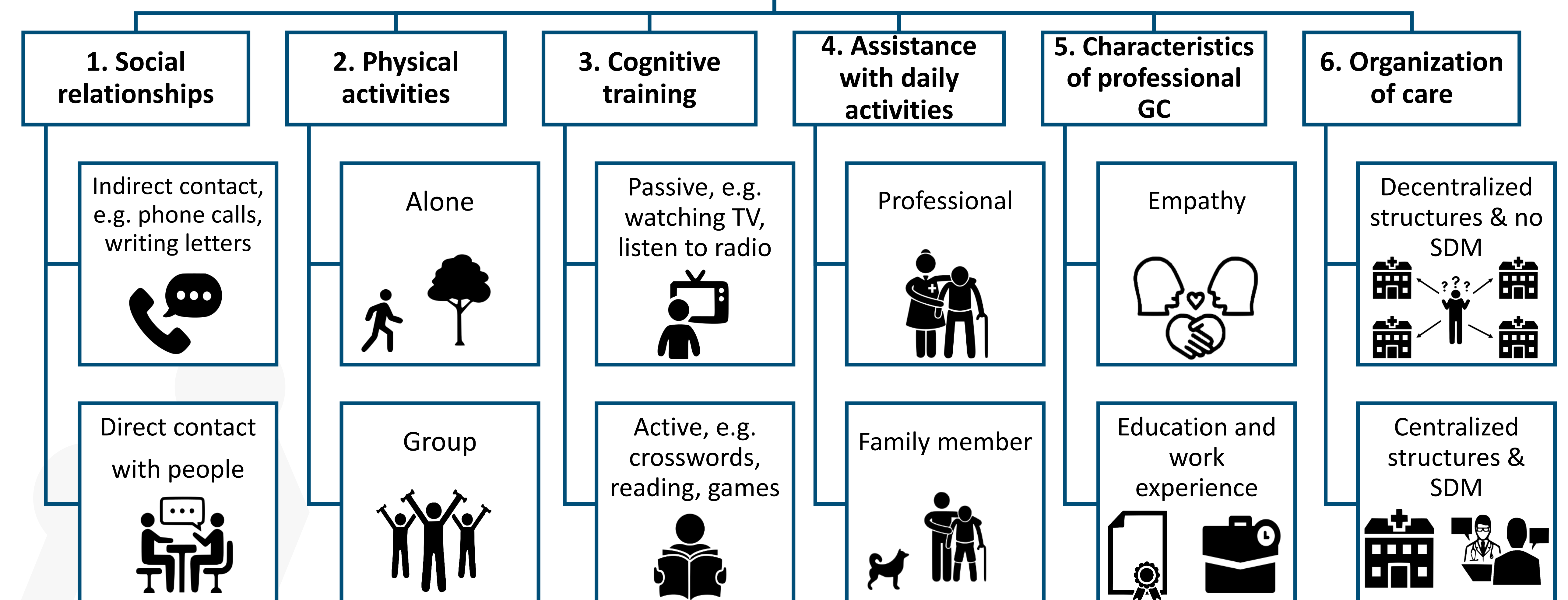
Aim

Our study aimed to present a rigorous process report of (sub)criteria identification for the design of an Analytic Hierarchy Process (AHP), to elicit patient preferences for PCC among community-dwelling PlwD.

Methods

- Overarching stated preference-study '**PreDemCare**'⁷ adopts a sequential **mixed-methods-design** for instrument development
 - Approved by the Ethics Committee at the University Medicine Greifswald April, 9 2021 (Ref.-No.: BB018-21)
- Pre-study:** initial **systematic review**⁸ to identify conceptual (sub)criteria, followed by **qualitative interviews** to identify actually patient-relevant (sub)criteria
- Expert interviews** with **n=2** internal dementia specific qualified nurses, so-called **Dementia Care Managers (DCMs)**⁹
- Patient interviews** with **n=10** community-dwelling **PlwD** and **n=3** **informal CGs**
- Typical case sampling¹⁰ (purposive sampling¹¹) until expected saturation¹¹, participants accessed via DCMs as gatekeepers
- Expert interviews via video conference software, review of content, language, format, layout
- Individual patient interviews**, subject to prior informed written consent, conducted in PlwD's homes or day clinics Apr-May 2021 incl. **semi-structured interview guide** and **card game**
- Card game results analyzed in Microsoft Excel
- Interviews transcribed verbatim**, coded and analyzed by two reviewers with **qualitative content analysis**¹²

Patient-relevant criteria of PCC for PlwD



Results: Other emerging topics

- Wording and comprehensibility
 - General / abstract formulations are difficult to process – concrete examples needed so patients can relate
 - Dementia is an extremely sensitive topic – avoid “dementia”-related wording
- Fear of being tested
- Inclusion of family caregivers, setting boundaries as interviewer
- COVID-19 was a present topic during the participants' elaborations, especially concerning criteria 1 and 2

Conclusions

- To the best of our knowledge the first evidence about patient-relevant (sub)criteria of PCC for PlwD to design a quantitative preference instrument
- Future research should pay particular attention to dementia-sensitive wording and the balance between comprehensibility vs. realizability, completeness, independence and relevance of the criteria and sub-criteria in this population.

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