

# 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 known<sup>1</sup>
- Data on stated preferences for care are scarce among People living with Dementia and Mild Cognitive Impairment (hereafter commonly 'PlwD')<sup>2</sup>
- Elicitation of stated preferences requires a priori information about patient relevant criteria<sup>3, 4</sup>
- Poorly identified criteria can have negative implications for the design and conduct of stated preference-surveys<sup>5</sup>
- A combination of methods, e.g. literature reviews, expert opinion reviews, professional recommendations, and qualitative research with patients, has been recommended, to ensure patient relevance<sup>6</sup>

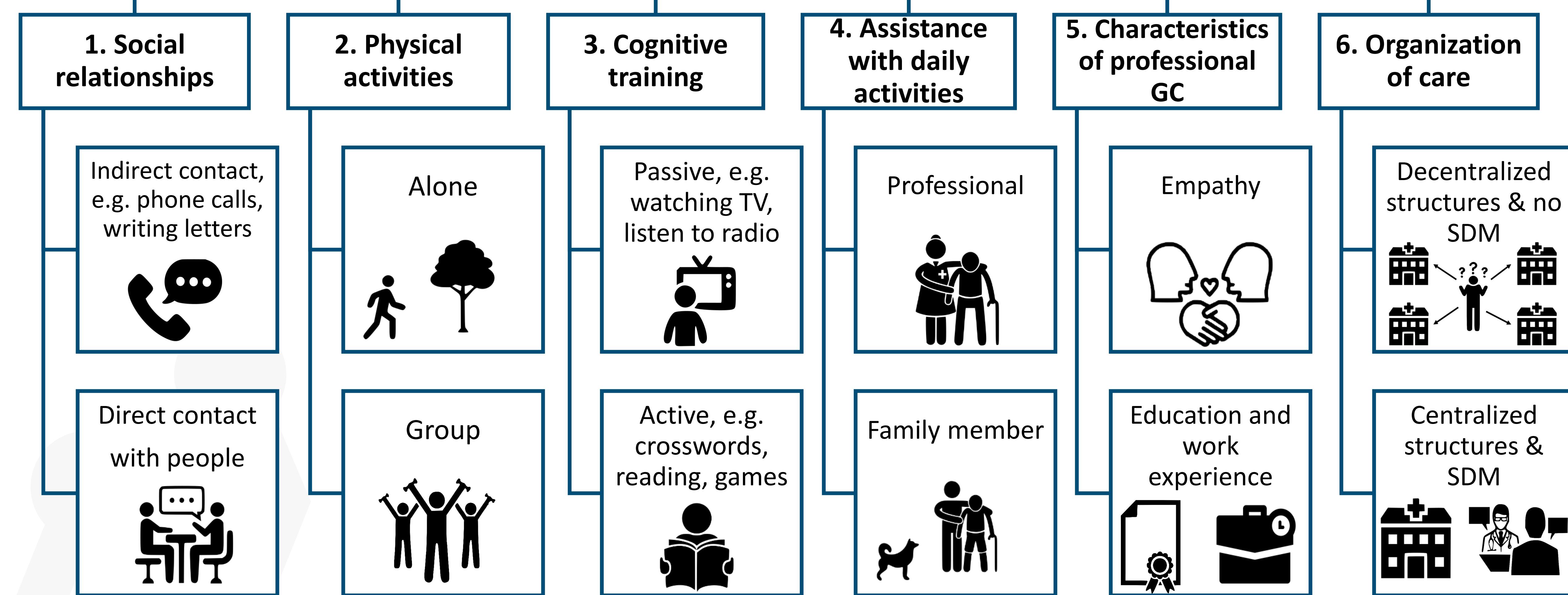
## Aim

*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**'<sup>7</sup> 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**<sup>8</sup> 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)**<sup>9</sup>
- **Patient interviews** with n=10 community-dwelling PlwD and n=3 informal CGs
- Typical case sampling<sup>10</sup> (purposive sampling<sup>11</sup>) until expected saturation<sup>11</sup>, 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**<sup>12</sup>

## 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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