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Thema: Moving towards Person-Centered Care of People with Dementia – Elicitation of Patient Preferences and Physicians‘ Judgements for Care

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Overview of articles

This thesis is based on the results from the *PreDemCare*-Study (Moving towards Person-Centered Care of People with Dementia – Elicitation of Patient and Physician Preferences for Care) and consists of four articles published in peer-reviewed journals:

1. **Mohr W,** Rädke A, Afi A, Edvardsson D, Mühlichen F, Platen M, Roes M, Michalowsky B, Hoffmann W. Key Intervention Categories to Provide Person-Centered Dementia Care: A Systematic Review of Person-Centered Interventions. *J Alzheimers Dis.* 2021;84(1):343-366. doi:10.3233/JAD-210647
2. **Mohr W,** Rädke A, Afi A, Mühlichen F, Platen M, Michalowsky B, Hoffmann W. Development of a Quantitative Instrument to Elicit Patient Preferences for Person-Centered Dementia Care Stage 1: A Formative Qualitative Study to Identify Patient Relevant Criteria for Experimental Design of an Analytic Hierarchy Process. *Int J Environ Res Public Health.* 2022;19(13):7629. doi:10.3390/ijerph19137629
3. **Mohr W**, Rädke A, Afi A, Mühlichen F, Platen M, Scharf A, Michalowsky B, Hoffmann W. Development of a Quantitative Preference Instrument for Person-Centered Dementia Care-Stage 2: Insights from a Formative Qualitative Study to Design and Pretest a Dementia-Friendly Analytic Hierarchy Process Survey. *Int J Environ Res Public Health.* 2022;19(14):8554. doi:10.3390/ijerph19148554
4. **Mohr W,** Rädke A, Afi A, Weber N, Platen M, Mühlichen F, Scharf A, Michalowsky B, Hoffmann W. Do They Align? Congruence Between Patient Preferences of People Living with Cognitive Impairments and Physicians' Judgements for Person-Centered Care: An Analytic Hierarchy Process Study. *J Alzheimers Dis.* 2023;91(2):727-741. doi:10.3233/JAD-220753

An additional fifth first-author publication – the study protocol for the *PreDemCare*-Study – is included for completeness of presentation of the PhD-project:

Mohr W, Rädke A, Michalowsky B, Hoffmann W. Elicitation of quantitative, choice-based preferences for Person-Centered Care among People living with Dementia in comparison to physicians' judgements in Germany: study protocol for the mixed-methods PreDemCare-study. *BMC Geriatr.* 2022;22(1):567. doi:10.1186/s12877-022-03238-6

Figures and tables

List of abbreviations

APPX.	Appendix
AHP	Analytic Hierarchy Process
BWS	Best-Worst-Scaling
CG	Caregiver
CF.	Confer/ Conferatur, compare
CR	Consistency Ratio
DCE	Discrete Choice Experiment
DCM	Dementia Care Manager
E.G.	Exempli gratia, for example
GBD	Global Burden of Disease-Study
I.A.	Inter alia, amongst others
I.E.	Id est, meaning
ISPOR	International Society for Pharmacoeconomics and Outcomes Research
MCDA	Multi-Criteria Decision Analysis
MCI	Mild Cognitive Impairment
MmD	Menschen mit Demenz
MMSE	Mini-Mental State Examination
PELI	Preferences for Everyday Living Inventory
PlwD	People living with Dementia
PCC	Person-Centered Care
pzV	personenzentrierte Versorgung
QoL	Quality of Life
SDM	Shared Decision Making

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Kurzzusammenfassung

Hintergrund & Ziel: Die personenzentrierte Versorgung (pzV) erfordert Wissen um Patient*innenpräferenzen. Von Menschen mit Demenz (MmD) gibt es nur begrenzte Daten zu Präferenzen, insbesondere zu quantitativen Präferenzen. Darüber hinaus fehlen Daten zur Kongruenz von Präferenzen der MmD und ärztlichen Beurteilungen für pzV. Es wird erwartet, dass Informationen zu Präferenzen von MmD und deren Kongruenz mit ärztlichen Beurteilungen die gemeinsame Entscheidungsfindung und damit die Umsetzung der pzV bei Demenz unterstützen. Ziel dieser Dissertation war die Analyse der Präferenzen von MmD und ärztlichen Beurteilungen für pzV, einschließlich einer Kongruenzbewertung, basierend auf Daten aus der Mixed-Methods *PreDemCare*-Studie. (Finanzierung: Promotionsstipendium, Hans & Ilse Breuer-Stiftung). *Methoden:* Entwicklung und Durchführung einer Analytic Hierarchy Process (AHP)-Querschnittsbefragung mit n=50 MmD und n=25 Ärzt*innen. Individuelle AHP-Gewichte wurden mit der rechten Haupt-Eigenvektor-Methode berechnet und pro Gruppe mittels der Aggregation von individuellen Prioritäten (AIP)-Methode aggregiert. Individuelle Konsistenzverhältniszahlen (CRs) wurden berechnet und pro Gruppe aggregiert. Gruppenunterschiede wurden deskriptiv mittels AIP-abgeleiteten Mittelwerten und Standardabweichungen der AHP-Gewichte, der resultierenden Ränge und Boxplots analysiert. Zusätzlich wurden Gruppenunterschiede mittels unabhängigen gepaarten T-Tests bzw. Mann Whitney U-Tests untersucht. Die Sensitivität der AHP-Ergebnisse auf der Ebene der Kriterien wurde durch den Ausschluss inkonsistenter Antworten in beiden Gruppen getestet, mit einem akzeptierten Schwellenwert des individuellen CR von ≤ 0,3 für MmD und ≤ 0,2 für Ärzt*innen. *Ergebnisse:* Entgegen der Erwartungen unterschieden sich die Bewertungen der AHP-Elemente von MmD und Ärzt*innen nicht bedeutend. Gedächtnisübungen war das einzige AHP-Kriterium, bei welchem ein signifikanter Unterschied in der AHP-Gewichtung festgestellt werden konnte (p-Wert = 0,01). Der Ausschluss inkonsistenter Antworten führte zu keinen Rangumkehrungen der AHP-Kriterien. Auf Kriterienebene lag die durchschnittliche CR von MmD bei 0,261 und von Ärzt*innen bei 0,181, d.h. unter dem festgelegten Schwellenwert. *Schlussfolgerung:* In der ausgewählten Studienumgebung der *PreDemCare*-Studie stimmten die Präferenzen der MmD und die ärztlichen Beurteilungen für Elemente der pzV bei Demenz entgegen den Erwartungen überein. Die Ergebnisse können, unter dem Vorbehalt kleiner Stichproben, eine Grundlage für die Umsetzung einer präferenzbasierten, personenzentrierten Demenzversorgung bilden.

Short summary

Background & Aim: Person-Centered-Care (PCC) requires knowledge about patient preferences. Among People living with Dementia (PlwD) only limited evidence about patient preferences, more specifically quantitative preferences, is available. Additionally, data on congruence of patient preferences with physicians' judgements are missing. Information on patient preferences and their congruence with physicians' judgements is expected to support Shared Decision-Making and respectively support the implementation of PCC in dementia. The aim of this dissertation was to analyze patient preferences and physicians' judgements for PCC, including an assessment of their congruence, based on data from the mixed-methods *PreDemCare*-study. (Funding: Doctoral Scholarship from the Hans & Ilse Breuer-Stiftung.)

Methods: Development and conduct of a cross-sectional Analytic Hierarchy Process (AHP) survey with n=50 PlwD and n=25 physicians. Individual AHP-weights were calculated with the principal right eigenvector method and aggregated per group by Aggregation of Individual Priorities (AIP) mode. Individual consistency ratios (CRs) were calculated and aggregated per group. Group differences were analyzed descriptively by AIP-derived means and standard deviations of AHP-weights, resulting ranks, and boxplots. Additionally, differences between groups were investigated with independent paired t-tests or Mann Whitney-U tests. The sensitivity of AHP-results at the level of criteria was tested by an exclusion of inconsistent respondents in both groups, with an accepted threshold of the individual CR at ≤ 0.3 for PlwD and ≤ 0.2 for physicians.

Results: Contrary to expectation, PlwD's and physician's ranking of AHP-elements did not differ meaningfully. *Memory Exercises* was the only AHP-criterion, for which a significant difference in AHP-weights could be identified (p-value = 0.01). After inconsistent participants had been excluded, no rank reversals occurred. At the level of criteria, the mean CR for PlwD was 0.261 and 0.181 for physicians, id est (i.e.) below the defined threshold.

Conclusion: In the selected study setting of the *PreDemCare*-study, patient preferences and physicians' judgements for elements of PCC in dementia aligned well, contrary to expectations. Subject to restrictions by small sample sizes, the findings may form a basis to guide the implementation of preference-based, person-centered dementia care.

1. Introduction

1.1. Background

Dementia diseases pose a challenge for health and social care systems worldwide [6]. Analyses from the *Global Burden of Diseases (GBD) Study 2019* suggest an increase from 57.4 million cases globally in 2019 to 152.8 million cases in 2050 [6]. Currently, no curative or disease-modifying therapies are available [6]. People living with Dementia (PlwD) need an early differential diagnosis [7], as well as post-diagnostic, evidence-based [8] and personalized care, which ensures a high Quality of Life (QoL) [9].

The *Alzheimer's Associations' Dementia Care Practice Recommendations* illustrate a focus on *'person-centeredness'* as the core of quality in care for PlwD across all stages of the disease and care settings [9]. Some countries [10-13] have included the principles of 'Person-Centered Care' (PCC) [14] in their national dementia plans and/or treatment/care guidelines, for an overview in the European Union confer (cf.) Monsees & Schmachtenberg et al. [15]. PCC requires knowledge about the care recipients' needs and preferences [16,17]. Among PlwD, some evidence on preferences exists, however often limited to qualitative methods or Likert-scales [18-20], id est (i.e.) methods, which do not require a choice including a trade-off between two elements from the decision-maker, and thus fall short to *quantify, weigh* and *rank* patient-relevant elements of care, for identification of most/least preferred choices. One may hence question, whether these methods can be used to elicit a '*preference'* [21,22], as it is possible with quantitative, *choice-based* preference elicitation methods, exempli gratia (e.g.) such from *Multi-Criteria Decision Analysis* (MCDA) [23]; *Discrete Choice Experiments* (DCEs) [24], *Best-Worst Scaling* (BWS) [25], and the *Analytic Hierarchy Process* (AHP) [26,27]. In dementia, evidence on preferences elicited through such methods from PlwD themselves is limited [28], but the AHP has been suggested suitable for aged adults with cognitive impairments due to simple pairwise comparisons with only two individual aspects of a complex decision problem, such as health care decisions [29]. Quantitative patient preference data in dementia from Germany elicited with an AHP are, to the best of knowledge, missing entirely [1]. Aside from the necessary knowledge about patient preferences, *Shared Decision-Making (SDM)* between the patient and the health care provider is important to support PCC [30]. Previous studies on alignment of patient preferences and physicians' judgements from other indication areas imply a divergence between these [31].

Before MCDA methods based preference instruments, such as an AHP, can be applied to elicit patient preferences, the identification of patient-relevant elements and hereupon based development of an experimental decision-model is required [32,33]. The internal validity of an experimental decision-model and hereupon-based survey instrument is dependent on 1) an appropriate identification and specification of the included elements, as well as 2) thorough pretesting of the survey to ensure meaningful and culturally competent language, as well as the understandability of instructions (i.e., comprehension) and layout (e.g., length, complexity and overall experience) [34,35]. For these formative pre-study phases, a combination of methods e.g. literature reviews, expert opinions, and qualitative, participatory research with patients, has been recommended, to ensure patient relevance of the selected decision model [26,34].

1.2. Objectives and research question

Little is known about quantitative, choice-based preferences for PCC in dementia. Additionally, there is a lack of evidence regarding the congruence of patient preferences and physicians' judgements to ensure SDM, a core element of PCC. Before a preference instrument can be applied, formative participatory research is required for development of an experimental decision-model and pretesting of the preference survey instrument. Hence, the aims of this dissertation where:

1. Identification and specification of relevant (sub)criteria in PCC for the design of an AHP decision hierarchy and development of an AHP survey with both PlwD as experts by experience and clinical experts.
2. Development and pretesting of an AHP survey for PCC in dementia to ensure face- and content validity with both PlwD as experts by experience and clinical experts.
3. Elicitation of patient preferences and physicians' judgements for PCC in dementia.
4. Analysis of congruence between patient preferences vs. physicians' judgements.

It is hypothesized that PlwD have clear preferences for PCC and can express as well as name them. Additionally, it is assumed that the AHP is a suitable method for determining the preferences of PlwD. Analogous to previous patient preference studies, it is hypothesized that patient preferences and physicians' judgements for person-centered dementia care will show a divergence.

2. Material and Methods

2.1. Study design and setting

The analyses for this dissertation were based on data from the *PreDemCare*-study (funding: Alzheimer Doctoral Scholarship from the Hans & Ilse Breuer-Stiftung), a sequential mixed-methods-study for elicitation of quantitative, choice-based patient preferences and physicians' judgements for person-centered dementia care [1], cf. Appendix (Appx.) 5: Additional article. The study aimed to develop and apply a quantitative preference instrument, an AHP survey, and was divided in two sub-studies; 1) a pre-study phase including qualitative interviews [36] and pretests [3], and 2) main-study phase including the AHP survey and evaluation [4], based on an initial literature review [37], as depicted in Figure 1.

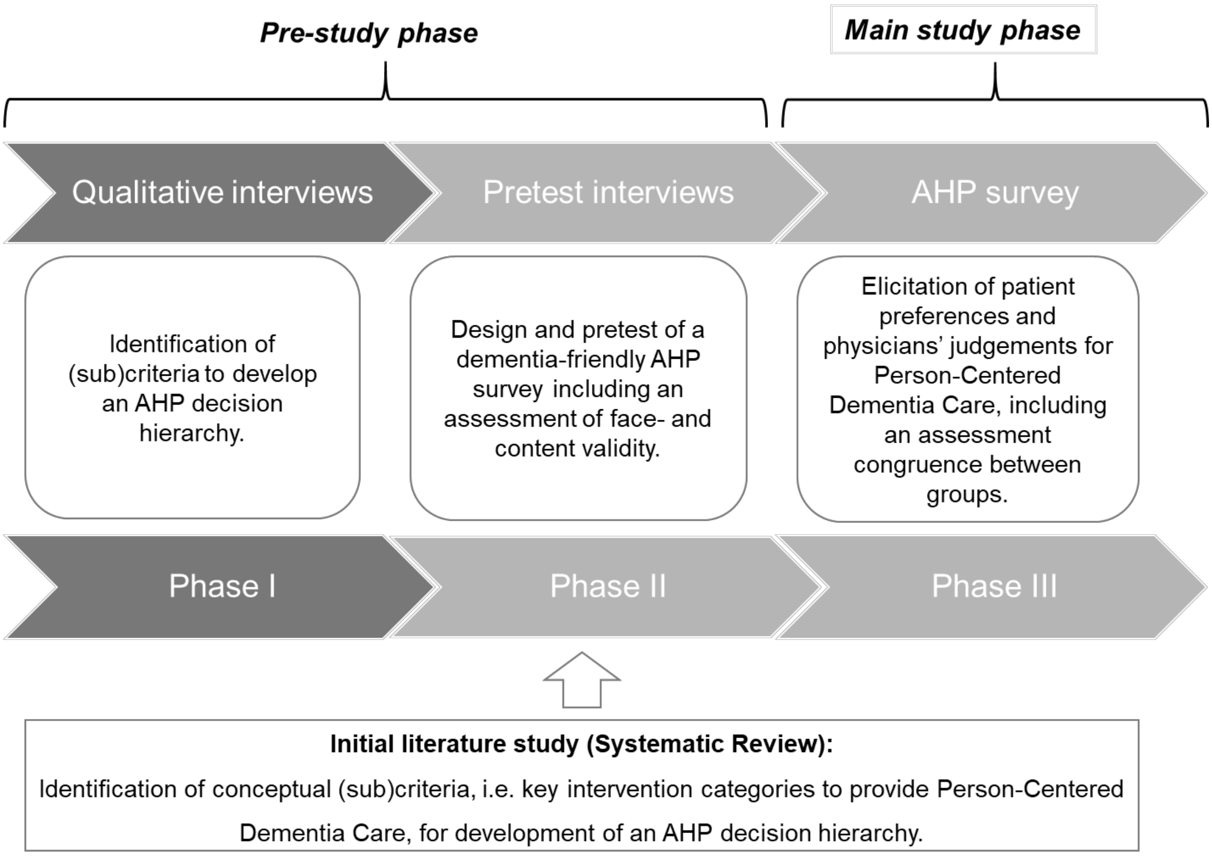

Figure 1. The mixed-methods design for the *PreDemCare*-study (own illustration developed based on source: additional article, [1(p. 4/12)]).

Note: The systematic review refers to Mohr et al. [37]. Abbreviations: AHP = Analytic Hierarchy Process.

Study population and setting were community-dwelling PlwD in the German federal state Mecklenburg Western-Pomerania and physicians from any specialty and setting with previous experience in dementia treatment and care. The *PreDemCare*-study [1] was evaluated and approved by the Ethics Committee at the University Medicine Greifswald (Ref.-No.: BB018-21).

2.2. Study population

PlwD were selected from clinical trials (ClinicalTrials.gov identifiers: NCT04741932, NCT01401582, NCT03359408, German Clinical Trials Register Reference No.: DRKS00025074) and the memory clinic at site of the DZNE Rostock/ Greifswald. Eligibility criteria were: ≥ 60 years, indication of Mild Cognitive Impairment (MCI) or early to moderate-stage dementia based on either physician diagnosis or cognitive test-result (e.g. DemTect <13 [38] or Mini-Mental-State-Examination (MMSE) <27 [39,40]), capable to understand written and oral German, and written informed consent provided by PlwD/ legal guardian [1]. Study nurses at site functioned as gatekeepers to access the PlwD. Informal caregivers (CGs) were invited to join as silent supporters. The study nurses underlined independence of the *PreDemCare*-study from the clinical trials. Clinical experts for the formative, qualitative pre-study phases included Dementia Care Managers (DCMs), i.e. dementia-specific qualified nurses [41,42], from the DZNE Greifswald and physicians recruited via personal contact and friendship networks [43]. Physicians for the AHP survey in the main study of the *PreDemCare*-study were likewise to the PlwD identified by networks from the study nurses. Eligibility criteria were: experience (past/current) in the treatment of PlwD, from any setting in the federal state Mecklenburg-Western Pomerania, any age group, any specialty. Physicians were invited via phone, e-mail or ground mail to participate in the AHP survey.

2.3. Data assessment

In the *PreDemCare*-study, data assessment was based on a variety of methods including a systematic literature review, qualitative interviews with both PlwD as experts by experience and clinical experts, as well as a quantitative survey instrument.

2.3.1. Pre-study phases: literature review, qualitative interviews, pretests

As recommended in the literature [32,33], the development of the AHP survey and respective conceptual identification of the AHP decision goal and potential (sub)criteria was initiated with a systematic review of the literature, which aimed to identify key intervention categories for the practical application of PCC in dementia, cf. Appx. 1: Article Nr. 1. The literature-derived conceptual (sub)criteria were reviewed for content by a small expert panel with n=2 DCMs, data were the remarks and notes on the (sub)criteria, changed directly in the descriptions of the (sub)criteria. In subsequent semi-structured individual interviews with n=10 PlwD and n=3 informal/ family caregivers (CGs), the (sub)criteria were presented during a card game to specify the PlwD-relevant (sub)criteria for inclusion in the AHP survey. Data included field notes, pictures of the card game results, and audio recordings, transcribed verbatim, cf. Appx. 2: Article Nr. 2. The specified (sub)criteria were structured into an AHP decision hierarchy with a 6x2 experimental design to not cognitively overburden the decision-makers [44]. AHP survey versions for both PlwD and physicians were developed. The survey versions were reviewed by two expert panels in focus group interviews with n=4 DCMs and n=4 physicians to ensure content validity, and pretested during individual “think-aloud” pretest-interviews [45] with n=11 PlwD and n=3 family CGs to ensure face validity. Data included field notes and audio recordings, partially transcribed. Subsequently, the AHP decision hierarchy and survey versions were finalized, cf. Appx. 3: Article Nr. 3.

2.3.2. Main study phase: AHP survey with PlwD and physicians

Subsequently, a paper-and-pencil AHP survey was conducted with n=50 PlwD including interviewer-assistance and n=25 physicians without interviewer assistance, cf. Appx. 4: Article Nr. 4. For both groups, the questionnaire was structured as follows: 1) a description of the study and an introduction to the criteria in lay language, followed by an example question to explain the pairwise comparison procedure, 2) the first part of the AHP survey (15 pairwise comparisons of criteria plus one retest question), 3) an introduction to the sub-criteria, 4) the second part of the AHP survey (6 pairwise comparisons of sub-criteria plus one retest question), 5) a short self-developed sociodemographic (and for PlwD disease-related or for physicians work-related) questionnaire (different for both groups). For assessment of the pairwise comparisons, i.e. the choice tasks, the AHP judgement scale with verbal explanations of numeric values by Saaty [2(p.246)] was used. Earlier graphical displays of the assessment scale, such as by Danner et al. [29(p.486)], were deemed too abstract for the surveyed group, i.e. PlwD. Hence, the graphical display of the scale was adjusted together with PlwD during the pretest study phase [3], to ensure comprehension, cf. Figure 2.

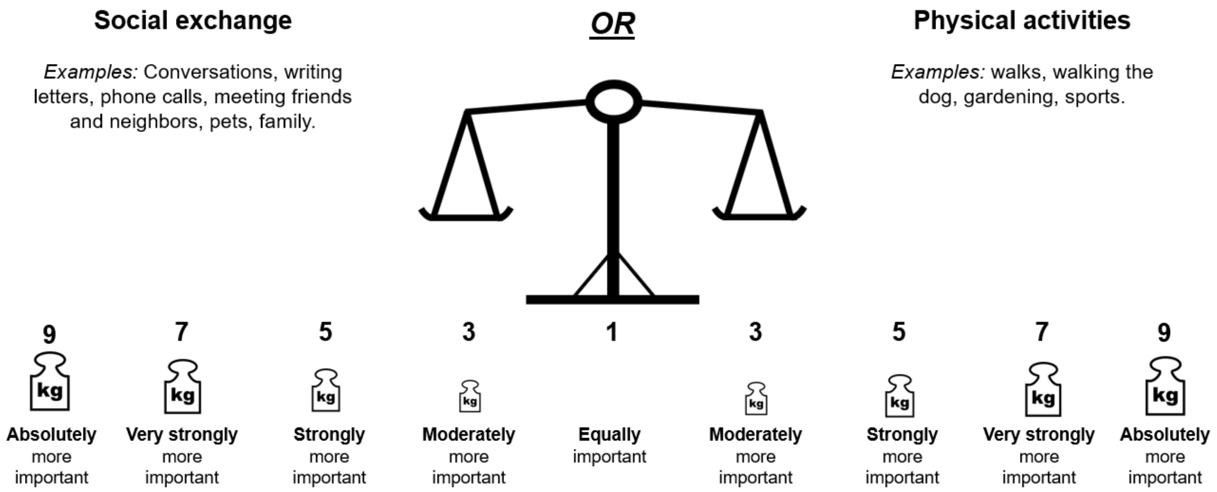

Figure 2. Patient group adjusted graphical display of AHP rating scale with verbal judgements, cf. Saaty [2(p.246)], including example of one choice task with criteria *Social exchange* and *Physical activities* (own illustration developed inspired by source: article nr. 3, [3(p. 11/21)]).

Interviewer assistance for the patient surveys was oriented in a standardized interview procedure by Danner et al. [46] to ensure the individual pairwise comparisons/ tradeoffs were understood, e.g.: *"With your judgement you are saying that [X] is very much more important to you than [Y]; is this what you wanted to express?"* [46(p.1)]. The survey versions for both PlwD and physicians included a final evaluative question for self-rated assessment of survey difficulty (easy, rather easy, neutral, rather difficult, and difficult).

For *PlwD*, sociodemographic data included age, gender, family status, highest educational degree, previous occupation [47], income, and living situation, all collected as categorical variables. Disease-related data included severity of cognitive impairment, medication, non-pharmacological treatments [8], and self-rated general health. Severity of cognitive impairment was assessed by the DemTect test [38] and the Mini-Mental Status Examination (MMSE) [39,40], psychometric testing procedures to categorize the severity of a person's cognitive impairment. Since the MMSE is less sensitive for detection of milder forms of cognitive impairment [48], the DemTect, which had shown a higher sensitivity for detection of milder forms of cognitive impairment [49], was included as well. DemTect scores were categorized as: age-appropriate cognitive performance (13-18 points), mild cognitive impairment (MCI) (9-12 points), suspected dementia (≤ 8 points) [38]. MMSE scores were categorized as: no indication (MMSE score > 26 points), mild (MMSE score 20-26 points), moderate (MMSE score 10–19 points), and severe (MMSE score 0-10 points) cognitive deficits [8,39]. Medication was systematically evaluated to generate a variable of “number of drugs per person” and polypharmacy (≥ 5 drugs, yes/no). PlwD were also asked whether they received any non-pharmacological treatment such as memory work, occupational therapy, physical training, art therapy, and sense-stimulation. Finally, PlwD were asked to self-rate their general health (very good, good, satisfactory, less good, poor).

For *physicians*, sociodemographic and work-related data included age, gender, form of employment (self-employed/ employed), setting of practice (private practice, medical center, hospital, other), location of work place (rural/ urban area), and field of specialty, all collected as categorical variables. Additionally, we asked about the self-estimated number of PlwD the physician was currently treating and had treated in the past, whether the respondent had knowledge about the PCC-concept and knowledge about the SDM-concept.

2.4. Data analysis

2.4.1. Literature analysis

A detailed report on the extracted data, synthesis of data [50,51], risk of bias assessment [52,53] of included studies, and a literature derived definition [50,51] of identified conceptual (sub)criteria can be found in Appx. 1: Article Nr. 1.

2.4.2. Qualitative analysis of interviews

A detailed report on the qualitative content analysis [54-56] of verbatim transcribed audio recordings and field notes, as well as the analysis of card games for identification and specification of AHP criteria can be found in Appx. 2: Article Nr. 2.

2.4.3. Qualitative analysis of pretest interviews

A detailed report on the iterative constant comparative analysis [57] of field notes in survey-documents complemented by partially transcribed audio recordings can be found in Appx. 3: Article Nr. 3.

2.4.4. Mathematical analyses of quantitative survey data in main study

2.4.4.1. Calculation of AHP weights by principal right eigenvector method

As described in Appx. 4: Article Nr. 4, local importance weights, i.e. patients’ preferences and physicians’ judgements, for the (sub)criteria were calculated for each participant with the principal right eigenvector method by matrix multiplication [58-62]. The vector of weights (w) for included elements in an AHP hierarchy (i.e. the (sub)criteria) is represented by the principal right eigenvector [26,58]. Multiplied by a matrix A, in the case of a non-negative reciprocal matrix A, the principal right eigenvector equals the matrix's maximal eigenvalue, lambda max (λmax), multiplied by w (**$A*w = \lambda_{max}*w$**) [58].

2.4.4.2. Aggregation of individual priorities

As AHP data in the *PreDemCare*-study were collected from individual representatives of a group and not in a group setting, individual priorities of the respondents were aggregated by the Aggregation of Individual Priorities (AIP) mode [63], i.e. individual AHP weights were averaged arithmetically, cf. Appx. 4: Article Nr. 4.

2.4.4.3. Local and global AHP weights

Per cluster in the AHP hierarchy, local weights for the (sub)criteria summarize to one. To make the sub-criteria weights comparable across the complete 2nd level of the AHP hierarchy, global weights were calculated for each participant by multiplication of the local sub-criteria weights with the local/global weight of the respective parent-criterion [29]. Calculated global sub-criteria weights were likewise to the local (sub)criteria weights aggregated arithmetically [63].

2.4.4.4. Individual inconsistency

At the level of criteria, the consistency ratio (CR), a measure of logical and consistent judgement performance in an AHP survey [26,64], was calculated for each participant cf. Appx. 4: Article Nr. 4. If e.g. A is greater than B, A > B, and B is greater than C, B > C, consequently A should be greater than C, A > C [26]. For sub-criteria the CR = 0, as only two elements were compared.

Consistency indices and consistency ratio of a given choice are defined by

$$CR = \left(\frac{\lambda \max - n}{n-1}\right)\left(\frac{1}{RI}\right)$$

where λmax is the maximum eigenvalue of the pairwise comparison vector and n is the number of attributes [5]. The RI is a random consistency index, which presents empirical values tested in previous test series [26,59]. Table 1 shows a RI that was generated from a test series of 500.000 simulations [5]. Other RI(n) values from other test series can be found in Alonso & Lamata [65]. The individual consistency is dependent on the size of the evaluation matrix and the RI increases with an increase in n [26], cf. Table 1.

Table 1. Random index by size of matrix based on included number of elements n (source: Cho, F. Measuring and visualizing consistency in Analytic Hierarchy Process for Survey Data in R [5])

Size of matrix	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Random index *(RI)*	0	0	0.525	0.884	1.11	1.25	1.34	1.41	1.45	1.49

For accepted inconsistency, the literature usually recommends a consistency threshold of 0.1 to 0.2 [59,66]. However, previous research has applied a threshold of higher or equal to 0.3 [67,68]. For practical applications of an AHP, particular circumstances as e.g. older age and cognitive capacities of surveyed participants can necessitate to accept a higher threshold of > 0.3 [67,68]. After a discussion in the *PreDemCare*-study team based on the referenced literature, a threshold for the individual CR was set at at ≤ 0.3 for PlwD and ≤ 0.2 for physicians. Oriented in Danner et al. [29], this threshold was applied to test the influence of inconsistency on the AHP results by an exclusion of inconsistent respondents in the analyses to evaluate, whether rank reversals in aggregated priorities per group occurred.

2.4.5. Statistical analyses

For the report on participant characteristics frequency counts (%), means, and standard deviations (SDs) were calculated. Further statistical analyses included the assessment of congruence between patient preferences and physicians' judgements, i.e. both local and global AHP importance weights. At first a descriptive statistical display of AIP-mode derived means (SDs), sorted from highest ranked to lowest ranked (sub)criterion, was developed. To the best of knowledge, no clear definition of what constitutes a meaningful difference in preferences [31,69-71], and more specifically, what constitutes a meaningful rank reversal of AHP-elements between two groups, exists. After discussion in the *PreDemCare*-study team, AHP-element rank reversals of two or more ranks were considered meaningful. Additionally, aggregated results were presented as boxplots of assigned weights, layered with the derived means and SDs by AIP-mode. At the level of criteria, differences in AHP weights between both groups were tested by univariable analyses, concretely independent paired t-tests or Mann Whitney U-Tests in case of violations of assumptions.

2.4.6. Software

AHP importance weights and CRs were calculated with ExpertChoice Comparion® [72] and the R-package 'ahpsurvey' [73] in RStudio. Analysis of sociodemographic (and disease-related or work-related) participant characteristics, including ratings of questionnaire difficulty, by frequency counts (%) and means (SDs) as well as univariable analyses for statistical assessment of differences in AHP weights were calculated with R in RStudio.

3. Results

3.1. Pre-study: literature analysis, qualitative analyses

Detailed results from the pre-study phase of the *PreDemCare*-study, i.e. the literature analysis and qualitative analyses of interviews and pretests can be found in Appendices 1-3, Articles 1-3. The main result of the pre-study phase, the final AHP decision hierarchy, can be reviewed in Figure 3.

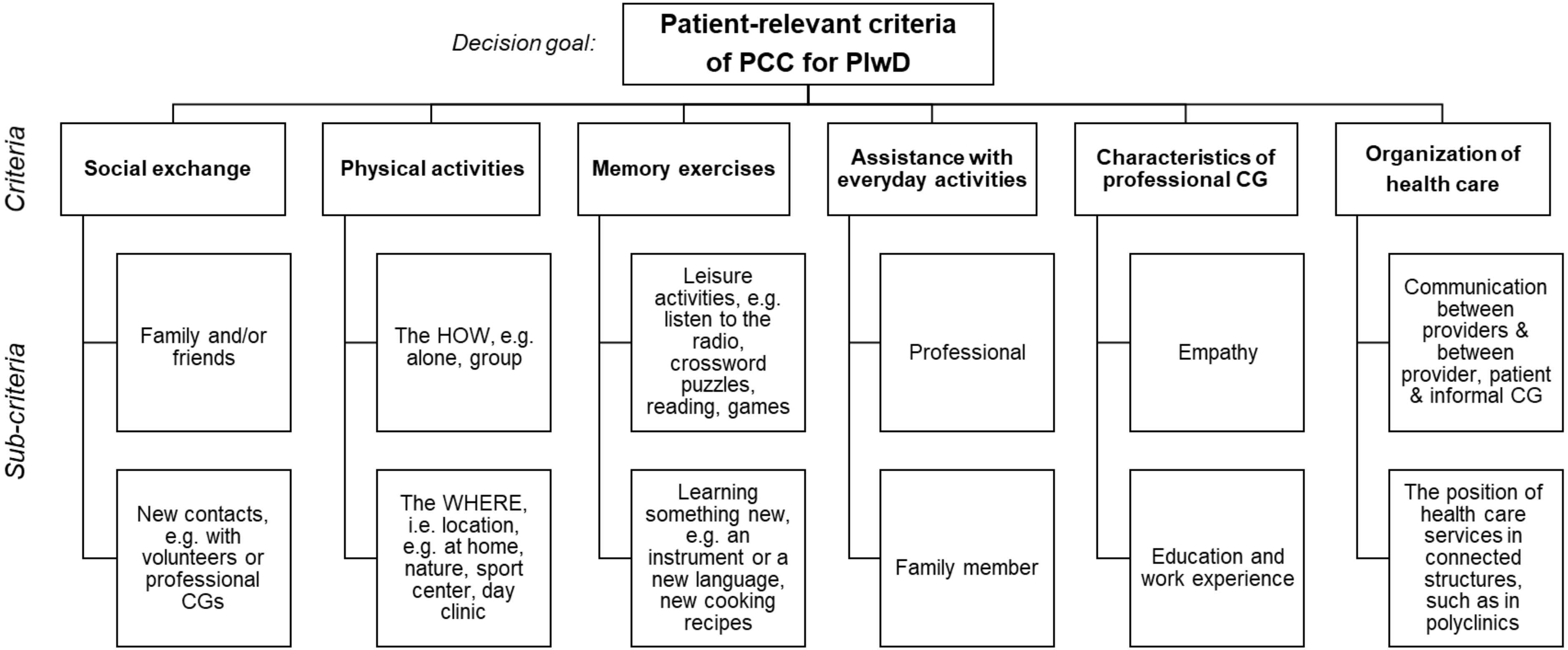

Figure 3. Final AHP hierarchy with PlwD-relevant (sub)criteria of PCC (source: article nr. 3, [3(p.8/21)]).

Abbreviations: CG = caregiver, PCC = Person-Centered Care, PlwD = People living with Dementia.

3.2. Main study: analysis of patient preferences and physicians' judgements

3.2.1. Participant characteristics main study

Detailed participant characteristics for the AHP survey can be found in Appx. 4: Article Nr. 4, Supplementary Material 1, Tables 1a-b. Among PlwD 56% (n=28) were 81 to > 90 and 44% (n=22) 60 to 80 years old. 56% (n=28) were of female gender, 80% (n=40) had a diagnosis of MCI/dementia (ICD-10: F00.1, F00.2, F00.9, F01.3, F01.9, F02.3, F03, F06.7, G30, U51.02, U51.11, U51.12), and no participant was per diagnosis and/or indicated by cognitive test results at an advanced stage of dementia. Most (86%, n=43) rated their general health status as good/satisfactory. Among physicians, 52% (n=13) were aged 30-50 years and a majority (72%, n=18) were of female gender. The majority worked as general practitioners (64%, n=16).

3.2.2. Aggregated importance weights and rankings per group, congruence of weights and rankings

The aggregated importance weights for criteria per group (patients/physicians and consistent patients/consistent physicians) are depicted in Table 2. Patient preferences and physicians' judgements were mostly aligned. *Assistance with Everyday Activities* was ranked highest in both groups (mean AHP weights: 0.206 (SD: 0.102) vs. 0.217 (SD: 0.087), p=0.65). Rank reversals for remaining criteria occurred, but the majority was not meaningful, i.e. the criteria did not reverse with two or more ranks. Only in AHP-weights for the criterion *Memory Exercises*, a statistically significant difference could be identified (mean: 0.135 (SD: 0.066), fifth rank for patients vs. mean: 0.099 (SD: 0.068), sixth rank for physicians, p=0.01).

Table 2 Aggregated AHP importance weights for (sub)criteria by patients and physicians (source: article nr. 4, [4(p.733)]) [i]

Criteria and sub-criteria (rank-order)	**All patients (n=50),** local weights, mean (SD)	**Consistent patients (n=36)** [c] local weights, mean (SD)	**Criteria and sub-criteria (rank-order)**	**All physicians (n=25),** local weights, mean (SD)	**Consistent physicians (n=21)** [d] local weights, mean (SD)
Assistance with everyday activities	0.206 (0.102)	0.210 (0.112)	Assistance with everyday activities	0.217 (0.087)	0.212 (0.089)
– Informal/ family CG	0.572 (0.263)	– N/A	– Informal/ family CG	0.620 (0.218)	N/A
– Professional CG	0.428 (0.263)	– N/A	– Professional CG	0.380 (0.218)	N/A
Social exchange	0.201 (0.008)	0.199 (0.095)	Organization of health care	0.192 (0.113)	0.199 (0.107)
– Family and/or friends	0.700 (0.184)	– N/A	– Communication	0.658 (0.237)	N/A
– New contacts	0.300 (0.184)	– N/A	– Integrated care structures	0.342 (0.237)	N/A
Organization of health care	0.173 (0.082)	0.159 (0.080)	Social exchange	0.183 (0.091)	0.179 (0.095)
– Communication	0.532 (0.235)	– N/A	– Family and/or friends	0.735 (0.196)	N/A
– Integrated care structures	0.468 (0.235)	– N/A	– New contacts	0.265 (0.196)	N/A
Characteristics of professional CGs	0.163 (0.079)	0.152 (0.076)	Characteristics of professional CGs	0.175 (0.072)	0.174 (0.075)
– Empathy	0.513 (0.193)	– N/A	– Empathy	0.726 (0.161)	N/A
– Education and work experience	0.487 (0.193)	– N/A	– Education and work experience	0.274 (0.161)	N/A
Memory exercises	**0.135 (0.066)** [a]	**0.147 (0.058)** [b]	Physical activities	0.134 (0.061)	0.134 (0.052)
– Leisure activities	0.653 (0.207)	– N/A	– How? (Format)	0.584 (0.245)	N/A
– Learning something new	0.347 (0.207)	– N/A	– Where? (Location)	0.416 (0.245)	N/A
Physical activities	0.121 (0.079)	0.133 (0.079)	Memory exercises	**0.099 (0.068)** [a]	0.102 (0.072)
– Where? (Location)	0.502 (0.253)	– N/A	– Leisure activities	0.697 (0.225)	N/A
– How? (Format)	0.498 (0.253)	– N/A	– Learning something new	0.303 (0.225)	N/A

Note: Sub-criteria weights were not calculated for consistent patients and physicians, as consistency ratio was calculated at level of criteria. For sub-criteria the CR = 0, as only two elements were compared. [a] Numbers in bold indicate statistically significant differences ($p < 0.05$) between two independent groups (patients vs. physicians) as calculated with Mann-Whitney U test due to violation of assumptions. [b] Numbers in bold indicate statistically significant differences ($p < 0.05$) between two independent groups (consistent vs. inconsistent patients based on CR-threshold of CR ≤ 0.3) as calculated with Mann-Whitney U test due to violation of assumptions. [c] Those patients with an individual consistency ratio of ≤ 0.3 [67,68]. [d] Those physicians with an individual consistency ratio of CR ≤ 0.2 [59,66].

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[i] Reprinted from *Journal of Alzheimer's Disease*, vol. 91, no. 2, Mohr W, Rädke A, Afi A, Weber N, Platen M, Mühlichen F, Scharf A, Michalowsky B, Hoffmann W, Do They Align? Congruence Between Patient Preferences of People Living with Cognitive Impairments and Physicians' Judgements for Person-Centered Care: An Analytic Hierarchy Process Study, pp. 727-741, Copyright 2023, with permission from IOS Press. The publication is available at IOS Press through http://dx.doi.org/10.3233/JAD-220753.

Aggregated global weights for sub-criteria per group are depicted in Figure 4, sorted from highest to lowest mean-value per cluster in each group. Both PlwD and physicians prioritized Social Exchange with *Family and/or friends* highest, whilst Social Exchange with *New Contacts* and Memory Exercises by *Learning something new* was ranked lowest. Differences between groups (patients vs. physicians) could be seen in global weights for *Empathy* vs. *Education and work experience* as Characteristics of Professional CGs and *Communication vs. Integrated care structures* for Organization of Health Care, where physicians gave greater importance to *Empathy* and *Communication* than the PlwD.

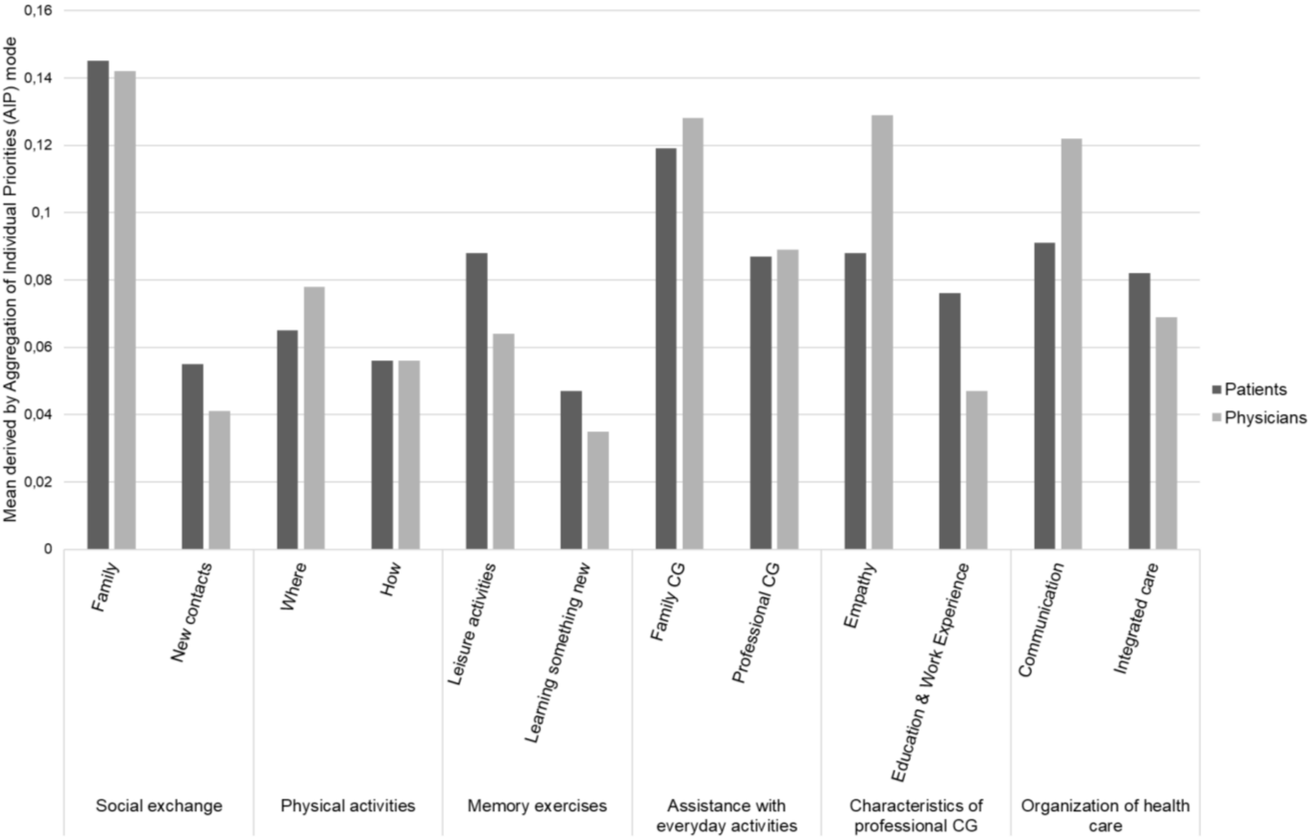

Figure 4. Global weights (aggregated, mean) for sub-criteria among patients (n=50) and physicians (n=25) (source: article nr. 4, [4(p.735)]) [ii]

3.2.3. Inconsistency and sensitivity of results

At the criteria level, the mean CR for PlwD was 0.261, for physicians 0.181, i.e. model inconsistency for both groups was below the predefined thresholds (PlwD CR ≤ 0.3,

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physicians CR ≤ 0.2). 14 PlwD (28%, CR > 0.3) and 4 physicians (16%, CR > 0.2) made inconsistent judgements. In both groups, no rank reversals of criteria occurred after inconsistent participants were excluded, cf. table 2. A significant difference in mean AHP-weights for *Memory Exercises* was found between consistent vs. inconsistent PlwD (mean: 0.147 (SD: 0.058) vs. mean: 0.105 (SD: 0.077), p=0.02), but for no other criterion.

3.2.4. AHP survey evaluation

The majority of PlwD (66%) rated the survey as rather easy or neutral, no one as difficult. 18/25 physicians rated the survey as easy, rather easy or neutral, 7/25 as rather difficult or difficult, respectively, cf. Appx. 4: Article Nr. 4, Supplementary Material 1, Tables 1a-b. Furthermore, the AHP survey had no missing answers.

4. Discussion

4.1. To measure 'preferences' with aged adults and PlwD

By application of an AHP survey, developed during an extensive pre-study phase (including a systematic literature review, qualitative interviews and pretest interviews with multiple stakeholders), PlwD had clear preferences for PCC and could express as well as name them. When considering the measurement of preferences, one may at first discuss what can be defined as a *"preference"*. The word *"preference"* or *"prefer"* originates from the Latin word *"praeferre",* which translates to *"place or set before, carry in front"*, from *prae "before"* + *ferre "to carry, to bear"* [21]. The Merriam-Webster dictionary defines a "preference" as *"1b: the power or opportunity of choosing"* or *"3: the act, fact or principle of giving advantages to some over others"* [22]. The aforementioned definitions imply the necessity to make a choice, i.e. a trade-off between two elements to express a preference.

Previous research aimed at the elicitation of "preferences" for Person-Centered Care from community-dwelling aged adults includes inter alia (i.a.) the *Preferences for Everyday Living Inventory (PELI*) developed by van Haitsma et al. [20], which is being translated for application in German care settings for aged adults with no cognitive impairment or MCI [74]. The PELI is similar to the *PreDemCare* preference instrument focused on preferences for psychosocial activities [4]. However, preferences in the PELI, i.e. the importance of each of the 72 PELI main items, are reported to be assessed by 4-point Likert-type scales and open-ended questions [20,75]. In this regard, one may question, whether these methods meet the requirements of the aforementioned preference definition, as these methods may not explicitly require a choice, i.e. trade-off between two elements [4]. The AHP-method including the scale used in the *PreDemCare*-study for this PhD project, cf. figure 2, explicitly demanded a trade-off by the requirement of deciding for one criterion over another and assigning a value for by how much [2]. Preferences elicited in the *PreDemCare*-study may be viewed as “true” preferences per definition, which may increase confidence in the results.

4.2. Patient preferences and intervention adherence

A continued application of the developed survey instrument may help to gain a deeper understanding on the association between patient preferences and adherence to interventions for better effects of care [76]. This may be particularly interesting for preventive interventions such as *Physical Activities* and *Memory Exercises,* e.g. as components in multi-modal preventive trials such as the Age.Well-study [77]. In 2017, the *Lancet* Commission on dementia prevention presented results from modeling analyses following which nine potentially modifiable risk factors, i.a. physical inactivity, together could be associated with 35% of the population attributable fraction of dementia worldwide [78]. In the 2020 report of the *Lancet* Commission, which included new analyses, the previous findings were updated to a 12 risk factor life-course model of dementia prevention [79]. These 12 modifiable risk factors together account for 40% of worldwide dementias, which theoretically could be prevented or delayed [79]. However, in a critical review of the earlier calculations from the *Lancet* Commission from 2017 [78], Montero-Odasso, Ismail & Livingston [80] highlighted that large randomized controlled trials (RCTs), i.e. with > 250 participants per arm, minimum of 6 months follow-up, to test multi-modal lifestyle interventions had so far only resulted in modest or even negative findings. One may question whether the modest or negative findings from RCTs with lifestyle interventions potentially were affected by low adherence of the participants due to low preferences for the respective interventions. Baseline-analyses from the Age.Well-study [81] including 1,030 participants showed that 51.8% of participants engaged in physical activity ≥ 2 times per week for at least 30 min. Cardona et al. [81] found self-efficacy, i.e. a person’s belief in the ability to succeed in a given task [82], to be an important predictor of participation in physical activity among people at risk of dementia and multi-morbidity ($p < 0.001$). Other research by Reed, Mikels & Löckenhoff [83] noted that self-efficacy drove individuals to prefer more challenging tasks and show endurance in case of hurdles encountered. To summarize, it could be discussed whether greater self-efficacy could influence individuals' preferences for challenging tasks and potentially predict adherence to interventions, such as physical activity. Future clinical trials investigating the effect of non-pharmacological, preventive lifestyle interventions may consider to assess preferences alongside the trial and study the association between preferences and adherence in more detail. Likewise, it could be interesting to compare groups; 1) people who report regular exercise as aforementioned, cf. Cardona et al. [81], and 2) people who do report no regular exercise in terms of their preferences for psychosocial aspects of care, e.g. by application of the preference survey instrument developed in the *PreDemCare*-study.

4.3. Congruence between groups, Shared Decision-Making and Person-Centered Care, Elements of Person-Centered Dementia Care

Unexpected as per initial hypothesis, patient preferences and physicians' judgements showed an overall congruence. Our finding may differ from findings in previous research by Mühlbacher & Juhnke [31], who had reviewed this relationship in the literature and found that patient preferences and physicians' judgements often differed. However, Mühlbacher & Juhnke [31] analyzed further 1) whether different preference elicitation techniques and methods could cause a divergence of patient preferences and physicians' judgements, 2) whether different types of diseases (chronic vs. acute) could result in varying degrees of agreement, and finally 3) whether the congruence of preferences and judgements depends on the included attributes/ criteria in the respective preference instruments. For the different elicitation methods, Mühlbacher & Juhnke [31] could not conclude that a certain method would always result in a disagreement while another would result in an agreement of preferences and judgements. On the other hand, they [31] found a higher degree of congruence between patients and clinical experts (physicians, nurses and other health care professionals), when the condition in question for preference or judgement elicitation was a chronic disease or a preventative service. In contrast, patient preferences and physicians' judgements differed, when the underlying condition was an acute and potentially life threatening disease. Mühlbacher & Juhnke [31] connected the latter phenomenon to the *Construal Level Theory*, which assumes that decision making is dependent on psychological distance [84]. Respectively, preferences for health care might change depending on the psychological distance to the disease. I.e., the more abstract and further away a disease is (cf. chronic vs. acute condition), the easier it may be for the patient to make a rational decision, equal to a physician's judgement, which due to her/his/their social distance is assumed to be an abstract and rational decision maker [31,84,85]. With regard to their third research question, Mühlbacher & Juhnke [31] found that several common attributes/ criteria used for preference and judgement elicitation resulted in a divergence of the latter. Respectively, they [31] found physicians to overestimate the value that patients give to clinical outcomes, safety and effectiveness/efficacy, whilst the patients themselves gave greater importance to quality of life and social values .

The by Mühlbacher & Juhnke [31] described relationship between *Construal Level Theory* [84] and acute vs. chronic diseases , may be an explanation for the unexpected finding of a congruence between PlwD and physicians in the *PreDemCare*-study, due to the chronic nature of MCI and dementia diseases. However, the found congruence may also arise from a selection bias in the physician's sample. The physicians had been recruited via the study nurses' networks from previous or ongoing studies at site. The n=25 participating physicians may in general be more engaged than the average physician in our study setting with regard to the care of their patients. This in turn might have resulted in the unexpected congruence of preferences and judgements, which in other settings with potentially less engaged physicians might not be identifiable. An application of the developed survey instrument in other settings and with larger sample sizes would be valuable. The by Mühlbacher & Juhnke [31] described greater importance for clinical outcomes among physicians in contrast to greater importance for quality of life and social values among patients, may in the findings of the *PreDemCare*-study be expressed by the rank reversal of *Social Exchange* and *Organization of health care*, where physicians gave greater importance to the latter, whilst patients gave greater importance to *Social exchange*, cf. Table 2.

Mühlbacher & Juhnke [31] underlined furthermore that divergences may reflect ineffective communication between patient and provider. Ineffective communication may halt SDM, which in turn may halt the implementation of PCC. However, a congruence of patient preferences and physicians' judgements, as found in the *PreDemCare*-study, could be viewed as an enhancer of SDM and help to promote PCC. Hence, in the selected study setting effective communication between patients and physicians, SDM, and PCC may be easier implemented based on the aligning preferences and judgements among PlwD and their physicians than in other settings described by Mühlbacher & Juhnke [31].

Nevertheless, one should remember that other core elements of PCC as identified in the initial systematic literature review [37], laying the foundation for the *PreDemCare*-study, cf. Figure 1, had not been included in the final AHP decision hierarchy and survey. One may therefore question, whether exclusion of the PCC-elements *Adjustment of the environment* and *Activities for sensory stimulation or relaxation* [36,37] may impede the implementation of PCC, as preferences for the latter were not assessed in the final preference instrument. Still, the assessment of preferences from the care recipients, PlwD, as such can be viewed as an enhancement of person-centeredness in dementia care [17] in our setting. Additionally, the care recipients themselves had defined the important elements to be included in the AHP survey and early on decided that *Adjustment of the environment* and *Activities for sensory stimulation or relaxation* were not as important as the other included elements in the provision of PCC during the formative qualitative pre-study phase of the *PreDemCare*-study [36]. Guidelines on use of MCDA-methods in health care decision making published in 2016 by the *MCDA Emerging Good Practices Task Force* from the *International Society for Pharmacoeconomics and Outcomes Research* (ISPOR) emphasize the importance to report and justify the methods used for identification of (sub)criteria for the quantitative preference instrument [33]. Hollin et al. [34] underlined in their recently published guidelines for formative qualitative preference research that the use of qualitative evidence for development of any quantitative preference study protocol or instrument is central. Still, the use of formative qualitative research remains generally underreported in the preference literature. Additionally, Hollin et al. [34] underlined that the quality of reported qualitative methods tends to be inadequate, which in turn makes it difficult to determine the sufficiency in rigor for conduct of the formative qualitative research. To comply with the aforementioned guidelines [33,34] and respectively increase validity and trustworthiness in the *PreDemCare* preference instrument, the *PreDemCare*-study team had purposefully decided to include a combination of research methods (literature review complemented with formative qualitative research methods) and perspectives (PlwD as experts by experience and clinical experts (DCMs, physicians)), as well as to rigorously report these development stages [3,36,37]. In summary, despite the aforementioned exclusion of other PCC-elements from the AHP decision hierarchy and survey, the final instrument and hereupon based results are, respective to the required properties of a set of criteria (= completeness, nonredundancy, nonoverlap, and preference independence, cf. Marsh et al. [33]), viewed with confidence to support PCC-implementation.

4.4. Limitations

The findings in this study should be viewed with some caution due to certain limitations.

4.4.1. Participant heterogeneities and sensitivity of AHP-results

To gain a deeper understanding on the sensitivity of patient preferences elicited with MCDA-methods, e.g. an AHP as applied in this study, heterogeneities among the survey participants should be considered, and how these may affect the stability of elicited preferences/judgements – in an AHP the weights-based priority ranks. These may differ in certain sub-groups, e.g. between female and male participants [86,87]. Sub-group analyses can provide an evaluation of how sensitive (sub)criteria priority ranks are by stratifying the decision makers' based on selected sociodemographic (and, in case of PlwD disease-related, in case of physicians work-related) characteristics. Extensive sub-group analyses were outside the scope of this PhD-project. However, selected sub-group analyses have been conducted by the *PreDemCare*-study team [88] and are being prepared for publication. Due to the limited sample size in the *PreDemCare*-study, subgroup-differences in criteria-ranks were mainly investigated with descriptive statistics by the same principles as described before for assessment of congruence between PlwD and physicians. Respectively, means and standard deviations (SDs) of per AIP-mode arithmetically averaged AHP-weights per subgroup were calculated and criteria ranked from highest to lowest mean. Similar as before, rank reversals were considered meaningful, if criteria were reversed by at least two ranks. The following sociodemographic, (and for PlwD disease-related, as well as for physicians work-related) characteristics have been considered for subgroup-development: PlwD's gender, age, family- and living status, education, cognitive function, dementia diagnosis, polypharmacy, non-pharmacological treatments, self-rated health, as well as physicians' age, gender, workplace location, specialization, and knowledge about PCC or SDM. For PlwD stratified by living and family status, cognitive function and diagnosis, polypharmacy, as well as self-rated health status, analyses revealed meaningful rank reversals of the criteria *Social Exchange* and *Organization of Health Care*, i.e. ranks included the full range of ranks 1-4. Similar was found for physicians stratified by gender, age, place of work, and field of specialty, where analyses revealed meaningful rank reversals of the criterion *Social Exchange*. Generally, *Social Exchange* plays an important role in PlwD's care, as presented by Ziegert, Ross, & Rodriguez [89] in their recently published research report for the DZNE study *"Identification of relevant psychosocial factors in the development, treatment and care of people with dementia"*. However, the heterogeneity in priority ranks for *Social Exchange* and *Organization of Health Care* in different subgroups may have to be taken into account when the elicitation of quantitative preferences for PCC would be translated into practical health care. Further subgroup analyses revealed that *Assistance with Everyday Activities* occurred as the most important criterion (ranks 1/2) across all subgroups among both PlwD and physicians. On the other hand, *Physical Activities* and *Memory Exercises* were consistently ranked as least important across subgroups (ranks 5/6), and *Characteristics of Professional CGs* were ranked as moderate important (ranks 3/4).

4.4.2. Methodological considerations: consistency, reliability, acceptance

Methodological considerations of whether the challenges of a MCDA tool such as the AHP can be handled by PlwD are important, and it should to be reflected whether these methodological considerations could extent to the interpretation of our findings. Aside from the assessment of internal consistency in an AHP instrument [26,64], a deeper statistical analysis of whether the individual CR may be correlated with the number of times a value of ≥ 5 and = 1 was chosen on the AHP judgement scale [2], based on previous findings on observed inconsistency from Danner et al. [29], could be of interest. Additionally, an analysis of whether the individual CR may be correlated with the severity of cognitive impairment (DemTect- and MMSE score), the existence of a diagnosis (MCI/ dementia), and with the status of the participants (PlwD or physician) could be of interest. Furthermore, the included test-retest pairwise comparison questions at the criteria and sub-criteria level may be used to assess the instrument's reliability [90]. Finally, missing values and the inclusion of an evaluative question at the end of the quantitative preference instrument may yield indication on the overall acceptance of the survey. The suggested further analyses of consistency and reliability were outside the scope of this dissertation, but need to be considered in future analyses of the *PreDemCare*-study. As aforementioned, the AHP survey had no missing values and two third of PlwD rated the survey as rather easy or neutral, none as difficult. 6/25 physicians rated the survey as easy, 8/25 as neutral, and 4/25 as rather easy or difficult respectively. Overall, this may indicate a good acceptance of the developed quantitative preference instrument. However, due to the limited sample sizes in the *PreDemCare*-study, the findings should be further validated in larger samples.

4.5. Practical implications and conclusion

In consideration of a currently still unavailable curative or disease-modifying treatment for all PlwD, an early diagnosis, which gives access to post-diagnostic, evidence-based and person-centered treatment and care is essential to ensure a high QoL of PlwD for as long as possible. If health care systems aim to provide PCC in dementia, the care recipients' preferences need to be elicited and acknowledged. An acknowledgement of preferences can support patient participation and SDM as important elements in PCC for PlwD. The application of a MCDA-based preference instrument, such as the one presented in the *PreDemCare*-study, ensures, by a required trade-off between two alternatives, that an actual 'preference' per definition is obtained. Based on the in this dissertation presented findings from the *PreDemCare*-study, future person-centered dementia care may in particular seek to prioritize interventions focused on *Assistance with everyday activities, Social exchange* and an *Organization of health care* that includes good communication between providers, PlwD and informal CGs, i.e. SDM, as well as health care services in connected care structures. The importance of these interventions in PCC provision is based both on the expressed preferences from the PlwD themselves and the physicians' judgements.

Future research should, however, investigate how preferences are related to intervention adherence, in particular for such interventions that are important in the prevention of dementia diseases, e.g. *Physical activities* and *Memory exercises*. This may include an investigation of, how an increased preference and potentially an increase in intervention adherence can be achieved for preventive efforts such as *Physical activities* and *Memory exercises*. Nevertheless, an acknowledgment of PlwDs' preferences in health care decisions may yield better adherence and, ultimately, better results of care.

In the selected study setting of the *PreDemCare* study, circumstances conducive for PCC provision may already be present, given the found congruence of patient preferences and physician judgments, contrary to initial hypothesis. The identified overall alignment of patient preferences and physicians' judgements may foster improved patient-physician communication and respectively SDM.

The presented findings are based on small sample sizes and need to be further validated in larger samples. Additionally, further analyses for consideration of participant heterogeneities and the sensitivity of the found AHP-results would be helpful for a better understanding of whether preferences may differ in certain subgroups and, respectively, prioritization of interventions in PCC may need to be adjusted in these groups. Finally, a more detailed analysis on methodological properties of the developed survey instrument, including further analyses on reasons for inconsistency, the instrument’s reliability, as well as overall acceptance would be beneficial for further validation of the developed instrument.

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Declaration of own part in publications

1. **Mohr W,** Rädke A, Afi A, Edvardsson D, Mühlichen F, Platen M, Roes M, Michalowsky B, Hoffmann W. Key Intervention Categories to Provide Person-Centered Dementia Care: A Systematic Review of Person-Centered Interventions. *J Alzheimers Dis.* 2021;84(1):343-366. doi:10.3233/JAD-210647

Own part in publication: conceptualization and study design, data collection, data analysis, preparation of manuscript including development of tables.

2. **Mohr W,** Rädke A, Afi A, Mühlichen F, Platen M, Michalowsky B, Hoffmann W. Development of a Quantitative Instrument to Elicit Patient Preferences for Person-Centered Dementia Care Stage 1: A Formative Qualitative Study to Identify Patient Relevant Criteria for Experimental Design of an Analytic Hierarchy Process. *Int J Environ Res Public Health.* 2022;19(13):7629. doi:10.3390/ijerph19137629

Own part in publication: conceptualization and study design, field work and data collection, data analysis, preparation of manuscript including development of tables and figures.

3. **Mohr W,** Rädke A, Afi A, Mühlichen F, Platen M, Scharf A, Michalowsky B, Hoffmann W. Development of a Quantitative Preference Instrument for Person-Centered Dementia Care-Stage 2: Insights from a Formative Qualitative Study to Design and Pretest a Dementia-Friendly Analytic Hierarchy Process Survey. *Int J Environ Res Public Health.* 2022;19(14):8554. doi:10.3390/ijerph19148554

Own part in publication: conceptualization and study design, field work and data collection, data analysis, preparation of manuscript including development of tables and figures.

4. **Mohr W,** Rädke A, Afi A, Weber N, Platen M, Mühlichen F, Scharf A, Michalowsky B, Hoffmann W. Do They Align? Congruence Between Patient Preferences of People Living with Cognitive Impairments and Physicians' Judgements for Person-Centered Care: An Analytic Hierarchy Process Study. *J Alzheimers Dis.* 2023;91(2):727-741. doi:10.3233/JAD-220753

Own part in publication: conceptualization and study design, field work and data collection, data analysis, preparation of manuscript including development of tables and figures.

Mohr W, Rädke A, Michalowsky B, Hoffmann W. Elicitation of quantitative, choice-based preferences for Person-Centered Care among People living with Dementia in comparison to physicians' judgements in Germany: study protocol for the mixed-methods PreDemCare-study. *BMC Geriatr.* 2022;22(1):567. doi:10.1186/s12877-022-03238-6

Own part in publication: conceptualization and study design, preparation of manuscript including development of tables and figures.

Appendix 1: Article Nr. 1 “Key Intervention Categories to Provide Person-Centered Dementia Care: A Systematic Review of Person-Centered Interventions.”

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Key Intervention Categories to Provide Person-Centered Dementia Care: A Systematic Review of Person-Centered Interventions

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Abstract.

Background: Person-centered care (PCC) is an important concept in many countries' national guidelines and dementia plans. Key intervention categories, i.e., a taxonomy of person-centered (PC)-interventions, to provide person-centered dementia care, are difficult to identify from literature.

Objective: This systematic review aimed to identify and categorize published PC-interventions into key intervention categories to guide the provision of person-centered dementia care.

Methods: Conduct of this systematic review followed Cochrane guidelines. A search of the dimensions 'Dementia', 'Person-Centered Care', and 'Intervention' combined was performed in PubMed, EMBASE, and Web of Science. Study selection was based on 2-stage screening against eligibility criteria, limited to controlled study designs. Information about interventions and outcomes was extracted into an "Effects Table". The identified PC-interventions were categorized in intervention categories to provide person-centered dementia care.

Results: Searches identified 1,806 records. 19 studies were included. These covered a range of psychosocial interventions, oftentimes multi-component interventions, which followed heterogeneous approaches. Studies were conducted in long-term care/hospital settings. Nine key intervention categories were identified: social contact, physical activities, cognitive training, sensory enhancement, daily living assistance, life history oriented emotional support, training and support for professional caregivers, environmental adjustments, and care organization.

Conclusion: Our findings provide a current overview of published PC-interventions in dementia, which followed heterogeneous approaches under the PCC-concept. The heterogeneity made it challenging to identify a well-defined concept of PCC and common key intervention categories. An effectiveness-evaluation of "PC", including "relationship-centered"-interventions may be valuable, to assess whether an explicit focus on relationships around PCC-interventions yields an added benefit.

PROSPERO-ID: CRD42021225084.

Keywords: Alzheimer's disease, dementia, patient-centered care, patient-focused care, patient preferences, person-centered care, person-centered dementia care, person-centered interventions, psychosocial intervention

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INTRODUCTION

With aging populations, dementia increasingly represents a challenge for public health and health care systems worldwide [1]. Globally, around 50 million people have dementia, and there are nearly 10 million new cases every year [2]. According to findings from the *Global Burden of Disease Study 2019*, Alzheimer's disease and other dementias were the fourth leading cause of death globally in the age groups 75 years and older [3]. Despite the recent approval of aducanumab for Alzheimer's disease by the U.S. Food and Drug Administration [4], no curative treatment for all people living with dementia (PlwD) exists. PlwD need a timely differential diagnosis and care, which ensures a high quality of life (QoL) [1, 5].

Person-centered care (PCC), a prominent concept in dementia care, has been suggested synonymous with good quality care [6]. Many countries include a PCC-approach in their national guidelines and dementia plans [7–13]. The concept is covered by a multiplicity of terms in the literature, dependent on the context in which care is provided. It challenges the traditional clinician-centered or disease-focused medical model to a model of care, which is customized to each person [14]. Some argue, PCC's origins trace back to Florence Nightingale, "who differentiated nursing from medicine by its focus on the patient rather than the disease" (p. 246) [15]. Carl Rogers' work on client centered psychotherapy noted "person-centeredness" in the early 1940s [16]. Until Tom Kitwood in 1988 noted PCC-approaches in dementia care [17], the term had not been used in the dementia care field [18]. Often, Kitwood is described as the founder of the concept of person-centered dementia care [19], developed in response to the reductionist regarded biomedical view of dementia, which downgrades the person to a carrier of a chronic disease and hereby ignores personal experiences, well-being, dignity, and worth [20, 21]. Despite the prominence and frequent use of PCC, some have noted the missing consensus or explicit agreement on its definition, the complexity of the concept, and a related need for more clarification [22–24]. Some have questioned, whether PCC is achievable [25], while others pointed out that PCC indirectly emphasizes autonomy and independence rather than the importance of relationships [26], even though Kitwood noted relationships as essential to understand dementia [19]. Relationship-centered care (RCC) may be seen as the next development of PCC, which pays more attention to the reciprocity of care between the care recipient and the caregiver (CG), by some [27, 28].

What PCC means in in clinical practice has been described broadly; it includes the incorporation of personal knowledge of the PlwD, to conduct meaningful activities, to make well-being a priority, and to improve the quality of relationships between the health care professional and the PlwD [18, 29]. Based on a non-pharmacological and sociopsychological treatment approach, PCC recognizes the need to personalize and tailor care to the recipient's needs and preferences to guide care provision [30, 31]. Previous PCC-literature has focused on its theory and theoretical frameworks [18, 19, 30, 32–35], qualitative studies about the understanding of PCC [29, 36, 37], and tools to measure PCC [38–42]. Earlier published reviews of PCC for PlwD showed beneficial effects to manage challenging behaviors (such as agitation), reduce the use of antipsychotic drugs, neuropsychiatric symptoms, depression, and to improve QoL, as well as to improve healthcare professionals' quality of work-life [43–47].

However, to the best of our knowledge, no previous review has tried to identify key intervention categories to guide the provision of person-centered dementia care, including who does what, where, and how, from the published literature. Hence, the following research questions arose:

1. What are the characteristics of published PCC-interventional studies for PlwD?
2. How can the interventions described in PCC-interventional studies for PlwD be synthesized into categories to guide the provision of person-centered dementia care?
3. What a) content, b) provider, c) format, d) setting, e) intensity, and f) fidelity describe key intervention categories to provide person-centered dementia care?

METHODS

For the identification of key intervention categories, we performed a systematic review of PC-interventions for PlwD. The review was guided by the established guidelines in the *Cochrane Handbook for Systematic Reviews of Interventions* [48]. For this report, the PRISMA Checklist was followed [49], which can be reviewed in Supplementary Table 1.

Table 1
Inclusion/exclusion criteria

Population	*Include:* Studies that include dementia populations as main group of study participants from any setting, who had any type of dementia diagnosed by health professionals. The dementia may be mild, moderate or severe. *Exclude:* Publications focused on non-human populations, persons with other diagnoses than dementia, or populations with mild cognitive impairment (MCI). Publications where the study a) investigates effects of interventions on or b) merely is tailored towards other persons than the People living with Dementia (PlwD) themselves, e.g., informal caregivers (CGs) or healthcare professionals.
Intervention	*Include:* Interventional studies, which focus on Person-Centered Care (PCC) applying the following terminology: a) "person-centered care" or respective synonyms as identified in the search string (see Supplementary Material 2) or b) highlight the perspectives, needs and preferences of the individuals studied. *Exclude:* Any studies that did not describe a health or social care interventional study. "Interventional study" is defined based on the WHO-definition for "health intervention": "*A health intervention is an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions.*" [95]
Comparators	*Include:* Care as usual or placebo. For some groups, this may include pharmacological interventions. *Exclude:* Any publication that did not include a control group.
Outcomes	*Include:* At least one of the following outcomes for the PlwD had to be reported in the study: 1. Time to care home admission/institutionalization 2. Hospital admissions 3. Quality of Life (QoL) 4. Well-being 5. Activities of daily living (ADLs) 6. Behavior (e.g., neuropsychiatric symptoms, NPS) 7. Cognition 8. Mood (e.g., level of depression) 9. Acceptance and adherence 10. Satisfaction 11. Social participation 12. Overall survival (OS) 13. Progression free survival (PFS) 14. Use of medication 15. Falls 16. Hydration *Exclude:* Any publication that did not report any outcome measures. Any publication that did not report at least one of the patient-relevant outcomes for PlwD as listed above.
Study Design	*Include:* Only original research, concretely studies designed as Randomized Controlled Trials (RCTs) and Non-Randomized Controlled Studies (NRS) [96], e.g., non-randomized controlled trials, controlled before-and-after studies, interrupted time series studies, historically controlled studies, cohort studies, case-control studies and cross-sectional studies, which report patient relevant outcome measurements of PC-interventions, were included. *Exclude:* Any publication that was not available in English or German language. Publications not available as a full text journal article (i.e. conference abstracts or proceedings, books, letters or correspondence, editorials), or those that do not describe the methodology of investigation, were excluded. Similarly, reviews, protocols, pilot/exploratory studies, case reports, professional discussions, opinion pieces and descriptive studies of general service use not involving a designated intervention, as well as all qualitative research were excluded.

Protocol and registration

A protocol for the review was registered with PROSPERO (Reference/ID No: CRD42021225084). We strictly followed this protocol for the systematic review process. For the report of our findings, we have adjusted some terminology for clarity and refocused the discussion and application of results to make the review suitable for a broader audience.

Study eligibility criteria

The definition of eligibility criteria for this systematic review was based on the PICOS (Population, Intervention, Comparison, Outcome, Study Design) format of study design questions [50]. Records were included/excluded if they met the criteria as depicted in Table 1.

Information sources and search strategy

The three dimensions, 1) Dementia, 2) Person-Centered Care, and 3) Intervention, were used for the development of the search strategy. The keywords used (see Supplementary Material 2 for complete search string) included Dementia (MeSH), Alzheimer's Disease, Patient-Centered Care (MeSH), Person-Centered Care, Relationship-Centered Care, and all possible synonyms to this concept as identified via the MeSH-database [51] and previous literature, e.g., [38, 52, 53], in U.S.- and U.K.-English spelling, as well as Therapy (MeSH), intervention, and treatment, focused on those of non-pharmacological and psychosocial nature. The search was piloted prior to the development of the protocol. Time period restriction was not applied, language was limited to English and German. The databases searched included PubMed, Web of Science, and Embase, following recommendations from Bramer et al. [54] for optimal database combinations in literature searches. The last search was conducted on November 5, 2020.

Study selection

De-duplication of identified records followed the systematic approach by Bramer et al. [55]. The first stage of study selection entailed the screening of titles and abstracts, performed by two reviewers (WM and AA). The screening process included to compare information presented in the title and abstract with the pre-defined in- and exclusion criteria. Eventual discrepancies were resolved by discussion between reviewers (WM and AA) until consensus was reached, and where this was not possible, a third researcher (AR, BM, FM, or MP) was consulted. All records where titles and abstracts were considered to conform with the eligibility criteria were included for full-text screening. The second stage of data selection, full-text review, performed by two reviewers (WM and AA), followed the aforementioned strategy. Both stages of the screening process were performed in the online software Rayyan [56]. Per PC-interventional study, only one published record in accordance with eligibility criteria was included.

Data extraction

The following information was collected: author, country, setting, sample size, age in years of the target group, intervention, control group, duration/follow-up, dementia severity based on stated scores and/or stages, outcome measures, and study design. To organize the evidence data were entered into an "Effects Table", a qualitative tool to display a concise summary of the included studies' interventions and outcomes/effects.

Risk of bias assessment

Two reviewers (WM and AA) examined the risk of bias for all included studies by application of two validated analysis tools: 1) the Cochrane Collaboration's Risk of Bias tool 2 (RoB2) [57] for randomized controlled trials (RCTs) and 2) the Newcastle-Ottawa Scale (NOS) [58] for cohort-studies to assess the quality of the non-randomized controlled studies (NRS). Where discrepancies arose, a third researcher (AR, BM, MR, WH) was involved in the discussion.

Data synthesis

A concise narrative summary was undertaken to identify key intervention categories. PC-interventions were analyzed for the distinct activities performed under their scheme, and respectively synthesized and categorized into named intervention categories with shared characteristics oriented in Dickson et al. [59], and Clarkson et al. [60]. The synthetization and categorization covered information about a) content (individual PC-interventions), b) provider(s), c) format, d) setting, e) intensity, and f) fidelity [61] for the distinct intervention categories.

RESULTS

Study selection

The searches identified a total of 1,806 records. After removal of duplicates, 1,162 records were identified for title/abstract-screening, out of which 41 records underwent full-text review. The majority of records were excluded because of ineligible populations or study designs. The selection process is depicted in Fig. 1.

Following the screening of the full texts of selected records, 19 interventional studies were identified. 14 studies of those applied a RCT-design [62–75], and one study further used a quasi-experimental pre- and post-test design including randomization [76]. The remaining four [77–80] applied NRS-designs, including one cohort [78] and three non-randomized quasi-experimental, prospective, longitudinal studies [77, 79, 80].

Characteristics of included studies

The summary of characteristics for the 19 included studies is depicted in Table 2. The summative Table 2 covers the information extracted and organized in the aforementioned Effects Table in a comprehensive display.

The majority of studies were conducted in high-income countries in Northern-America and Europe

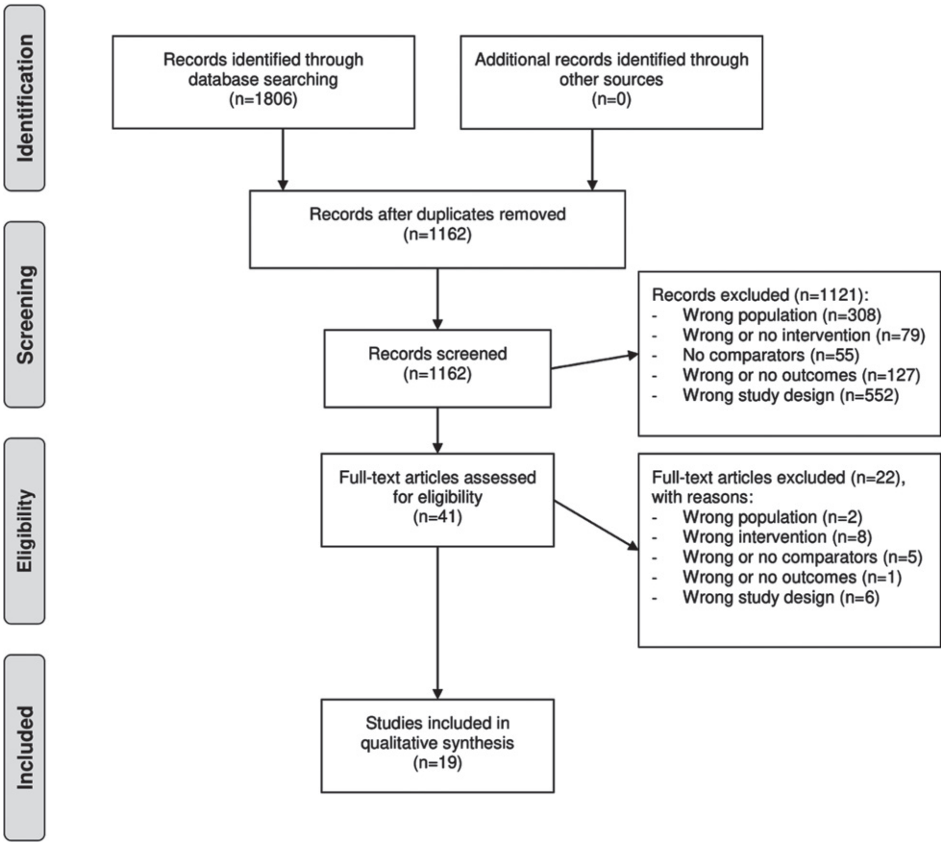

Fig. 1. Study flow diagram. Note: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009) Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* **6**, e1000097. For more information, visit www.prisma-statement.org.

(USA [65, 68, 70, 75], UK [62, 67], Australia [63, 64, 74], Canada [66], the Netherlands [73, 76, 77, 79], Belgium [72], Norway [69, 71], Spain [80]) and in Asia (Singapore [78]). 18 studies were conducted in long-term care facilities without further specification on the operational model of the respective institutions (for profit or not for profit), one study was conducted at a hospital [78]. No studies were conducted in homecare/primary care settings. Sample sizes varied between 52 to 847. The majority of participants in the studies were, on average, above 80 years of age. The studies covered a wide range of interventions, oftentimes delivered as multi-component interventions [62–65, 67–69, 73, 74, 77–79]. Eight studies concretely stated an assessment of preferences or needs prior to the intervention [63–66, 72, 75–77], among which three [72, 75, 76] assessed preferences or needs by direct involvement of the PlwD, while the remaining relied on information from care plans and/or informal and professional CGs. Others mentioned the necessity to adjust the intervention to the PlwD’s preferences and needs, but did not report concrete assessments of the latter [68–71, 73, 74, 78]. Three studies [65, 69, 74] used placebo interventions, while the remaining provided usual care in the control group. The duration of the studies ranged from two weeks [65] up to 18 months [76]. Dementia severity varied, with many participants at moderate to severe stage. Seven studies found a significant positive effect on QoL [62, 63, 66, 77, 78, 80], nine studies found a significant positive effect on agitation [62–65, 70–72, 74, 78]. A comprehensive list of outcome measures including the respective measurement tools and an indication of effectiveness is depicted in the right column of Table 2.

Quality of the included studies

Following the risk of bias assessment with RoB2 [57] for randomized study designs and with NOS [58] for non-randomized study designs, the overall quality of the included studies varied between low to

Table 2

Narrative summary of characteristics for included studies

Author	Country	Setting	Sample size (N)	Age in years mean (SD)	Intervention	Control group	Duration/ follow-up	Dementia severity	Outcome measures[b]
RCTs									
Ballard et al. [62]	UK	Nursing home	847	88.5 (0.50)	The **WHELD** program, which combined: 1) staff training (training in PCC for staff and promoting tailored person-centered activities and social interactions), 2) social interaction, and 3) guidance on use of antipsychotic medications	TAU	9 months	FAST stage: *Mild or less* TAU: 35 (7.90%) WHELD: 47 (11.64%) *Moderate* TAU: 38 (8.58%) WHELD: 39 (9.65%) *Moderately severe* TAU: 267 (60.27%) WHELD: 241 (59.65%) *Severe* TAU: 103 (23.23%) WHELD: 77 (19.06%)	*Primary:* - **QoL (DEMQOL-Proxy)** *Secondary:* - **Agitation (CMAI)** - **NPS (NPI-NH)** - Antipsychotic use (Med. charts) - Global deterioration (CDR) - Mood (CSDD) - Unmet needs (CANE) - Mortality - **Quality of interactions (QUIS)** - Pain (APS) - Cost
Chenoweth et al. [64]	Australia	Urban residential sites	289	DCM: 83 (7.6) PCC: 84 (6.4) UC: 85 (6.6)	**DCM:** 2 healthcare professionals at each site were trained to become certified mappers in a 2-day course. The remaining staff was trained by the certified mappers and applied PCC plans. Additional support was provided via regular telephone support from experts in DCM. **PCC:** Bradford University training manual was applied in a 2-day training session for staff, central to the practices was a careful review of residents' life histories.	UC, characterized by custodial and physical task-oriented practices	4 months Follow-up: 4 months	GDS, mean (SD) DCM = 5,6 (1,3) PCC = 5,6 (0,73) CAU = 5,3 (1,1)	*Primary:* - **Agitation (CMAI)** *Secondary:* - NPS (NPI-NH) - QoL (QUALID) - **Falls (Records)**[c] - Use of antipsychotic drugs (Records) - Use of physical restraint (QUIS) - Cost of treatment
Chenoweth et al. [63]	Australia	Residential aged care homes	601	CAU = 86 (7) PCC = 84 (8) PCE = 84 (8) PCC + PCE = 84 (7)	**PCC:** Five staff from each of the 19 PCC homes received 32 hours off-site training, which focused on paying attention to the residents' feelings when agitated, interacting with residents in a person-centered way and using person-centered care planning to meet the residents' psychosocial needs, followed by on-site supervision in these processes (range 2–16 hours) and telephone support. These staff trained remaining staff after completion of their own training. **PCE:** Included improvements to the safety, accessibility and utility of outdoor spaces, provision of a greater variety of social spaces and using color and objects for way-finding and to improve feelings of familiarity. Two experts in PCE principles planned and supervised implementation of recommended PCE interventions with a maximum budget of AUD$10,000 per home.	UC and UE	4 months, FU: 8 months	GDS severe/very severe in % UC = 88 PCC = 90 PCE = 82 PCC + PCE = 85	*Co-primary outcomes:* - **QoL (DEMQoL self-report and proxy interview)** - **Agitation (CMAI)**[d] - **Emotional responses in care (ERIC)**[e] - Depression (CSDD) *Secondary outcome:* - **Care interaction quality (QUIS)**[e]

Cohen-Mansfield et al. [65]	USA	Nursing homes	231	TREA: 85.9 (8.62) Control: 85.3 (9.62) Total: 85.7 (8.89)	**TREA** including individually tailored non-pharmacologic interventions (e.g., simulated social contact, magazine/reading/book on tape (audio drama), music, physical activities, sensory stimulation, puzzles and games, sorting, videos and television, group activities). Delivered by research team (experts in gerontology and psychology).	Placebo intervention (in-service education for care staff members about the syndromes, etiologies, and possible non-pharmacological treatments for agitation).	2 weeks	MMSE Mean (SD) TREA: 7.62 (6.33) Control: 9.38 (6.76) Total = 8.12 (6.48)	*Primary:* - **Agitation (ABMI)** *Secondary:* - **Observed affect (Lawton's Modified Behavior Stream)**
Eritz et al. [66]	Canada	Nursing homes	73	85.98 (7.49)	**Life history intervention:** Each history, derived from proxy (majorly children and spouses) interviews, was approximately two pages, including one page of photographs, shown to care staff. Family members were encouraged to submit resident's photographs as well as artefacts from the past to be included. The residents' life histories or medical histories were written by the primary researcher or a trained research assistant.	Medical history (CAU)	3 months	Average CPS-score (SD): 4.17 (1.57)	- Aggression (ABS) - Agitation (CMAI) - **QoL (ADRQL-R)**
Fossey et al. [67]	UK	Nursing homes	349	Control: 82 (53-101)* Intervention: 82 (60-98)	**PCC-staff training** including an intervention package: care staff were trained in the philosophy and application of PCC. This included ongoing training and group supervision with support and feedback by researchers.	CAU	10 months	CDR, n (%): *None, questionable, or mild* Control: 37/163 (23) Intervention: 25/170 (15) *Moderate* Control: 32/163 (20) Intervention: 46/170 (27) *Severe* Control: 94/163 (58) Intervention: 99/170 (58)	*Primary:* - **Neuroleptic use and dose of neuroleptic** *Secondary:* - Agitation (CMAI) - Quality of life - Proportion of patients taking other psychotropic drugs (Med. records) - Adverse events (including documented falls) (Med. records) - Incidents involving irritable behavior directed at staff or other residents
Lawton et al. [68]	USA	Nursing homes	182	N/A	The **"stimulation-retreat"** model: The intervention program attempted to modulate different perspectives by acknowledging various needs for stimulation both across individuals and at different times within the same person. The major treatment task was to be sensitive to individual preference, individual capability, and contextual appropriateness. The major components of the program were staff training, interdisciplinary care planning, family support, and activity programming, with the choice of a specific type of one-to-one contact being determined by consensus at the care planning session; the most frequent types of contact were conversation, music, reading, or looking at pictures with the resident.	No further information except from "controls".	12 months	GDS, mean Total (baseline) = 5.53 Total (FU) = 5.87	- Cognitive status (MDRS, GDS) - Functional health (PSMS) - Negative behaviors (BEHAVE-AD) - Agitation (CMAI) - Affective states (incl. depression, externally engaging behaviors) (MOSES) - Externally engaging behaviors (MOSES, Behavior Rating Scale, Activity Participation Scale) - Behavior streams (The Psion event recorder, The Observer, PGCARS,) - Composite factor scores for Problem Behaviors, Depression, Social Quality, and Time Use (MDS)

(Continued)

Table 2
(Continued)

Author	Country	Setting	Sample size (N)	Age in years mean (SD)	Intervention	Control group	Duration/ follow-up	Dementia severity	Outcome measures[b]
Rokstad et al. [69]	Norway	Nursing homes	624	Total: 85.7 (8.3) DCM: 85.1 (8.7) VPM: 85.1 (8.5) Control: 87.0 (8.3)	**DCM**: From each participating ward in the intervention group, two care staff attended a DCM course and became certified mappers. The remaining staff were trained in PCC with lectures by the researchers. The certified staff conducted the mapping and trained the remaining staff members. Feedback sessions occurred during the intervention period. **VPM**: From each participating nursing home, two nurses were appointed as VPM coach including the attendance of a VPM-training course. The VPM coaches trained the remaining staff with lectures applying the VPM manual [97].	Placebo incl. DVD with lectures about dementia (no information about PCC) + CAU.	10 months	CDR, mean sum of boxes (SD) Total: 12.8 (4.1) DCM: 12.4 (4.0) VPM: 13.5 (4.4) Control: 12.4 (3.9)	*Primary outcome:* - Agitation (BARS) *Secondary outcomes:* - **NPS (NPI-Q),** - **Depression (CSDD)**[f] - **QoL (QUALID)**[g]
Sloane et al. [70]	USA	Nursing homes	73	Control: 86.9 (6.1) Intervention: 86.0 (8.6)	**Person-centered showering** sought to individualize the experience for the resident by using a wide variety of techniques, such as providing choices, covering with towels to maintain resident warmth, distracting attention (e.g., by providing food), using bathing products recommended by family and staff, using no-rinse soap, and modifying the shower spray. **The towel bath** is an in-bed method in which the caregiver uses two bath blankets, two bath towels, a no rinse soap, and 2 quarts of warm water; keeps the resident covered at all times; and cleanses the body using gentle massage.	Usual methods of showering	3 months	MMSE, mean (SD): Control: 2.1 (4.1) Intervention: 2.2 (4.0)	*Primary outcomes:* - **Agitation (CAREBA, The Observer Video-Pro)** - **Aggressive behaviors (CAREBA, The Observer Video-Pro)** - **Discomfort (Modified discomfort scale for dementia of the Alzheimer type)** *Secondary measures of effect:* - **Bath duration and completeness (the number of body parts bathed and the number of minutes spent being bathed)** - **Skin condition (Hardy Skin Condition Data Form)** - **Skin microbial flora (Skin Cultures)**
Testad et al. [71]	Norway	Nursing homes	274	- Intervention: 88.2 (8.2) Control: 85.2 (8.2)	The **"Trust Before Restraint"** intervention was based on the evidence of the Relation Related Care (RRC) intervention and decision-making process (DMP), the Norwegian legislation on restraint and best practice for PCC. Included elements of shared decision making and a life history/ bibliographical approach.	TAU	7 months	CDR, sum of boxes mean (SD) Intervention: 12.2 (4.8) Control: 12.6 (4.2)	*Primary outcomes:* - **Use of restraint (standardized interview)** *Secondary outcomes:* - **Agitation (CMAI, NPI)** - Use of psychotropic drugs (Medical Journals)
Van Bogaert et al. [72]	Belgium	Nursing homes	72	Total: 84 (78–90)** Intervention: 84 (79.5–90.5) Control: 84 (76–89)	**SolCos** transformational reminiscence model was performed by trained nursing home volunteers as facilitators.	CAU	10 weeks	MMSE: Intervention: 18 (15–22)** Control: 15 (12.5–20)	*Primary outcomes:* - **Depression (CSDD)** *Secondary outcomes:* - Cognition (MMSE, FAB) - Behavior (NPI)
van de Ven et al. [73]	The Netherlands	Nursing homes	268	Intervention: 84.6 (6.1) Control: 83.5 (6.6)	**DCM**: two staff from each care home receiving the intervention were trained and became certified mappers. Initially, an external expert delivered a lecture on PCC. Subsequently, the certified staff conducted the mapping and trained the rest of the staff members. In the beginning of the intervention, members of care staff were given a lecture in both DCM and PCC.	CAU	4 months, FU 8 months	N/A	*Primary outcomes:* - Agitation (CMAI) *Secondary outcomes:* - NPS (NPI-NH) - QoL (Qualidem, EQ-5D)

van der Ploeg et al. [74]	Australia	Residential facilities	57	Total: 78.1 (9.8)	Personalized one-to-one activities that were delivered by a trained psychologist and higher degree psychology student applying **Montessori** principles. Typical selections included listening and singing along to favorite music, looking at and sorting pictures, arranging flowers, sorting dry pastas, folding towels, screwing nuts and bolts together, planting seeds, and making puzzles.	Placebo: social interaction via general conversation	4 weeks	MMSE (range = 0–23) Mean (SD): 6 (8)	*Primary outcomes:* - **Agitation (direct observation and count of frequency of agitated behaviors)** *Secondary outcomes:* - **Affect (PGCARS)** - **Engagement (MPES)**
Van Haitsma et al. [75]	USA	Nursing homes	195	Total: 88.7 (64–105)****	**Individualized Positive Psychosocial Intervention (IPPI):** The intervention offered five basic types of activities reflective of the most common resident-preferences. Within each category, two or more specific options were offered (30 activity options total). Physical exercise included the option to take an outdoor walk or work with clay. Music included singing or listening to a favorite artist; reminiscence, reviewing family photos, or writing letters; ADLs, manicures, or preparing a snack; and sensory stimulation could mean a hand massage with lotion or smelling fresh flowers.	UC + attention control	3 weeks	MMSE (range 0–24), mean (SD) Total: 9.0 (7.6)	- Negative affect (sadness, **anger**, anxiety) - **Positive affect (pleasure, alertness)** - **Verbal behavior**[h] (very negative, negative, positive, **very positive**, no verbal) - Nonverbal behavior (psychosocial task, restlessness, null behavior, eyes closed, aggression, uncooperative, positive touch)[h] Outcome measures were collected through direct observations in the form of 10-min "behavior streams", using The Psion event recorder and The Observer software.
van Weert et al. [76][a]	The Netherlands	Nursing homes	129	Intervention: 84.01 (8.7) Control: 82.60 (8.2)	Staff was trained in principles of **Snoezelen**. The training focused in particular on: the development of CNAs awareness of the residents' physical, social and emotional needs, making contact with demented residents and showing affection and empathy, supporting demented residents in responsiveness, avoiding to correct the residents' subjective reality, avoiding to spread useless cognitive information and to test the residents' remaining cognitive knowledge. The training paid attention to practical skills needed for the application of multi-sensory stimulation, such as taking a life style history interview with family members, arranging a stimulus preference screening to find out which sensory stimuli the resident likes most and writing a snoezel care plan describing how to approach the resident and how to integrate multi-sensory stimuli in 24 h care.	Usual care	18 months	BIP7; 0–21***, mean score (SD) Intervention: 14.61 (3.1) Control: 13.37 (4.0)	- **Communicative behavior (RIAS)** - **Nonverbal behavior, e.g., gazing, affective touch, smiling (Observation Scheme with Indicators)**

(Continued)

Table 2

(Continued)

Author	Country	Setting	Sample size (N)	Age in years mean (SD)	Intervention	Control group	Duration/ follow-up	Dementia severity	Outcome measures^b
NRS									
Boersma et al. [77]	The Netherlands	Nursing homes	212	Intervention: 85.3 (7.5) Control: 85.9 (7.8)	**Veder Contact Method (VCM):** VCM aims to stimulate contact between the person with dementia and the caregiver, by using *theatrical, poetic and musical communication* in combination with elements of existing care methods, that is, reminiscence, validation, and neurolinguistics programming. Care staff were trained in VCM.	CAU	9 months, FU 3 months	MMSE, mean (SD) Intervention: 13.9 (8.9) Control: 14.6 (7.3)	- **QoL (QUALIDEM)** - Behavior and interactions (INTERACT) - Mood (FACE, a three-point Likert scale) DCM to collect observational data on residents and caregivers.
Tay et al. [78]	Singapore	Hospital, Dementia Specific Care Unit	230	Intervention: 82.45 Control: 84.37	**CAMIE:** (1) enhanced medical care protocol, which includes moderating intrusive interventions, a physical restraints-free policy, appropriate and modest use of psychotropic medications, careful attention to hydration, bowel and bladder care, and encouraging mobilization and (2) enhanced psychosocial care protocol, which includes prioritizing patient needs over tasks, encouraging family members and volunteers to provide companionship, and engaging in daily structured activities (e.g., music therapy, recreational/group activities). CAMIE is run by a multidisciplinary team of doctors, nurses, and allied health professionals including a social worker, dietician, pharmacist, as well as physio, occupational, and speech and music therapists.	Conventional geriatric ward	6 months	DSM-IIIR, n and % *Mild* Intervention: 14 (8.20) Control: 2 (3.30) *Moderate* Intervention: 102 (60.00) Control: 37 (61.70) *Severe* Intervention: 54 (31.80) Control: 21 (35.00)	- **Well-being (WB- and IB-Score)** - **Functional ability (MBI)** - **QoL (EQ-5D Index Score)** - **Agitation (PAS)** - Use of psychotropic medications (Medical records) - Length of stay - **Cost-effectiveness**
Verbeek et al. [79]	The Netherlands	Long-term institutional nursing care (i.e., small-scale living facilities and traditional psychogeriatric wards)	259	Intervention: 82.4 (7.9) Control: 83.1 (6.5)	**SSLF**: These facilities were selected based on six characteristics: (1) eight residents per house or unit at most; (2) daily household duties were centered around activities of daily life; e.g., all meals were prepared in the unit's kitchen by nursing staff together with the residents and/or their family caregivers; (3) staff performed integrated tasks: alongside medical and personal care, they also carried out household chores and organized activities; (4) a small consistent team of staff took care of the residents; (5) daily life was largely determined by the residents, family caregivers, and nursing staff; and (6) the physical environment resembled an archetypal house SSLF are based on a care concept, which emphasizes the normalization of daily life, encourages residents' participation and autonomy, and a person-centered attitude towards care.	Traditional psychogeriatric wards	12 months incl. FU	MMSE (0-30), mean (SD) Intervention: 11.1 (7) Control: 10.5 (6.6)	*Outcome measures:* - NPS (NPI-NH, CMAI) - Depression (CSDD) *Additional variables:* - **Social engagement (Subscale ISE from RAI-MDS)** - **Use of physical restraint (Questionnaire, type and no. of times)** - **Psychotropic medication (Medical Journals)**

Villar et al. [80]	Spain	Nursing homes	52	Total: 86.7 (7.3)	**ICP program:** Residents were invited to participate in ICP multidisciplinary meetings, attended by staff members (including doctors, nurses, psychologists, social workers and auxiliary CGs) who reached agreements on treatments and recommended intervention strategies. Staff were asked to welcome residents, orientate them in time and space, detail the goals of the meeting, address their interventions to them and take their perspective into account, explain the agreements reached and ask them for their opinion about the treatment and its implementation.	Usual care, i.e., care planning meetings without the patient.	10 months	MMSE, mean (SD): 16.1 (4.0)	- **QoL (GENCAT, proxy-measure)**

Abbreviations: ABMI, agitation behavior mapping instrument, ADRQL-R, Alzheimer's Disease-related Quality of Life-Revised, APS, Abbey Pain Scale, BARS, Brief Agitation Rating Scale, BEHAVE-AD: Clinical Rating Scale for the Assessment of Pharmacologically Remediable Behavioral Symptomatology in Alzheimer's Disease, BIP7, Dutch Behavior Observation Scale for Psychogeriatric In-patients Version 7, CANE, Camberwell Assessment of Need for the Elderly, CAU, Care as usual, CAMIE, Care for Acute Mentally Infirm Elders, CAREBA, Care Recipient Behavior Assessment, CDR, clinical dementia rating, CMAI, Cohen-Mansfield's agitation inventory, CPS, Cognitive Performance Scale, CSDD, Cornell Scale for Depression in Dementia, DCM, Dementia Care Mapping, DemQOL, dementia quality of life, DSM-IIIR, Diagnostic and Statistical Manual of Mental Disorders, DVD, digital video disk, EQ-5D, European Quality of Life 5 Dimensions, ERIC, Emotional Response in Care, FAB, Frontal Assessment Battery, FACE, Face expression scale, FAST, functional assessment staging of Alzheimer's disease, FU, Follow-up, GDS, Geriatric Depression Scale, GENCAT, Government of Catalonia Scale for Assessment of Residents' QoL, ICP, Individualized care planning, INTERACT, Mood and Behavior of persons with dementia, ISE, Index of Social Engagement, MBI, Modified Barthel Index, MDRS, Mattis Dementia Rating Scale, MDS, minimum data set, MMSE, mini mental state exam, MOSES, Multidimensional Observation Scale for Elderly Subjects, MPES, Menorah Park Engagement Scale, NPI, Neuropsychiatric Inventory, NPI-NH, Neuropsychiatric Inventory–Nursing Home, NPI-Q, Neuropsychiatric Inventory Questionnaire, NPS, Neuropsychiatric Symptoms, NRS, Non-Randomized Studies, PAS, Pittsburgh Agitation Scale, PCC, Person-Centered Care, PCE, Person-Centered Environment, PGCARS, Philadelphia Geriatric Center Affect Rating Scale, PSMS, Physical Self-maintenance Scale, QoL, Quality of Life, QUALID, quality of life in late-stage dementia, QUALIDEM, Quality of Life of people with Dementia, QUIS, questionnaire for user interaction satisfaction, RAI-MDS, Resident Assessment Instrument – Minimum Data Set, RCT, Randomized Controlled Trial, RIAS, Roter Interaction Analysis System, SD, Standard Deviation, SSLF, Small-scale living facilities, TAU, Treatment as usual, TREA, Treatment Routes for Exploring Agitation, UC, Usual Care, UE, Usual environment, VIPS Framework, valuing people with dementia (V), individualized care (I), understanding the world from the patient's perspective (P) and providing a social environment that supports the needs of the patient (S), VPM, VIPS Practice Model, WHELD, Improving Wellbeing and Health for People Living with Dementia.

*Median (range).

**Median (IQR).

***The underlined scores indicate the most favorable score (least impairment) for the scale.

****Mean (range).

[a] Note: van Weert et al. (2005) applied a quasi-experimental pre- and post-test design, including randomization, hence this study was assessed with RoB2 for risk of bias and is for consistency portrayed in the RCT-category of this table.

[b] Significant effects are marked in bold.

[c] At follow-up, there were fewer falls with DCM than with usual care ($p = 0.02$) and more falls with PCC than with usual care ($p = 0.03$).

[d] Those in PCC + PCE had non-significant changes.

[e] The percentage of positive emotional responses to care (ERIC) improved significantly over time for the PCC + PCE group (by 7% on average, $p = 0.01$), but as the group-by-time interaction was not significant (0.07), differences among groups for emotional responses cannot be inferred. QUIS improvements did not occur in the other groups than PCC + PCE (group-by-time interaction $p = 0.007$).

[f] Significant for VPM.

[g] Significant for DCM.

[h] More negative verbal behaviors by AC- compared to UC or IPPI-groups. AC-group showed more positive behaviors than IPPI; AC- and IPPI-groups showed more positive behaviors than UC-group. The IPPI-group showed significantly more very positive responses than either UC- or AC-groups. Nonverbal responses were significantly higher for the UC-group compared to AC- and IPPI-groups.

Table 3
Assessment of risk of bias for included RCTs

Author	Randomization process	Deviations from intended interventions	Missing outcome data	Measurement of outcome	Selection of the reported result
Ballard et al. [62]	o	o	o	o	o
Chenoweth et al. [64]	v	o	o	o	o
Chenoweth et al. [63]	o	o	o	o	o
Cohen-Mansfield et al. [65]	o	o	v	v	o
Eritz et al. [66]	v	o	o	v	o
Fossey et al. [67]	o	o	o	o	o
Lawton et al. [68]	o	x	v	v	o
Rokstad et al. [69]	v	o	o	o	o
Sloane et al. [70]	o	o	o	o	o
Testad et al. [71]	v	o	x	o	o
van Bogaert et al. [72]	o	v	v	o	o
van de Ven et al. [73]	o	o	v	v	o
van der Ploeg et al. [74]	o	o	v	o	o
van Haitsma et al. [75]	o	v	o	v	o
van Weert et al. [76]*	o	x	v	o	o

Note: Low risk of bias (o), moderate risk of bias (v), high risk of bias (x). Abbreviations: RCTs, randomized controlled trials.
*van Weert et al. (2005) applied a quasi-experimental pre- and post-test design including randomization, hence this study was analyzed with Rob2 for risk of bias of included RCTs.

Table 4
Assessment of risk of bias for included NRS

Author	Selection	Comparability	Outcome
Boersma et al. [77][a]	★ ★ ★ ★		★ ★ ★
Tay et al. [78][b]	★ ★ ★ ★	★ ★	★ ★ ★
Verbeek et al. [79][a]	★ ★ ★ ★	★ ★	★ ★
Villar et al. [80][a]	★ ★ ★ ★		★

[a]Prospective, longitudinal quasi-experimental trials, assessed as cohort by proxy, [b]Prospective naturalistic cohort study. Note: A study can be awarded a maximum of one star for each numbered item within the Selection (4 stars) and Outcome (3 stars) categories. A maximum of two stars can be given for Comparability. Maximum no. of stars in total is nine.

moderate. The results of potential bias assessment in each study are reported in Table 3 for the randomized study designs and Table 4 for the non-randomized study designs.

Among the randomized studies, 11 studies [62, 63, 65, 67, 68, 70, 72–76] had a low risk of bias with concern to the randomization process, and four studies had a moderate risk of bias [64, 66, 69, 71]. There was a moderate to high risk of bias for several studies due to deviations from intended interventions [68, 72, 75, 76] or missing outcome data [65, 68, 71–74, 76]. Due to the nature of the study populations, a substantial loss of study participants by decease occurred in the majority of studies, however in three [66, 70, 75] no major loss to follow-up occurred. In general, the authors acknowledged the missing data and reported the reasons. However, none of the studies with moderate to high risk of bias due to missing outcome data [65, 68, 71–74, 76] reported sufficient evidence to judge whether or not their result was biased by missing outcome data, i.e., analysis methods that correct for bias and/or sensitivity analyses. For some studies [65, 66, 68, 73, 75] there were some concerns for risk of bias with regard to the measurement of the outcomes, mostly because blinding of outcome assessors could not be assured. All randomized studies had a low risk of bias in selection of the reported results, i.e., authors were consistent and transparent in the report of their study results.

Among the included NRS, all four studies [77–80] had a low risk of bias associated with the selection process of the exposed and non-exposed cohorts/the experimental and control group. Two studies [78, 79] had a low risk of bias concerning the comparability of cohorts/groups, based on the analysis, while the two other studies [77, 80] had a high risk of bias due to missing information about controlling analyses for confounders and/or covariates. With regards to the outcome assessment (including length and adequacy of follow-up), for two studies [77, 78] there was a low risk of bias, whilst two other studies [79, 80] had some concerns for risk of bias due to self-reported assessments of outcome.

Synthesis

A summary of key intervention categories, including content (interventions), provider, format, setting, intensity, and fidelity is depicted in Table 5. A total of nine key intervention categories to guide the provision of Person-Centered Dementia Care

Table 5

Narrative summary of synthesis: intervention categories including descriptions

Intervention category incl. description*	Studies (Author(s), year)	Content (Interventions)	Provider***	Format	Setting	Intensity	Fidelity**
Social contact: Provision of different forms of social contact to counterbalance the potentially limited contact with others. This social contact can be real or simulated [60].	Ballard et al. [62], Boersma et al. [77], Cohen-Mansfield et al. [65], Fossey et al. [67], Lawton et al. [68], Tay et al. [78], van der Ploeg et al. [74], van Haitsma et al. [75], Verbeek et al. [79]	Social simulation tool (e.g., robotic animal, lifelike baby doll, baby video, respite video, stuffed animal, family pictures and family video, writing letters) One-on-one interaction (incl. active listening and communication) Conversation (e.g., General and based on e.g., newspaper stories and pictures) Group activity	Trained care staff, researchers in gerontology and psychology, trained psychologist, occupational therapist, nurse, CNAs, rabbi, social workers, a trained multidisciplinary team of doctors, nurses, dietician, pharmacist, physiotherapist, speech therapist, music therapists, volunteers, (higher degree psychology) students, family caregivers	Mostly individual but also and/or group	Nursing home Hospital specialized care unit Residential facilities Long-term institutional nursing care	7AM – 3 PM or 3PM – 11 PM, 10 min – 4 h per week, 1 – 7 days per week, 2 weeks – 12 months	Substantial loss to follow-up (deaths) yielding high non-completion rates. Lack of staff and time, hence lack of therapeutic communication style in care main obstacles to wider implementation of PCC-interventions. A culture of resistance against intervention/suspicion about intrusion of outsiders among staff and management, hence problem with protocol adherence. Treatment facilitators tempted to deliver intervention to controls when control approach failed. Aggressive or non-cooperative participants. Allocation not randomized, some differences in outcomes existed already at baseline.
Physical activities: Provision of structured exercise to create meaningful and engaging experiences that can be a useful counterbalance to difficult behaviors [60].	Ballard et al. [62], Cohen-Mansfield et al. [65], Tay et al. [78], van der Ploeg et al. [74], van Haitsma et al. [75]	Physical activity (e.g., outdoor walks) Gardening	Trained care staff, researchers in gerontology and psychology, a trained multidisciplinary team of doctors, nurses, social worker, dietician, pharmacist, physiotherapist, occupational therapist, speech therapist, music therapists, volunteers, (higher degree psychology) students, CNAs	Individual and/or group	Nursing home Hospital specialized care unit Residential facilities	7AM – 3 PM or 3PM – 11 PM, 10 min – 4 h per week, 1 – 7 days per week, 2 weeks – 7 months	Substantial loss to follow-up (deaths) yielding high non-completion rates. Lack of staff and time, hence lack of therapeutic communication style in care main obstacles to wider implementation of PCC-interventions. Treatment facilitators tempted to deliver intervention to controls when control approach failed. Aggressive or non-cooperative participants. Problems with protocol adherence.
Cognitive training: Provision of stimulation for cognitive functions through a set of standard tasks, which reflect memory, attention or problem solving [60].	Ballard et al. [62], Boersma et al. [77], Cohen-Mansfield et al. [65], Lawton et al. [68], Tay et al. [78], van der Ploeg et al. [74], van Haitsma et al. [75], Verbeek et al. [79]	Puzzles and games Magazine/reading/book on tape Poetry Theatre Arts and crafts (e.g., screwing nuts and bolts together, working with clay, working with fabric) Work like activities, housekeeping tasks (e.g., folding towels) Videos and television Sorting (e.g., sorting pictures, arranging flowers, sorting dry pastas)	Trained care staff, researchers in gerontology and psychology, CNAs, psychologist, rabbi, social workers, a trained multidisciplinary team of doctors, nurses, a social worker, dietician, pharmacist, physiotherapist, occupational therapist, speech therapist, music therapists, volunteers, (higher degree psychology) students, family caregivers	Individual and/or group	Nursing home Hospital specialized care unit Residential facilities Long-term institutional nursing care	7AM – 3 PM or 3PM – 11 PM, 10 – 60 min per week, 1-7 days per week, 3 weeks – 12 months	Substantial loss to follow-up (deaths) yielding high non-completion rates. Lack of staff and time, hence lack of therapeutic communication style in care main obstacles to wider implementation of PCC-interventions. A culture of resistance against intervention/suspicion about intrusion of outsiders among staff and management, hence problem with protocol adherence. Treatment facilitators tempted to deliver intervention to controls when control approach failed. Aggressive or non-cooperative participants. Allocation not randomized, some differences in outcomes existed already at baseline.

(Continued)

Table 5
(Continued)

Intervention category incl. description*	Studies (Author(s), year)	Content (Interventions)	Provider***	Format	Setting	Intensity	Fidelity**
Sensory enhancement: Enhancement or relaxation of the overall level of sensory stimulation in the environment, intended to counterbalance the negative impact of sensory deprivation/stimulation [60].	Ballard et al. [62], Boersma et al. [77], Cohen-Mansfield et al. [65], Lawton et al. [68], Tay et al. [78], van der Ploeg et al. [74], van Haitsma et al. [75], van Weert et al. [76]	Music (e.g., listening, singing along, including in conversations and care) Snoezelen Sensory stimulation (e.g., hand massage with lotion, smelling fresh flowers)	Trained care staff, researchers in gerontology and psychology, CNAs, psychologist, rabbi, social workers, a trained multidisciplinary team of doctors, nurses, a social worker, dietician, pharmacist, physiotherapist, occupational therapist, speech therapist, music therapists, volunteers, (higher degree psychology) students	Mostly individual but also and/or group Individual	Nursing home Hospital specialized care unit Residential facilities	10 min – 24 h, 1 – 7 days per week, 3 weeks – 18 months	Substantial loss to follow-up (deaths) yielding high non-completion rates. Lack of staff and time, hence lack of therapeutic communication style in care main obstacles to wider implementation of PCC-interventions. A culture of resistance against intervention/suspicion about intrusion of outsiders among staff and management, hence problem with protocol adherence. Treatment facilitators tempted to deliver intervention to controls, when control approach failed/ intervention was delivered to some control wards. Aggressive or non-cooperative participants.
Daily living assistance: Assistance with basic care, e.g., provision of laundry services, basic nutrition and help with activities of daily living [60].	Ballard et al. [62], Cohen-Mansfield et al. [65], Sloane et al. [70], van Haitsma et al. [75], Verbeek et al. [79]	Care (e.g., taking person to bathroom, bringing a sweater or blanket, getting nursing staff, discussing medical condition with physician, repositioning person, taking person to his/her room, bringing eyeglasses, manicure, and other care activities) Food or drink, making snacks Activities of daily living Person-centered showering, towel bath	Trained care staff, researchers in gerontology and psychology, CNAs under supervision of clinical nurse specialist, psychologist or researchers, family caregivers	Individual and/or group	Nursing home Long-term institutional nursing care	7AM – 3 PM or 3PM – 11 PM, 10 min – 4 h per week, 2, 3 or 7 days per week, 2 weeks – 12 months	Substantial loss to follow-up (deaths) yielding high non-completion rates. Lack of staff and time, hence lack of therapeutic communication style in care main obstacles to wider implementation of PCC-interventions. Problems with protocol adherence. Allocation not randomized, some differences in outcomes existed already at baseline.
Life history oriented emotional support: Support with feelings and emotional needs through discussion or stimulation of memories to enable the person to share their experiences and life stories; intended to counterbalance and help people manage difficult feelings and emotions [60].	Ballard et al. [62], Boersma et al. [77], Chenoweth et al. [64], Eritz et al. [66], Fossey et al. [67], Rokstad et al. [69], Testad et al. [71], van Bogaert et al. [72], van Haitsma et al. [75]	Reminiscence and validation Life history/bibliographical approach interventions	Trained care staff (under supervision of researchers), DCM and VPM champions, special care aides, registered nurses, licensed practical nurses, registered psychiatric nurses, resident care coordinator, trained psychologist, occupational therapist, clinical research nurses, trained nursing home volunteers, supervised CNAs	Individual	Nursing home Urban residential sites	7AM – 3 PM or 3PM – 11 PM, 10 min – 6 h, 2–3 days a week – 2 days per 4 months, 2 weeks – 10 months	Substantial loss to follow-up (deaths) yielding high non-completion rates. Interruptions in intervention and data collection due to external factors (e.g., influenza outbreak, changes in local laws). Affecting the culture of care within a nursing home. Problems with protocol adherence. Study design did not allow to identify long-term effects nor effect on pharmacological status. Participation decreases in later sessions suggesting necessity to switch over to a maintenance dose.

Training and support for professional caregivers (CG): A change of interactions between professional CGs and patients with dementia, including: psycho-education; integrated family support, training in awareness and problem solving; and support groups [59].	Ballard et al. [62], Boersma et al. [77], Chenoweth et al. [64], Chenoweth et al. [63], Eritz et al. [66], Fossey et al. [67], Lawton et al. [68], Rokstad et al. [69], Tay et al. [78], Testad et al. [71], van Bogaert et al. [72], van de Ven et al. [73], van Weert et al. [76], Verbeek et al. [79]	Prof CG education and training (incl. education in antipsychotic drug use) Prof CG support Family support (education/emotional support for family, including family in care decisions)	Trained care staff (under supervision of researchers/external experts from e.g., patient association groups), DCM and VPM champions, special care aides, registered nurses, licensed practical nurses, registered psychiatric nurses, resident care coordinator, trained psychologist, occupational therapist, CNAs, rabbi, social workers, a trained multidisciplinary team of doctors, nurses, a social worker, dietician, pharmacist, physio-, occupational-, speech- and music therapists and volunteers, trained and certified DCM-mappers, family caregivers	Individual and/or group	Nursing home Urban residential sites Residential aged care homes Hospital specialized care unit Long-term institutional nursing care	*Training* 2 – 4 days once – 4 – 7 h twice monthly, 4 – 12 months *Supervision:* 2 – 16 h once – 1 – 2 days weekly, 4 – 10 months	Substantial loss to follow-up (deaths) yielding high non-completion rates. Inability to control for facility-initiated improvements in the control group. Interruptions in intervention and data collection due to external factors (e.g., influenza outbreak, changes in local laws). Intervention was delivered to some control wards. Problems with protocol adherence/compliance. A culture of resistance against intervention/suspicion about intrusion of outsiders among staff and management, hence problem with protocol adherence. Study design did not allow to identify long-term effects nor effect on pharmacological status. Participation decreases in later sessions suggesting necessity to switch over to a maintenance dose. Allocation not randomized, some differences in outcomes existed already at baseline.
Environmental adjustments: Modifications of the living environment, including the visual environment, to ease agitation and/or wandering and promote safety [60].	Ballard et al. [62], Chenoweth et al. [63], Fossey et al. [67], Verbeek et al. [79]	Physical aids, adaptions of environment, assistive technology, signage, reduce noise and clutter, small-scale home-like care environment	Trained care staff, facilitators trained by external experts among staff at each site, trained psychologist, occupational therapist, CNAs, family caregivers	Individual and/or group	Nursing home Residential aged care homes Long-term institutional nursing care	60 min weekly, 1 – 7 days per week, 4 – 12 months	Substantial loss to follow-up (deaths) yielding high non-completion rates. Inability to control for facility-initiated improvements in the control group. Problems with protocol adherence/compliance. A culture of resistance against intervention/suspicion about intrusion of outsiders among staff and management, incl. lack of willingness to make PCE-changes. Allocation not randomized, some differences in outcomes existed already at baseline.

(Continued)

Table 5

(Continued)

Intervention category incl. description*	Studies (Author(s), year)	Content (Interventions)	Provider***	Format	Setting	Intensity	Fidelity**
Care organization: Connection of different services around the person; advice and negotiation about the delivery of services from multiple providers on behalf of the person [60].	Ballard et al. [62], Chenoweth et al. [64], Chenoweth et al. [63], Fossey et al. [67], Lawton et al. [68], Rokstad et al. [69], Tay et al. [78], Testad et al. [71], van de Ven et al. [73], Verbeek et al. [79], Villar et al. [80]	Interdisciplinary/integrated care planning (incl. consistent staffing), case management Special units (e.g., in hospitals) Shared decision making	Trained care staff (under supervision of researchers), facilitators (e.g., clinical research nurses) trained by external experts among staff at each site, DCM and VPM champions, trained psychologist, occupational therapist, CNAs, rabbi, social workers, a trained multidisciplinary team of doctors, nurses, a social worker, dietician, pharmacist, physio-, occupational-, speech- and music therapists and volunteers, trained and certified DCM-mappers, family caregivers	Individual and/or group	Nursing home Urban residential sites Residential aged care homes Hospital specialized care unit Long-term institutional nursing care	20 min – 6 h, 2 days per week, 2 weeks – 12 months	Substantial loss to follow-up (deaths) yielding high non-completion rates. Inability to control for facility-initiated improvements in the control group. Problems with protocol adherence/compliance. A culture of resistance against intervention/suspicion about intrusion of outsiders among staff and management, incl. lack of willingness to make PCE-changes. Interruptions in intervention and data collection due to external factors (e.g., changes in local laws). Allocation not randomized, some differences in outcomes existed already at baseline.

Abbreviations: CNAs, Certified Nurse Aides; DCM, Dementia Care Mapping; VIPS Framework, valuing people with dementia (V), individualized care (I), understanding the world from the patient's perspective (P) and providing a social environment that supports the needs of the patient (S); VPM, VIPS Practice Model.

*Oriented in Dickson et al. [59] and Clarkson et al. [60].

**As indicated in text, where concrete information about the interventions' implementation process could not be identified, we report information about problems and/or (methodological) limitations the authors faced.

***As the multi-component intervention studies included several interventions, which allowed for categorization of the study in several categories, some listed provider descriptions are repeated in several columns.

was identified from synthesis and categorization: 1) social contact, 2) physical activities, 3) cognitive training, including arts/creative activities, 4) sensory enhancement, 5) daily living assistance, 6) life history oriented emotional support, 7) training and support for professional CGs, 8) environmental adjustments, and 9) care organization. The categories including a short description oriented in Dickson et al. [59] and Clarkson et al. [60] are depicted in column one in Table 5.

Content

The PC-interventions followed heterogeneous approaches under the concept of PCC and details available with regard to the description of the delivered PC-interventions, i.e. what was delivered to the PlwD, varied, especially for the multi-component interventions [62–65, 67–69, 73, 74, 77–79]. Some (e.g. [65]) provided detailed lists of activities included in their multi-component interventions. Others more generally described the provided multi-component interventions as "PCC", without detailed information about the concrete activities provided to the patients [67, 69] or scarcely described information about activities included [64]. Multi-component interventions with detailed descriptions about each intervention component were respectively assigned to several categories. Some studies limited their intervention-descriptions to the trainings provided to the professional CGs, but did not provide details about which interventions were delivered to the PlwD [64, 67, 69]. Interventional studies conducted under the term RCC aimed at an effect among the PlwD that fit eligibility criteria could not be identified.

Provider

Details about the provider(s) were generally described well throughout all included studies. Interventions were delivered by a range of professional CGs, researchers, volunteers, and family CGs. Professional CGs usually received a specified training, some studies had a particular focus on CG training and support, e.g. education in antipsychotic drug use and regular supervision by researchers or external experts in PCC [62–64, 66–69, 71–73, 76–79]. Some multi-component interventions incorporated, aside from intervention components for the PlwD, education and support for family CGs or otherwise inclusion of the family CGs in care decisions [62, 67, 68, 78, 79].

Format and setting

The format differed according to the respective intervention category, but both individual and group formats were applied. The predominant setting was long-term institutional care, except from one study which was conducted in a hospital [78].

Intensity

There was a substantial variation in the intensity of the delivered interventions and detailed information was not available in all studies. Some studies chose a short overall timeframe of a few weeks [65, 74, 75], others up to 18 months [76]. Table 5 captures the ranges (min. and max.) of different timeframes applied in the studies for each distinctive intervention category, i.e. time of the day, how many minutes/hours per week, how many days per week, how many weeks per month and so on.

Fidelity

Where the included studies contained little information on the delivery process of the interventions, it was challenging to judge their fidelity, i.e. had the intervention always been delivered as intended or had there been challenges to delivery [61]. The term "fidelity" was only mentioned in two studies, [77] and [75]. Where concrete information about the interventions' delivery process could not be identified, information about problems and/or (methodological) limitations is reported. All studies of longer duration faced problems with a loss to follow-up, due to participants' decease, which resulted in high non-completion rates. Some reported failure to show a significant effect may reflect difficulties inherent in affecting the culture of care within a nursing home [67], including resistance against the intervention and suspicion about the intrusion of outsiders (i.e. the researchers) among care staff and the management [63, 68]. Some studies reported problems with protocol-adherence [72–75], including provision of the intervention in the control groups [76]. In some studies [66, 71], external factors (e.g. influenza outbreaks on sites, changes in national laws to restrict use of restraint) were discussed to have influenced the outcome of the intervention.

DISCUSSION

This systematic review identified a total of nine key intervention categories to guide the provision of person-centered dementia care. The categories comprised a wide range PC-interventions, oftentimes delivered as multi-component interventions, which followed heterogeneous approaches under the concept of PCC. Details in description of the interventions, especially the multi-component interventions, varied. Interventional studies conducted under the term RCC aimed at an effect among the PlwD that fit eligibility criteria could not be identified. The predominant setting was long-term institutional care. No studies were undertaken with PlwD at home. The overall quality of the included interventional studies varied between low to moderate.

The key intervention categories were oriented in those named by earlier reviews [59, 60]. However, Clarkson et al. [60] performed a review of systematic reviews about psychosocial interventions, without a particular emphasis on PCC and interventions published under this concept. In our categorization of PC-interventions, "arts/creative activities" were not allocated their own category, even though they constitute an important segment of PC-activities. However, "music" or "to make music" made this allocation challenging, as some may recognize this as part of arts/creative activities in line with Schneider [81], while others may recognize this as "sensory enhancement" in line with Dickson et al. [59] and Clarkson et al. [60]. Respectively to previous research, arts/creative activities were categorized under cognitive training [82, 83] and music under sensory enhancement [59, 60]. The in this study identified and categorized PC-interventions were similar to the psychosocial interventions identified by Dickson et al. [59] and Clarkson et al. [60]. Future research may want to consider a clearer differentiation between psychosocial interventions and PC-interventions. It may be that PCC is a subset of psychosocial interventions, or the opposite, as PCC by some arguably could be conceptualized in clinical interventions as well, cf. 'personalized medicine'.

The variation in descriptions of the PC-interventions, especially the multi-component interventions, made the judgement and decision about categorization, as well as descriptions of content, provider, format, intensity, and fidelity, challenging. Only a few concretely reported an assessment of preferences and or needs prior to the intervention, among which only three assessed preferences by a direct involvement of the PlwD. Additionally, no study with multi-component interventions provided a detailed description of which exact activity was delivered to whom, by whom, for how long, and aimed at which outcome measure. Thus, it cannot be differentiated which single activity from the multi-component interventions yielded a potentially significant effect. Generally, it may be considered, whether effectiveness of PC-interventions can be determined in a study, where the intervention was implemented for two weeks [65]. However, a recent systematic review and meta-analysis by Kim and Park [47] identified a significant effect to reduce agitation for the two-week-intervention by Cohen-Mansfield et al. [65]. Aside from agitation, Kim and Park [47] found PC-interventions to reduce neuropsychiatric symptoms, and depression, as well as to improve the quality of life. Their review included some of the studies as we included in our review [63–65, 67, 69, 73, 74]. Similar to our review, Kim and Park [47] did not distinguish between multi-component interventions and single-component interventions for their assessment of the effectiveness of PC-interventions. Future work with PC-interventions may want to consider a clearer differentiation between multi-component interventions and single-component interventions, to increase the accuracy in assessment of PC-interventions for key intervention categories, including potential assessments of relative effectiveness. Additionally, future research may want to consider a standardization for the report of PC-interventions in studies and respective research papers. This includes more detailed descriptions on what it is that constitutes "person-centered" in this intervention, such as preferences-/needs-assessments and/or relationship facilitation and here upon provided interventions, to increase comparability and identify a common approach under the concept of PCC. The definition of an appropriate time frame for the provision of PC-interventions to measure their effectiveness might be valuable.

Despite the inclusion of RCC in the search string to account for the aforementioned development of the PCC concept, we could not identify interventional studies conducted under this concept that met our eligibility criteria. The importance of relationships was built into Tom Kitwood's original formulations, although in PCC concepts built upon the relational aspect are invariant [19, 28]. Current experiences during the ongoing COVID-19 pandemic underline the need to focus more on the relationship between PlwD, their significant others, and providers [84, 85]. Furthermore, it may be interesting to analyze how COVID-19 affects the capacity of care organizations to deliver person-centered dementia care. It may be interesting for future studies to evaluate the relative effectiveness of "person-centered"-

including “relationship-centered”-interventions to assess whether an explicit focus on relationships around PCC-interventions yields an added benefit, not just for the receivers of care but also for the providers. A review of lay literature on PCC for PlwD may be valuable.

The predominant setting was long-term institutional care, which is similar to findings by Kim and Park [47]. The operational model (for profit or not for profit) of the long-term care facilities in the included studies could not be identified. Future research may want to examine whether respective institutions have tendencies to implement certain types of PC-interventions. Aside from the operational model of long-term care facilities, an examination of whether a potential culture change movement in long-term care promotes PCC for PlwD would be interesting. Only a few reported on cultural change in the intervention facilities [63, 67, 68, 77], however, with rather negative observations. Future research on PCC in long-term institutional care facilities may want to examine, whether a potential cultural change that promotes the provision of PCC for PlwD nevertheless is underway, e.g. by a review of qualitative research with both professional and family CGs.

No studies were undertaken with PlwD at home. It is recognized that the concept of PCC has been developed and implemented with a focus on residential homes for the aged [38, 47]. The choice of setting could also be associated with the human and financial resources required to deliver PC-interventions to PlwD at home. Additionally, PC-interventions for PlwD at home might not have been identified by the term “intervention”. For this reason, “home services” instead of “intervention” as third dimension was included during pilot searches, which, however, yielded a scarce number of hits. Kim and Park [47] identified two studies conducted in people’s homes [86, 87], both of which applied the term “intervention”. We did not find a study conducted with PlwD at home and only one PC-intervention study at a hospital. Two recent systematic reviews [88, 89] focused their research on needs of PlwD and registered nurses’ experiences with PCC in the hospital setting. As there is an aim by policy makers to move care delivery to the home [90] and many aged people prefer to receive care at home [91], this setting should find greater consideration in future investigations about PCC and PC-interventions. Aside from the home/primary care setting, future research may want to consider a greater focus on hospital settings with particular focus on assessment of patients’ needs and training for staff.

The overall quality of the included interventional studies varied between low to moderate, similar to findings by Kim and Park [47], who remarked future research should focus on utilization of precise methods for randomization, allocation concealment, and blinding of those who collect the data, to confirm validity of findings in systematic reviews. In this review, most studies had a low risk of bias with regard to the randomization process. However, assessment blinding likewise formed ground for risk of bias in many studies, as did a substantial loss to follow up due to participants’ decease in most studies. Still, the nature of the included populations, i.e. people of very high age, as well as the type of interventions assessed, i.e. psychosocial non-pharmacological interventions, which are known to pose a challenge with regards to blinding of assessors, should be remembered. Hence, in line with previous literature [47], more studies with rigorous designs are recommended to address the aforementioned areas for future research with an evidence base of sufficient high-quality.

Limitations

This review has several limitations. Despite great efforts, including an extensive review of the MeSH-database [51] and previous literature, e.g. [38, 52, 53] to develop a comprehensive list of terms for PCC and a thoroughly piloted search, we cannot be fully certain to have identified all terms that comprise all PC-interventions for PlwD. PC-interventions for PlwD at home might be covered by the term “community care”, as suggested in [27, 92, 93], which was not included in the search string. However, we included terms such as client-centered, consumer-centered, client-focused, person-focused, client-directed, and consumer-driven care, noted by [38, 52, 53], to identify PCC and PC-interventions for PlwD at home. Furthermore, eligible interventional studies conducted under the concept of RCC might have been covered by terms focused on “family involvement” [94], which was not included in the search string. Future reviews should pay particular attention to the choice of terms to identify interventions conducted under the RCC-concept and in the home care setting, i.e. to apply a broad lens during the development of the search string. Similar to Kim and Park [47], our small sample size of papers that fit into the defined parameters limits the effectiveness to capture the varied interventions that may be available under the concept of PCC. It could be that important ideas and interventions were discarded due to the qualitative nature of research needed to capture the effectiveness of interventions attempted in real life care situations without controlled settings, which is a major limitation of this review focused on published PC-interventional research. Hence, a further review with less strict inclusion parameters including published lay literature might be of value to capture PCC-initiatives outside the published academic literature. Searches could have been performed in further databases to raise sensitivity, however, with the chosen combination of databases, we hope to have identified all relevant records and inclusion of additional databases was not expected to yield additional information. Due to language skills in the team, we only included English and German records, which might have excluded other eventually relevant studies. Even though we applied a thorough protocol and strategy for study selection, data extraction, risk of bias assessment, and synthesis, we cannot rule out potential errors in any of the systematic steps. However, since every step of this systematic review entailed a review by several reviewers, these potential errors were minimized. This study applied the NOS Cohort risk of bias tool non-adapted for the included quasi-experimental studies, which is not ideal. Nevertheless, as the particular studies had prospective and longitudinal designs, we considered this approach acceptable in terms of pragmatism, simplicity in use and due to lack of a better, equally validated tool. No statistician was involved in the risk of bias assessment. However, several reviewers in the team (AR, BM, MR, WH) hold senior level experience with statistical methods, and guided the two main reviewers (WM and AA). The heterogeneity in reporting and application of the PCC-concept in the included interventional studies makes comparisons both within this review and with other reviews such as Kim and Park's [47] difficult. Still, our detailed approach to identify key intervention categories for better guidance on the provision of person-centered dementia care, including who did what, where, and how, is an attempt to provide an opportunity for better comparison of PC-interventions. Protocols and process-evaluations of the included studies were not checked, as these would not comply with eligibility criteria and per study, only one published record was included. Any deviations from protocol were expected to be mentioned in the published reports on findings. Judgements about the dementia severity and the inclusion criterion, whether a diagnosis by health professionals exists, were challenging as this was rarely reported. Some had a dementia diagnosis as inclusion criterion and reported this [63, 64]. However, with the exception of one study [73], all remaining studies reported on assessed dementia scores with validated tools (see 2nd column from the right in Table 2), which indicated dementia severity. Van de Ven et al. [73] conducted their study at Dementia Special Care Units. Hence, we interpreted the eligibility criterion with regard to dementia severity criterion to be fulfilled. We did not perform a meta-analysis, as an assessment of relative effectiveness only recently has been reported [47]. The quality of a meta-analysis with a wide range of various outcome measures, as included in this review, would have been questionable. Furthermore, this review analyzed the distinct activities performed under the scheme of the PC-interventions, as a result of which the multi-component interventions are listed in several categories. For an assessment of relative effectiveness, the interventions need to be assessed as a whole, cf. [47], which contradicts the strategy of this review. Finally, it may seem at odds with the notion of PCC as a holistic philosophy of care, to refer to discrete interventions and intervention categories of person-centered dementia care. In this regard it may further be questioned, whether PCC is just good care, as suggested by some [6], and accordingly be recognized that good care manifests in different ways in different contexts and hence probably is hard to categorize and standardize. Nevertheless, to offer clearer guidance on the provision of person-centered dementia care, including who does what, where and how, information about key intervention categories of person-centered dementia care needed to be identified, as this review provides the evidence for.

CONCLUSIONS

This systematic review provides a current state overview of published PC-interventional studies in dementia and identified nine key categories to provide person-centered dementia care, including who did what, where and how. the interventions followed heterogeneous approaches under the concept of person-centered dementia care. this heterogeneity made it challenging to identify a similar approach of person-centered dementia care and respective key intervention categories. Future research may want to consider a clearer differentiation between multi-component- and single-component interventions to operationalize the theoretical person-centered dementia care concept under a homogenous approach. Furthermore, attention to an appropriate time frame for the provision of PC-interventions with regard to effectiveness assessments may be considered.

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SUPPLEMENTARY MATERIAL

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Appendix 2: Article Nr. 2 “Development of a Quantitative Instrument to Elicit Patient Preferences for Person-Centered Dementia Care Stage 1: A Formative Qualitative Study to Identify Patient Relevant Criteria for Experimental Design of an Analytic Hierarchy Process.”

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Article

Development of a Quantitative Instrument to Elicit Patient Preferences for Person-Centered Dementia Care Stage 1: A Formative Qualitative Study to Identify Patient Relevant Criteria for Experimental Design of an Analytic Hierarchy Process

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Abstract: Background: Person-centered care (PCC) requires knowledge about patient preferences. This formative qualitative study aimed to identify (sub)criteria of PCC for the design of a quantitative, choice-based instrument to elicit patient preferences for person-centered dementia care. **Method:** Interviews were conducted with $n = 2$ dementia care managers, $n = 10$ People living with Dementia (PlwD), and $n = 3$ caregivers (CGs), which followed a semi-structured interview guide including a card game with PCC criteria identified from the literature. Criteria cards were shown to explore the PlwD's conception. PlwD were asked to rank the cards to identify patient-relevant criteria of PCC. Audios were verbatim-transcribed and analyzed with qualitative content analysis. Card game results were coded on a 10-point-scale, and sums and means for criteria were calculated. **Results:** Six criteria with two sub-criteria emerged from the analysis; social relationships (indirect contact, direct contact), cognitive training (passive, active), organization of care (decentralized structures and no shared decision making, centralized structures and shared decision making), assistance with daily activities (professional, family member), characteristics of care professionals (empathy, education and work experience) and physical activities (alone, group). Dementia-sensitive wording and balance between comprehensibility vs. completeness of the (sub)criteria emerged as additional themes. **Conclusions:** Our formative study provides initial data about patient-relevant criteria of PCC to design a quantitative patient preference instrument. Future research may want to consider the balance between (sub)criteria comprehensibility vs. completeness.

Keywords: patient-centered care; dementia; mild cognitive impairment; patient preferences; patient participation; qualitative research; attributes

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1. Introduction

With aging populations, dementia represents a challenge for health care systems worldwide [1]. Globally, around 55 million people have dementia, and there are nearly 10 million new cases every year [2]. The *Global Burden of Disease Study 2019* estimates Alzheimer's disease and other dementias as the fourth-leading cause of death globally in the age group 75 years and older [3]. Currently, no curative, disease-modifying treatment for all People living with Dementia and Mild Cognitive Impairment [hereinafter commonly referred to as "PlwD"] exists. PlwD need a timely differential diagnosis as well as evidence-based treatment and care, which ensures a high Quality of Life (QoL) [1,4].

Person-centered care (PCC) is the underlying philosophy of the Alzheimer's Association Dementia Care Practice Recommendations. A person-centered focus is viewed as the core of quality care in dementia [5]. Many countries include a PCC approach in their national guidelines and dementia plans [6–12]. It follows a non-pharmacological, sociopsychological treatment approach and challenges the traditional clinician-centered or disease-focused medical model to instead suggest a model of care, which is customized to each person [13]. This customization requires knowledge about the recipient's needs and preferences [14,15]. Among PlwD, some research about preferences exists, however, little is known about preferences elicited through quantitative, in particular, choice-based preference methods [16,17]. A recent literature review focused on *decision-making tools* with PlwD by Ho et al. [18] found that earlier studies often applied qualitative methods and Likert-type scales. Harrison Dening et al. [19] elicited preferences from dyads during qualitative interviews, van Haitsma et al. developed an extensive Likert-scale based *Preferences for Everyday Living Inventory (PELI)* for elicitation of preferences in community-dwelling aged adults [20]. These methods, however, fall short in *quantifying*, *weighing* and *ranking* patient-relevant elements of care to measure their relative importance and identify most/least preferred choices. Such information can be assessed with quantitative, choice-based preference measurement techniques from multi-criteria decision analysis (MCDA) [21]. Groenewoud et al. [22] addressed relevant aspects of outpatient care and support services for people with Alzheimer's disease by application of a quantitative, choice-based preference instrument (Discrete Choice Experiment (DCE)), which, however, was carried out with patient representatives and not the patients themselves. Other MCDA techniques commonly used in health care include best–worse scaling (BWS) [23] and the Analytic Hierarchy Process (AHP) [24]. The AHP, depending on the number of elements included, may require to ask many questions. DCEs, depending on the number of choice sets included (full vs. fractional factorial design), usually include fewer but cognitively more challenging questions. BWS distinguishes between three basic cases; object scaling (case 1), attribute or profile scaling (case 2) and multi-profiling (case 3), each case including various experimental designs, number of choice sets and questions. Hence, in BWS, the cognitive demands of included questions increase with each case [23]. To elicit patient preferences from people with cognitive impairments, the AHP has been suggested, as it may be more feasible than other MCDA techniques due to simple pairwise comparisons with only two individual aspects of a complex decision problem [25]. To keep the number of choice questions doable, the number of elements to include in the AHP model needs to be considered in the early development stages.

MCDA techniques, including the AHP, comprise the development of attribute/criteria-based experimental decision models for preference measurement [26,27]. The validity of an attribute/criteria-based experiment depends on the researcher's ability to appropriately identify and specify the included criteria [24,26–28]. Poorly identified criteria can have negative implications for the design and conduct of AHP surveys and increase the risk of inaccurate results, which in turn can misinform potential policy implementation. The risk of bias, i.e., researcher bias, in quantitative preference measurement studies can be reduced by a rigorous, systematic, and transparently reported identification of (sub)criteria [28,29]. Several methods have been suggested for AHP development, e.g., literature reviews, existing conceptual and policy-relevant outcome measures, theoretical arguments, expert opinion reviews, professional recommendations, patient surveys, nominal group ranking techniques and qualitative research methods [24]. Coast et al. [30] emphasize the limitation of attribute and level derivation only from a review of the literature and suggest the additional application of qualitative methods for attribute elicitation. These methods include the right instruments to capture and reflect the perspective and experiences of the decision makers. Only accurately described *formative* qualitative studies applied to derive (sub)criteria give readers the opportunity to judge the quality of the resulting decision model for preference elicitation [29]. Despite a recent increase in publications about pertinent studies, there is still a lack of both evidence and experience.

To the best of our knowledge, no previous research has reported the qualitative identification of patient-relevant (sub)criteria of PCC among community-dwelling PlwD. Our study aimed to fill this gap with this rigorous process report on (sub)criteria identification for the design of a quantitative, choice-based instrument, an AHP, to elicit patient preferences for PCC among community-dwelling PlwD.

2. Methods

We followed the guidelines for reporting *formative* qualitative research to support the development of quantitative preference survey instruments by Hollin et al. [29].

2.1. Qualitative Approach

We applied a narrative qualitative approach to cover the PlwD's individual experiences [31]. As this study employed a flexible strategy, characterized by the inclusion of life histories and interpretive analysis, the research paradigm followed critical realism [32].

2.2. Theoretical Framework

The overarching AHP-study, *"PreDemCare"* [33,34] adopts a sequential mixed-methods design for final instrument development [35], depicted in Figure 1. For the pre-study phase, we followed a qualitative design informed by a previous systematic review to identify relevant (sub)criteria, which would serve the development of an AHP. This report focuses exclusively on the pre-study phase of the overarching AHP study and describes the first qualitative component in detail.

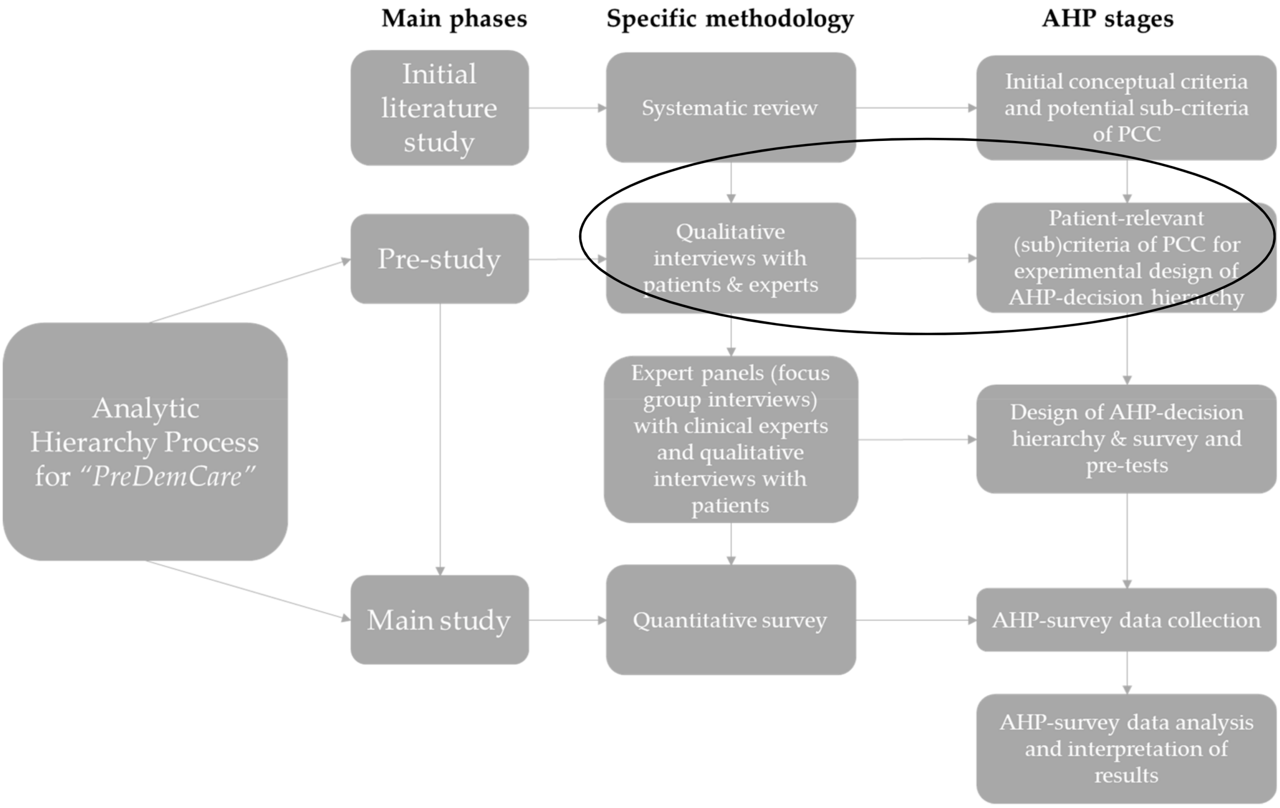

Figure 1. The mixed-methods design of the AHP for *PreDemCare* (own illustration inspired by [28]). Note: The initial literature study refers to a previously conducted systematic review [36]. AHP survey data will be analyzed with the principal right eigenvector method following Saaty [37]. Abbreviations: AHP = Analytic Hierarchy Process, PCC = person-centered care.

2.2.1. Theoretical Perspective

The theoretical perspective behind the overarching *PreDemCare* study, including this formative qualitative study, is guided by the theoretical foundations of the AHP, cf. Mühlbacher and Kaczynski [24]. The AHP is a method of prescriptive or normative decision theory, which provides the decision maker with techniques to reach a meaningful and plausible/rational decision [24,38]. The decision maker solves the decision problem based on predefined decision goal criteria and individual or group-specific priorities to identify the use-maximizing alternative systematically.

2.2.2. Initial Systematic Literature Review

The process of (sub)criteria identification [24] was based on a systematic review, which aimed to identify key intervention categories of PCC for PlwD. The results can be reviewed elsewhere [36]. Nine key components of PCC for PlwD were identified: *Social contact, physical activities, cognitive training, sensory enhancement, daily living assistance, life history-oriented emotional support, training and support for professional caregivers, environmental adjustments, and care organization.* Based on these findings from the literature, a comprehensive list of conceptual (sub)criteria was derived, depicted in Table 1.

The qualitative pre-study entailed (1) an expert panel with internal dementia-specific qualified nurses, so-called *Dementia Care Managers* (DCMs) [39] and (2) patient interviews with community-dwelling PlwD and informal caregivers (CGs) as silent supporters who live in diverse regions in rural German Mecklenburg-Western Pomerania.

2.3. Researcher Characteristics and Reflexivity

The authors WM and AR, public health scientists with qualitative research experience, conducted the interviews. AR has many years of quantitative patient preference research experience [24,40]. If one interviewer was hindered to participate, an experienced DCM from the site took over this role. Study nurses in ongoing clinical trials at the site (ClinicalTrials.gov identifiers: NCT04741932, NCT01401582, German Clinical Trials Register Reference No.: DRKS00025074) functioned as gatekeepers to access the PlwD for patient interviews, as they may be perceived as trustworthy by the participants. None of the PlwD and informal CGs interviewed knew the scientists beforehand but were aware of their professional roles.

2.4. Sampling Strategy and Process

For the expert panel, two of the most experienced DCMs were selected at the site. PlwD for the patient interviews were selected by typical case sampling [41,42], a type of purposive sampling [43], from ongoing clinical trials at the site. The gatekeepers emphasized the independence of this study from the ongoing clinical trials. Informal CGs were invited to join as silent supporters.

2.5. Sampling Adequacy

For the determination of sampling adequacy in a *formative* qualitative study, such as ours, to support the development of a quantitative preference instrument, we oriented ourselves in recently published recommendations by Hollin et al. [29]. Following these, the focus should not be the number of subjects, which may differ from *general* qualitative research, but the strategical collection of actionable input for the development process. The latter includes the requirement of diversity in perspectives.

Table 1. Conceptual criteria and potential sub-criteria oriented in systematic literature review [36].

Function (Descriptions Oriented in [44,45])	*Oriented in named intervention categories by Dickson et al. [44] & Clarkson et al. [45], as well as attributes and levels defined in a previous Discrete Choice Experiment by Chester et al. [46]*	
	Potential criteria (oriented in intervention categories to provide Person-Centered Dementia Care as identified in Mohr et al. [36])	*Plausible sub-criteria (oriented in provider, format, setting and/or intensity as identified in Mohr et al. [36])*
To provide access to different forms of social contact to counterbalance the limited contact with others that may be characteristic of the experience of dementia. This social contact may be real or simulated [45]. **Examples of activities [47–52]:** Social simulation tool (e.g., robotic animal, lifelike baby doll, baby video, respite video, stuffed animal, family pictures and family video, writing letters), one-on-one interaction (incl. active listening and communication), conversation (e.g., general and based on newspaper stories, pictures, etc.), group activity	**(1) Possibilities for social activities**	1. Difficult to access 2. Group activities, e.g., in the local community house 3. 1-to−1 contact at home with family member/professional CG/volunteers
To provide structured activities and/or exercise to provide meaningful and engaging experiences that can be a useful counterbalance to difficult behaviors [45]. **Examples of activities [47,49,52–54]:** outdoor walks, gardening.	**(2) Possibilities for physical activities**	1. Difficult to access 2. Group activities, e.g., in fitness studio 3. Individual activities with a personalized trainer at home
To provide enhancement and stimulation of cognitive functions through guided practice on a set of standard tasks, reflecting memory, attention or problem solving [45]. **Examples of activities [47–49,51–55]:** puzzles and games, reading, poetry, theatre, arts and crafts, work-like activities, housekeeping tasks, videos and television, sorting.	**(3) Cognitive training**	1. Difficult to access 2. Activities outside the home, e.g., in memory clinic 3. Activities at home with family member/speech therapist/ergo therapist/volunteers
To increase or relax the overall level of sensory stimulation in the environment to counterbalance the negative impact of sensory deprivation/stimulation common in dementia [45]. **Examples of activities [47–49,51–54,56]:** music (e.g., listening, singing along, including in conversations and care), sensory stimulation with different materials, e.g., hand massage with lotion, smelling fresh flowers, preferably in a white and quiet room (refers to Snoezelen).	**(4) Activities for sensory stimulation or relaxation**	1. Difficult to access 2. Activities to access outside home, e.g., in physiotherapy- and massage clinic 3. Activities at home with physio therapist/masseur/music therapist

Table 1. *Cont.*

Function (Descriptions Oriented in [44,45])	*Oriented in named intervention categories by Dickson et al. [44] & Clarkson et al. [45], as well as attributes and levels defined in a previous Discrete Choice Experiment by Chester et al. [46]*	
	Potential criteria (oriented in intervention categories to provide Person-Centered Dementia Care as identified in Mohr et al. [36])	*Plausible sub-criteria (oriented in provider, format, setting and/or intensity as identified in Mohr et al. [36])*
To assist with basic care, e.g., provision of laundry services, basic nutrition and help with activities of daily living [45]. **Examples of activities [47,49,54,55,57]:** care (e.g., help with personal hygiene and dressing, discussions about health status with physician), food or drinks, person-centered showering/towel bath.	**(5) Help with activities of daily living**	1. Rarely available 2. Three times per week with educated staff and consistent staffing 3. Once per day with educated staff, but changing staff
To address feelings and emotional needs through prompts, discussion or by stimulating memories and enabling the person to share their experiences and life stories; undertaken to counterbalance and help people manage difficult feelings and emotions [45]. **Examples of activities [47,48,50,54,58–62]:** telling life histories, work with reminiscence and self-validation.	**(6) Attention and support with worries, feelings and memories**	1. Rarely available 2. Accessible via a telephone hotline 3. Through specifically educated advisor/priest/professional CG/family member
To change interactions between CGs and PlwD, including: psycho-education; integrated family support, such as counseling and advocacy; training in awareness and problem solving; and support groups [44]. **Examples of activities [47,48,50–52,55,56,58–64]:** training, further education and counseling of professional caregivers (e.g., about dementia-related medication), work experience	**(7) Dementia- and PCC specialized training for professional CGs [a]**	1. CG assistant with three years of work experience 2. Examined professional CG with 1.5 years of work experience 3. Examined professional CG with additional certifications and half a year of work experience
Provision and access of information about dementia, as well as PCC for informal CGs. Emotional support of informal CGs. Inclusion of the family in care decisions. **Examples of activities [47,48,50–52,55,56,58–64]:** access to informational material via GP, Dementia support groups or the internet, self-help groups for informal caregivers, inclusion in care decisions by professional CG and/or GP.	**(8) Dementia focused information and support for family CGs [a]**	1. Difficult to receive 2. Easy to receive 3. Very easy to receive

Table 1. *Cont.*

Function (Descriptions Oriented in [44,45])	*Oriented in named intervention categories by Dickson et al. [44] & Clarkson et al. [45], as well as attributes and levels defined in a previous Discrete Choice Experiment by Chester et al. [46]*	
	Potential criteria (oriented in intervention categories to provide Person-Centered Dementia Care as identified in Mohr et al. [36])	*Plausible sub-criteria (oriented in provider, format, setting and/or intensity as identified in Mohr et al. [36])*
To modify the living environment, including the visual environment, in order to lessen agitation and/or to wander and promote safety [45]. **Examples of activities [47,50,55,63]:** Physical aids, homey adaptions to environment, assistive technology, sign-age, reduction of noise and clutter.	**(9) Adjustments of the environment**	1. Not accessible 2. In one room, e.g., the bathroom 3. In the complete living area
To connect and bring together different services around the person; to advise on and negotiate the delivery of services from multiple providers on behalf of the person to provide benefit [45]. **Examples of activities [47,50–52,55,58,60,61,63–65]:** shared decision- making between professional CG and/or GP and PlwD, interdisciplinary and integrated care planning incl. consistent staffing, case management, special dementia units in hospitals.	**(10) Organization of care**	1. No shared decision making and integrated health services 2. Some shared decision making and integrated health services 3. Always shared decision making and integrated health services
Possible additional out-of-pocket payments.	**(11) Additional cost** [b]	1. 20 € per month (240 € per year) 2. 40 € per month (480 € per year) 3. 80 € per month (960 € per year)
Possible additional waiting time, which would have to be taken into account for certain offers.	**(12) Waiting time** [b]	1. 11–14 days 2. 7–10 days 3. 3–6 days

Abbreviations: CG = Caregiver, GP = General Practitioner, PlwD = Person living with Dementia. [a] Initially, these criteria were one intervention category in the systematic review. To avoid too long criteria labels, we decided to split this category into two potential criteria—one focused on professional caregivers, one focused on informal caregivers. [b] The cost and waiting time criteria were added to the conceptual criteria from the literature, as these are common criteria in other quantitative preference research studies [66].

We addressed the diversity of perspectives by the inclusion of different stakeholders. Additionally, the initial overall sample size for the patient interviews *n* = 10 was informed by the expected saturation point [43] based on experiences from previous formative qualitative research for the development of quantitative preference instruments [67–72] and expected restricted access to PlwD due to the COVID-19 pandemic. The latter included ethical reflections in the study team to limit the risk associated with contact for both the vulnerable patient group and team members.

The identified (sub)criteria were subsequently revisited and assessed again during pretests of the to-be-developed AHP survey instrument in two expert panels with *n* = 4 DCMs, *n* = 4 physicians and *n* = 11 PlwD, cf. Figure 1. However, details on this subsequent stage in instrument development for the *PreDemCare*-study [34] lie outside the scope of this report.

2.6. Sample

The expert panel included *n* = 2 DCMs from the site's staff. Patient interviews included *n* = 10 PlwD and *n* = 3 informal CGs (mainly as silent supporters).

2.7. Ethical Review

The overarching preference study *PreDemCare*, including this pre-study, was evaluated and approved by the Ethics Committee at the University Medicine Greifswald (Ref.-No.: BB018-21, BB018-21a, BB018-21b).

2.8. Data Collection Methods, Sources and Instruments

WM conducted the expert interview via video conference software. After translation to German, the DCMs reviewed the literature-derived conceptual criteria and their descriptions, as well as the sub-criteria, including respective icons for comprehensibility, and made suggestions for improvement. The expert interview was not recorded or transcribed. Data were collected with field notes. Changes were implemented immediately. The expert-reviewed material was prepared for the subsequent patient interviews.

Subsequently, individual narrative interviews [43] were conducted with PlwD in their homes or in day-care centers over the time period April–May 2021. All interviews were conducted in adherence to a strict hygiene protocol developed at the site during the COVID-19 pandemic. Method and setting were chosen to consider the vulnerability of this population appropriately. To ensure a comfortable and non-stressful interview situation, PlwD could invite their informal CGs to support them during interviews. It was, however, emphasized that the informal CGs should not act as proxies and answer the majority of the questions on behalf of the PlwD. WM conducted the interviews, while a second interviewer (AR or a DCM) took field notes. All interviews were recorded. All participants were informed about the purpose and content of the study, i.e., to obtain their opinion about relevant criteria of individualized homecare via the interview, including a card game, which would be used in research for the subsequent development of a survey. The interviewers explicitly stated that no tests would be performed. The audio tape was started after the introduction of the participants to ensure privacy. The average interview time was 60 min.

We used a self-developed semi-structured interview guide, oriented in Danner et al. [73], to ensure an efficient structure of the interview and simultaneously give the participants room to elaborate freely. Oriented in Danner et al. [25], we repeated after each pairwise comparison during the card games what the patient said with his/her judgement, e.g., *"With your judgement you are saying that [Criterion X] is very much more important to you than [Criterion Y]; is this what you wanted to express?"*, to make sure the information and tradeoffs presented during the card games were understood. We included an initial self-developed sociodemographic questionnaire for patient characteristics. Time since diagnosis and severity of cognitive impairment was determined during recruitment based on inclusion criteria (indication of MCI or early to moderate staged dementia) by the internal study nurses as gatekeepers based on their most recent assessment with a validated instrument in the respective clinical trial (Mini Mental Status Test (MMST)) [74] and/or Structured Interview for the Diagnosis of Dementia of the Alzheimer Type, multi-infarct dementia and dementias of other etiology according to DSM-III-R and ICD-10 score (SISCO) [75]).

The literature-based and expert-reviewed conceptual (sub)criteria were printed on cards in A5 format. Oriented in Danner et al. [73], criteria cards were presented to the PlwD as part of three card games to identify the most important and patient-relevant criteria of PCC. Card game 1 included sorting the criteria cards on three stacks (important, neutral, not important). Card game 2 included sorting the important criteria cards from card game 1 on two stacks (very important, less important). Results from the final ranking game, which included sorting the very important criteria cards from card game 2 in ranking order, were numbered according to their position awarded in this ranking. All results were documented with photographs and field notes. Blank cards were kept aside in case the PlwD mentioned additional criteria that had not been identified from the literature or in the expert interviews. Sub-criteria cards were only presented if there was time and energy left. If so, we asked about the appropriateness of the sub-criteria, their wording and the graphical design of included visual aids (ICONs).

By the described utilization of diverse data collection methods and different observers, we ensured both data and investigator triangulation [43].

2.9. Data Processing and Analysis

2.9.1. Card Games

Card game results were transferred into Microsoft®Excel2019 for a comprehensive overview. Ranking results were coded on a 10-point scale (rank 1 = 10 points, rank 2 = 9 points and so forth; excluded criteria were assigned zero points), whereupon sums and means for criteria across interviews were calculated.

2.9.2. Audio Recordings

Audio recordings were transcribed verbatim by WM. If names had been mentioned during the interview, these were not transcribed but replaced with, e.g., "XXX", to ensure privacy. Two reviewers, WM and AA, coded transcripts line by line with qualitative content analysis [76–78] in Microsoft®Word2019. Oriented in Hshie & Shannon [78], we used elements from both conventional and directed qualitative content analysis, i.e., deductive analysis was guided by the interview guide and focused on information necessary to collect, cf. categories 1.–5. in Supplementary Material Codebook S1, but inductively other observations made were allowed to arise as additional categories from the transcripts, cf. category 6 in the Codebook S1. Concretely, each reviewer coded the first interview independently based on the interview guide and the conceptual criteria identified from the literature, cf. Table 1, but allowed for new categories to emerge. Subsequently, the reviewers discussed their codes and categories and agreed on a codebook. The codebook was revisited after independent coding of the second interview, and the strategy suggested was confirmed by both reviewers. Each reviewer coded the remaining interviews ($n = 8$) independently.

For categorization of the coded meaning units, coded transcripts from both reviewers were printed. Coded meaning units were discussed by both reviewers, cut out and assigned a tracker (interview number_lines in transcript). By this, we could trace back the distinct coded section and review it in its context, if necessary. Meaning units were hence sorted into the categories as given by the matrix from the Codebook S1.

Transcript and card game analyses were discussed in a final meeting between all authors until consensus on categorization was achieved. The finally categorized meaning units were transferred into digital format with Microsoft® Word2019.

3. Results

Patient characteristics are depicted in Table 2.

Table 2. Patient Characteristics (n = 10).

Characteristic		***n***
Age		
	60–71	2
	71–80	2
	81–90	4
	>90	2
Gender		
	Female	4
	Male	6
Family status		
	Married	5
	Widowed	3
	Divorced or separated	2
Highest educational degree		
	No degree	1
	8th/9th grade	4
	10th grade	2
	Degree from a technical/vocational college	1
	Degree from a university of applied sciences or university	2
Monthly net income		
	500–1000 €	2
	1001–1500 €	2
	1501–2000 €	1
	Prefer not to say	5
Time since diagnosis of dementia [a]		
	1–2 years	3
	2–5 years	3
	More than 5 years	3
	Not known	1
Stage of cognitive impairment [b]		
	Early	8
	Moderate	2
Subjective assessment of current health status		
	Good	4
	Satisfactory	5
	Less good	1

[a] Determined by study nurses during most recent visit in clinical trial the participant had been recruited from.
[b] Determined by study nurses based on most recent assessment with validated instrument (MMST [74] and/or SISCO [75]) during most recent visit in clinical trial.

Six categories emerged from the analysis of the material: (1) patient-relevant criteria of PCC, (2) new criteria of PCC from the patient's perspective, (3) plausible sub-criteria, (4) overlapping of criteria, (5) wording and comprehensibility and (6) other observations; (6a) reactions by patient, (6b) interaction with informal CG, (6c) explorative vs. ranking card game, (6d) setting and (6e) COVID-19.

3.1. Patient-Relevant Criteria

PlwD had preferences, and by use of the sorting and ranking card game, PlwD were able to express their preferences. Table 3 presents the list of criteria as identified after an analysis of the ranking card game. Six criteria were chosen for final inclusion in the AHP decision model and survey; social relationships, cognitive training, organization of health care, assistance with daily activities, characteristics of professional caregivers and physical activities.

Table 3. Derivation of list of AHP criteria and plausible sub-criteria (ordered from most preferred to least per card game results).

Criterion	Examples a	Key Quotations from Qualitative Data (Individual Interviews with *n* = 10 PlwD and *n* = 3 Informal CGs)	Plausible Sub-Criteria	Final Inclusion
Social relationships	Conversations, writing letters, phone calls, meeting friends, club room in facility of community housing, attention and support with worries and feelings	*P: So. That you are in touch with other people. That you don't say no to the connection to other people, but that you look for it [the connection].* (Int9, lls. 14–15) *I1: Do you prefer direct contact with people?* *P: Yes yes.* *I1: Ok. How about a phone call?* *P: Well I can make a phone call, but I mostly avoid it.* *I1: Because you prefer direct contact?* *P: Yes.* (Int9, lls. 24–29)	1. Indirect contact, e.g., phone calls, writing letters 2. Direct contact with people	Yes
Cognitive training	Listening to the radio, crossword puzzles, puzzles and games, reading the newspaper, reading books, theater, arts and crafts, work-related tasks, watching TV, cleaning.	*P: News. All the news I can get. Or comments. So the radio is important to me. I've already bought a portable radio like this. So I was looking for the smallest and that was the smallest. Smaller was not possible. And that's important to me.* (Int7, lls. 155–157) *P: Yeah ... I do that ... well play ... we used to play Skat [German card-game] too. [...] But now ... because of Corona ... we always played Skat on Sundays and then it was also the afternoon of games ... we had an afternoon where we sat and talked at a long table ...* (Int2, lls. 93–97)	1. Passive, e.g., watching TV, listen to the radio 2. Active, e.g., crossword puzzles, reading, games	Yes
Organization of health care	*See sub-criteria.*	*I1: [...] Polyclinics. You surely know them from the GDR, where everything was under one roof. [...]* *P: Hmm, we still have that in the medical center.* *I1: Hm, do you think that's good?* *P: I think that's good. That is still like before. [...]* *I1: And would it be important to you that it stays that way, because it's a good concept or would you say that it works even if the doctors are distributed?* *P: Nah no ... I don't think that's good at all. I got all of them close by, the doctors, so I don't have to drive far.* (Int10, lls. 602–603, 608–610, 630–633) P: Well, not that they said "go to the clinic"—I was asked... I1: Exactly and you think that's good? *P: Yes. I think that is good.* (Int10, lls. 648–650)	1. Decentralized structures, doctors distributed in single clinics. The doctor takes the decisions without involving the patient or informal CG. 2. Centralized structures such as polyclinics and medical centers. Shared decision making between doctor, patient and informal CG.	Yes

Table 3. *Cont.*

Criterion	**Examples** $_a$	**Key Quotations from Qualitative Data (Individual Interviews with** n **= 10 PlwD and** n **= 3 Informal CGs)**	**Plausible Sub-Criteria**	**Final Inclusion**
Assistance with daily activities	Grocery shopping, cleaning, getting dressed, showering, eating and drinking	*P: Well it has to! There is a bit of a must behind it . . . I don't know what would be without them [mobile nursing service].* (Int8, lls. 226–227) *P: So the help from my wife is very important.* (Int9, lls. 256) *CG: Nope. No nursing service. They came before [. . .], but they didn't always come [at times we preferred] and then I said I'll learn it and do it myself. [. . .] because we are less bound to them like this, otherwise you are always bound to them. Because they don't come when they want, but when they have time.* (Int1, lls. 117–119, 160–161)	1. Professional 2. Family member	Yes
Characteristics of professional CG	*See sub-criteria.*	*P: [. . .] The important thing is that you can deal with people, you are nice and friendly, you do the work that needs to be done. But I don't need to study for that [. . .] I think that's nonsense. [...]* (Int10, lls. 474–476, 493–494) *P: Well I mean sure. I mean that they know what they are doing in their job, right?* *I1: Okay . . . so that's important to you, the training and professional experience [of the nursing staff]?* *P: Well, I don't have an overview of what they have to learn and don't have to learn, but I mean if a nurse comes here [...] when I need help, I assume she knows how to help me.* *I1: And that is why training is important to you?* *P: Yes, that's how I think about it. At the moment I don't need it, but it can happen that I need it and then . . .* (Int2, lls. 203–210)	1. Empathy 2. Education and work experience	Yes

Table 3. *Cont.*

Criterion	**Examples** $_a$	**Key Quotations from Qualitative Data (Individual Interviews with** n **= 10 PlwD and** n **= 3 Informal CGs)**	**Plausible Sub-Criteria**	**Final Inclusion**
Physical activities	Walks, gardening, sports, fishing, cleaning	*P: [Physical activity] I do for myself . . .* (Int5, lls. 110) *CG: Yes. Aren't you doing group sports with your hands?* *I2: Exercise?* *P: Ooooooh yes! Then we sit there like that [hands up] and off we go. With the feet too!* (Int1, lls. 79–81) *I1: [...] the physical activity . . . so you said walking and gardening . . . but if you compare it to the social [activities], would it be important to you for your care that you have that [physical activities], or is it just the way it is?* *P: Yes, so that is important . . . that I can get out!* (Int7, lls. 127–130)	1. Alone 2. Group	Yes
Dementia focused information and support for family CGs	Access to informational material via GP, Dementia support groups or the internet, self-help groups for informal CGs, inclusion in care decisions by professional CG and/or GP.	*I1: Is it important to you that your children [. . .] are informed about your condition?* *P: Yes, my boy comes with me to the heart specialist . . . [. . .] with Dr. XXX . . . I always let them [children] come with me. I always say four ears hear more than two.* (Int10, lls. 543–546)	1. Difficult to receive 2. Easy to receive 3. Very easy to receive	Merged
Adjustments of the environment	Physical aids, homey adaptions of environment, assistive technology, sign-age, reduction of noise and clutter.	*P: Oh so for the apartment now [adjustments]?* *I1: Exactly.* *P: This is all fine here.* *I1: Have you preinstalled this here, for example handles in the shower to hold on to?* *P: Yes, everything preinstalled* *I1: Do you think that's good?* *P: I think that's good. But I don't need it.* (Int7, lls. 420–427)	1. Not accessible 2. In one room, e.g., the bathroom 3. In the complete living area	No

Table 3. *Cont.*

Criterion	Examples $_a$	Key Quotations from Qualitative Data (Individual Interviews with n = 10 PlwD and n = 3 Informal CGs)	Plausible Sub-Criteria	Final Inclusion
Activities for sensory stimulation or relaxation	Music (e.g., listening, singing along, including in conversations and care), sensory stimulation with different materials, e.g., hand massage with lotion, smelling fresh flowers, preferably in a white and quiet room (refers to Snoezelen).	*I1: Do you like to touch this? Does that feel good?* *P: Well . . .* *I1: Or is that just part of life?* *P: Well . . . I haven't given it that much thought yet . . .* (Int9, lls. 176–179) *I2: I'll put it this way, it is just part of life.* *P: Yes, exactly . . . I mean when you've got some flowers . . . [. . .] of course you smell them. But is that so [something important]?* (Int2, lls. 147–149)	1. Difficult to access 2. Activities to access outside home, e.g., in physiotherapy- and massage clinic 3. Activities at home with physio therapist/masseur/music therapist	No
Attention and support with worries, feelings and memories	Telling life histories, work with reminiscence and self-validation.	*P: [. . .] I don't need that . . .* *I1: Don't you have any worries?* *P: No, what should I worry about? [Shrugs shoulders]* (Int8, lls. 232–234) *P: No, here [day clinic] . . . I don't have anyone I want to talk to about the problems. I'd rather be with a friend or something . . . but this, as I said, is intimate for me.* *I1: So with family, friends . . . ?* *P: Hm.* (Int5, lls. 254–259)	1. Rarely available 2. Accessible via a telephone hotline 3. Through specifically educated advisor/priest/professional CG/family member	Merged
Waiting time	Possible additional waiting time, which would have to be taken into account for certain offers.	*P: Well, I mean . . . as a pensioner you have time and if you sit and wait for a quarter of an hour, that doesn't matter.* (Int8, lls. 495–496) *P: [. . .] People shouldn't always complain right away anyway [. . .] I don't know any waiting time or almost not.* *I1: Ok. So you have had very good experiences?* *P: [. . .] I mean [. . .] I know how it works in a clinic. And I have no problem with that.* *I1: That means it doesn't matter to you whether you wait a week or 14 days for an appointment.* *P: No.* *I1: And when you are at the doctor, you don't care . . .* *P: It's just the way it is.* (Int5, lls. 405–414)	1. 11–14 days 2. 7–10 days 3. 3–6 days	No

Table 3. *Cont.*

Criterion	**Examples** $_a$	**Key Quotations from Qualitative Data (Individual Interviews with** ***n*** **= 10 PlwD and** ***n*** **= 3 Informal CGs)**	**Plausible Sub-Criteria**	**Final Inclusion**
Additional cost	Possible additional out-of-pocket payments.	*P: Important? It is there. That's the way it is and if I want something, then I pay for it.* (Int4, lls. 427) *I1 [. . .] Is this an issue for you or . . .* *P: No, not at all.* *I1: . . . is that how it is?* *P: I have a good pension and I can get by with it. [...] these are co-payments. There is nothing more to it.* (Int7, lls. 483–486, 496)	1. 20 € per month (240 € per year) 2. 40 € per month (480 € per year) 3. 80 € per month (960 € per year)	No

Abbreviations: CG = Caregiver, GDR = German Democratic Republic, GP = General Practitioner, I1 = Interviewer 1, I2 = Interviewer 2, Int = Interview, P = Patient. $_a$ As we realized during the interviews that the People living with Dementia most easily can understand and relate to the criteria by review of examples, we decided to delete extensive descriptions of the criteria as depicted in column one of Table 1 and only keep examples as lay terminology for the criteria.

3.2. New Criteria of PCC

All PlwD were asked whether we had missed criteria of PCC, which were important to them and not included in the criteria presented by us. No PlwD gave an indication of new criteria necessary to include, cf. Table 4. Hence, the literature-derived criteria were confirmed while reduced to a doable amount of criteria for the design of the AHP decision model and survey.

3.3. Plausible Sub-Criteria

Based on our observations during the patient interviews, where most participants got tired after ~60 min before we could show the sub-criteria cards, we decided that the AHP decision model and survey had to be kept as simple and short as possible. To limit the pairwise comparisons and to reduce the length and complexity of the planned survey, we decided to elicit and include only two sub-criteria per criterion in the AHP decision model, based on the PlwD's initial elaborations about the presented criteria cards. Plausible sub-criteria are depicted in column four in Table 3.

Table 4. Results: Key quotations for categories 2, 4–6.

Category #	Key Quotations from Qualitative Data (Individual Interviews with n = 10 PlwD (and n = 3 Informal CGs))
(2) New patient relevant criteria of PCC	*I1: Is there anything, which was not included in the cards, but which you think we should write down? Because we also have blank cards and can create new criteria [. . .] Is there anything we forgot?* *P: No.* *I1: It is well illustrated?* *P: It is well illustrated.* (Int3, lls. 289–295)
(4) Overlapping of criteria	*P: We find someone in the house to talk to. Sometimes, we sat outside on the bench. But that I [talk with other's about my worries] well. Here with them [other residents in the apartment building]...I am the one who says "no, do this, do that". [...]* *I1: Do you think that this [Criterion 6, Table 1] overlaps a bit or is the same as the social activities? Because you there [Criterion 1, Table 1] you also talk?* *P: Possible.* (Int8, lls. 238–245)
(5) Wording and comprehensibility	*P: Social aspects [Criterion 1, Table 1] means . . . [reads] that this will be and the other is in the future.* *I1: You don't have to make it that complicated.* *P: No?* *I1: What is that for you? Do you have friends? Do you have a dog?* *P: I would have only thought about the medical side of this now. [...].* (Int5, lls. 13–17)
(6) Observations during interviews	
(a) Reactions by patient	*P: Let's say the...how should you say this... what happens but...no...so...[participant is nervous] eh could you ask your question again briefly?* (Int5, lls 29–30) *I2: Um, this [criterion 8, Table 1] is about information and support if you have family members. [. . .] you said you do everything by yourself, right? Hence, this might be a bit difficult to answer that [about criterion 8, Table 1]* *P: Family members . . . dementia. Yes, the dementia patients need us, they cannot be without us.* (Int6, lls 201–204) *P: And that they know [what to do], the nursing specialists [cf. criterion 7, Table 1] that is very clearly [important]. [...].* (Int2, lls. 432)

Table 4. *Cont.*

Category #	Key Quotations from Qualitative Data (Individual Interviews with *n* = 10 PlwD (and *n* = 3 Informal CGs))
(b) Interaction with informal CG	*P: What are you doing now? [towards informal CG]* *CG: No! That we both can [do something]. That you are with me is of no use to you either, you have to be with people who are just as sick as you!* *P: Yes yes, hm.* *CG: They talk to each other very differently . . .* *P: Well if you want to deport me . . .* (Int1, lls. 309–314) *P: Yes, I need a change. I need it...very often...anyways, my wife is an impediment with regard to this question because she is afraid that I will somehow tip over or something. But personally...* *CG: Well, I'm always afraid that he will fall there, because it is not flat in the garden. And he fell there a few times. And then I'm afraid that he will fall again. And that's why I only let him do things where the danger of falling is not likely. Where he doesn't have to bend down, where he can stand up straight.* (Int9, lls. 207–212) *I1: Ok. Great. You're doing really well. That helps us a lot. So activities of daily living. It's like eating, showering, everything you do every day. Getting dressed...I think you are still very physically fit. You can still do it all [by yourself].* *P: Yeah.* *I1: Do you currently need help with [anything] or do you do everything on your own?* *P: I do a lot of things on my own. I don't want to say everything, but a lot.* *I2: Most of it, yes?* *P: Yes.* *I1: If you should ever need help, would it be important for you to get help?* *P: Yeah. Well. I have a wife who knows everything. She also studied.* (Int4, lls. 235–244)
(c) Explorative vs. card game	*I1: We thought that [social] activities for example could be individual or group discussions, writing letters, videos, working with figures. But you cannot relate anything to that?* *P: No. Why should we waste our time with this?* (Int1, lls. 25–27) *I1: Okay. So you would say that this [criterion 10, Table 1] is maybe of middle importance?* *P: Yeah well...not at the moment, as long as I can still do it by myself. But if I then...so if I were to forget that...then...[. . .] We chose Dr. [XXX]. We didn't know her...but she was nearby. So we didn't have to walk far. Or take the bus or something.* *I1: Okay. So. Proximity is important...it's kind of important. [...].* (Int2, lls. 303–310) *I1: How would that be, should you ever need that [adjustments of the environment]? Would you like to have that then?* *P: I think I can take my time. Doesn't have to be now... from now on I'm sick and now I have to [get help] . . .* (Int5, lls. 347–349)
(d) Context	*I1: Exactly. [laughs] And there used to be polyclinics in the GDR.* *P: Yes.* *I1: How do you like that, the concept?* *P: Very good! In general I find everything related to GDR very good.* (Int4, lls. 391–394)

Table 4. *Cont.*

Category #	Key Quotations from Qualitative Data (Individual Interviews with n = 10 PlwD (and n = 3 Informal CGs))
(e) COVID-19	*P: Well, what can I think of [ad criterion 1, Table 1]—well now, due to Corona, drinking coffee has been cancelled. Otherwise, we always had 1–2 h of drinking coffee together [in the community housing clubroom] on Wednesdays and Thursdays in the afternoons.* (Int2, lls. 15–16) *I1: And do you think it's good that you can do something like that . . . go for a walk and something?* *P: Yeah well, I have to like it. I can no longer travel, I imagined my retirement to be different. But everything is gone and now the disease [is there] too. The big one.* *I1: You mean Corona?* *P: Corona, that's exactly what I mean. I always forget the name.* (Int7, lls. 101–105) *P: Yes, but this is no longer . . . otherwise you would have had more contact [sad].* *I1: Hm. Because of Corona it is no longer [the contact]?* *P: Yes.* *CG: Yes, unfortunately it is...really bad with Corona.* (Int9, lls. 39–42) *CG: We did sports until Corona. We're still in the sports group, but we'll cancel our membership because he can't do it anymore. He can no longer participate, no matter what we did there. It doesn't work anymore. He has lost so much lately.* (Int9, lls. 83–85)

Abbreviations: CG = Caregiver, GDR = German Democratic Republic, I1 = Interviewer 1, I2 = Interviewer 2, Int = Interview, lls = lines, P = Patient, PCC = Person-Centered Care.

3.4. Overlapping of Criteria

The participant's elaborations about the cards gave indications about the potential overlap of criteria, cf. Table 4. Consequently, we decided to merge literature-derived criteria 1 *(Social Activities)* and 6 *(Support with worries)*, as well as criteria 8 *(Information for informal CGs)* and 10 *(Organization of care)*, cf. Table 1, which resulted in the criteria *"social relationships"* and *"organization of health care"*, cf. Table 3.

3.5. Wording and Comprehensibility

The participants had difficulties with the criteria's general formulations, cf. Table 4. Once provided with concrete examples, the participants could relate well to the criteria. We decided to delete extensive criteria descriptions and instead described them with examples from the participant's elaborations, cf. Table 3, column two.

Dementia is a sensitive topic. To prevent discontinuation of interviews, we had to adapt dementia-related terms in the interview guide and the card game. Consequently, the final (sub)criteria in Table 3 avoid dementia-related wording.

3.6. Other Observations

Several inductive observations emerged from data analysis, as presented in the following.

3.6.1. Reactions by PlwD

Initially, some participants were nervous, as some expected a test and wanted to "perform well", despite explicit explanations by the interviewers that only their opinion was important to inform the subsequent development of a survey and no test would be performed. Some participants had difficulties dealing with "dementia" as a topic. During interviews with informal CGs or a DCM as a second interviewer present, some participants were "keen to please".

3.6.2. Interaction with Informal CGs

During three interviews, informal CGs joined the PlwD. Some PlwD displayed concern about losing their informal CG, cf. Table 4. The relationship between PlwD and CG was at times affected by the better fitness of the CGs, who could be overstepping.

During elaborations about help with, e.g., daily activities, particularly male PlwD showed expectations that their wife would take care of this.

3.6.3. Explorative vs. Card-Game Responses

Some PlwD had difficulties with the initial explorative part, which required abstract thinking to elaborate on the presented criteria and related experiences and wishes, cf. Table 4. The subsequent card game, which included concrete comparisons and sorting of the cards, did not pose a problem for the PlwD.

Many PlwD were still physically fit and did not need help with daily activities or adjustments to the living environment. Some elaborated "imagine if ... " thoughts, i.e., if they would require help in the future would they be happy to receive it and how they would want to receive it. Others did not want to think about the unknown future and could not elaborate on what they would wish for their care, cf. Table 4.

3.6.4. Setting

The interviews were conducted in the German Federal State Mecklenburg-Western Pomerania, a former part of the German Democratic Republic (GDR). Elaborations about certain criteria, e.g., criterion 10, cf. Table 1 were associated with examples related to this setting. These examples from the past political and economic systems helped with the PlwDs' understanding of the criteria, cf. Table 4. Consequently, we decided to include these examples (e.g., polyclinics in the GDR) to describe the patient relevant criteria and sub-criteria, cf. Table 3.

3.6.5. COVID-19

The PlwD's elaborations were affected by COVID-19, cf. Table 4. Especially the criteria "access to social activities" and "physical activities" were mentioned as impacted by the COVID-19 restrictions.

4. Discussion

Our article contributes to the limited literature with a report on the systematic process of initial (sub)criteria derivation for the development of an AHP decision hierarchy and survey to elicit patient preferences for PCC among community-dwelling PlwD. This *formative*, qualitative research study was built on the previous identification of conceptual (sub)criteria by a systematic literature review. PlwD had preferences, and by use of the card game, they were able to express their preferences. The analysis resulted in six patient-relevant criteria, each with two sub-criteria; *social relationships (indirect contact, direct contact), cognitive training (passive, active), organization of care (decentralized structures & no shared decision-making, centralized structures and shared decision making), assistance with daily activities (professional, family member), characteristics of professional CG (empathy, education and work experience) and physical activities (alone, group)*. No further criteria emerged from the interviews. Overlapping criteria were merged. The wording had to be substantially simplified by deletion of extensive criteria descriptions and replacement with concrete examples, and adjusted to dementia-sensitive language. Some PlwD initially were nervous to "perform well", as they expected to be tested despite explicit explanations by the interviewers that this was not the case. COVID-19 was a present topic during the participants' elaborations.

The initial systematic review allowed us to identify a preliminary broad set of possibly patient-relevant (sub)criteria. Key quotations presented in Table 3 give a clear indication that the selection of (sub)criteria was rooted in and supported by the voices of the decision makers. Furthermore, this qualitative pre-study gave us the opportunity to identify and exclude overlapping criteria in compliance with the credibility criteria of an AHP decision model [24].

Three of the identified six criteria—social relationships, cognitive training and assistance with daily activities—reflect attributes used in a previous quantitative, choice-based preference study with PlwD and their informal CGs [46]. We had oriented ourselves in

Chester et al. [46] for the derivation of conceptual sub-criteria prior to the interviews, cf. Table 1. However, Chester et al. [46] applied another MCDA technique, a DCE, and included both PlwD and their informal CGs as respondents.

If we had relied only on results from the initial systematic review [36] and Chester et al. [46], the final list of (sub)criteria and the resulting number of pairwise comparisons would have become too extensive for this patient group. Furthermore, we would not have known if all identified criteria were relevant and important from the patient's perspective. Hence, we tested if the criteria from the literature review were patient-relevant in terms of future decision making. This underlines the importance and necessity of conducting *formative* qualitative studies for contextual and population-specific appropriateness of the AHP (sub)criteria [24,26,27,30].

Despite explicit explanations by the interviewers, some PlwD were initially nervous to "perform well" as they expected a test. This reaction may be based on experiences with assessments for cognitive impairment in the clinical trials which we had recruited from. It may also be that the participants tried to hide their cognitive impairment due to the associated stigma with the diseases, as found by Xanthopoulou & McCabe [79], and hence wanted to perform well during the interview. Future quantitative preference research with PlwD may want to pay particular attention to avoiding expected or perceived test situations and preparation, respectively.

Corona (COVID-19) was a present topic during the participants' elaborations, especially concerning access to social and physical activities. Lack of access to services and support due to COVID-19-related lockdowns has only recently been raised as a topic of great concern for this patient group [80,81]. It may be that the importance of criteria was affected by the COVID-19 measures, i.e., that the criteria's relative importance was affected by current unmet needs. However, preferences are based on the processing of needs, values and goals and may shift as the social environment or contextual circumstances change [82]. It might also be that the COVID-19 measures simply enforced existing preferences for PCC criteria among PlwD. This phenomenon could be examined further by future research.

Even though potential clinical implications of our findings based on a small sample size are limited, the identified (sub)criteria of PCC serve the development of an AHP survey, which hence shall be used to elicit patient preferences for person-centered dementia care on a larger scale. Van Til and Ijzerman highlighted the advantage of quantitative preference elicitation methods for measurement of patient preferences on a larger and representative scale, which in turn would allow for reflection of the patient perspective in regulatory/health policy decisions [83]. As indicated by Mühlbacher [21], knowledge about most/least preferred health care options may help to increase acceptance and adherence to interventions among patients. Prioritization in the provision of those interventions accepted and preferred and avoidance of those options less preferred may reduce the financial pressure on health care systems [21]. This may affect both routine care and new concepts of care [40]. PCC requires knowledge about patient preferences [14,15,20,84]. Furthermore, *Shared Decision Making* between the health care provider and the patient is a core element of PCC [36,85]. PlwD as patients are "experts by experience"—hence, incorporation of their perspective in care decision making is of importance. Jayadevappa et al. [86], who applied a quantitative, choice-based preference instrument, saw i.a. improved satisfaction with care and decision, as well as reduced regrets. Quantitative preference elicitation instruments, such as the AHP, may form a powerful instrument for consideration of the patient perspective in dementia care decision making on a larger scale [83]. However, the validity of quantitative, criteria-based preference elicitation instruments depends on appropriate identification of the included criteria to reduce the risk of bias and inaccurate results [24,26–28]. The latter can be reduced by a rigorous, systematic and transparently reported identification of (sub)criteria [28,29], as in this current study, which provides initial data of patient-relevant (sub)criteria for the design of an AHP decision hierarchy and survey for person-centered dementia care.

Limitations

Our study has several limitations. Conceptual (sub)criteria identified from literature had to be translated from English to German. Information could have been lost in translation or content compromised by language errors. However, the translation by WM was reviewed by the other authors, as well as by the DCMs during the expert panel, which mitigated the probability of possible translation flaws. The expert panel included a small number of participants ($n = 2$), who were internal colleagues of members of the study team. However, expert perspectives were not the primary objective of this pre-study. Consultation with clinical experts can, nonetheless, provide the basis for identifying the full set of (sub)criteria for subsequent qualitative research with patients and is in accordance with good research practices in patient preference research [87]. Similar to our study, Kløjgaard et al. [88] only included $n = 2$ experts in the formative qualitative study phase for the development of the quantitative preference instrument. Compared to usual sample sizes in general qualitative research, the number of participants during the patient interviews may appear low. As aforementioned, cf. Section 2.5, we oriented ourselves in a recent publication by Hollin et al. [29], which entailed guidelines for *formative* qualitative research, such as ours, to support the development of quantitative preference instruments. The authors emphasize that sampling in these study phases should not focus on the number of units but on collecting actionable input for the development process, which needs a diversity of perspectives. They underline that sampling adequacy in *formative* qualitative research may entail smaller samples than in *general* qualitative work, which given the limited study purpose, may be adequate [29]. To complement suggestions by Hollin et al. [29] and inform the expected saturation point as guidance for sample size determination, we oriented ourselves in previous quantitative patient preference research, including works by second author AR, which report similar sample sizes in the *formative* pre-study phase(s) [67–72]. In this formative qualitative study, saturation started to appear from patient interview number six. The remaining four interviews clarified and consolidated the ranking of criteria, especially of "social relationships", "cognitive training", and "physical activities". By the inclusion of several stakeholders, we ensured a diversity of perspectives. We could have conducted focus group interviews with the PlwD as Danner et al. [73]. However, due to the sensitivity of the topic, the vulnerability of the patient group, and COVID-19-related restrictions on group meetings, we refrained from this option. Another option might have been to administer the card game as an online patient survey for the identification of patient-relevant (sub)criteria [24], by which risks associated with contact during the COVID-19 pandemic would have been limited, and the sample size potentially could have been increased. However, an online patient survey without interviewer assistance with this particular patient group—aged adults with cognitive impairments, oftentimes living in rural areas, which may have limited access to the internet and a lack of necessary digital literacy [89]—was deemed not feasible by the study team based on previous research [25] and experiences from other projects at the site [90]. As criteria-related questions and card games took longer than expected and most PlwD got tired, we could not show the sub-criteria cards and ask for feedback on their appropriateness and comprehensibility. Instead, we elicited plausible sub-criteria from the participants' initial elaborations about the criteria cards, which, together with the designed ICONs, were planned to be tested for their appropriateness during the subsequent pretests of the AHP survey, cf. Figure 1. Generally, interviewers should not guide interviewees and rather aim for open interview questions [91]. This requirement was difficult to fulfill with this patient group and research aim. PlwD had difficulties with open/abstract questions and needed guidance throughout the interviews with concrete questions to create a comfortable interview situation, as observed in previous research [92]. Future patient preference research with a cognitively impaired population may want to consider these observations. For some PlwD, elaborations about selected criteria required imagination of potential scenarios in the future. This resulted in some inconsistency between the explorative part and card games, which could be an early indication of a known methodological problem with the AHP. Thus, the AHP is criticized for the mere pairwise comparisons not fully reflecting to a real decision-making situation, as the decision maker never is confronted with the entirety of a decision problem but only with individual aspects of an overall decision [93]. It could also be an indicator that the cognitively impaired patient group did not understand the information and tradeoffs presented during the card games. However, we followed the same approach as Danner et al. [25], i.e., to repeat after each pairwise comparison during the card games what the patient said with his/her judgement, to counteract this potential problem. Per our observations, cf. Sections 3.1 and 3.6.3, the patients understood the information and tradeoffs presented during the card games well, compared to the more explorative part at the beginning of the interviews. Hence, we are confident in the results of the presented tradeoffs. As we remained compliant with our research focus and collected a manageable amount of data in a short period of time, the requirements for credibility and dependability with regard to the study's trustworthiness were viewed as fulfilled [94]. Transferability of findings is limited due to the aforementioned rather small sample sizes of included subjects, the specificities of our setting and related cultural differences. Nevertheless, due to the rigor of the methodological process and reporting, we consider our findings trustworthy.

5. Conclusions

This formative qualitative study complements the limited literature with initial data about patient-relevant criteria of PCC for PlwD to design a quantitative preference instrument. To the best of our knowledge, our research is among the first to provide insight into the methodological processes of (sub)criteria development for the subsequent design of an AHP for a cognitively impaired population. PlwD had preferences and, by use of the card game, were able to express their preferences. The transferability of our findings is limited due to the comparatively small sample sizes of included subjects. Aside from the consideration of larger sample sizes, future research should pay particular attention (a) to clarify the purpose of the study and to ensure tradeoffs are understood by the participants, (b) to include simple and concrete rather than abstract as well as dementia-sensitive wording and (c) to account for the energy required in relation to the age and cognitive status of the participants, as well as challenges in qualitative research with this population, which requires great researcher flexibility. A consideration of our observations in future quantitative preference research with PlwD may help to increase the confidence in such research.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/ijerph19137629/s1, Supplemental Codebook S1.

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Appendix 3: Article Nr. 3 “Development of a Quantitative Preference Instrument for Person-Centered Dementia Care—Stage 2: Insights from a Formative Qualitative Study to Design and Pretest a Dementia-Friendly Analytic Hierarchy Process Survey.”

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Article

Development of a Quantitative Preference Instrument for Person-Centered Dementia Care—Stage 2: Insights from a Formative Qualitative Study to Design and Pretest a Dementia-Friendly Analytic Hierarchy Process Survey

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Abstract: Person-centered care (PCC) requires knowledge about patient preferences. An analytic hierarchy process (AHP) is one approach to *quantify*, *weigh* and *rank* patient preferences suitable for People living with Dementia (PlwD), due to simple pairwise comparisons of individual criteria from a complex decision problem. The objective of the present study was to design and pretest a dementia-friendly AHP survey. **Methods:** Two expert panels consisting of $n = 4$ Dementia Care Managers and $n = 4$ physicians to ensure content-validity, and "thinking-aloud" interviews with $n = 11$ PlwD and $n = 3$ family caregivers to ensure the face validity of the AHP survey. Following a semi-structured interview guide, PlwD were asked to assess appropriateness and comprehensibility. Data, field notes and partial interview transcripts were analyzed with a constant comparative approach, and feedback was incorporated continuously until PlwD had no further comments or struggles with survey completion. Consistency ratios (CRs) were calculated with Microsoft® Excel and ExpertChoice Comparion®. **Results:** Three main categories with sub-categories emerged: (1) *Content:* clear task introduction, (sub)criteria description, criteria homogeneity, (sub)criteria appropriateness, retest questions and sociodemography for heterogeneity; (2) *Format:* survey structure, pairwise comparison sequence, survey length, graphical design (incl. AHP scale), survey procedure explanation, survey assistance and response perspective; and (3) *Layout:* easy wording, short sentences and visual aids. Individual CRs ranged from 0.08 to 0.859, and the consolidated CR was 0.37 (0.038). **Conclusions:** Our formative qualitative study provides initial data for the design of a dementia-friendly AHP survey. Consideration of our findings may contribute to face and content validity in future quantitative preference research in dementia.

Keywords: patient preferences; dementia; participatory research; survey; shared decision making; multi-criteria decision analysis; analytic hierarchy process; person-centered care

1. Introduction

Dementia diseases represent a challenge for healthcare systems worldwide [1]. Globally, approximately 55 million people live with a form of dementia, with nearly 10 million new cases diagnosed every year [2]. Alzheimer's disease (AD) and other dementias are estimated as the fourth leading cause of death in people aged 75+ years according to the *Global Burden of Disease Study 2019* [3]. No curative treatment exists for People living with Dementia and mild cognitive impairment (hereafter referred to as 'PlwD'). PlwD require a timely differential diagnosis [1,4] and care, which ensures a high quality of life (QoL) [5].

Person-centered care (PCC) is the underlying philosophy of the *Alzheimer's Associations' Dementia Care Practice Recommendations* [5] committed to improve the QoL of PlwD and has been included in many national guidelines and dementia plans [6–12]. PCC challenges the traditional clinician-centered/disease-focused medical model with an alternative model of care customized to each person [13]. This customization requires knowledge about the recipients' preferences [14,15]. Among PlwD, some data is available about preferences for care [16–18], mostly elicited by application of qualitative methods, e.g., Harrison Dening et al. [19], and Likert-type scales, e.g., van Haitsma et al. [20]. These methods fall short to *quantify, weigh* and *rank* patient-relevant elements of care to measure their relative importance and, as such, in identifying the most/least preferred choices. The latter can be assessed with quantitative preference instruments from Multi-Criteria Decision Analysis (MCDA) [21]. An example of the latter is a Discrete Choice Experiment (DCE), such as applied by Groenewoud et al. [22] to address relevant aspects of outpatient care and support services for people with AD, although with patient representatives and not patients themselves. Other MCDA techniques commonly used in health care include best–worse scaling (BWS) [23] and the Analytic Hierarchy Process (AHP) [24]. The AHP has been suggested as feasible for elicitation of patient preferences among people with cognitive impairments due to simple pairwise comparisons with only two individual aspects of a complex decision problem [25].

The AHP, like other MCDA-techniques, involves the development of attribute/criteria-based experimental decision models for subsequent design of a quantitative preference instrument [26,27]. One important aspect of the model's internal validity is appropriate identification and specification of the included attributes/criteria [24,26,27]. Another important step in development of a quantitative preference instrument is thorough pretesting [28]. This can help to establish content validity by ensuring meaningful and culturally competent language and the understandability of instructions (i.e., comprehension), as well as the layout (e.g., length, complexity and overall experience) [28,29]. Particularly in research with PlwD, consideration of these issues is important to ensure a dementia-friendly design of the quantitative preference instrument [30]. Furthermore, the appropriateness of previously defined (sub)criteria [31] and local translations, as well as the comprehensibility of (sub)criteria within the choice sets have to undergo final pretesting.

To the best of our knowledge, no previous research has reported details about the critical development phase of a quantitative preference instrument in dementia care, i.e., an AHP survey. The aim of our study was to fill this gap with a rigorous process report about comprehension and layout to design a dementia-friendly AHP survey, including an assessment of the appropriateness of previously defined (sub)criteria.

2. Materials and Methods

2.1. Qualitative Approach

For the report of this pretest study, we followed the guidelines for reporting formative qualitative research proposed by Hollin et al. [28], who, i.a., listed language refinement, task/instrument design and testing as common objectives of formative qualitative research, such as this study, to design a quantitative preference instrument. The pretest interviews followed a cognitive interview approach guided by the think-aloud and paraphrasing technique [32] for individual patient interviews. We conducted two focus group interviews [33] as expert panels with (1) internal, i.e., colleagues of the research team on site, dementia-specific qualified nurses (so-called Dementia Care Managers, DCMs) [34–36] and (2) physicians.

2.2. Theoretical Framework

The overarching AHP study *'PreDemCare'* [37,38] adopts a sequential mixed-methods design [39] for final instrument development. Details about the *PreDemCare* study can be found in [37,38], and a process outline is provided by Mohr et al. [31]. Based on findings from a previous systematic review [40], stage 1 of the pre-study, including a small expert panel and qualitative interviews [31], was conducted to identify relevant (sub)criteria of PCC to develop an AHP hierarchy of relevance to (future) decision makers. Six criteria with two sub-criteria emerged from analyses: *social relationships (indirect contact and direct contact), cognitive training (passive or active), organization of care (decentralized structures and no shared decision making* vs. *centralized structures and shared decision making), assistance with daily activities (professional or family member), characteristics of care professionals (empathy, education and work experience) and physical activities (alone or group)*. The current report focuses exclusively on stage 2 of the pre-study in the overarching *PreDemCare* study, i.e., the pretest phase for development of a dementia-friendly AHP survey. The to-be-developed quantitative preference instrument is intended to assess patient preferences and physician judgements for PCC, including an assessment of their congruence. Details of the subsequent main study in the *PreDemCare* study [37,38] lie outside the scope of this report.

2.3. Researcher Characteristics and Reflexivity

W.M., a public health scientist with qualitative research experience, conducted the pretest interviews. W.M. was overseen by A.R., a public health scientist with many years of experience in quantitative preference research [24,41]. Study nurses in ongoing clinical trials on site (ClinicalTrials.gov identifiers: NCT04741932, NCT01401582, German Clinical Trials Register Reference No.: DRKS00025074) functioned as gatekeepers to access the PlwD for patient interviews.

2.4. Sampling Strategy and Process

DCMs for Expert Panel 1 (EP1) were selected from ongoing clinical trials on site. PlwD for the patient interviews were selected by typical case sampling [42,43], a type of purposive sampling [33], from the clinical trial participant pool on site. The gatekeepers emphasized the independence of the present study. Informal caregivers (CGs) were invited to join. Physicians for Expert Panel 2 (EP2) were recruited via personal contact and friendship networks as recommended by Asch et al. [44] based on different specialty fields important in dementia care.

2.5. Sampling Adequacy

For sample size determination in a *formative* qualitative study, in order to develop a quantitative preference instrument, we oriented ourselves in Hollin et al. [28]. The authors underline that the focus should not be the number of subjects, which may be different from *general* qualitative research, but the strategic collection of actionable input for the development process. Hence, a diversity of perspectives is required [28].

In the current pretest study, we addressed the latter requirement by including different stakeholders (DCMs, patients and physicians). Furthermore, the sample size for the patient interviews of $n = 10$ was guided by expected saturation point based on experiences from previous formative qualitative research for the development of quantitative preference instruments [45–50], as well as restricted access to PlwD due to the ongoing COVID-19 pandemic. Transmission risk during contact with this vulnerable patient group was minimized to the greatest extent possible. All interviews were conducted in accordance with a strict hygiene protocol developed on site.

2.6. Sample

The total sample of interview participants was $n = 22$. Expert panels included (1) $n = 4$ DCMs and (2) $n = 4$ physicians. The final patient sample included $n = 11$ PlwD, three of whom were accompanied by $n = 3$ informal CGs as silent supporters. Eligibility criteria for PlwD included $\geq$60 years of age, indication of mild cognitive impairment (MCI) or early-to-moderate-stage dementia by diagnosis or cognitive test result (e.g., DemTect < 13 [51] or Mini-Mental State Examination (MMSE) < 27 [52,53]), ability to understand written and oral German and written consent provided by patient/legal guardian [37].

2.7. Ethical Review

This pretest study was as part of the overarching preference study *PreDemCare* [38] and approved by the Ethics Committee of the University Medicine Greifswald (Ref.-No.: BB018-21, BB018-21a, BB018-21b).

2.8. Data Collection Methods, Sources and Instruments

EP1 was conducted on site. Prior to EP1, the researchers developed a first draft of the AHP survey, which was shared with the DCMs in preparation for discussions. During EP1, the DCMs reviewed and discussed the survey's content, comprehensibility and layout. EP1 was recorded. Field notes taken directly in the survey formed the main data from EP1. Changes were implemented immediately, and an expert-reviewed survey draft was prepared for the patient interviews.

Individual patient interviews were conducted with PlwD and informal CGs in their homes or in day clinics from July to August 2021. Based on our experiences with previous interviews in pre-study stage 1 [31], we chose an individual interview format with a single interviewer (WM), settings known to the patients and the possibility of inviting an informal CG as a silent supporter to create a comfortable interview situation [54]. Participation in the interview required prior provided informed written consent, which could be provided by the PlwD or a legal guardian. All interviews were recorded. The audio recording was started after both the informed consent procedure and introduction of the participants to ensure privacy. The average interview time was 60 min.

We used a semi-structured interview guide oriented in the one proposed by Danner et al. [55] to ensure an efficient interview structure and give the PlwD the opportunity to freely provide feedback about the presented survey. The survey, developed oriented in a previous AHP survey with an aged population proposed by Danner et al. [55], included three paragraphs: (1) information about the content of the survey; (2) the AHP survey, including pairwise comparisons for the a) criteria and b) sub-criteria; and (3) a self-developed sociodemographic questionnaire for patient characteristics and related potential subgroup analyses. The participants were asked to assess the question formulations for their appropriateness and comprehensibility, as well as to provide information about the underlying motivation determining their answers. We used the AHP judgement scale with verbal explanations of numeric values [56]; an example of a graphical display can be found in Hummel et al. [57].

The main source of data was field notes taken on the paper survey presented to each individual patient. These notes included concrete feedback about wording, format, layout and related comprehensibility. After each pretest interview, the study team met for a short debriefing discussion to decide on changes to be implemented in the survey prior to the next pretest interview. Feedback was incorporated on a continuous basis until the PlwD had no further comments/struggles with completion of the survey.

After n = 11 patient interviews, EP2 was conducted by W.M. and A.A. with n = 4 specialist physicians via LifeSize [58], a video conference software. W.M. acted as 1st moderator and A.A. as 2nd moderator, taking field notes and keeping track of time. The focus group interview was audio-recorded. The DCM- and patient-reviewed survey was translated to a first draft of the physician's version of the AHP survey, which included the same pairwise comparisons. In the initially drafted version, physicians were asked "to assume the patient's perspective", i.e., to answer the survey as a proxy. The content of the complete survey was similar to that of the patient's version, likewise ending with a short self-developed sociodemographic survey focused on the physician's background. During EP2, physicians were asked (1) to review the content of the AHP survey for whether or not it included all relevant aspects of person-centered home care for PlwD from an expert point of view; (2) to assess the comprehensibility and layout of the physician's version, as well as length of the survey; (3) to express their opinions about the respective point of view to answer the survey, i.e., proxy rating or physician's judgement; and (4) whether all relevant sociodemographic aspects in the physician's version had been covered. Furthermore, the physicians were encouraged to raise other topics they considered relevant. After EP2, another two patient pretest interviews were performed for a final review of a few changes based on the expert opinion.

2.9. Data Processing and Analysis, Incl. Techniques to Enhance Trustworthiness

Data processing and analysis were conducted according to Coast et al. [59], who recommend iterative constant comparative approaches for analyses during the stage of language refinement (i.e., comprehension of (sub)criteria), as these approaches are more efficient than methods whereby data are collected in advance and analyzed afterwards. Iterative studies yield the ability to adapt questions, formulations, layout, etc., in both a timely and continuous manner based on the findings generated in the study process.

Field notes in the patient survey were analyzed on a continuous basis by W.M. and A.A. and overseen by A.R. as a third reviewer. Additionally, partial transcripts of the patient interviews, likewise reviewed by two reviewers with a third reviewer present in case of disagreement, complemented the field notes respective to themes that appeared important with regard to the comprehension and layout of a dementia-friendly AHP survey, as well as the appropriateness of previously defined (sub)criteria. If names were mentioned during the interview, they were replaced, e.g., with "XXX", to ensure privacy.

Furthermore, AHP data from the completed PlwD surveys were transferred and analyzed with a Microsoft® Excel-based AHP tool [60] and Expert Choice Comparion® [61], to, i.a., review both individual consistency ratios (CRs) and the consolidated result for PlwD by application of arithmetic (geometric) mean for aggregation of individual priorities (judgements) [62]. For CRs, the literature usually recommends a consistency threshold of 0.1–0.2 [57,63]; however, particular circumstances, such as cognitive capacities of surveyed participants, may warrant the acceptance of a higher value at 0.3 [60,64].

Analysis of patient characteristics was based on the self-developed sociodemographic questions. Severity of cognitive impairment was determined during recruitment based on inclusion criteria, cf. Section 2.6, by the internal study nurses as gatekeepers based on their most recent assessment with a validated instrument (MMSE) [52] in the clinical trial from which patients had been recruited.

With our choice of diverse data collection and analysis methods and the inclusion of a diversity of participants and perspectives, we aimed to ensure data triangulation [33]. For quality control, the final versions of the surveys (patients and physicians) were discussed and agreed upon in a final meeting of the research team.

3. Results

PlwD characteristics are depicted in Table 1. The majority of DCMs (75%) were women aged between 31 and 40 years with education as geriatric (50%) or registered nurses (50%). Years of work experience in dementia care ranged from 8 to 30 years. All DCMs had previous experience with the Dementia Care Management-intervention developed on site [34–36] as part of clinical trials (ClinicalTrials.gov identifiers: NCT04741932, NCT01401582, NCT03359408; German Clinical Trials Register No: DRKS00013555, DRKS00025074), with the number of PlwD previously under their care ranging from 150 to 300 patients. Among physicians, half (50%) were aged 61–70 and 51–60 years, respectively, with the majority (75%) of male gender and employed. All practiced in an urban area in different settings (local health authority, special service health, individual practice or ambulatory healthcare center). Fields of specialty included psychiatry/psychotherapy, general medicine, anesthesiology, pain therapy and palliative care. One was familiar with PCC, and two knew about *Shared Decision-Making*.

Table 1. Patient characteristics (*n* = 11).

Characteristic		***n* (%)**
Age	60–71	2 (18.2)
	71–80	4 (36.4)
	81–90	3 (27.2)
	>90	2 (18.2)
Gender	Female	6 (54.5)
	Male	5 (45.5)
Family status	Married	6 (54.5)
	Widowed	4 (36.4)
	Divorced or separated	1 (9.1)
Highest educational degree	No degree	1 (9.1)
	8th/9th grade	1 (9.1)
	10th grade	2 (18.2)
	Degree from a technical/vocational college	4 (36.4)
	Degree from a university of applied sciences or university	3 (27.2)
Previous occupation [65]	Skilled worker	2 (18.2)
	Employee with limited decision-making powers (e.g., cashier)	6 (54.5)
	Lower grade with high qualification in employment (e.g., doctor, professor, engineer)	3 (27.2)
Monthly net income	EUR 1001–1500	1 (9.1)
	EUR 1501–2000	3 (27.2)
	Not known	3 (27.3)
	Prefer not to say	4 (36.4)
Stage of cognitive impairment [a]	Early	9 (81.8)
	Moderate	2 (18.2)
Non-pharmacological treatment		7 (63.6)
	Memory work (e.g., memory exercises, rehabilitation)	2 (28.6) [b]
	Occupational therapy	2 (28.6) [b]
	Physical training (e.g., physiotherapy, sports groups)	7 (100.0) [b]
	Artistic therapy (e.g., music therapy, art therapy, dance therapy, theater therapy)	1 (14.29) [b]
	Other (speech therapy)	1(14.29) [b]
Self-rated general health	Good	5 (45.5)
	Satisfactory	5 (45.5)
	Less good	1 (9.1)

[a] Determined by study nurses as gatekeepers based on latest assessment with a validated tool (MMSE) [52] in the clinical trial from which the patients were recruited. [b] Percentage calculated based on those (*n* = 7) who indicated that they received non-pharmacological treatment. Multiple selections possible.

Three main categories with sub-categories emerged from data analysis of field notes and partial transcripts. Categories with respective key quotations from all participants are depicted in Supplementary Materials File S1.

3.1. Content

3.1.1. Survey Title Page for PlwD

During the previous qualitative interviews [31], we experienced some PlwD to be nervous, as some expected a test and wanted to "perform well", cf. Supplementary Materials File S1, row 1, which was confirmed by EP1. Hence, we emphasized with bold and underlined font on the title page that the survey does not include a test but asks about the PlwD's opinion.

3.1.2. Survey Title Page for Physicians

EP2 emphasized that the title page should state the severity of cognitive impairment to consider during completion of the survey clearly, as care and medical needs may differ, cf. Supplementary Materials File S1, row 2, paragraphs (para.(s)) 1–2.

The initial draft of the physician's survey asked clinicians to answer the survey from the perspective of their patients, i.e., from a proxy perspective. EP2 revealed concerns about this format and potential risk of bias. The panelists recommended to instead ask for an 'expert opinion', i.e., physicians' judgments with respect to their patients, cf. Supplementary Materials File S1, row 2, para.(s) 3–7. The physician's AHP survey was adapted accordingly.

3.1.3. Description of (Sub)Criteria for PlwD

During the previous interviews [31], we found that extensive technically descriptive sentences of the (sub)criteria should be avoided and that the abstract (sub)criteria titles should be described by concrete examples the PlwD can relate to, which was confirmed by EP1.

During the first pretest, the assisting interviewer observed the participant to repeatedly read all the (sub)criteria-describing examples, which increased the interview time substantially. Hence, we tested the removal of the examples describing the (sub)criteria from the pairwise comparison questions throughout the complete survey from pretests 2 to 8. Without the concrete examples, the reading time was decreased, but the subsequent participants had difficulty understanding the mere abstract titles of the (sub)criteria. Thus, we decided to return the examples describing the (sub)criteria in pretest 9 and included them in the final version of the survey.

3.1.4. Formerly Merged Criteria Demerged

After the card games during the previous interviews [31], we decided to merge two criteria—'*Attention & support with worries, feelings and memories*' and '*Social relationships*'—as during the previous stage, participants had indicated overlapping of these two criteria, cf. Mohr et al. [31]. In the current study, one participant expressed confusion about '*Attention & support with worries, feelings and memories*'. Therefore, we decided to demerge the formerly merged criteria and remove '*Attention & support with worries, feelings and memories*' from the survey, cf. Supplementary Materials File S1, row 4, para. 1.

3.1.5. AHP Axiom 2

EP2 expressed concerns about the homogeneity of the criteria, in particular related to criterion (6) '*Organization of Health Care*', cf. Supplementary Materials File S1, row 5, para.(s) 1–5. However, one expert emphasized that the pairwise comparisons of the criteria should be considered from the point of view of the PlwD, cf. Supplementary Materials File S1, row 5, para. 6.

3.1.6. Introduction of Sub-Criteria in the PlwD Version of the AHP Survey

Initially, the criteria-describing examples had been stated under the abstract criteria-titles just above the to-be-introduced sub-criteria, cf. Supplementary Materials File S1, row 6, para. 1. To reduce the amount of words in the introduction of the sub-criteria and to avoid behavior such as that described in Section 3.1.3, we decided to remove the criteria-describing examples from the introduction of the sub-criteria.

3.1.7. Appropriateness of (Sub)Criteria

EP2 criticized the content of the sub-criteria for (1) *Social Exchange*, (2) *Physical Activity*, (3) *Memory Exercises* and, in particular, (6) *Organization of Health Care*, cf. Supplementary Materials File S1, row 7, para.(s) 1–5. Panelists noted that the respective sub-criteria were presented on an ordinal scale, whereas sub-criteria for criteria 4 and 5 were presented on a nominal scale. Most criticism arose around the sub-criteria for criterion (6), as EP2 did not agree that the structures of health care and shared decision making are correlated, cf. Supplementary Materials File S1, row 7, para.(s) 1–5. W.M., as interviewer, emphasized that the content had been developed based on literature and, first and foremost, on the feedback from the patients, (e.g., Supplementary Materials File S2). We revisited both the transcripts from the previous interviews, as well as field notes and audio recordings from the pretest interviews, to revise the sub-criteria for criteria 1, 2, 3 and 6. The revised sub-criteria were pretested again with two PlwD (pretests 11 and 12), who approved the revised sub-criteria, cf. Supplementary Materials File S1, row 7, para(s). 6–22. Subsequently, the surveys for both populations were finalized, including the changes. The final AHP hierarchy is depicted in Figure 1.

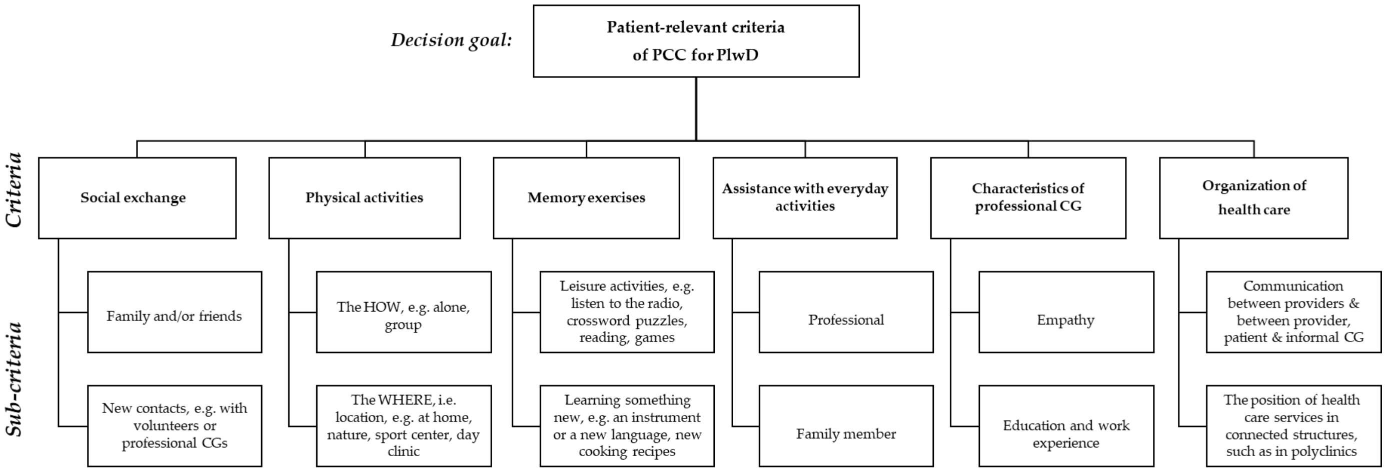


Figure 1. Final AHP hierarchy with patient-relevant (sub)criteria of person-centered dementia care.

3.1.8. Validity and Inconsistency in the AHP Survey

To check for validity of PlwD responses, we included retest questions. Initially, we had included two example questions. The first example question (*No social relationships* vs. *a lot of social relationships*) asked for a comparison of the extreme ends for criterion (1) *Social Exchange*. The second (*social relationships* vs. *additional cost*) asked for a comparison of the most important and the least important criterion based on the results from the previous qualitative interviews [31]. Additionally, we repeated the pairwise comparison *social exchange* vs. *physical activities* twice. EP1 raised concerns about multiple repetitions of questions, as some patients might be irritated by this, cf. Supplementary Materials File S1, row 8, para.(s) 1–3. Additionally, survey completion during the first patient pretest took more than one hour, cf. Section 3.2.3. Hence, we deleted the second example question and one of the repeated criteria questions to avoid excessive repetitions and to reduce the length of the survey. The sub-criteria comparison for criterion (1) *Social Exchange* was repeated once and was not changed.

The results of retest questions among PlwD are depicted in Table 2. Two participants (pretests 2 and pretest 4) chose differently at the level of criteria, which was also contradictory to their answer in the first example question (no vs. a lot of social exchange). Four participants (pretests 3, 5, 8 and 11) chose the same (sub)criteria but assigned different values, with pretest 8 and 11 showing minor deviations (7 instead of 6 on the rating scale).

The individual CRs among PlwD at the level of criteria are depicted in Table 3a. At the level of sub-criteria, no CRs can be stated, as inconsistency of a pairwise comparison between two (sub)criteria always equals zero. Consolidated CRs for all participants are depicted in Table 3b. Individual CRs ranged from 0.08 to 0.86, with a consolidated CR of $n = 11$ PlwD at 0.37 (0.038) based on the arithmetic (geometric) mean for aggregation of individual priorities (judgements).

Table 2. Results of retest questions among PlwD.

	PT1	**PT2**	**PT3**	**PT4**	**PT5**	**PT6**	**PT7**	**PT8**	**PT9**	**PT10**	**PT11**
Examples											
No social exchange	1/9	1/3	1/3	1/7	1/5	1/6	1/5	1/5	1/3	1/3	1/5
A lot of social exchange	9	3	3	7	5	6	5	5	3	3	5
Social relationships	9	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Additional cost	1/9	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Criteria											
Social exchange	9	1/5	**3**	**5**	**5**	5	5	9	3	1	**6**
Physical activities	1/9	**5**	1/3	1/5	1/5	1/5	1/5	1/9	1/3	1	1/6
Social exchange (2)	7	**3**	**7**	1/6	**1**	5	5	9	3	1	**7**
Physical activities (2)	1/7	1/3	1/7	**6**	1	1/5	1/5	1/9	1/3	1	1/7
Social exchange (3)	9	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Physical activities (3)	1/9	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Sub-criteria											
Indirect contact	1/9	1/3	1/5	1/6	1/5	1/3	1/5	**6**	1/3	1	7
Direct contact	9	3	5	6	5	3	5	1/6	3	1	1/7
Indirect contact (2)	1/9	1/3	1/5	1/6	1/5	1/3	1/5	**7**	1/3	1	7
Direct contact (2)	9	3	5	6	5	3	5	1/7	3	1	1/7

Notes: The retest questions "*Social relationships* vs. *additional cost*" and "*Social exchange* vs. *physical activities* (3)" were removed after the first pretest interview to reduce the length of the survey. The bold numbers indicate a difference in first vs. retest judgement. Abbreviations: PT = pretest.

Table 3. (**a**) Overview of individual consistency ratios for PlwD at the level of criteria. (**b**) Consolidated consistency ratio for group decision among PlwD (criteria level).

(a)

PT	**Principal Eigenvalue**	**GCI**	**CR (in %)**
1	8.826	1.46	45.1%
2	7.265	0.7	20.2%
3	7.795	0.96	28.6%
4	9.271	1.67	52.2%
5	6.599	0.35	9.6%
6	11.382	2.63	85.9%
7	9.574	1.77	57.0%
8	7.631	0.88	26.0%
9	6.819	0.46	13.1%
10	6.504	0.29	8.0%
11	9.814	1.85	60.8%

(b)

Consistency $n = 11$	
Principal Eigenvalue	6.237
CI	0.14
CR (in %), GM	3.8%
CR (in %), AM	36.9%

Abbreviations: CR = consistency ratio, GCI = geometric consistency index, PT = pretest, CI = consistency index, GM = geometric mean, AM = arithmetic mean.

3.1.9. Heterogeneity of Respondents

EP2 suggested considering the heterogeneity of the patients and that this may influence the responses, cf. Supplementary Materials File S1, row 9, para. 1. Heterogeneity of respondents and respective potential subgroup analyses in both populations were accounted for by the survey developers through inclusion of a comprehensive self-developed sociodemographic questionnaires. The PlwD sociodemographic questionnaire includes age group, gender, family status, educational status, (previous) occupation, income group, severity of cognitive impairment, regular medication intake, psychosocial treatment(s) and subjective assessment of health status. The physician's sociodemographic questionnaire includes age group, gender, mode of employment, setting (hospital, individual practice, etc.), area (rural, urban), field of specialty, number of patients with dementia diseases treated currently and in the past, knowledge about PCC and knowledge about shared decision making.

3.1.10. Sociodemographic Questions for PlwD

Both EPs gave positive feedback about our self-developed sociodemographic survey. EP2 suggested including the living situation of PlwD as an additional question for potential subgroup analyses, as preferences may differ, cf. Supplementary Materials File S1, row 10, para.(s) 1–3.

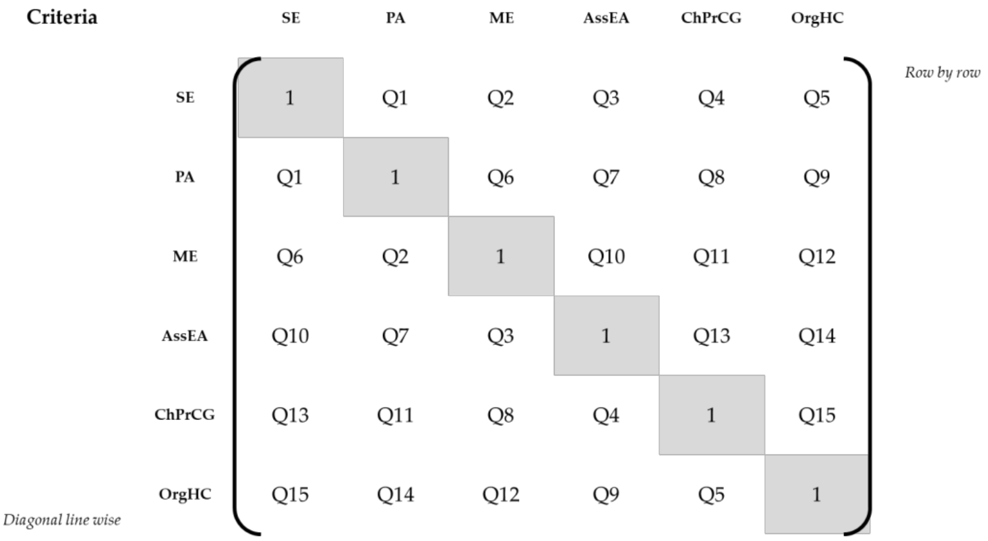
3.2. Format

3.2.1. Outline of the Survey

We aimed to accommodate the needs of the patient group in the outline of the final survey, which may differ from those of other AHP surveys. Sociodemographic questions were moved to the end of the survey, as these were deemed easy to complete and would not require much energy, which EP1 agreed upon, cf. Supplementary Materials File S1, row 11, para.(s) 1–2. EP1 suggested to start with the pairwise comparisons at the sub-criteria level, as these comparisons were easier to understand due to the use of icons as visual aids. After discussions among the research team, we decided to start the survey with the most challenging part, the pairwise comparisons at the criteria level, as this part was expected to require the most energy.

3.2.2. Sequence of Criteria-Related Pairwise Comparison Questions

During pretests 1–4, the sequence of the criteria-related pairwise comparison questions was presented as row-by-row comparisons, as depicted in Figure 2. The first pairwise comparison was *Social Exchange* vs. *Physical Activities*, the second was *Social Exchange* vs. *Memory Exercises*, etc.



Criteria	SE	PA	ME	AssEA	ChPrCG	OrgHC
SE	1	Q1	Q2	Q3	Q4	Q5
PA	Q1	1	Q6	Q7	Q8	Q9
ME	Q6	Q2	1	Q10	Q11	Q12
AssEA	Q10	Q7	Q3	1	Q13	Q14
ChPrCG	Q13	Q11	Q8	Q4	1	Q15
OrgHC	Q15	Q14	Q12	Q9	Q5	1

Figure 2. Sequence of criteria pairwise comparisons. Abbreviations: SE = social exchange, PA = physical activities, ME = memory exercises, AssEA = assistance with everyday activities, ChPrCG = characteristics of professional caregivers, OrgHC = organization of health care, Q1–15 = pairwise comparison questions Nos. 1–15.

Because the participants were confused by repetition of the same criterion in subsequent comparison questions (cf. Supplementary Materials File S1, row 12, para.(s) 1–3), we changed the sequence to diagonal line-wise comparison questions, cf. Figure 2. The first pairwise comparison was *Social Exchange* vs. *Physical Activities*, the second was *Physical Activities* vs. *Memory Exercises*, etc. During pretests 5–8 and 10, we pretested this sequence setup. We observed the highest inconsistency ratio during pretest 6 (85.9%), with a rating of the survey as "rather difficult" by the participant. The participants in pretests 5–8 and 10 continued to criticize the repetition of criteria, despite the better mix of questions. The participants also had a harder time remembering their responses to previous criteria comparison questions, including the same criteria. Hence, the final survey version was changed back to the initial row-by-row sequence of the pairwise comparisons.

3.2.3. Length of Survey

EP1 emphasized that the survey should be kept as short as possible. Despite an effort to shorten the survey substantially, pretest 1 lasted 1 h and 23 min, cf. Supplementary Materials File S1, row 13, para. 1. Subsequently, the content was reduced to the absolute minimum of information that would still allow for enough information to ensure an informed completion of the survey by the participants in the upcoming main study [37].

3.2.4. Formatting

We observed that the survey should be formatted as simply as possible in order to minimize the amount of visual stimuli and thus increase comprehensibility for the PlwD. This includes the choice of an eye-friendly font with of least size 14 for those patients who want to read by themselves. The first PlwD was overwhelmed by the initial page number layout ("page x out of y"). Hence, we changed this to only show "page x", cf. Supplementary Materials File S1, row 14, para.(s) 1–2.

3.2.5. Layout: Transformation of the AHP Rating Scale

One of the biggest challenges was to adjust the AHP rating scale (layout) to an understandable format for this patient population, which also was emphasized by EP1 with respect to the number of answer options. Our revised AHP rating scale based on participant feedback is depicted in Figure 3.

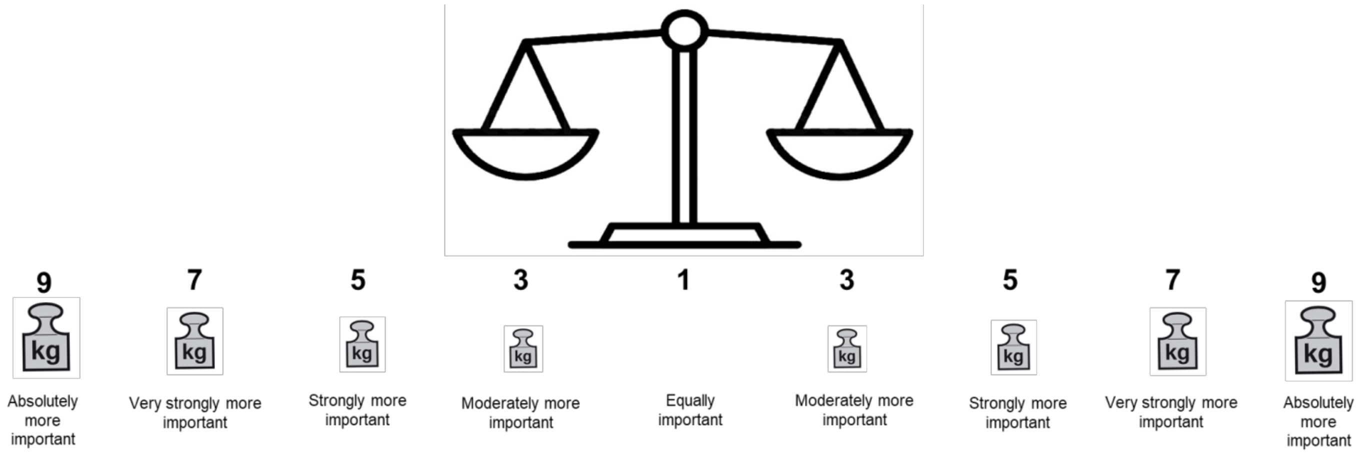


Figure 3. Final layout of the patient-group-adjusted AHP rating scale with verbal judgements [56].

During pretest 2, W.M. drew a scale similar to that shown in Figure 3 to assist the participant with comprehension of the rating scale. This layout received positive feedback from the participant (cf. Supplementary Materials File S1, row 15, para.(s) 5–9) and was kept for the final version of the AHP survey.

3.2.6. Explanation of Survey Procedure with Pairwise Comparisons

Initially, we used the pairwise comparison of *Social Exchange* vs. *Support with Everyday Activities* as an example to explain the survey procedure, including pairwise comparisons. As the first participant had difficulties with this example (cf. Supplementary Materials File S1, row 16, para. 1), we exchanged it with a simple example involving the choice of a side dish at a restaurant, as described by Danner et al. [55]. This example was received well by the participants (cf. Supplementary Materials File S1, row 16, para.(s) 2–6) and kept for the final survey version.

3.2.7. Simplification of Pairwise Comparisons

During pretest 1, W.M. attempted to assist the PlwD with the pairwise comparisons with "*A or B*" questions (left or right criterion), cf. Supplementary Materials File S1, row 17, para.(s) 1–2. To avoid memory effects, we decided against implementation of "*A or B*" next to the (sub)criteria.

3.2.8. Assistance during Patient Survey

EP1 confirmed our experiences from the previous interviews [31], cf. Supplementary Materials File S1, row 18, para.(s) 1–2. Hence, we decided to have only one and the same interviewer assist with the patient surveys both during the pretest study and planned main study.

3.2.9. Perspective during Responses to Pairwise Comparisons

Some PlwD struggled with which perspective to apply during completion of the AHP survey. The assisting interviewer, W.M., instructed participants to apply today's perspective and emphasized that this may change in the future, cf. Supplementary Materials File S1, row 19, para.(s) 1–9.

3.3. Language

3.3.1. Laypeople Words for "Criteria" and "Sub-Criteria" in a German AHP Survey

For the AHP-related technical terms "criteria" (in German, "Kriterien") and "sub-criteria" (in German, "Subkriterien"), synonyms understandable by laypeople and, in particular, PlwD had to be identified. "Criteria" were hence termed "characteristics" (in German, "Merkmale"), and sub-criteria, which are usually translated as "manifestations" (in German, "Ausprägungen") were termed "form of appearance" (in German, "Erscheinungsform"), cf. Supplementary Materials File S1, row 20, para.(s) 1–4.

3.3.2. Avoid Long Sentences

In the survey's first draft, criteria questions stated: "*In your opinion: Which characteristic of personalized care for the aged living at home do you place greater value on in comparison? And how big is the difference between the two characteristics?*" To shorten questions, this was changed to: "*Which characteristic of care is more important to you and by how much*?".

During pretest 1, long interrogative clauses halted the progress of the survey, as the participant stopped to reread the questions, despite explanations from W.M. that the question and related task was the same throughout the survey, cf. Supplementary Materials File S1, row 21, para.(s) 1–2. During pretest 2, the participant emphasized difficulties with excessively long sentences, cf. Supplementary Materials File S1, row 21, para.(s) 3–8. Based on these experiences, sentences throughout the survey were shortened substantially. Criteria questions were revised to only state the complete question the first time, whereas subsequent questions stated "*Choice question nr. X*" to avoid experiences as such as those reported during pretest 1.

3.3.3. Choice of Words Matters

Throughout survey development, the choice of words was a topic of concern. Attentiveness to PlwD reactions to wording during the pretest interviews was important, cf. Supplementary Materials File S1, row 22, para.(s) 1–5. EP1 recommended avoiding the use of 'foreign' words, e.g., "transparent".

It was challenging to find titles for the criteria using words that would incorporate the definition of the criteria and, at the same time, be understandable for the PlwD. This was particularly apparent for criterion (1) *Social exchange*, which developed from *"social contact"* to *"social relationships"* to *"social exchange"*. Criterion (1) incorporates *"Provision of different* *forms of social contact to counterbalance the potentially limited contact with others. This social contact can be real or simulated."* [40,66]. When asked about social *'contact'*, participants tended to broadly relate it to any contact they may encounter, even if not necessarily helpful to counterbalance potentially limited social contact. When asked about social *'relationships'*, participants tended to relate this to intimate relationships, e.g., marriage, which was too narrow per the definition. Social *'exchange'* (in German, 'sozialer Austausch') was best understood by PlwD to capture the definition of this criterion, cf. Supplementary Materials File S1, row 22, para.(s) 6–12. Similarly, criterion (6) *Organization of health care* was challenging to find a title for that incorporated the definition. Organization of 'care' did not incorporate the definition per the participants' understanding, cf. Supplementary Materials File S1, row 22, para.(s) 15–18. Hence, the title was adjusted to organization of 'health care' (in German, 'Gesundheitswesen'). *'Cognitive training'*, titled per findings from the previous qualitative interviews, was difficult for participants to understand. *'Memory exercises'* was better understood, cf. Supplementary Materials File S1, row 22, para. 8.

3.3.4. Use of Icons as Visual Aids

We developed a set of icons as visual aids for sub-criteria for previous qualitative interviews [31]. Due to limited interview time, we were not able to test the appropriateness of these icons during the former interviews. Hence, these were pretested during the pretest interviews and partially adjusted based on patient feedback (cf. Supplementary Materials File S1, row 23, para.(s) 1–12) and EP2 feedback with respect to sub-criteria in general, cf. Section 3.1.7.

4. Discussion

Our study provides a rigorous process report about comprehension and layout to design a dementia-friendly AHP survey, including the appropriateness of previously defined (sub)criteria to elicit patient preferences for PCC among community-dwelling PlwD, which, to the best of our knowledge, is the first of its kind. Extensive technically descriptive sentences of the (sub)criteria should be avoided—the abstract (sub)criteria titles should instead be described by concrete examples the PlwD can relate to. The homogeneity of (sub)criteria *(AHP Axiom 2)*, i.e., the comparability of the included elements in the AHP hierarchy, may not always be easy to adhere to when different perspectives need to be accommodated. The appropriateness and the scale at which elements are presented should be reflected upon early by survey developers. As in any AHP study, the validity and consistency of responses may pose a challenge. Layout and presentation of the not-immediately-intuitive AHP scale for an aged and cognitively impaired patient population may be a challenge, but the needs of the population can be accommodated by creativity among survey developers. PlwD may express difficulties with respect to which perspective to apply during completion of an AHP survey; here, the assisting interviewer may help with clarification. The heterogeneity of participants should be considered by including sociodemographic questions that allow for potential subgroup analyses. Assistance is required during completion of an AHP survey with an aged and cognitively impaired patient group.

Extensive technical and abstract description sentences of the (sub)criteria, which are more dependent on cognition, were not observed as helpful for the PlwD to understand the (sub)criteria and their content. As noted in previous qualitative interviews [31], the abstract (sub)criteria became more comprehensible for the PlwD when described by concrete examples the PlwD can relate to. These observations align with previous findings reported by Murdoch et al. [67], who observed greater impairment in those components of language more highly dependent on cognition in people living with AD. Reilly, Troche and Grossman [68] noted sentence comprehension difficulties in AD patients. However, Joubert et al. [69], who studied the comprehension of concrete and abstract words in semantic-variant primary progressive aphasia (svPPA) and AD, found concrete, abstract and abstract emotional words to be processed similarly in the group of AD participants.

Patients in the svPPA group were significantly more impaired with respect to processing concrete words than abstract words. Nevertheless, we observed greater difficulties associated with survey completion among our study participants after the descriptive examples had been removed from the pairwise comparisons of the (sub)criteria in order to reduce reading time and the length of the survey. Hence, the final PlwD survey includes concrete descriptive examples for all pairwise comparisons of (sub)criteria, but no technical or abstract descriptive sentences, which are more dependent on cognition.

EP2 expressed concerns about the homogeneity of the criteria. Homogeneity is essential for meaningful comparisons, as the human mind cannot compare widely disparate elements [70]. In the case of considerable disparity between two (sub)criteria, the elements should be placed in separate clusters of comparable size or at different levels altogether [70]. Two physicians noted that pairwise comparisons in particular, including criterion (6) '*Organization of Health Care*', were perceived as incomparable with other criteria, such as (3) '*Memory Exercises*'. Another physician suggested viewing the pairwise comparisons from the point of view of the PlwD. As mentioned by I1 (W.M.) during EP2 (cf. Supplementary Materials File S1, row 5, para. 2), similar discussions had already occurred in the researcher team. A.R. and W.M. referred to *Axiom 4 (the Axiom of Expectations)*, according which all alternatives, criteria and expectations can be and should be represented in a hierarchy, i.e., that the beliefs of thoughtful individuals should be adequately represented in the decision model [70,71]. Criterion (6) '*Organization of Health Care*' was observed as the third most important criterion during previous qualitative interviews with PlwD [31]. Based on our previous observations, supported by the argument from one physician and the referral to Axiom 4, we decided to keep Criterion (6) '*Organization of Health Care*' as part of the AHP hierarchy and survey.

Experts from EP2 criticized the sub-criteria with regard to the different scales these were presented on (ordinal vs. nominal). In particular, the sub-criteria for criteria 1–3 and 6, previously presented on an ordinal scale [31], were criticized for displaying a range from "bad to good", which was perceived as "tendentious". The sub-criteria should rather be presented independently on a nominal scale. The latter presentation of sub-criteria corresponds to the suggestion by Hummel, Bridges and IJzerman [57], who presented the sub-criteria independently on a nominal scale for their AHP analysis of the benefits and risks of tissue regeneration to repair small cartilage lesions in the knee. Danner et al. [55], however, presented the sub-criteria for their AHP decision model of treatment characteristics of different treatments for age-related macular degeneration levelled on an ordinal scale. The AHP model for a pilot project to elicit patient preferences in the indication area "depression" by the *Institute for Quality and Efficiency in Germany* [72] presented sub-criteria both on an ordinal and a nominal scale. Particular criticism of the sub-criteria of criterion (6) was shared among the research team, and we decided to revisit the transcripts of previous qualitative interviews, as well as field notes and audio recordings from the pretest interviews to revise sub-criteria for criteria 1, 2, 3 and 6. The revisions were approved by two PlwD during pretests 11 and 12, and the changes were implemented in survey versions for both PlwD and physicians.

Despite the small sample size during this pretest study (n = 11 PlwD) we made an initial assessment of validity and internal consistency. As noted by Ozdemir [73], redundancy is required for validity; on the other hand, a small number of comparisons is required for consistency. For the sake of efficiency, AHP survey developers need to make a tradeoff between consistency and redundancy to obtain validity [73]. With these considerations in mind, we included a number of retest questions for validity, cf. Section 3.1.8. and Table 2. The initial inclusion of five retest questions made the survey too long. Inconsistency for pretest 1 was rather high, with an individual CR of 0.45. Therefore, based on the considerations proposed by Ozdemir [73], we decided to reduce the number of retest questions and, consequently, the length of the survey. Only two participants (pretests 2 and 4) during the subsequent pretest interviews answered completely opposite to their previous choice at the level of criteria. The remaining participants chose the correct side on the AHP rating scale, with some deviations in assigned values. However, a solid assessment of this issue would require a larger sample size, such as that in a study by Brod, Stewart, Sands and Walton [74], who developed a simple dementia QoL instrument (DQoL), which was tested on 99 participants. Nearly all participants were able to respond to questions appropriately, suggesting that people with mild-to-moderate dementia could be considered good informants of their own subjective states, paving the way for consideration of patient responses as the gold standard for assessment of QoL in PlwD [74]. Individual CRs at the level of criteria ranged from 0.08 to 0.86, with a consolidated CR of n = 11 PlwD of 0.37 (0.038) based on the arithmetic (geometric) mean for aggregation of individual priorities (judgements). With a strict consistency threshold of 0.1, as suggested by Saaty [63], we would have had to exclude n = 9 participants from the analyses. Application of the generally accepted cutoff at 0.2 [57,75–77] would still have resulted in an exclusion of n = 7 participants from our analyses. As noted by Goepel [60], the application of the ten-percent rule and even the twenty-percent rule may be too strict for certain practical applications. Particular circumstances may warrant the acceptance of a higher value—even as much as 0.3 [64]. Furthermore, the achievement of low inconsistency should not be the only goal of the decision-making process. Reasonable consistency is necessary but not sufficient for a good decision [78]. A cutoff at inconsistencies above 0.3 would have resulted in n = 5 participants excluded from our analyses, i.e., slightly less than half of the total sample. One option also was discussed by Danner et al. [55] is to ask participants with high inconsistencies to reconcile their judgements. However, and similarly to Danner et al. [55], who also surveyed an aged and sometimes cognitively impaired patient group, we observed that participants became confused when their choices were questioned by the interviewer, as they thought they did not "perform" as they should have. A practical obstacle is the use of a paper-and-pencil survey, which does not allow for immediate and accurate calculation of CRs and subsequent query of the participants to revise their judgements. Additionally, high inconsistencies may have been caused by an inappropriate use of 'extreme judgements', as also noted by Danner et al. [55]. However, this assessment requires a larger sample size than that used in the present study and should be examined in future research, as planned for the main study in the overarching *PreDemCare* study [37,38]. No standard for sample size determination exists for AHP surveys. Hence, sample size for the planned main study was likewise to IJzerman et al. [75] oriented in sample size determination for conjoint analysis. A detailed description of this method lies outside the scope of this report but can be found elsewhere [37].

One of the most considerable challenges was to find an appropriate display of the AHP rating scale that would be well understood by PlwD. The research team considered the layout suggested by Danner et al. [55]. However, we perceived the layout as too abstract for PlwD to relate to. Apart from the visual layout, the number of answer options was discussed among the research team based on feedback from EP1 and patients, as well as recommendations for the design of dementia-friendly surveys to preferably not include more than three answer options for each question [30]. Because the layout displayed in Figure 3 was well-received by the pretest participants, we decided to keep this version of the rating scale, i.e., a simpler visual layout than that proposed by Danner et al. [55], but to keep the main answer options (1, 3, 5, 7 and 9) of the original AHP rating scale [56].

When PlwD struggled with which perspective to apply during completion of the AHP survey, the assisting interviewer, W.M., instructed the to apply "today's perspective" and emphasized that preferences may change in the future. Some authors argue that patient preferences need to remain stable over time to be reliable [79]. However, as noted by van Haitsma et al. [80], preferences are based on the processing of needs, values and goals and therefore may shift as the social environment or contextual circumstances change. Particularly during the ongoing COVID-19 pandemic, many contextual circumstances for this patient group, such as access to social activities, may change. Hence, we conducted pretest-interviews under recognition of van Haitsma et al. [80].

Limitations

Our study has several limitations. The overall sample sizes (n = 11 PlwD, n = 4 DCMs, n = 4 physicians) of this current *formative* qualitative study were small compared to usual sample sizes in *general* qualitative research. However, as previously mentioned (cf. Section 2.5), we followed the guidelines presented by Hollin et al. [28], who emphasized that sampling should not focus on the number of units, but actionable input for the development process, i.e., a diversity of perspectives. Hence, sampling adequacy in formative qualitative research, such as the current study, may include smaller samples than general qualitative work, which, based on the limited study purpose, can be viewed as adequate [28]. Aside from Hollin et al. [28], we oriented ourselves in the existing literature on quantitative patient preference research for expected saturation point, including previous research by the second author, A.R., who reported similar sample sizes in the *formative* pre-study phase(s) [45–50]. The complete *formative* pre-study phase in the overarching *PreDemCare*-study [37,38] included two subphases: qualitative interviews for (sub)criteria identification including n = 10 PlwD and n = 2 DCMs, i.e., a total of n = 12 participants (Stage 1) [31], and the current study for pretest and design of the AHP survey(s) including n = 4 DCMs, n = 11 PlwD and n = 4 physicians, i.e., a total of n = 19 participants. The complete formative prestudy phase therefore included n = 31 participants, which is similar to sample sizes reported in general qualitative research [33]. By including different stakeholders, we ensured a diversity of perspectives for provision of actionable input, as emphasized by Hollin et al. [28]. A question remains at to whether the choice of qualitative research methods in the development of a quantitative preference instrument suffice to provide actionable input. However, Hollin et al. underlined that the use of formative qualitative research in the developmental phase is essential to ensure both face and content validity [28]. Furthermore, as recommended by the Alzheimer's Society UK [30], it is important to pilot and consult with PlwD themselves in survey instrument development. Based on our experience on site with this patient group, we deemed it necessary to conduct interviews with the "thinking-aloud technique" [32] to capture PlwDs' thoughts as meticulously as possible and ensure comprehensibility of the final quantitative preference instrument. By including patients, as well as clinical experts, in different stages of the overall pre-study phase, we aimed to increase the face and content validity of the final instrument [28].

An often-mentioned limitation of patient preference studies is heterogeneity in the surveyed populations. Depending on certain characteristics, patients may respond differently to specific interventions and differ in terms of how they value particular attributes of interventions [81]. This may be particularly true for an aged and often multimorbid patient group, such as PlwD [82]. To account for potential heterogeneities in preferences in both populations, we included extensive self-developed sociodemographic questionnaires for subsequent subgroup analyses. In contrast to other methods, which only allow for analysis of aggregated data, the AHP allows for evaluation of preferences on an individual basis [24]. This information can then be used to assess heterogeneity. The advantage of the AHP method is that both group decisions and individual decisions are possible.

As in previous patient preference studies [55], we conducted a pretest survey with interviewer assistance. The survey had to be interviewer-assisted, as most participants had visual impairments and needed assistance with reading. Danner et al. [55] conducted 10 surveys with two interviewers. Attendance of one or two interviewers was discussed extensively among the research team and during EP1. Previous qualitative interviews [31] showed that attendance of two interviewers made the PlwD more nervous, which was also confirmed by the DCMs during EP1. Hence, we decided to have only one interviewer (W.M.) assist during the pretest surveys. W.M. strictly adhered to the standardized interviewing procedure presented by Danner et al. [55] and, prior to pretests, was trained with members of the researcher team and study nurses on site with extensive experience in interviews with PlwD. These considerations should be reflected upon prior to future patient preference research with an aged and cognitively impaired patient group.

With regard to the requirements of credibility and dependability as criteria of trustworthiness, we remained compliant with our research focus and collected a manageable amount of data in a short period of time, which enhanced our study's trustworthiness [83]. However, the transferability of findings is limited due to the rather small sample sizes of included subjects, the specificities of our setting and respective cultural differences. Still, due to the rigor in the methodological process and report, we consider our findings trustworthy.

5. Conclusions

Our study provides initial data from a pretest study of a dementia-friendly AHP survey. Extensive technically descriptive sentences of the (sub)criteria should be avoided. Validity and consistency of responses may pose a challenge that requires consideration about an appropriate CR threshold. Layout and presentation of the AHP scale not immediately intuitive for an aged and cognitively impaired patient population may be a challenge but can be addressed by creativity among survey developers. The heterogeneity of an often multimorbid, aged and cognitively impaired patient group should be considered by inclusion of sociodemographic questionnaires for potential subsequent subgroup analyses. Assistance during completion of an AHP survey with an aged and cognitively impaired patient group is required. Consideration of our findings may contribute to content and face validity, as well as internal consistency, which still needs to be tested with a larger sample size. Our detailed process report may increase reproducibility in future preference research on dementia with application of quantitative preference instruments.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/ijerph19148554/s1, File S1: Main categories with sub-categories and respective key quotations from expert panels and individual pretest interviews; File S2: Partial Transcript Pretest—Interview 8.

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Informed Consent Statement: Informed consent was obtained from all participants in this study. Written informed consent was obtained from the patient(s) to publish this paper.

Data Availability Statement: Data and methods used are presented in sufficient detail in the paper so that other researchers can replicate the work. Raw data will not be made publicly available to protect participant confidentiality.

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Appendix 4: Article Nr. 4: “Do They Align? Congruence Between Patient Preferences of People Living with Cognitive Impairments and Physicians' Judgements for Person-Centered Care: An Analytic Hierarchy Process Study.”

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Do They Align? Congruence Between Patient Preferences of People Living with Cognitive Impairments and Physicians' Judgements for Person-Centered Care: An Analytic Hierarchy Process Study

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Abstract.

Background: Person-centered care (PCC) requires knowledge about patient preferences. Among people living with cognitive impairments (PlwCI), evidence on quantitative, choice-based preferences, which allow to quantify, weigh, and rank care elements, is limited. Furthermore, data on the congruence of patient preferences with physicians' judgements for PCC are missing. Such information is expected to support the implementation of PCC; state-of-the-art medical care aligned with patients' preferences.

Objective: To elicit patient preferences and physicians' judgements for PCC and their congruence.

Methods: Data from the mixed-methods PreDemCare study, including a cross-sectional, paper-and-pencil, interviewer-assisted analytic hierarchy process (AHP) survey conducted with $n = 50$ community-dwelling PlwCI and $n = 25$ physicians. Individual AHP weights (preferences/judgements) were calculated with the principal eigenvector method and aggregated per group by aggregation of individual priorities mode. Individual consistency ratios (CRs) were calculated and aggregated per group. Group differences in preferences/judgements were investigated descriptively by means and standard deviations (SDs) of AHP weights, resulting ranks, and boxplots. Additionally, differences between groups were investigated with independent paired t-test/Mann Whitney U-test. Sensitivity of AHP results was tested by inclusion/exclusion of inconsistent respondents, with an accepted threshold at $\mathrm{CR} \leq 0.3$ for patients, and $\mathrm{CR} \leq 0.2$ for physicians, due to better cognitive fitness of the latter group.

Results: Patient preferences and physicians' judgements did not differ significantly, except for the criterion *Memory Exercises* (AHP weights (mean (SD)): 0.135 (0.066) versus 0.099 (0.068), $p = 0.01$). We did not see rank-reversals of criteria after exclusion of inconsistent participants. Mean CR for patients at the criteria level was 0.261, and 0.181 for physicians.

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Conclusion: Physicians' judgements in our setting aligned well with patients' preferences. Our findings may be used to guide the implementation of preference-based PCC.

Keywords: Dementia care, mild cognitive impairment, participatory research, patient-centered care, patient empowerment, patient engagement, patient preference, physician-patient relations, shared decision-making

INTRODUCTION

Populations around the globe face demographic aging [1]. An increase in age-associated diseases, e.g., dementia diseases, is a challenge for health care systems worldwide [2]. Recent evidence from the Global Burden of Disease Study estimates the number of people living with a dementia disease to increase from 57.4 (95% uncertainty interval (UI) 50.4–65.1) million cases globally in 2019 to 152.8 (UI 130.8–175.9) million cases by 2050 [3]. In the development of dementia diseases, subjective and objective evidence of cognitive decline, e.g., mild cognitive impairment (MCI), have been found as transitional states, suggesting an increased risk for the development of a dementia disease [4, 5]. Currently, no curative disease-modifying treatment for people living with cognitive impairments (PlwCI) exists. PlwCI need a timely differential diagnosis [2, 6] and care, which ensures a high quality of life (QoL) [7].

According to the Alzheimer's Association Dementia Care Practice Recommendations, a person-centered focus is the core of individualized and high-quality care across all care settings and throughout the disease course [7]. Over the years, person-centered care (PCC) has been included in many countries' national guidelines and dementia plans [8–14], aimed at an improvement of QoL. PCC practices usually follow a non-pharmacological, sociopsychological treatment approach and are often delivered as multi-modal interventions [15], which have shown some success in delay of cognitive decline [3]. The PCC concept requires person customization of care [16], which in turn requires knowledge about the care recipient's needs and preferences [17–20]. Among PlwCI and dementia, some evidence about preferences exists. However, evidence about preferences elicited through quantitative, in particular choice-based preference methods is limited [21, 22]. This includes a consideration of what can be defined as a "preference". "Preference" or "prefer" stems from Latin "*praeferre*", which means "place or set before" [23]. A preference can hence be defined as "*1b: the power or opportunity of choosing*" or "*3: the act, fact or principle of giving advantages to some over others*" [24], which may imply the necessity to make a choice to express a preference. Harrison Dening et al. [25] elicited preferences from dyads (people living with dementia and their family carers) during qualitative interviews. Van Haitsma et al. developed an extensive Preferences for Everyday Living Inventory (PELI) for elicitation of preferences in community-dwelling aged adults by inter alia (i.a.) Likert-type scales and open-ended questions [20]. These methods fall short to quantify, weigh, and rank patient-relevant elements of care, to measure their relative importance and identify most/least preferred choices, id est (i.e.) per definition "preferences". Such information can be assessed with quantitative, choice-based preference measurement techniques from multi-criteria decision analysis (MCDA) [26]. MCDA techniques commonly used in health care research include i.a. discrete choice experiments (DCEs) [27], Best Worse Scaling (BWS) [28], and the Analytic Hierarchy Process (AHP) [29, 30]. For elicitation of quantitative, choice-based preferences among PlwCI, the AHP has been suggested suitable, due to the simple pairwise comparisons with only two individual aspects of a complex decision problem [31]. With the AHP, which supports systematic decision-making that takes multiple criteria into account, it may be possible to involve PlwCI in future care decisions (patient participation and shared decision-making) and ensure implementation of truly PCC for PlwCI.

To the best of our knowledge, the alignment of patient preferences with physicians' judgments for PCC of PlwCI has not been investigated. Earlier studies of patient preferences versus physicians' judgements in other indication areas found that experts' judgements do not correlate well with subjective preferences of patients [32]. Knowledge about physicians' judgments and their alignment with PlwCIs' preferences is important, as physicians make decisions for their patients, are responsible for the diagnosis and monitoring of cognitive decline in their patients, and the provision of PCC, i.e., state of the art medical care aligned with patient's preferences.

Hence, the aim of this study was to elicit patient preferences and physicians' judgements for PCC of PlwCI, including an assessment of congruence of patient preferences and physicians' judgements.

MATERIALS AND METHODS

Study design, sample size, study population, and setting

This report is based on data from the main study in the sequential mixed methods PreDemCare study [33], which followed the core components in the design of a patient preference study using methods of MCDA [34, 35]. The study team developed, pretested, and conducted a cross-sectional, (assisted) paper-and-pencil AHP survey. Detailed information about the complete course of the PreDemCare study can be found in the study protocol (see Mohr & Rädke et al. [33]).

Due to lack of an appropriate sample size calculation method for an AHP survey, we followed Ijzerman et al. [36], and applied the equation for sample size determination used in conjoint analysis ($(NxTxA)/C \geq 500$, where N = number of respondents, T = number of choice sets per respondent, A = number of scenarios per choice set, and C = maximum number of levels) [37, 38]. Thus, we needed to include a minimum of $n = 24$ participants per group. As we planned to conduct subgroup analyses including respective statistical analyses, we recruited $n = 75$ participants ($n = 50$ PlwCI and $n = 25$ physicians) [33]. Community-dwelling PlwCI for the patient survey were selected from clinical trials (ClinicalTrials.gov identifiers: NCT04741932, NCT01401582, NCT03359408, German Clinical Trials Register Reference No.: DRKS00025074) and the memory clinic at site of the DZNE Rostock/Greifswald, Mecklenburg Western-Pomerania, Germany. Eligibility criteria were: ≥ 60 years, indication of MCI or early- to moderate-stage dementia by diagnosis or cognitive test-result (e.g., DemTect < 13 [39], Mini-Mental State Examination (MMSE) < 27 [40, 41]), capable to understand written and oral German, written consent provided by patient/legal guardian [33]. Study nurses identified eligible patients and functioned as gatekeepers to access the PlwCI for the AHP survey, as they are known and perceived as trustworthy by participants. The gatekeepers emphasized the independence of this study from the clinical trials. Informal caregivers (CGs) were invited to join as silent supporters. Additionally, the study nurses identified eligible physicians from their networks (with experience (past/current) in the treatment of dementia patients, from any setting in the federal state Mecklenburg-Western Pomerania, any age group, any specialty), who subsequently were invited via phone, e-mail, or ground mail to participate in the (non-assisted) AHP survey. The PreDemCare study [33] was evaluated and approved by the Ethics Committee at the University Medicine Greifswald (Ref.-No.: BB018-21).

Data collection

Decision goal, (sub)criteria the AHP decision hierarchy, and survey

In line with recommendations [34, 35], the identification of the decision goal and sub(criteria) was initiated based on results from a previous literature study about key intervention categories to provide PCC in dementia [15]. Literature-derived conceptual (sub)criteria were reviewed by a small expert panel with $n = 2$ Dementia Care Managers (DCMs), i.e., dementia-specific qualified nurses [42–44] from site. Subsequently, individual interviews including a card game with $n = 10$ PlwCI and $n = 3$ informal/family CGs were conducted to identify patient-relevant (sub)criteria of PCC for inclusion in the AHP decision hierarchy. Detailed information about the qualitative interviews is reported in Mohr et al. [45]. The identified (sub)criteria were structured into an AHP decision hierarchy with 6×2 (sub)criteria to not cognitively overburden the decision-makers [46, 47]. A preliminary AHP survey for both patients and physicians was developed. Both survey versions were reviewed and pretested extensively during two clinical expert panels with $n = 4$ DCMs and $n = 4$ physicians to ensure content validity, and during individual pretests with $n = 11$ PlwCI as experts by experience and $n = 3$ family CGs to ensure face validity [48]. Subsequently, we finalized the AHP decision hierarchy and survey versions.

All $n = 75$ participants in this report completed the surveys individually. Among physicians, the paper-pencil questionnaire was distributed via e-mail or ground mail. Among patients, data were collected as interviewer-assisted paper-pencil questionnaires in their homes or daycare centers from October 2021 to January 2022. To ensure a comfortable and non-stressful survey situation, PlwCI could invite their informal CGs to support them during the survey. It was emphasized that informal CGs should not act as proxies and answer questions on behalf of the PlwCI.

The AHP survey had to be interviewer-assisted, as many patients had visual impairments and needed help with reading. The interviewer conducted all surveys under strict adherence to a standardized interviewing procedure by Danner et al. [31]. The choice to have only one interviewer assist was based on observations from the previous interviews [45, 48], where attendance of two interviewers had resulted in nervousness among some PlwCI. All participants were informed about the purpose and content of the study, i.e., to elicit their care preferences and later on compare these to the physicians' judgements. Participation required prior provided informed written consent, which the PlwCI or a legal guardian could provide.

The questionnaire for both groups was structured as follows: 1) a description of the study and an introduction to the criteria in lay language, including an example question with a pairwise comparison example to choose a side dish oriented in Danner et al. [31], 2) first part of the AHP survey (15 criteria pairwise comparisons), 3) introduction to sub-criteria, 4) second part of the AHP survey (6 sub-criteria pairwise comparisons), 5) a short self-developed sociodemographic questionnaire (different for both groups, see the Supplementary Material) including an evaluative question about survey difficulty. For a detailed description of included elements in the AHP survey, we refer to Mohr et al. [15, 45, 48]. We used the AHP judgement scale with verbal explanations of numeric values [49], including an adjustment of graphic design to meet the specific needs of this participant group [48]. Oriented in the standardized interview procedure [31], the assisting interviewer repeated after each pairwise comparison what the PlwCI said with her/his/their judgement, e.g.: *"With your judgement you are saying that [X] is very much more important to you than [Y]; is this what you wanted to express?"*, to make sure the tradeoffs presented were understood. Since the survey was administered as paper-pencil questionnaire for both groups, individual consistency could not be assessed immediately and participants could respectively not be asked to revise their judgements.

Sociodemographic and clinical factors

Participant characteristics in both groups, including age, gender, etc., were collected as categorical data to ensure anonymity. Subject to explicit informed written consent, PlwCI were asked whether data about 1) a diagnosis of MCI and/or dementia and 2) the most recent cognitive test result from the MMSE [41], could be obtained from the informal CGs, or from the study nurses at site. Furthermore, PlwCI were asked whether they could share a current medication plan. If not at hand, PlwCI were asked whether this information similarly could be obtained from the informal CGs or the study nurses at site. As part of the sociodemographic questionnaire and likewise subject to initial explicit informed written consent, PlwCI were asked to participate in a short cognitive test (DemTect [39]) to obtain a current cognitive test result.

Data analyses

Mathematical analyses: AHP

Importance weights for the (sub)criteria were calculated for each individual participant with the principal right eigenvector method [49–51]. The vector of weights (w) of the included (sub)criteria is represented by the principal right eigenvector [30, 31]. Multiplied by a matrix A, in case of a non-negative reciprocal matrix A, the principal right eigenvector is equal to the maximal eigenvalue, λ_{max}, multiplied by w ($\mathbf{A^*\ w = \lambda_{max}{}^*w}$) of the matrix [31]. The principal right eigenvector can thus be calculated by matrix multiplication [31, 52]. To aggregate weights in both groups, individual weights were averaged arithmetically, i.e., by the aggregation of individual priorities (AIP) method. A detailed overview of both individual weights and aggregation calculations can be found in Danner et al. [31]. Local weights for (sub)criteria for each cluster summarize to one. Global weights for sub-criteria were calculated for each individual participant by multiplication of the local sub-criteria weights with the local weight of the respective criterion. Global sub-criteria weights were likewise aggregated by AIP method. At the criteria level, the consistency ratio (CR), as a measure of logical judgement performance in an AHP survey, was calculated [47]. The literature usually recommends a consistency threshold of 0.1–0.2 [53, 54]. However, particular circumstances, such as cognitive capacities of surveyed participants, can warrant the acceptance of a higher value at 0.3 [55, 56]. To achieve low inconsistency should not be the mere goal of the decision-making process; reasonable consistency is necessary, but does not suffice for calling a decision "a good decision" [57]. Reasons for observed inconsistency have been described in detail elsewhere [31, 57]. We used Expert Choice Comparion® [58] and the package 'ahpsurvey' [59] in RStudio to calculate weights and CRs. Likewise to Danner et al. [31], the sensitivity of AHP results was tested by inclusion and exclusion of inconsistent respondents in the analyses, as further sensitivity analyses were limited by lack of alternatives in the AHP hierarchy [29].

Statistical analyses: Participant characteristics, AHP rankings

Sociodemographic/clinical participant characteristics, including participants' ratings of questionnaire difficulty, were analyzed by frequency counts (%) and means (standard deviations (SDs)). Due to the comparatively small sample sizes in both groups (patients/physicians), it was decided to recode/dichotomize the variables for patients' age group (60–80 / 81 to > 90), living situation (own home / assisted living), family status (not alone / alone), education (10 years and below />10 years), self-rated health status (good / moderate / bad), and physicians' age group (30–50 / 51 to > 70) as well as specialization (general practitioner (GP) / other specialists) for a more comprehensible reporting of participant characteristics. The original age groups as well as PlwCIs' self-rated health status groups can be found in the Supplementary Material. AA, who has a pharmaceutical background, analyzed the medication plans oriented in Richling [60] in Microsoft®Excel. Based on the analyses, AA developed a continuous variable on sum of medications, which subsequently was used for report of patient characteristics (Supplementary Material). AA's analyses were reviewed by NW, who is a medical doctor.

Group differences in rankings of (sub)criteria were initially investigated by descriptive statistics. This comprised calculation of means (by AIP method) and SDs of individual AHP weights per group, as well as the subsequent assignment of (sub)criteria rank from highest to lowest mean. If AHP elements ranks between groups reversed with two or more ranks, these were considered meaningful. As an additional graphical analysis, boxplots layered with means and SDs were developed. To further analyze differences in mean AHP weights for the six criteria (dependent variables) between groups, i.e., status (patient/ physician) and consistent/inconsistent participants (independent variables), we conducted univariable analyses with independent paired *t*-tests and Mann Whitney U-tests in case of violations of assumptions. All statistical analyses were conducted with R/RStudio.

Table 1A
Patients' ($n = 50$) characteristics *

Characteristic	*n* (%)
Age groups (recoded)	
60–80	22 (44.0)
81 to > 90	28 (56.0)
Gender	
Female	28 (56.0)
Male	22 (44.0)
Living situation (recoded)	
Own home	37 (74.0)
Assisted living	12 (24.0)
Missing (Do not know)	1 (2.0)
DemTect	8.02 (3.49) [a]
MMSE	23.5 (4.2) [a]
Diagnosis of MCI or dementia [b]	40 (80.0)
Self-rated general health (recoded)	
Good	18 (36.0)
Moderate	25 (50.0)
Bad	7 (14.0)
Self-rated assessment of survey difficulty	
Easy	8 (16.0)
Rather easy	16 (32.0)
Neutral	17 (34.0)
Rather difficult	9 (18.0)
Difficult	N/A

*Complete characteristics of patients can be reviewed in Supplementary Table 1A. Original age groups: 60–70, 71–80, 81–90, >90; original living situation groups: own home, assisted living, community housing (e.g., with children), original self-rated general health groups: very good, good, satisfactory, less good, bad. [a]Mean (SD); [b]ICD-10: F00.1, F00.2, F00.9, F01.3, F01.9, F02.3, F03, F06.7, G30, U51.02, U51.11, U51.12.

RESULTS

Participant characteristics

Short versions of participant characteristics are depicted in Tables 1A and B. A comprehensive version can be viewed in the Supplementary Material.

56% of patients were 81 to > 90 years of age and indicated female gender. 80% had a diagnosis of MCI or dementia (Table 1A). No patient was per diagnosis and/or indicated by cognitive test results at an advanced stage of dementia (Table 1A and Supplementary Material). The majority (86%) rated their general health status as good or moderate. Among physicians, 52% were aged 30–50 years. The majority indicated female gender (72%) and worked as general practitioners (64%).

(Sub)criteria importance weights, rankings per group, and congruence between groups

Aggregated local AHP importance weights for each (sub)criterion per group for all patients

Table 1B
Physicians' ($n = 25$) characteristics *

Characteristic	n (%)
Age groups (recoded)	
30–50	13 (52.0)
51 to > 70	12 (48.0)
Gender	
Female	18 (72.0)
Male	7 (28.0)
Field of specialty (recoded)	
Family medicine/ general practitioner	16 (64.0)
Other specialist	9 (36.0)
Self-rated assessment of survey difficulty [a]	
Easy	6 (24.0)
Rather easy	4 (16.0)
Neutral	8 (32.0)
Rather difficult	3 (12.0)
Difficult	4 (16.0)
Missing	1 (4.0)

*Complete characteristics of physicians can be reviewed in Supplementary Table 1B. Original age groups: 30–40, 41–50, 51–60, 61–70, >70; original other specialist groups: psychiatry, neurology, and internal medicine. [a]One participant chose both, hence percentage out of all 25 for both groups separately calculated.

($n = 50$), consistent patients (CR $n = 36$), all physicians ($n = 25$), and consistent physicians ($n = 21$) are depicted in Table 2.

Both patients and physicians rated Assistance with Everyday Activities highest (mean AHP weights: 0.206 (SD: 0.102) versus 0.217 (SD: 0.087), $p = 0.65$). While patients viewed *Social Exchange* as the second most important criterion (mean: 0.201 (SD: 0.008), $p = 0.43$), physicians judged *Organization of Health Care* to be the second most important (mean: 0.192 (SD: 0.113), $p = 0.43$), and *Social Exchange* third most important (mean: 0.183 (SD: 0.091), $p = 0.43$). *Characteristics of Professional CGs* took the fourth place in both groups (mean: 0.163 (SD: 0.079) versus mean: 0.175 (SD: 0.072), $p = 0.53$). *Memory Exercises* was the only criterion, where we found a significant difference in AHP weights between groups (mean: 0.135 (SD: 0.066), fifth place for patients versus mean: 0.099 (SD: 0.068), sixth place for physicians, $p = 0.01$). A graphical display of patients' preferences versus physicians' judgements for criteria is depicted in Fig. 1.

Figure 2 shows aggregated global weights per group for sub-criteria, sorted from highest to lowest mean-value per cluster. Social Exchange with *Family and/or friends* was prioritized highest among both patients and physicians, whilst Social Exchange with *New Contacts* and Memory Exercises by *Learning something new* was prioritized lowest in both groups. Global weights differed in particular for *Empathy* versus *Education and work experience* as Characteristics of Professional CGs and *Communication versus Integrated care structures* for Organization of Health Care. Physicians gave greater importance to *Empathy* and *Communication* than the patients (Fig. 2).

Inconsistency in judgements and sensitivity of results

Mean CR for patients at the criteria level was 0.261 for patients, and 0.181 for physicians, with model inconsistency for both groups just below the defined threshold (patients CR ≤ 0.3, physicians CR ≤ 0.2). At the level of sub-criteria, the CR was 0, as this results when only two elements are compared. Among patients, 14 (28%) provided judgments with a CR of > 0.3, among physicians, 4 (16%) provided judgements with a CR of > 0.2.

For both patients and physicians, we could not see rank reversals of criteria when inconsistent respondents were excluded (Table 2). We found a significant difference between consistent versus inconsistent patients for the AHP weights of *Memory Exercises* (mean: 0.147 (SD: 0.058) versus mean: 0.105 (SD: 0.077), $p = 0.02$), but not for any other criterion. No significant differences in AHP weights of criteria between consistent versus inconsistent physicians could be identified.

Rating of questionnaire difficulty

Among patients, the majority of respondents (66%) rated the survey as rather easy or neutral. No patient rated the survey as difficult. 12/25 physicians rated the survey as easy/neutral, and 4/25 as rather easy/difficult respectively.

DISCUSSION

The aim of this study was to elicit patient preferences and physicians' judgements for PCC of PlwCI, including an assessment of congruence. For both groups "*Assistance with everyday activities*" was the most important criterion. "*Physical activities*" and "*Memory exercises*" were least important in both groups. Overall, patient preferences and physicians' judgements in terms of AHP elements' ranking aligned well. We did not see rank reversals of criteria after exclusion of inconsistent respondents in either group. Significant differences in weights per group were found for *Memory Exercises*, both between patients versus physicians and consistent

Table 2
AHP importance weights for (sub)criteria by patients and physicians

Criteria and sub-criteria (rank-order)	Patients ($n = 50$), local weights, mean (SD)	Consistent patients ($n = 36$) [c] local weights, mean (SD)	Criteria and sub-criteria (rank-order)	Physicians ($n = 25$), local weights, mean (SD)	Consistent physicians ($n = 21$)[d] local weights, mean (SD)
Assistance with everyday activities	0.206 (0.102)	0.210 (0.112)	Assistance with everyday activities	0.217 (0.087)	0.212 (0.089)
– Informal/ family CG	0.572 (0.263)	– N/A	– Informal/ family CG	0.620 (0.218)	N/A
– Professional CG	0.428 (0.263)	– N/A	– Professional CG	0.380 (0.218)	N/A
Social exchange	0.201 (0.008)	0.199 (0.095)	Organization of health care	0.192 (0.113)	0.199 (0.107)
– Family and/or friends	0.700 (0.184)	– N/A	– Communication	0.658 (0.237)	N/A
– New contacts	0.300 (0.184)	– N/A	– Integrated care structures	0.342 (0.237)	N/A
Organization of health care	0.173 (0.082)	0.159 (0.080)	Social exchange	0.183 (0.091)	0.179 (0.095)
– Communication	0.532 (0.235)	– N/A	– Family and/or friends	0.735 (0.196)	N/A
– Integrated care structures	0.468 (0.235)	– N/A	– New contacts	0.265 (0.196)	N/A
Characteristics of professional CGs	0.163 (0.079)	0.152 (0.076)	Characteristics of professional CGs	0.175 (0.072)	0.174 (0.075)
– Empathy	0.513 (0.193)	– N/A	– Empathy	0.726 (0.161)	N/A
– Education and work experience	0.487 (0.193)	– N/A	– Education and work experience	0.274 (0.161)	N/A
Memory exercises	**0.135 (0.066)**[a]	**0.147 (0.058)**[b]	Physical activities	0.134 (0.061)	0.134 (0.052)
– Leisure activities	0.653 (0.207)	– N/A	– How? (Format)	0.584 (0.245)	N/A
– Learning something new	0.347 (0.207)	– N/A	– Where? (Location)	0.416 (0.245)	N/A
Physical activities	0.121 (0.079)	0.133 (0.079)	Memory exercises	**0.099 (0.068)**[a]	0.102 (0.072)
– Where? (Location)	0.502 (0.253)	– N/A	– Leisure activities	0.697 (0.225)	N/A
– How? (Format)	0.498 (0.253)	– N/A	– Learning something new	0.303 (0.225)	N/A

As surveys were conducted individually and not as group decision, individual weights were calculated by the principal eigenvalue method [51] and aggregated by arithmetic mean similar to Danner et al. [31]. Sub-criteria weights were not calculated for consistent patients and physicians, as consistency ratio was calculated at level of criteria. For sub-criteria the CR = 0, as only two elements were compared. [a]Numbers in bold indicate significant differences ($p < 0.05$) between two independent groups (patients versus physicians) as calculated with Mann Whitney U test due to violation of assumptions. [b]Numbers in bold indicate significant differences ($p < 0.05$) between two independent groups (consistent versus inconsistent patients based on CR-threshold of CR ≤ 0.3) as calculated with Mann Whitney U test due to violation of assumptions. [c]Consistency ration of ≤ 0.3 [55, 56]. [d]Consistency ratio of CR ≤ 0.2 [53, 54].

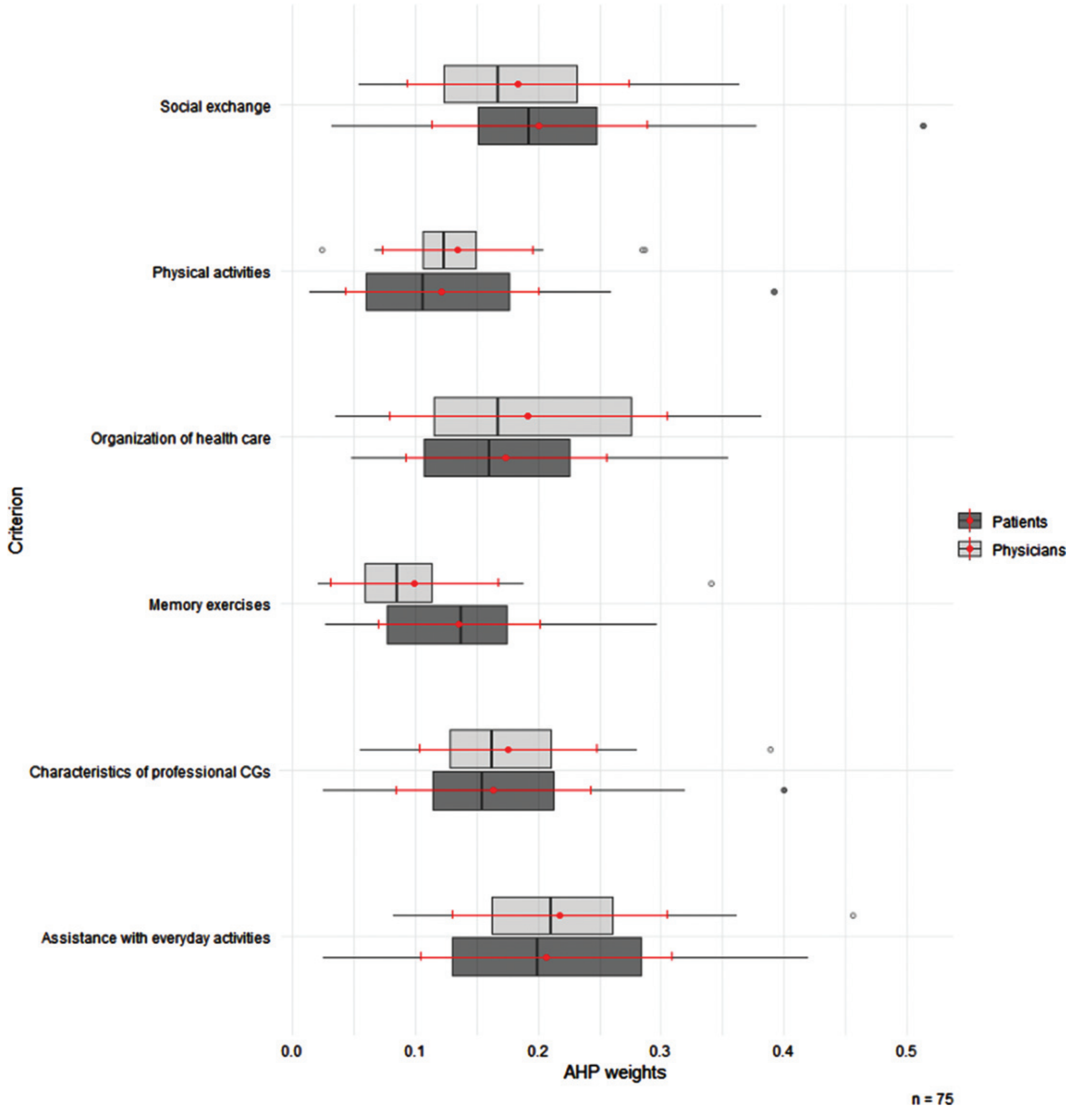

Fig. 1. Box plots of AHP weights by patients and physicians for the criteria of PCC for PlwCI. The circles are outliers. The ends of each box represent the 25th and 75th percentiles, and the ends of each line show the 95% confidence interval. Lines within boxes represent medians (i.e., 50th percentiles). The red point shows the mean, the red lines the standard deviation (Table 2). AHP, Analytic Hierarchy Process; PlwCI, People living with Cognitive Impairments. Tests for differences between groups (patients/ physicians) in AHP-weights for *Memory Exercises* with Mann Whitney U test showed a slightly significant difference (p-value = 0.01). For remaining criteria, no significant differences in AHP-weights between groups was found.

versus inconsistent patients. Model inconsistency in both groups was below the defined threshold, which may contribute to confidence in our results. The majority of patients rated the survey as rather easy or neutral.

Some (sub)criteria in our study are similar to important elements of care in other studies. Chester et al. [61] likewise identified "*social and recreational activities*" as an attribute of importance. However, the authors used a DCE with dyads. The use of a DCE for our study had been discussed among the authors, but the method was deemed too cognitively demanding for PlwCI. Carpenter et al. [62] conducted a concept mapping to identify domains for psychosocial preference measurements. The authors did not focus on PlwCI, but generally included aged adults. Still, the identified domains are similar to our (sub)criteria: social contact, growth activities, leisure activities, self-dominion, support aids, CGs, and care. Another instrument for preference elicita-

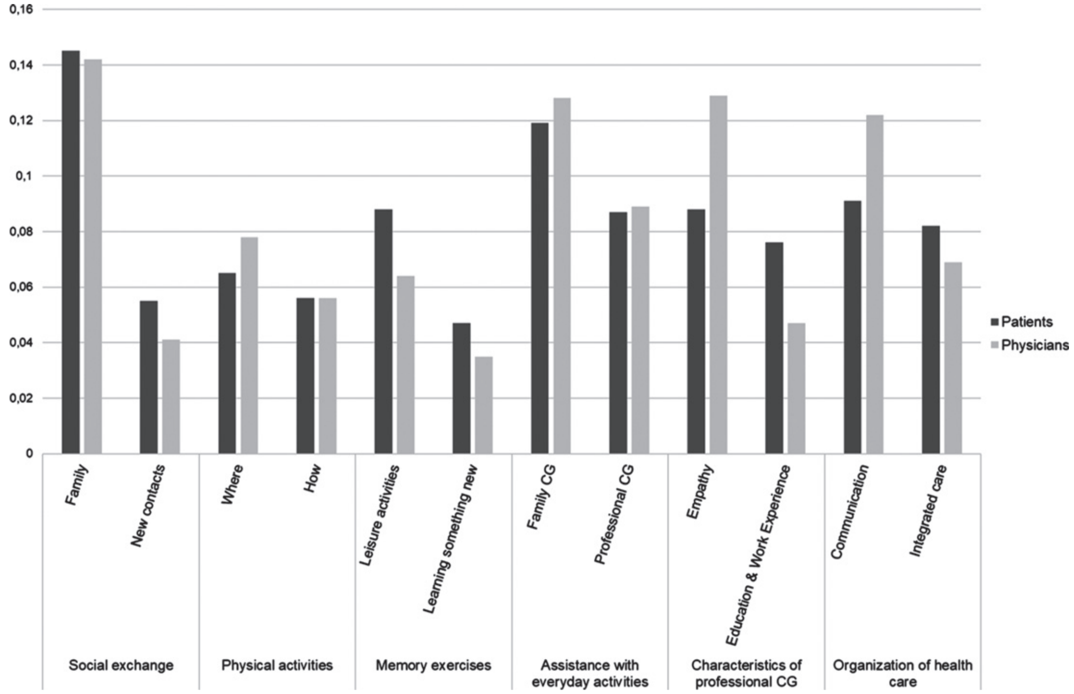

Fig. 2. Global weights (aggregated, mean), for sub-criteria among patients ($n = 50$) and physicians ($n = 25$). Global weights are the local weights of sub-criteria multiplied by the local weights of the respective parent criterion per person. CG, Caregiver.

tion among aged adults is the PELI by van Haitsma et al. [20], which similar to our instrument focuses on preferences for psychosocial activities. However, preferences in the PELI are reported to be assessed by Likert-type scales and open-ended questions. Hence, PELI differs from a choice-based preference elicitation instrument such as ours, as it not explicitly may require a choice, i.e., to express a "preference" per definition [23, 24]. The scale used in our instrument explicitly demands a choice, by asking which of two elements is more important and by how much [49, 63]. Another recent study [64] reports the understanding of patient preferences among individuals with Lewy bodies dementia, however focused on clinical care elements. The study was conducted as interview study without a choice-based preference elicitation instrument and included dyads. The authors identified "communication" and "finding local resources" as elements of importance, probably related to our criteria *1) Social Exchange* and *6) Organization of health care*. To summarize, despite the methodological and sample differences of earlier research, similar care elements of importance as in our study were identified, which contributes to confidence in our results. The application of a choice-based preference elicitation instrument assures that we elicited actual preferences per definition [23, 24].

Our study investigates the congruence between patient preferences and physicians' judgements for PCC of PlwCI. Mühlbacher & Juhnke [32] reviewed studies that examined this relationship across different indications and methodologies, and found that patient preferences and physicians' judgements often differed. In our study, patient's and physician's rank order of criteria did not show any meaningful differences. We saw some differences in global AHP weights for sub-criteria, where, interestingly, physicians gave greater importance to *Empathy* as *Characteristic of Professional CGs* and *Communication* in *Organization of Health Care* than the patients (Fig. 2). At the level of criteria, significant differences in AHP weights could be identified for *Memory Exercises*. Two rank reversals of criteria could be identified between groups. However, in both cases the criteria switched only one place in the ranking and did not jump considerably. Casparie & van der Waal [65] reported considerable jumps of elements important in the care of people living with diabetes, however, still rated patients' and diabetologists' preferences to show a rather high degree of agreement. In this regard, the authors emphasized that both patients and diabetologists' ranked the same criterion highest, a phenomenon we also saw in our study for the criterion *Assistance with everyday activities*. Pfisterer et al. [66], on the other hand, found the level of agreement between patients and potential proxies (other than spouses) to be at best slight to fair. However, the authors looked at treatment options for urinary incontinence, which is difficult to compare to criteria of PCC for PlwCI as in our study. Overall, our study did not identify meaningful or significant differences in patient preferences and physicians' judgements, which is a promising result for the implementation of PCC in our setting. Physicians in our study setting may know well what matters in PCC of PlwCI, which could enhance shared decision-making and hence improve the quality of care for PlwCI. Future research may consider to use a different method to elicit preferences versus judgements for PCC of PlwCI, e.g., BWS or group decision-based AHP, to check the reliability of the obtained results. However, as concluded by Mühlbacher & Juhnke [32], one method or technique will not always result in a disagreement while another method will.

With regard to the physicians' judgements, an expert opinion, one might, however, have expected a different ranking of criteria. A recent systematic review by Bahar-Fuchs et al. [67] found cognitive training for people with mild to moderate dementia probably be associated with small to moderate positive effects on global cognition. Another systematic review by Blondell et al. [68] found an association between higher levels of physical activity and a reduced risk of cognitive decline and dementia. Based on the findings from these reviews, one might have expected the physicians as clinical experts to express greater importance for those criteria focused on individual health status, such as *Memory Exercises* and *Physical activities.* Despite this expectation, physicians ranked these lowest – similar to the patients. This may, however, be explained by the remaining included criteria. In particular, when confronted with the highest ranked criterion, *Assistance with everyday activities*, some patients emphasized verbally that none of the other criteria could be considered without *Assistance with everyday activities* being provided. Under consideration of the surveyed patient group, aged PlwCI, this may be expected. It may be that the criteria such as *Assistance with everyday activities*, *Characteristics of professional CGs*, and *Organization of health care* were perceived as minimum requirements for PCC by all participants, and this priority could explain why the criteria focused on improvement of individuals' health states were given lesser importance. A deeper understanding of why PlwCI assigned *Physical Activities* and *Memory Exercises* the lowest importance, might also be of interest for future qualitative research, to improve uptake of such health-promoting activities for healthy ageing and potentially improve adherence to respective components in large multi-modal prevention trials such as the Age.Well study [69]. In a recent debate article, Montero-Odasso, Ismail & Livingston [70] discussed the conclusion from the *Lancet Commission* on Dementia Prevention that up to 35% of dementia cases could be prevented by modifying nine risk factors. Per the *Lancet Commission's* 2020 report, 2% reduction in dementia prevalence could be achieved if physical inactivity in later life as modifiable risk factor would be eliminated [71]. However, Montero-Odasso et al. highlighted that large randomized controlled trials (>250 participants per arm, minimum of 6 months follow-up), primarily set to prevent dementia using lifestyle interventions, had merely shown modest or even negative results [70]. One may question whether these findings may have been impacted by low adherence due to low preferences for such interventions among the study participants. Cardona et al. [72] recently presented baseline analyses from the Age.Well study, which i.a. includes physical activity as one intervention component. The authors included 1,030 participants in their analyses. Approximately half (51.8%) engaged in physical activity ≥ 2 times per week for at least 30 min at baseline. Self-efficacy, i.e., the belief in one's ability to succeed in a given task [73], was an important predictor of physical activity participation among persons at risk of dementia and multi-morbidity ($p < 0.001$) in Cardona et al.'s analyses [72]. Previous research found that self-efficacy can drive individuals to prefer more challenging tasks and also persist more in the face of challenges encountered [74]. Hence, one could discuss whether better self-efficacy could influence individuals to express greater preference for challenging tasks, such as physical activity, and hence show better adherence to such interventions. However, results from the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) study found high self-reported adherence to the intervention component of physical activity (90%). Still, the overall effect from the multi-domain intervention of diet, exercise, cognitive training, and vascular risk monitoring on cognitive improvements in comparison to the control group was small [75]. Future clinical trials on the effect of non-pharmacological, preventive treatment approaches in dementia may include an assessment of preferences to study the relationship with treatment adherence in more detail. Finally, the low importance assigned to *Memory Exercises* and *Physical Activities* among physicians in our study, may be an expression of the fact that health-promoting/disease preventive approaches still are not well established in German primary care [76]. Whether importance differs according to the specialty of physicians may be of interest for future research.

Overall model consistency in both groups was below the defined threshold per group. Similar to Danner et al. [31], we observed those respondents with a lot of high judgements (judgements ≥ 5) to have higher internal inconsistency. Likewise, respondents with many equal judgements (judgements $= 1$) showed lower observed inconsistency. A deeper statistical analysis of how ranking behavior among respondents may have affected their individual CRs lies outside the scope of this paper. Still, it may be of interest for future research. Contrary to Danner et al. [31], the exclusion of inconsistent participants did not result in rank reversals of criteria in our sample, however a significant difference in weights for Memory Exercises among patients. The majority of PlwCI rated the AHP survey to be rather easy or neutral, which may be an indicator of good acceptability and feasibility with this patient group.

Limitations

Our study has several limitations. Our AHP decision hierarchy included qualitative (sub)criteria, which may yield room for interpretation and hence influence the assigned importance. However, we adjusted for interpretation by inclusion of patient-understandable descriptions and definitions for each (sub)criterion [45, 48]. Kuruoglu et al. [77] similarly incorporated qualitative criteria in their AHP decision hierarchy for choice of a family physician. The possibility to cover qualitative aspects, can also be viewed as a strength of the AHP method, which allows for the inclusion of potentially important qualitative (sub)criteria. Our AHP decision hierarchy had been developed with a variety of (participatory) research methods (literature review, qualitative interviews, pretests, expert panels) including both PlwCI as experts by experience and clinical experts. The variety of (participatory) research approaches contribute to confidence in the content- and face validity of our AHP decision hierarchy and the included (sub)criteria. An average of 60–90 min survey time in the patient group is rather long and may have resulted in fatigued and hence less concentrated respondents, which in turn may have led to greater inconsistency, as was observed previously [31]. We did, however, consider this problem by adaptation of the survey outline; first the most challenging pairwise comparisons of criteria and last sociodemographic questions and rating of survey difficulty. The inclusion of PlwCI based on i.a. MMSE results may raise the question about the specificity and sensitivity of the MMSE as a cognitive screening instrument amongst MCI and early-stage dementia. The DemTect has been found more sensitive to detect cognitive impairments in early stages [39, 78]. We considered this problem early on by inclusion of the DemTect in our survey, to obtain a recent cognitive test result. The physician's sample might suffer from a selection bias, i.e., the included physicians might be more engaged than the average with regard to the care of their patients. This might be reflected in our findings, which did not show meaningful differences in AHP element rankings. It could be that the included physicians due to their general higher engagement align better in their judgements with patient preferences than less engaged physicians. Here, subgroup analyses to consider heterogeneities in the sample, e.g., general practitioners versus other specialists or female versus male physicians, may yield some information on the extent of a potential selection bias. Heterogeneities by an analysis of weights and respective ranks in different subgroups were only briefly addressed in this report (patients versus physicians). However, extensive subgroup analyses lie outside the scope of this paper, which primary focus was to assess the congruence of patient preferences and physicians' judgements. One may question whether the AIP method for aggregation was appropriate for our study. As our study similarly to Danner et al. [31] was conducted with individual representatives of two populations and not in group settings, the AIP method for aggregation was deemed more appropriate than the aggregation of individual judgements method. The latter is commonly applied when the AHP is used as a group decision making instrument, as only this aggregation method by application of the geometric mean on individual judgements can assure the reciprocal axiom of the AHP for the combined judgements matrix [79]. Generalizability of our results, similar to other patient preference studies, is limited due to choice of setting [31]. This study was conducted in one federal state of Germany. Nevertheless, we surveyed community-dwelling PlwCI and physicians from different geographical areas in the state, which may contribute to diversity and generalizability of our results across this state, and possibly beyond. We did not exclude inconsistent respondents from our analyses, which may have prevented loss of external validity, as discussed by Mühlbacher et al. [80].

Conclusion

This study provides data about patient preferences and physicians' judgements for PCC of PlwCI, assessed with a quantitative, choice-based preference instrument. Our findings show that physicians judgements in the selected study setting aligned well with what their patients want and prefer in terms of care. Respectively, outpatient care for PlwCI may prioritize interventions focused on assistance with everyday activities, social exchange, and an organization of health care that includes shared decision-making and integrated care structures. Our findings may form a basis for the implementation of truly PCC for PlwCI, i.e., state-of-the-art medical care aligned with patients' preferences.

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SUPPLEMENTARY MATERIAL

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Supplementary Material

Do They Align? Congruence Between Patient Preferences of People Living with Cognitive Impairments and Physicians' Judgements for Person-Centered Care: An Analytic Hierarchy Process Study

Supplementary Table 1A. Patients (n = 50) characteristics

Characteristic	*n (%)*
Age (y, grouped)	
60-70	3 (6.0)
71-80	19 (38.0)
81-90	21 (42.0)
>90	7 (14.0)
Gender	
Female	28 (56.0)
Male	22 (44.0)
Family status (recoded)	
Not alone	25 (50.0)
Alone	24 (48.0)
Missing (Refusal to answer)	1 (2.0)
Highest educational degree (recoded)	
10 y and below	15 (30.0)
>10 y	34 (68.0)
Missing (Do not know)	1 (2.0)
Income	
No income	1 (2.0)
501 – 1,000 €	7 (14.0)
1,001 – 1,500 €	11 (22.0)
1,501 – 2,000 €	4 (8.0)
2,001 – 2,500 €	1 (2.0)
Above 2,500 €	2 (4.0)
Not known	10 (20.0)
Prefer not to say	11 (22.0)
Missing (Do not know)	3 (6.0)
Living situation (recoded)	
Own home	37 (74.0)
Assisted living	12 (24.0)
Missing (Do not know)	1 (2.0)
DemTect	8.02 (3.49) [a]
DemTect group [1]	
Age-appropriate cognitive performance, 13-18 total points	5 (10.0)
MCI, 9-12 total points	16 (32.0)
Suspected dementia, ≤8 total points	28 (56.0)
Missing (Refusal to answer)	1 (2.0)
MMSE	23.5 (4.2) [a]
MMSE group [2]	
No dementia, 27-30 total points	13 (26.0)
MCI and early stage dementia, 20-26 total points	26 (52.0)
Moderate stage dementia, 10-19 total points	11 (22.0)
Diagnosis of MCI or dementia [b]	40 (80.0)
Number of medications	9.38 (4.54) [a]
Non-pharmacological treatment	24 (48.0)
Memory work, such as memory exercises, rehabilitation	2 (8.3) [c]
Occupational therapy	5 (20.8) [c]
Sports and muscle exercises, i.e., physical training such as physiotherapy or sports groups)	16 (66.7) [c]
Artistic therapy, e.g., music therapy, art therapy, dance therapy, drama therapy	1 (4.2) [c]
Treatments to stimulate the senses, such as aromatherapy, multisensory procedures, massage/touch, light therapy	11 (45.8) [c]

Other	9 (37.5) [c, d]
Do not know	1 (4.2) [c]
Self-rated general health	
Very good	1 (2.0)
Good	17 (34.0)
Satisfactory	25 (50.0)
Less good	6 (12.0)
Bad	1 (2.0)
Self-rated assessment of survey difficulty	
Easy	8 (16.0)
Rather easy	16 (32.0)
Neutral	17 (34.0)
Rather difficult	9 (18.0)
Difficult	N/A

Original family status groups: married, widowed, divorced or separated, single, in a relationship, not married; original highest educational degree: no degree, 8th / 9th grade, 10th grade, general qualification for university entrance/ Abitur, degree from a technical/ vocational college, degree from a university of applied sciences or university, PhD/ habilitation; original living situation groups: own home, assisted living, community housing (e.g., with children).

[a] Mean (SD)

[b] ICD-10: F00.1, F00.2, F00.9, F01.3, F01.9, F02.3, F03, F06.7, G30, U51.02, U51.11, U51.12

[c] Percentage calculated based on those n=24 that indicated they received non-pharmacological treatment. Multiple selections possible.

[d] Other included: logopedia, lymph drainage, singing, pedicure, speech therapy.

Supplementary Table 1B. Physicians' (n = 25) characteristics

Characteristic	*n (%)*
Age (y, grouped)	
30-40	4 (16.0)
41-50	9 (36.0)
51-60	6 (24.0)
61-70	4 (16.0)
>70	2 (8.0)
Gender	
Female	18 (72.0)
Male	7 (28.0)
Form of employment [b]	
Self-employed	10 (40.0)
Employed	16 (64.0)
Setting of practice [c]	
Private practice	11 (44.0)
Medical center	1 (4.0)
Hospital	6 (24.0)
Other	8 (32.0) [d]
Location of work place	
Rural area	7 (28.0)
Urban area	18 (72.0)
Field of specialty (recoded)	
Family medicine/ general practitioner	16 (64.0)
Other specialist	9 (36.0)
Number of PlwD currently treating	58.6 (70.1) [a, e, j]
Number of PlwD treated in the past	305.6 (353.3) [a, f, g]
Knowledge about PCC?	
Yes	13 (52.0)
No	11 (44.0)
Missing	1 (4.0)
Knowledge about SDM?	
Yes	14 (56.0)
No	11 (44.0)
Self-rated assessment of survey difficulty [h]	
Easy	6 (24.0)
Rather easy	4 (16.0)
Neutral	8 (32.0)
Rather difficult	3 (12.0)
Difficult	4 (16.0)
Missing	1 (4.0)

Note: Original other specialist groups: psychiatry, neurology and internal medicine.

[a] Mean (SD)

[b] One participant chose both, hence percentage out of all 25 for both groups separately calculated.

[c] Some participants chose several groups, hence percentage out of all 25 for groups separately calculated.

[d] Other included: Research institute, pension fund, medical care center, joint practice, medical practice, shared practice

[e] Missing: 2 (Do not know), 1 (Refusal to answer)

[f] Missing: 2 (Do not know), 1 (Refusal to answer)

[g] Questions about number of patients with cognitive impairments treated currently and in the past were formulated without specification of timeframe. Self-made time indications by physicians were not considered, instead only the indicated number, to keep indications across physicians equal.

[h] One participant chose two options, hence percentage out of all 25 for both groups separately calculated.

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Appendix 5: Additional article: “Elicitation of quantitative, choice-based preferences for Person-Centered Care among People living with Dementia in comparison to physicians’ judgements in Germany: study protocol for the mixed-methods PreDemCare-study.”

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STUDY PROTOCOL

Open Access

Elicitation of quantitative, choice-based preferences for Person-Centered Care among People living with Dementia in comparison to physicians' judgements in Germany: study protocol for the mixed-methods *PreDemCare*-study

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Abstract

Background: Person-Centered-Care (PCC) requires knowledge about patient preferences. Among People-living-with-Dementia (PlwD) data on quantitative, choice-based preferences, which would allow to *quantify, weigh* and *rank* patient-relevant elements of dementia-care, and identify most/least preferred choices, are limited. The Analytic-Hierarchy-Process (AHP) may be one approach to elicit quantitative, choice-based preferences with PlwD, due to simple pairwise comparisons of individual criteria from a complex decision-problem, e.g. health care decisions. Furthermore, data on congruence of patient preferences with physicians' judgements for PCC are missing. If patient preferences and physicians' judgements differ, provision of PCC becomes unlikely. An understanding of patient preferences compared to physician's judgements will support the implementation of truly PCC, i.e. state of the art dementia-care aligned with patient preferences.

Methods: This mixed-methods-study will be based on the results from a previous systematic review and conducted in three phases: (I) literature-based key intervention-categories of PCC will be investigated during qualitative interviews with Dementia-Care-Managers (DCMs) and PlwD to identify actually patient-relevant (sub) criteria of PCC; (II) based on findings from phase I, an AHP-survey will be designed and pre-tested for face- and content-validity, and consistency during face-to-face "thinking-aloud"-interviews with PlwD and two expert panels (DCMs and physicians); (III) the developed survey will elicit patient preferences and physicians' judgements for PCC. To assess individual importance weights for (sub) criteria in both groups, the Principal-Eigenvector-Method will be applied. Weights will be aggregated per group by Aggregation-of-Individual-Priorities-mode. Descriptive and interferential statistical analyses will be conducted to assess congruence of importance-weights between groups. Subgroup-analyses shall

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investigate participant-heterogeneities, sensitivity of AHP-results shall be tested by inclusion/exclusion of inconsistent respondents.

Discussion: Little research is published on quantitative, choice-based preferences in dementia care. We expect that (1) PlwD have preferences and can express these, (2) that the AHP is a suitable technique to elicit quantitative, choice-based preferences among PlwD, and (3) to identify a divergence between patient preferences and physicians' judgements for PCC. With the help of the AHP-technique, which supports systematic decision-making including multiple criteria, it may be possible to involve PlwD in future care decisions (patient participation) and ensure implementation of truly Person-Centered-Dementia-Care.

Trial registration: Approval of the study was granted by the Ethics Committee at the University Medicine Greifswald the 09Apr2021 (Reg.-Nr.: BB 018–21, BB 018-21a, BB 018-21b).

Keywords: Patient preferences, Dementia, Person-centered care, Patient-centered care, Patient participation, Analytic hierarchy process, Multi-criteria decision analysis, Protocol, Decision-making

Background

With aging populations, age-associated diseases, such as dementia, represent a challenge for public health and health care systems worldwide [1]. According to findings from the *Global Burden of Disease Study 2019*, Alzheimer's disease (AD) and other dementias were the fourth leading cause of death globally in the age groups 75 years and older, causing 5.6 (2.6–12.2) percentage of Disability Adjusted Life Years (DALYs) [2] and an estimated 1.55 (0.35 to 4.54) million deaths globally in 2019 [3]. The accelerated approval of aducanumab for people living with early stage AD by the *U.S. Food and Drug Administration* in June 2021 raised expectations for better pharmacological treatment of AD [4]. However, with refusal of marketing authorization by the *European Medicines Agency* in December 2021 [5], confidence in a soon widely available pharmaceutical treatment of AD has declined. Currently, no curative treatment for all People living with Dementia and Mild Cognitive Impairment [hereinafter commonly referred to as 'PlwD'] exists. PlwD need a timely differential diagnosis [1, 6] and care, which ensures a high Quality of Life (QoL) [7].

According to the Alzheimer's Association Dementia-Care-Practice-Recommendation, a person-centered focus is the core of quality care in dementia [7]. *Person-Centered Care* (PCC) has over the years been included in many countries' national guidelines and dementia plans [8–14]. It challenges the traditional clinician-centered or disease-focused medical model to instead suggest a person-customized model of care [15–18]. The strategy of the PCC-model includes to incorporate personal knowledge and individual experiences of the PlwD, to conduct meaningful activities, to make well-being a priority, and to improve the quality of relationships between the health care professional and the PlwD [19–23]. Person-customization in PCC requires information about patient preferences [17, 18]. In dementia, some evidence about patient preferences exists. However, evidence about preferences elicited through quantitative, in particular choice-based preference methods is limited [24, 25]. A recent literature review focused on *decision-making tools* with PlwD from different countries by Ho et al. [26], found that earlier studies applied often qualitative methods and Likert-type scales. Harrison Dening et al. [27] elicited preferences from dyads during qualitative interviews. Van Haitsma et al. developed an extensive Likert-scale based *Preferences for Everyday Living Inventory (PELI)* for elicitation of preferences in community-dwelling aged adults [18]. These methods, however, fall short to *quantify, weigh* and *rank* patient-relevant elements of care, to measure their relative importance and identify most/least preferred choices. Such information can be assessed with quantitative, choice-based preference measurement techniques from Multi-Criteria Decision Analysis (MCDA) [28]. Groenewoud et al. [29], applied a quantitative, choice-based preference measurement tool (Discrete Choice Experiment (DCE)) focused on relevant aspects of outpatient care and support services for people with AD from the Netherlands, however with patient representatives and not patients themselves. Other MCDA-techniques commonly used in health care include Best-Worse-Scaling (BWS) [30] and the Analytic Hierarchy Process (AHP) [31, 32]. DCEs, depending on the number of choice sets included (full vs. fractional factorial design), usually include less, however cognitively more challenging questions. Depending on the number of elements included, the AHP may require to ask many questions. BWS distinguishes between three basic cases; object scaling (case 1), attribute or profile scaling (case 2) and multi-profiling (case 3), each case including various experimental designs, number of choice sets and questions. Hence, in BWS, the cognitive demands of included questions increases with each case [30]. For elicitation of patient preferences among people with cognitive impairments, the AHP has been suggested, as it may be more feasible than other MCDA-techniques, due to the simple pairwise comparisons with only two individual aspects of a complex decision problem [33].

Whether the challenges of the AHP can be handled by people living with Mild Cognitive Impairment or early to moderate-stage dementia is, to the best of our knowledge, still to be investigated [31]. Additionally, patient preference data elicited through quantitative, choice-based preference measurement tools in dementia from Germany are, to the best of our knowledge, missing entirely. Knowledge about patient preferences can inform provision of care that is most preferred by PlwD and avoidance of less preferred care, which is expected to have a positive effect on the life and care situation of PlwD, as well as to reduce the pressure on the health care system with limited resources by a prioritization of most preferred care options [28]. Additionally, the alignment of patient preferences with physicians' judgements for person-centered dementia care has, to the best of our knowledge, not been investigated. Earlier studies of patient preferences versus physicians' judgements in other indication areas found that experts' judgements do not correlate well with subjective preferences of patients [34]. Knowledge about physicians' judgments and their alignment with PlwD's preferences is important, as physicians make decisions for their patients, are responsible for the diagnosis and monitoring of cognitive decline in their patients, and the provision of person-centered dementia care, i.e. state of the art dementia-care aligned with patient preferences.

Methods/design

Overall objectives of the PreDemCare-study

The aim of this study is to develop and apply a quantitative, choice-based preference measurement tool for Person-Centered Dementia Care. This entails

1) To identify patient-relevant (sub) criteria of Person-Centered Dementia Care for Development of an AHP-decision hierarchy with both patients and clinical experts.
2) To design and pre-test a dementia-friendly AHP-survey by an assessment of face- and content validity, as well as internal consistency with both patients an clinical experts.
3) To elicit patient preferences and physicians' judgements for Person-Centered Dementia Care.
4) To analyze the congruence of PlwD and physician preferences for person-centered dementia care.
5) To identify preference and judgement patterns for person-centered dementia care associated with certain patient and physician characteristics.

Setting & participants

Community-dwelling adults ≥60 years of age with an indication of Mild Cognitive Impairment (MCI) and early to mid-stage dementia in Mecklenburg-Western Pomerania, Germany, will be invited as participants in this study. Additionally, clinical experts including dementia-specialized nurses, so-called *Dementia Care Managers (DCMs)* [35, 36], and physicians from different specialties relevant in dementia-care, will be invited.

Study design & methods

The *PreDemCare*-study [37] adopts a sequential mixed-methods-design [38] for final instrument development in line with core components in the design of a quantitative, choice-based preference study [39, 40]. An overview of the three phases of the *PreDemCare*-study, built upon a previous systematic review study [41], is shown in Fig. 1.

Phase 0 – the basis: previous systematic review

In line with methodological recommendations for the design of a quantitative, choice-based preference study [32, 39, 40], we base the development of our study on a previous systematic review, which aimed to identify key intervention categories to provide person-centered dementia care from the published literature. As PCC at first is a theoretical concept [16, 42], we were interested in key intervention categories to *provide* person-centered dementia care. We identified nine key intervention categories: *social contact, physical activities, cognitive training, sensory enhancement, daily living assistance, life history oriented emotional support, training and support for professional caregivers, environmental adjustments,* and *care organization.* A detailed report of this previous study can be reviewed in Mohr et al. [41].

Phase I: pre-study including qualitative interviews

For this formative qualitative pre-study phase, we orient our plan in recent guidelines by Hollin et al. [43].

Aim

The aim of phase I is to identify patient relevant (sub) criteria of PCC for PlwD to inform the development of an AHP-decision hierarchy. In consideration of the specific setting and context of community-dwelling PlwD in rural German Mecklenburg-Western Pomerania, a list of conceptual (sub) criteria will be developed prior to the interviews based on the key intervention categories of PCC identified by the previous systematic review [41]. This list will inform the qualitative data collection in phase I.

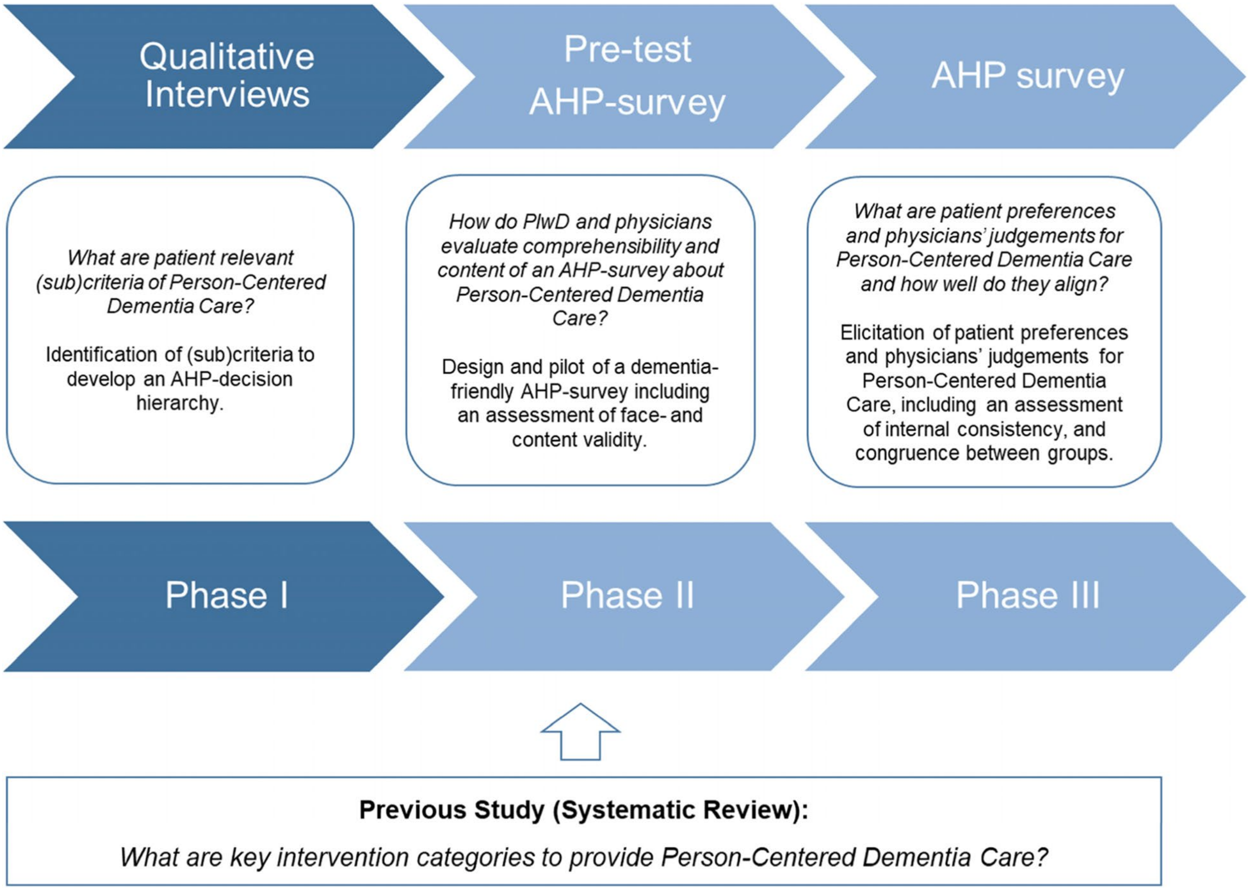

Fig. 1 The mixed-methods design for the *PreDemCare*-study. Note: Own illustration developed oriented in Gilbert AW, Jones J, Stokes M, Mentzakis E, May CR. Protocol for the CONNECT project: a mixed methods study investigating patient preferences for communication technology use in orthopaedic rehabilitation consultations. *BMJ Open*. 2019 Dec 11;9(12):e035210. doi: https://doi.org/10.1136/bmjopen-2019-035210. The systematic review refers to Mohr et al. [41]. Abbreviations: AHP = Analytic Hierarchy Process, PlwD = People living with Dementia and Mild Cognitive Impairment

Sampling strategy & setting

Following recommendations for development of quantitative, choice-based preference measurement tools [39, 40, 43], we aim to include a diversity of perspectives and hence to conduct both 1) expert interviews with DCMs, and 2) patient interviews with community-dwelling PlwD. The interviews with the DCMs will be conducted at site. The interviews with PlwD are planned to be conducted in their homes or in day clinics. During the patient-interviews, the from literature identified conceptual (sub) criteria of Person-Centered Dementia Care will be presented to the participants with the aim to determine patient relevance. Thus, the literature-based (sub) criteria of Person-Centered Dementia Care will be reduced in number to keep the final AHP-decision hierarchy and -survey comprehensible [44], defined in further detail and will reflect the patient perspective. Study nurses as team members in active clinical trials at site (ClinicalTrials.gov identifiers: NCT04741932, NCT01401582, German Clinical Trials Register Reference No.: DRKS00025074) will function as gatekeepers to access PlwD for patient interviews. The inclusion of study nurses in the study design is deliberate, as they may be perceived as trustworthy by potential participants and previous research has highlighted the importance to include nurses during recruitment of study participants in dementia research [45]. The study nurses will emphasize the independence of this study from the clinical trials. None of the PlwD to be interviewed will know the main interviewers (WM, AR) personally on beforehand, but be aware of their professional roles. Participants who are eligible to enroll will be given a participant information sheet. All participants will be asked to provide written informed consent, which can also be provided by a legal guardian. On receipt of consent, the participant will be recruited into the study. All participants will be offered a copy of the consent form

Table 1 Inclusion / exclusion criteria People living with Dementia in the *PreDemCare*-Study

Inclusion criteria	Exclusion criteria
Patient with indication of mild cognitive impairment or early to mid-stage dementia	Patient with no indication of mild cognitive impairment or early to mid-stage dementia
Age: ≥ 60	Age: < 60
Language skills: capable to understand written and oral German	Language skills: not capable to understand written and oral German
Written informed consent provided. This can also be provided by a legal guardian.	No written informed consent provided by either patient or legal guardian.

and a copy will also be saved in the project file. The same process will be applied for study phases II and III.

Sample size

For the expert interviews in phase I, $n = 2$ DCMs with a specialization and many years of work experience in dementia care will be interviewed. In this formative study phase we will aim to interview $n = 10$ PlwD, selected by purposive sampling [46] by aforementioned strategy. The sample size for the patient interviews has been determined based on the expected saturation point [46] and expected severely restricted access to patients due to the SARS-CoV2-pandemic. The latter i.a. includes ethical reflections in the study team to limit the risk associated with contact for both the vulnerable patient group and team members. All interviews will be conducted under adherence to a strict hygiene strategy developed at site.

Eligibility criteria

Eligibility criteria for PlwD for all phases are depicted in Table 1. To ensure a comfortable and non-stressful interview situation, PlwD can invite their informal CGs as silent supporters during interviews. It will however be communicated that the informal CGs shall not act as proxies and should not answer questions on behalf of the PlwD, if possible.

Data collection

We aim to conduct all interviews with two interviewers. Subject to participant consent, all interviews with PlwD will be audio recorded under consideration of participants' privacy, i.e. the recording will be started after introduction of the participants. Field notes will be taken. The average interview time is expected to be approximately 60 minutes. We will use a self-developed semi-structured interview guide, oriented in [47], to ensure an efficient structure of the interview, whilst at the same time give the participants room to express themselves freely. The literature derived conceptual (sub) criteria and their descriptions will be translated to German and printed on cards in A5 format. In addition, the cards will include graphics to visualize the sub-criteria. In line with methodological recommendations for the design of a quantitative, choice-based preference study [32, 39, 40], the cards will, prior to the patient interviews, be reviewed by clinical experts in dementia care, the DCMs, for an early stage consideration of appropriateness and comprehensibility of the conceptual (sub)criteria. Suggestions by the DCMs will be noted in field notes and implemented directly. Oriented in [47], the cards will subsequently be presented to the PlwD as part of a ranking game during the interview to identify actually patient relevant (sub) criteria of Person-Centered Dementia Care. Furthermore, blank cards will be kept ready to add further (sub) criteria that may arise as important to the patients. Card game results will be documented in field notes and with pictures.

Data analysis

Card game results will be transferred to and analysed in Microsoft®Excel2019. The audio recordings from patient interviews will be transcribed verbatim. Names mentioned during the interview will be redacted from transcripts, e.g. with "XXX", to ensure privacy. At least two reviewers will code transcripts with Qualitative Content Analysis [48, 49] in Microsoft®Word2019. The first interview will be coded independently by each reviewer based on the interview guide and the conceptual criteria identified from the literature, but allow for new categories to emerge. Subsequently, the reviewers will meet and discuss their codes and agree on a common strategy including a codebook and numerical code-identifiers for the remaining interviews. The codebook will be revisited after independent coding of the second interview to confirm the strategy by both reviewers. Subsequently, each reviewer will code the remaining interviews independently. Codes and emerging categories from transcript analyses, complemented with analyses of field notes and the card game results, will be discussed and agreed upon in a final common meeting between both reviewers and the research team. Specific coding software is not available. This study phase will entail a manifoldness of data sources (interview transcripts, field notes, card game results), which each have to be analyzed in different ways. To the best of our knowledge, no software is available that can incorporate all data sources respective to the planned analyses. The quality of data analyses in this study phase is deemed to be ensured by manual analyses in available software at site (Microsoft®Word2019 & Microsoft®Excel2019). Hence, the use of a specific coding software is not expected to yield an added benefit in comparison to cost for acquirement.

In accordance with recently published guidelines for formative qualitative research to support the development of quantitative preference studies [43], the findings of this qualitative phase are planned to be published.

Phase II: pre-test AHP-survey in qualitative interviews

After the identification of patient-relevant (sub) criteria of Person-Centered Dementia Care based on the previous systematic review study and qualitative interviews with both experts and patients in phase I, an AHP-decision hierarchy and hereon-based first draft of the AHP-survey will be developed.

Aim

The aim of phase II is to pre-test the AHP-survey. Similarly to phase I, we orient ourselves in Hollin et al. [43] for conduct of this study phase.

The Analytic Hierarchy Process – a brief introduction

The AHP, a MCDA-technique, was developed in the 1970s by the mathematician Thomas Saaty [50, 51]. Its application in the health care sector was introduced in 1989 by Dolan et al. [52]. As a method of decision aid the AHP has mainly been used in the U.S. and Asia, a respective establishment in the Germany is discussed [32, 53, 54]. With the AHP, complex and unstructured decision problems, e.g. decisions related to health care, can be structured hierarchically. This shall aid the decision maker, e.g. patients, to achieve a plausible decision, by simple pairwise comparisons with a 9-1-9-point scale of elements in an overall decision problem. Based on the values assigned in the pairwise comparisons, a comparison matrix is developed [32]. By means of the Principal-Eigenvector-Method, individual importance weights are calculated [50, 51, 55]. Depending on how the AHP is applied, i.e. with individual representatives of a population or in a group decision setting, either the Aggregation of Individual Priorities-mode or Aggregation-of-Individual-Judgements-mode respectively are applicable for aggregation of individual importance weights. A more detailed description of the AHP and its application in the health care sector are outside the range of this study protocol for the *PreDemCare*-study, but can be found in Saaty [50, 51, 56–59], Dolan [52], Schmidt et al. [31], Danner & Gerber-Grote [60], and Mühlbacher & Kaczynski [32].

Expert panel 1

Initially, we aim to conduct an expert panel with $n=4$ DCMs to review the first draft of the AHP-survey, including an assessment of appropriateness and comprehensibility, in preparation for subsequent patient interviews. Feedback from the experts will be documented as field notes in the survey and changes will be implemented immediately.

Patient interviews

For the patient interviews, we aim to recruit $n=10$ patients, following the same recruitment process as outlined in phase I, for evaluation of the AHP-survey during in-depth interviews with the so-called "thinking-aloud"-technique [61]. Eligibility criteria are the same as depicted in Table 1, prior written consent is similarly to the in phase I outlined process required. As difficulties in recruitment of study participants are a known problem in dementia research [45], we aim to ask participants from phase I after completion of the interviews, whether they can be contacted again for the pre-test phase of the *PreDemCare*-study. Should this not meet the required sample size, recruitment of further participants will follow the strategy outlined in phase I. The pre-test is intended to assess the face- and content validity, including appropriateness and comprehensibility, as well as internal consistency of the AHP-survey [32, 62]. During the patient interviews, the PlwD, who can be accompanied by their informal CGs as silent supporters/ not as proxy raters, are asked to fill out the survey whilst "thinking aloud" with the researcher present. The participants will be asked to assess the formulations of the questions for their appropriateness and comprehensibility, as well as to provide information about their motivation when they answer the questions. Additionally, the PlwD will be asked about the layout of the survey and the appropriateness of the previously defined (sub)criteria. The interviews are expected to last approx. 60 min. It is aimed to complete all sections of the AHP-survey during pre-tests. Should participants express the wish to end the pre-test earlier, non-covered sections will be covered with other participants. Subject to prior written consent, interviews will be audio recorded in order to ensure completeness of the feedback provided by the patients on the AHP-survey. Considerations about privacy follow the same as outlined in phase I. Based on the feedback from the patients, the survey will be revised and adapted in terms of language, wording, structure and content on a continuous basis. Hence, patients' feedback will be included in subsequent interviews until the patients have no further comments and no struggles with completion of the survey.

Expert panel 2

After the patient interviews, the resulting version of the survey will be assessed by a second expert panel with physicians to ensure incorporation of all relevant aspects, i.e. content validity of the survey. For the expert panel we aim to recruit a focus group of $n=5$ physicians from different specialties relevant to the treatment and care of dementia diseases.

Based on the results from the patient interviews and the expert panels, two AHP-survey versions will be developed. One version will be for the patients and one for the physicians. The versions will be similar in content, but the physician survey will ask for the respondent's professional judgement, i.e. their preferences as experts for Person-Centered Dementia Care.

Phase III: Analytic Hierarchy Process, (assisted) paper & pencil survey

Aim

The aim of phase III is to elicit patient preferences and physician's judgements for Person-Centered Dementia Care by application of the in phases I-II developed AHP-survey instrument.

Sampling strategy & setting

With regard to an appropriate sample size for an AHP-survey, no standard exists. IJzerman et al. [62] have applied the equation for sample size determination in conjoint analysis [63, 64] as a basis for the AHP. Following this, the sample sizes for this study will be determined based on a rule of thumb for Conjoint Analysis[1] [64]. Hence, we aim to recruit $n=50$ PlwD for study phase III. To investigate the correlation between patient preferences and physician's judgements we plan to recruit $n=24$ physicians, with the latter being the minimum number of participants needed based on the before outlined sample size calculation. Process for recruitment of PlwD will follow the same as outlined in study phase I, i.e. participants will mainly be recruited from clinical trials conducted at site (for a detailed description refer to ClinicalTrials.gov identifiers: NCT04741932, NCT01401582, NCT03359408, German Clinical Trials Register Reference No.: DRKS00025074) via study nurses. Experienced study nurses will be instructed to avoid selection bias during participant recruitment and hence obtain a sample, which is representative of the population intended to be analyzed, i.e. community-dwelling PlwD in the German Federal State Mecklenburg-Western Pomerania. If this should not yield enough participants, we aim to additionally recruit from the memory clinic at site [65]. Should these ways not yield enough participants, we plan to additionally recruit from external settings, e.g. day clinics and memory clinics. As participants will be community-dwelling PlwD from different areas in the federal state, this may enhance representativeness of the population and decrease selection bias. Eligibility criteria follow the same list depicted in Table 1, prior written consent is similarly to the in phase I outlined process required.

Data collection & analysis

The developed survey instrument will be provided as assisted paper & pencil survey for PlwD and non-assisted paper & pencil survey for physicians. The survey will consist of five sections:

1. A description of the study and an introduction to the criteria,
2. the first part of AHP-survey, i.e. pairwise comparison questions about criteria,
3. an introduction to the sub-criteria,
4. the second part of the AHP-survey, i.e. pairwise comparison questions about sub-criteria
5. a short sociodemographic survey including an evaluative question about the difficulty of the survey.

Initially, the participants will be presented with an explanation about the content of the survey and a description about the survey technique of the AHP. This includes a clarification about the hypothetical presentation of PCC, described by up to six criteria with each up to two sub-criteria. Apart from this, the participants will be presented with a laymen comprehensible description of each included (sub) criterion included in the survey. The pairwise comparisons will be presented in an appropriate context and explained. It is important that the participants receive enough information and details to be able to choose between the individual (sub)criteria. This will be supported by the inclusion of icons as visual aids for the different sub-criteria. Compared to other methods of preference elicitation, the AHP is expected to be particularly suitable for cognitively impaired patients, since the determination of patient preferences always takes only two individual aspects of a decision into account resulting in pairwise comparisons, which then are weighed against each other on the predefined AHP rating scale [31]. Aside from the PlwD, physicians will be asked to complete the survey based on their professional judgement, i.e. their preferences as experts for Person-Centred Dementia Care. In subsequent descriptive as well as interferential statistical analyses, the congruence between patient preferences and physician's judgements will be investigated.

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[1] $(NxTxA)/C \geq 500$, where N = number of respondents, T = number of choice sets per respondent, A = number of scenarios per choice set, and C = maximum number of levels

Sociodemographic and clinical variables will be analyzed with descriptive statistics. For the analysis of data collected with the AHP-survey, patient preferences will be elicited with coefficients of the included elements and a combination of both by application of the *Eigenvector*-method [50, 58]. This includes 1) local and global weights, i.e. relative preference weights, 2) estimates of the relative importance of the criteria, 3) data on consistency in response (consistency ratio for each pairwise comparison and respondent), 4) a sensitivity analysis by inclusion/ exclusion of inconsistent respondents, cf. Danner et al. [33] to assess, how changes in weights of criteria with a consistent model structure might influence the ranking of the different (sub) criteria, 5) a descriptive comparison of the patient preference/ physician judgement rankings of (sub) criteria for Person-Centered Dementia Care to assess the congruence and/or divergence, and finally depending on data completeness 6) univariable (e.g. independent paired t-tests, Mann Whitney-tests, one-way Analysis of Variance, Kruskal Wallis test, and Kendall's correlation) as well as multivariable (e.g. multivariable regression models) statistical methods to assess eventual differences in preferences in correlation with respondent status (patient/ physician), socio-economic characteristics, and clinical status.

Analyses are planned to be conducted by usage of available software such as Expert Choice®Comparion [66], R (package: ahpsurvey [67]), and Microsoft® Excel 2019.

Discussion

Little research is published on quantitative, choice-based preferences in dementia care [24, 25]. It is expected that PlwD have clear preferences for PCC and can express and name them. The AHP is expected to be a suitable technique for determination of care preferences among PlwD. The combination of qualitative sociological and quantitative mathematical research methods in participatory research is novel: there are only a few studies that determine the patients' perspective in dementia care based on quantitative, choice-based preference elicitation tools [24, 25]. To the best of our knowledge, the application of such tools with cognitively impaired patients in Germany is one of the first of its kind. Similarly, a comparison of patient preferences versus physicians' judgements in dementia in Germany is, to the best of our knowledge, one of the first of its kind.

To focus on a concept such as PCC for the experimental design of the AHP-decision hierarchy and -survey, may raise the question, whether a quantification of individual preferences can capture the core of PCC; an individualization of care and consideration of dementia as an individual process [19]. However and in contrast to other quantitative methods, which only allow to analyze aggregated data, the AHP allows for an evaluation of preferences on an individual basis for each participant, by which the individual process of dementia diseases may be considered [32]. Simultaneously, individual preferences can be aggregated and thus quantified for a group of decision makers, i.e. patients. Van Til & IJzerman [68] discussed the importance of patient preference consideration by regulatory and health policy decision bodies already in 2013. The authors highlighted the advantage of quantitative preference elicitation methods to measure patient preferences on a larger and representative scale, which in turn would allow decision committees to reflect the patient perspective in their regulatory/ health policy decisions [68]. The opportunity to elicit preferences in a large and representative sample of a patient population can improve the reliability and validity of preferences itself, and is necessary for comparability of preferences [68]. Knowledge about most/ least preferred health care options may further help to increase acceptance among patients and reduce the financial pressure on health care systems, as health policy makers could prioritize provision of those measures accepted and preferred by patients, i.e. patient—/ person-centered health care, and avoid less preferred options [28]. Still, some authors have questioned the stability and hence trust in predictability of patient preferences [69]. In this context, van Haitsma et al. [70] noted that preferences are based on the processing of needs, values, and goals, and hence can shift as the social environment or contextual circumstances change. To acknowledge that preferences may change could, in turn, contribute to consider the individual experience of dementia, an individualization of care, and thus fulfill the focus of PCC. However, PCC incorporates the necessity of relationship facilitation between the health care provider and patients [16]. It is questionable, how quantitative preferences can incorporate and represent a highly individual and complex process such as relationship facilitation. Nevertheless, PCC requires knowledge about patient preferences [16, 42]. Patients, including PlwD, are 'experts by experience' – hence, an incorporation of their perspective in care decision making is of importance [34]. Here, quantitative, choice-based preference elicitation tools, could form a powerful tool to consider the patient perspective on a larger and representative scale [68].

Analogous to the results of other patient preference studies [34], divergences between the preferences of PlwD and physicians' judgements are expected. One may question the pros and cons to compare patient preferences and physicians' judgements for Person-Centered Dementia Care, which is characterized by elements of nursing care and psychosocial support [41]. Hence, it may be questionable whether the comparison of patient preferences vs. nursing practitioners could be more appropriate, or in other words, whether physicians will be able to provide judgements about the importance of elements for dementia-care. A core element of PCC *is Shared-Decision Making* between the health care provider, including physicians, and the patient [41, 71, 72]. Here, the specific context of the German health care system needs to be considered; in the ambulatory health care setting, which community-dwelling people with mild cognitive impairment and early-moderate stage dementia i.a. navigate in, physicians, including both general practitioners and specialists, are essential in health care service provision, including the prescription of care services for these patients [73, 74]. A redistribution of tasks between specialized nurses and physicians, i.e. models of advanced nursing practice, are currently topic of research. But so far, such care models are not available in regular health care in Germany [74]. Due to the important role of physicians in German ambulatory health care service provision and the core element of *Shared Decision-Making* in PCC, an assessment of congruence between patient preferences vs. physicians' judgements for Person-Centered Dementia Care, as planned for the *PreDemCare*-study, is considered appropriate. It is expected that physicians will be able to provide judgements about the importance of elements in dementia care.

The aforementioned pros/ cons of quantifying individual preferences and a comparison of patient preferences vs. physicians' judgements in Person-Centered Dementia Care, may indicate how the expected results of our study can be used to improve standard dementia care procedures. The results may complement existing knowledge in national dementia guidelines, based on the results from clinical trials, with the patient perspective and hence support the implementation of truly person-centered, i.e. individualized care in dementia [16, 34, 42, 72]. If the AHP results to be a suitable technique to elicit patient preferences, this knowledge may be useful to enhance patient-physician communication, by greater focus on presentation of complex decision problems as simpler pairwise comparisons. Enhanced communication may facilitate relationships between physicians and patients, which, as mentioned before, is essential in the implementation of PCC [16, 42].

It has been purposefully decided by the research team to involve PlwD as 'experts by experience', as well as clinical professionals in the critical development-stages of the AHP-survey, to enhance both face and content validity [75]. The plan to access PlwD via study nurses as gatekeepers, and the invitation of informal CGs to join the interviews as silent supporters, as well as a rigorous informed consent process, which was reviewed and approved by the Local Ethics Committee at the University Medicine Greifswald the 9th of April 2021 (Reg.-Nr.: BB 018–21, BB 018-21a, BB 018-21b), shall ensure early consideration of consent and capacity [76]. Related to the planned sample sizes in the pre-study/ instrument development phases (phases I and II), one may question the sufficiency of planned number of participants, which compared to usual sample sizes in other qualitative research may appear low. For conduct of the pre-study phases (including sample size estimation), we oriented ourselves in a recent publication by Hollin et al. [43], which entails guidelines for formative qualitative research to support the development of quantitative preference survey instruments. The authors emphasize that sampling in these study phases should not focus on number of units, but to collect actionable input for the development process, which needs a diversity of perspectives. They also underline that sampling adequacy in formative qualitative research may entail smaller samples than in general qualitative work, which given the limited study purpose may be adequate [43]. To complement suggestions by Hollin et al. [43], we orient ourselves in previous quantitative patient preference research, including works by first author AR, which reports similar sample sizes in the pre-study phase(s) [77–82]. With regard to include different perspectives, the inclusion of a third cohort of informal CGs as informants in the pre-study phases has been discussed in the research team. Previous research often included informal CGs as research participants as proxies/in dyads, including a recent DCE-based patient preference study by Chester et al. [83], despite findings of rater discrepancies between PlwD and their informal CGs [84–86]. In consideration of these previous findings and the goal of our study; to assess patient preferences with PlwD themselves, and not their informal CGs, which requires an AHP-experimental design that covers *patient*-relevant aspects, it has been decided in the research team to not include informal CGs as more than silent supporters of the PlwD in the pre-study phase. By inclusion of a planned total number of $n=31$ participants in the instrument development phase including a variety of perspectives ($n=2$ DCMs + $n=10$ PlwD in the qualitative interviews for (sub) criteria identification, $n=4$ DCMs for first expert panel, $n=10$ PlwD for pretests of AHP-survey, $n=5$ physicians for second expert panel), we align with recommendations [43] and previous research [77–82]. Furthermore, the planned sample sizes consider the mere practical obstacle to patient recruitment imposed by the ongoing SARS-CoV2-pandemic [87]. It is expected that the ongoing SARS-CoV2-pandemic will impact the conduct of the *PreDemCare*-Study. The research team has prepared for this by implementation of a strict hygiene strategy developed at site, which i.a. involves continuous testing of study personnel to interview/ survey the participants, and hopefully will make it possible to conduct this study in a reasonable time frame. To increase confidence in the final AHP-survey instrument, it is planned to publish reports about all study phases and hereby enhance transparency and confidence in the final AHP-survey instrument.

As this research will be conducted in one federal state of Germany, Mecklenburg-Western Pomerania, it may hence not be fully representative of the population and the health care services nationwide, which can be viewed as a limitation. However, participants will be recruited from several regions in the federal state and interviews/ surveys will be conducted in peoples' homes, which enhances diversity of the study population in its respective region. Still, the exclusion of PlwD in nursing homes and people living with severe-stage dementia from the study population can be viewed as another limitation of this planned study. However, an early diagnosis and state of the art medical care aligned with patient's preferences elicited through participatory research methods is necessary to ensure truly Person-Centered Dementia Care and a high QoL [6, 18, 20]. With the help of the AHP-method applied in the *PreDemCare*-Study, which supports systematic decision-making that takes multiple criteria into account, it may be possible to involve PlwD in future care decisions (patient participation) and ensure implementation of truly Person-Centred Dementia Care.

Abbreviations

AHP: Analytic Hierarchy Process; CGs: Caregivers; DCMs: Dementia Care Managers; MCDA: Multi-Criteria Decision Analysis; PlwD: People living with Dementia; PCC: Person-Centered Care; QoL: Quality of Life.

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Authors' contributions

WM and AR drafted the manuscript and developed the project with the support of BM and WH. AR and WM contributed knowledge on qualitative research. AR substantially contributed knowledge on the Analytic Hierarchy Process. AR, BM and WH edited and critically revised the paper. All authors have read and approved the manuscript. WM and AR are the guarantees of the manuscript.

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Availability of data and materials

Not applicable.

For each phase of the study, a manuscript will be written and submitted to national and international conferences. Additionally, summaries in easy language will be developed and made available for patients and the public, .e.g. through dementia interest groups. All results from each phase of the study will be published in peer-reviewed journals. Links to research outputs will be made available on the *PreDemCare*-website, hosted by the German Center for Neurodegenerative Diseases e.V. (DZNE), available at: https://www.dzne.de/en/research/studies/projects/predemcare/.

Declarations

Ethics approval and consent to participate

To follow the German guidelines for Good Clinical Practice, ethics approval was sought for all parts of this study. Final approval for phases I-III of the study was granted by the Local Ethics Committee at the University Medicine Greifswald the 9th of April 2021 (Reg.-Nr.: BB 018–21, BB 018-21a, BB 018-21b). Participants will provide informed written consent prior to enrolment in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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