

What matters to whom? A consensus on core elements and methods for non-pharmacological intervention research in dementia

Sara Laureen Bartels¹, Federica D'Andrea², the INTERDEM Methodology Taskforce³, & Maud Graff^{4,5}

Affiliations: ¹ Department of Psychiatry and Neuropsychology and Alzheimer Centrum Limburg, Mental Health and Neuroscience Research Institute, Maastricht University, Maastricht, Netherlands; ² The Geller Institute of Ageing and Memory, School of Medicine and Biosciences, University of West London, United Kingdom; ³ INTERDEM: European Network for psychosocial dementia research (www.interdem.org); ⁴ Department of Rehabilitation, Radboudumc, Radboud University Medical Centre Nijmegen, Nijmegen, Netherlands; ⁵ Department of IQ Health, Radboudumc Alzheimer Center, Radboud University Medical Center Nijmegen, Nijmegen, Netherlands.

Background & Aim

The six core elements of the Medical Research Council (MRC) framework are recommended for the development, feasibility/piloting, evaluation, and implementation of complex interventions (Skivington et al., 2021) (Fig. 1). For non-pharmacological intervention research in dementia, it is unclear i) if these core elements are perceived as relevant by different stakeholders, ii) if additional elements should be considered, and iii) which research methods best operationalize them. The present study aims to reach a consensus on these questions.

Methods

This study is part of the METHODEM project and executed by the INTERDEM Methodology Taskforce (Alzheimer's Association ARCOM grant). A modified Delphi study, co-designed with an advisory group including people with lived experience of dementia, is executed involving iterative online surveys (i.e., rating importance of core elements/ suitability of methods) and discussion rounds. Participants are people living with dementia, carers, health and social care professionals (HSCP), policy makers (i.e., policy influencers and insurance company representatives), and psychosocial researchers. Consensus was defined as >70% of agreement (very important), and <15% disagreement (not important).

Results

Survey round 1 In total, n=134 participants signed informed consent and n=121 completed the first survey, including n=24 HSCPs, n=14 carers, n=11 people living with dementia, n=5 policy makers/ influencers and representatives from health insurance companies (Table 1), and n=69 researchers (Table 2).

Table 1. Survey ratings round 1 of carers, people with dementia, HCSP, and policy makers.

	No, not particularly	Yes, important	Yes, very important	Unable to provide feedback
Consider context				
Carers	-	8, 57.1	5, 35.7	1, 7.1
People with dementia	-	1, 9.1	9, 81.8	1, 9.1
HSCP	-	6, 25	18, 75	-
Policy makers	-	1, 20	4, 80	-
Develop, refine, (re)test program theory				
Carers	-	7, 50	7, 50	-
People with dementia	-	3, 27.3	8, 72.7	-
HSCP	1, 4.2	8, 33.3	15, 62.5	-
Policy makers	-	2, 40	3, 60	-
Engage stakeholders				
Carers	-	3, 21.4	11, 78.6	-
People with dementia	-	-	11, 100	-
HSCP	-	2, 8.3	21, 87.5	-
Policy makers	-	-	4, 80	1, 20
Identify key uncertainties				
Carers	-	5, 35.7	9, 64.3	-
People with dementia	1, 9.1	1, 9.1	9, 81.8	-
HSCP	-	7, 29.2	19, 79.2	-
Policy makers	1, 20	1, 20	3, 60	-
Refine intervention				
Carers	-	5, 35.7	9, 64.3	-
People with dementia	-	3, 27.3	8, 72.7	-
HSCP	-	6, 25	18, 75	-
Policy makers	-	-	3, 60	2, 40
Economic considerations				
Carers	1	1	12, 85.7	-
People with dementia	-	1, 9.1	9, 81.8	1, 9.1
HSCP	2, 8.3	9, 37.5	11, 45.8	-
Policy makers	-	2, 40	3, 60	-

Table 2. Survey ratings round 1 of n=69 researchers.

	Not at all important	Slightly important	Moderately important	Very important	Extremely important	Unable to provide feedback
Consider context						
Development	-	-	-	11, 15.9	58, 84.1	-
Feasibility/ pilot	-	1, 1.4	3, 4.3	13, 18.8	51, 73.9	1, 1.4
Evaluation	-	1, 1.4	5, 7.2	14, 20.3	49, 71	-
Implementation	-	-	-	10, 14.5	58, 84.1	1, 1.4
Develop, refine, (re)test program theory						
Development	-	3, 4.4	5, 7.4	21, 30.9	38, 55.9	1, 1.5
Feasibility/ pilot	-	2, 2.9	14, 20.6	34, 50	17, 25	1, 1.5
Evaluation	-	2, 2.9	5, 7.4	29, 42.6	32, 47.1	-
Implementation	-	4, 5.9	3, 4.4	32, 47.1	28, 41.2	1, 1.5
Engage stakeholders						
Development	-	1, 1.5	4, 5.9	15, 22.1	47, 69.1	1, 1.5
Feasibility/ pilot	-	1, 1.5	4, 5.9	18, 26.5	44, 64.7	1, 1.5
Evaluation	-	3, 4.4	6, 8.8	22, 32.4	35, 51.5	2, 2.9
Implementation	-	3, 4.4	2, 2.9	15, 22.1	46, 67.6	2, 2.9
Identify key uncertainties						
Development	-	3, 4.4	8, 11.8	23, 33.8	33, 48.5	1, 1.5
Feasibility/ pilot	-	-	7, 10.3	30, 44.1	31, 45.6	-
Evaluation	-	2, 2.9	14, 20.6	30, 44.1	21, 30.9	1, 1.5
Implementation	-	1, 1.5	7, 10.3	29, 42.6	29, 42.6	2, 2.9
Refine intervention						
Development	2, 2.9	2, 2.9	15, 22.1	16, 23.5	28, 41.2	5, 7.4
Feasibility/ pilot	-	4, 5.9	7, 10.3	21, 30.9	32, 47.1	4, 5.9
Evaluation	-	5, 7.4	13, 19.1	24, 35.3	22, 32.4	4, 5.9
Implementation	-	1, 1.5	5, 7.4	28, 41.2	28, 41.2	6, 8.8
Economic considerations						
Development	-	6, 8.8	18, 26.5	22, 32.4	20, 29.4	2, 2.9
Feasibility/ pilot	-	9, 13.2	22, 32.4	26, 38.2	9, 13.2	2, 2.9
Evaluation	2, 2.9	5, 7.4	13, 19.1	24, 35.3	22, 32.4	2, 2.9
Implementation	1, 1.5	1, 1.5	5, 7.4	18, 26.5	42, 61.8	1, 1.5

Next steps and preliminary conclusion

It is crucial to involve not just researchers but also other stakeholders in a consensus to ensure that academic efforts align with their preferences. From the initial results, stakeholders seem to prioritize core elements differently; through an iterative design, this study will further explore rationales for these preferences. Next to a list of ranked core elements per phase, an overview of methods will be proposed, which may advance future non-pharmacological intervention research in dementia.

Contact

 sara.bartels@maastrichtuniversity.nl ³ The INTERDEM Methodology Taskforce includes Patricia Masterson Algar, Andrea Nakakawa Bernal, Simone de Bruin, Maria Caulfield, Ilaria Chirico, Emma Elliott, Aisling Flynn, Lesley Garcia, Doris Gebhard, Melanie Handley, Niels Janssen, Marine Markaryan, Esme Moniz-Cook, Nathan Stephens, Martina Roes, Lieve van den Block.



Read more about the METHODEM project & methodologies/ methods for psychosocial interventions in dementia:

D'Andrea, F., Bartels, S. L., Markaryan, M., Masterson-Algar, P., Bernal, A. N., De Bruin, S. R., ... & Graff, M. (2026). Methodologies and methods for the development, evaluation and implementation of psychosocial interventions for dementia: protocol for a scoping review. *BMJ open*, 16(4), e114584.

Bartels, S. L., Stephens, N., D'Andrea, F., Handley, M., Markaryan, M., Nakakawa Bernal, A., ... & Graff, M. (2024). Discussing methodological gaps in psychosocial intervention research for dementia: an opinion article from the INTERDEM Methodology Taskforce guided by the MRC framework. *Frontiers in dementia*, 3, 1458023.