

Additional file 1: Variables and measures from the RightTimePlaceCare study data set, based on factors associated with the level of agreement between self- and proxy ratings identified in the empirical literature

Findings of the empirical literature		Measurements of the RightTimePlaceCare study							
Factors associated with the level of agreement	Studies	Outcome	Measure/variable	Subscales/ items	Setting: rater	Value range	Interpretation		
People with dementia	1.	Behavioural and psychological symptoms of dementia (BPSD)	n = 5 [18, 20, 25, 28, 36]	Challenging behaviour	Neuropsychiatric Inventory Questionnaire (NPI-Q) [49, 50]	12 items in 12 behavioural domains: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behaviour, sleep and night-time behaviour change, appetite and eating change	ILTC: professional carers HC: informal carers	0 – 36	Higher scores indicate the presence of more (severe) neuropsychiatric symptoms
		Cognitive impairment or severity of dementia	n = 5 [16, 17, 19, 25, 28]	Cognitive function	Standardized Mini Mental-State Examination (S-MMSE) [47, 51]	30-item assessment of global cognitive function with domains such as orientation, concentration, attention, memory, recall and calculation	ILTC+HC: person with dementia or routine data	0 – 30	Lower scores indicate severe cognitive impairment Sometimes used as a surrogate method for the staging of dementia: severe=0–10, moderate=11–20, mild=21–25, questionable=26–29, no=30 [52] → However, cut-off points to assist in the diagnosis of dementia or to determine dementia severity should be interpreted cautiously [1].
	2.	Depression	n = 3 [18–20]	Depressive symptoms	Cornell Scale for Depression in Dementia (CSDD) [53]	19 items covering 5 dimensions: mood-related signs, behavioural disturbance, physical signs, cyclic functions, ideational disturbance	ILTC: professional carers HC: informal carers	0 – 38	Higher scores indicate the presence of increased depressive symptoms > 6 points: presence of considerable depressive symptoms

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	3.	Functional status: independence	n = 2 [18, 28]	Functional status	Katz Index of Independence in Activities of Daily Living (KATZ ADL) [54]	6 activity domains: bathing, dressing, toileting, transferring, continence, feeding	ILTC: professional carers HC: informal carers	0 – 6 Higher scores indicate more independency in performing activities of daily living 6 points: independent, 3–5 points: moderate dependency, 0–2 points: severe dependency
		Anosognosia	n = 2 [19, 21]	Not measured				
		Quality of person with dementia-carer relationship	n = 2 [17, 36]	Not measured				
		Educational background	n = 2 [17, 20]	Sociodemographic data: length of formal education (years)			ILTC+HC: informal carers	
	4.	Domestic environment/ person with dementia living at home	n = 1 [17]	Sociodemographic data: care setting (HC vs. ILTC)				
Carers	1.	Caregiver burden	n = 4 [18, 22, 28, 36]	General caregiver burden	Zarit Burden Inventory (ZBI) [55]	22 items covering 5 domains of general caregiver burden: burden in relationship, emotional wellbeing, social and family life, finances, loss of control over one's life	ILTC+HC: informal carers	0 – 88 Higher scores indicate higher perceived general caregiver burden
				Caregiver distress due to BPSD of the person with dementia	Neuropsychiatric Inventory Questionnaire-Caregiver Distress (NPI-Q-D) [49, 50]	12 items in 12 behavioural domains of caregiver distress associated with symptoms of BPSD of the person with dementia: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behaviour, sleep and night-time behaviour change, appetite and eating change	HC only: informal carers	0 – 60 Higher scores indicate higher caregiver distress related to BPSD of the person with dementia

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Factors associated with the level of agreement	Studies	Outcome	Measure/variable	Subscales/ items	Setting: rater	Value range	Interpretation
		Reactions of informal carers to the care of chronically ill persons	Caregiver Reaction Assessment (CRA) [56]	Subscale: CRA-Lack of family support	ILTC+HC: informal carers	5 – 25	Higher scores indicate a more negative influence on carers' experience
2.	Depression of the carer n = 3 [17, 22]	Not measured					
3.	Quality of life of the carer n = 2 [22, 36]	Health-related quality of life	European Quality of Life Scale (EQ-5D) [57, 58]	EQ-5D-3L 5 items about 5 health dimensions: mobility, self-care, usual activities, pain/discomfort, anxiety/depression	ILTC+HC: informal carers	-0,594 – 1	Higher scores indicate better health-related quality of life
		Psychological well-being	General Health Questionnaire 12-item version (GHQ-12) [59]	12 items	HC: informal carers	0 – 36	Higher scores indicate a less psychological well-being
		Reactions of informal carers to the care of chronically ill persons	Caregiver Reaction Assessment (CRA) [56]	Subscale: CRA-Impact on health	ILTC+HC: informal carers	4 – 20	Higher scores indicate a more negative influence on carers' experience due to their own health problems
4.	Professional carer being a Primary Nurse n = 1 [27]	Not measured					
	Kinship status n = 1 [17]	Sociodemographic data: relationship to person with dementia			ILTC+HC: informal carers		

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Factors associated with the level of agreement	Studies	Outcome	Measure/variable	Subscales/ items	Setting: rater	Value range	Interpretation
	Gender of the carer	n = 1 [19]	Sociodemographic data: gender		ILTC+HC: informal carers		
	Income of the carer	n = 1 [22]	Not measured				

ILTC: institutional long-term nursing care; *HC*: professional home care.

All references mentioned in the table are cited in the ‘References’ section of the main publication.