BMC Palliative Care

RESEARCH

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Internal consistency and structural validity of the Swiss easy-read Integrated Palliative Care Outcome Scale for People with dementia: a secondary exploratory factor analysis

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Abstract

Background The Integrated Palliative Care Outcome Scale for People with Dementia (IPOS-Dem) was developed as a promising person-centred proxy measure of symptoms and concerns. We used the Swiss-German easy-read version, a measure designed to be completed individually by family members and frontline staff caring for people with dementia. In this secondary data analysis of multicentre trial data, we investigate the IPOS-Dem's structural validity and internal consistency of the version.

Methods A total of 257 people with dementia were assessed by frontline staff, while family members assessed 118 people residing in one of 23 participating Swiss-German long-term care facilities. Each IPOS-Dem version, corresponding to the two rater populations (family members and frontline staff), underwent exploratory factor analysis separately, using data from one assessment per person with dementia. A minimum residual solution with varimax rotation was calculated to determine the factor structure. Item reduction decisions were based on factor loadings and indices for internal consistency.

Results The construct validity of the Swiss-German easy-read IPOS-Dem for frontline staff is demonstrated by two factors: Dementia Interaction and Physical Impact (Cronbach's $\alpha = 0.83$) and Dementia Emotional and Behavioural Impact (Cronbach's $\alpha = 0.81$). Four factors, with Cronbach's α ranging from 0.77 to 0.86, were computed for the family member version: Dementia Interaction Impact, Easy-to-Assess Dementia Physical Impact, Hard-to-Assess Dementia Physical Impact and Dementia Emotional and Behavioural Impact.

Conclusions Like other reduced patient-related outcome measures, palliative care measures and their parent instrument IPOS we identified subscales in the easy-read IPOS-Dem that describe a psychosocial impact and a physical impact. Differences in the internal structure of the family and staff versions of the IPOS-Dem likely stem from variations in observation intervals, roles and perspectives, with family members often focusing on loss and past experiences whereas staff may equate quality of life with quality of care leading to differing ratings. However, the identified internal consistency indices between 0.77 and 0.86 indicate acceptable internal consistency for the subscales and the IPOS-Dem should be taken forward for further psychometric evaluation.

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Trial registration The overarching trial has been approved by the Swiss Regional Ethics Committee of the Canton of Zürich as the leading ethics committee for the involved regions, with clearance certification number BASEC2019-01847 (12/11/2019). The main study and secondary analysis are registered with the German Clinical Trials Register (DRKS00022339, 05/10/2020). Full registration is available online at http://www.drks.de/DRKS00022339.

Keywords Psychometrics, Internal consistency, Structural validity, Person-centred outcome measures, Symptom assessment, Symptom burden, Dementia, Nursing home, Family members

Background

The use of the Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem) can help carers recognise the symptoms and concerns of people with dementia. The brief and easy-to-use IPOS-Dem is built on a comprehensive family of person-centred self- and proxy-assessed palliative care outcome measures that are managed through www.pos-pal.org. The IPOS-Dem is a questionnaire designed to be completed by frontline staff in long-term care facilities (LTCFs) and by family members of people with dementia residing in LTCFs.

The Integrated Palliative Care Outcome Scale for People with Dementia (IPOS-Dem) is a multidimensional person-centred outcome measure. It focuses on capturing the most significant symptoms and concerns of individuals with dementia over a recall period of seven days. Examples of common symptoms addressed range from impaired mobility to emotional concerns such as anxiety or agitation (e.g. "Has she/he been feeling anxious or agitated?") [1]. Because of population shifts, the number of people with dementia is expected to rise dramatically in the coming decades [2]. A substantial proportion of people with dementia in Switzerland and other countries will move to live in LTCFs [2–4]. For frontline staff who care for people with dementia to provide person-centred care, it is important to routinely document the symptoms and concerns of the people they care for [5]. People with advanced dementia may lose their ability to communicate verbally, so systematic proxy assessment, as supported by IPOS-Dem, may be indicated but may not change caregiving on its own [6, 7]. Furthermore, most measures designed for this population and the people who care for them in LTCFs are deemed unfit for day-to-day practice and decision-making or are very specific to research applications [8].

The Swiss easy-read translation of the IPOS-Dem has 27 items about common symptoms and concerns of people with dementia [9]. Each item is scored on a five-point scale ranging from 0 (no concern) to 4 (overwhelming). Although mostly taking a self-proxy perspective, it asks three types of questions. After an introduction, there are three open questions regarding the main issues. Following the text boxes, the user is asked to rate a 19-item list of symptoms regarding how much they believe these impacted the person with dementia during the past week. The symptom list continues with eight more questions, switching to a proxy–proxy perspective by asking how frequently a situation occurred. IPOS-Dem closes with three scorable 'wild card' symptom fields. The IPOS-Dem was developed for the LTCF context, where its introduction to routine care was established as feasible and acceptable [7]. Our Swiss-German easy-language translation for frontline staff and family members established good face and content validity [9], even though results from the family member rater population remain to be written for publication. Our family member version differs minimally in semantics but not conceptually from the frontline staff version (e.g., asking, 'Have you or other family members felt anxious or worried?' instead of 'Have any of his/her family been anxious or worried about the person?'). Because of the recent challenges of recruiting people with dementia living in nursing homes for research studies, comprehensive psychometric testing for the versions of the IPOS-Dem remains to be completed [5, 9].

In our translation and validation work [9], we found the revised Edmonton Symptom Assessment System (ESAS-r) [10] o be a commonly occurring instrument for assessing symptoms in people with dementia in LTCFs. ESAS-r has been officially translated into German [11] and is known as Minimal Documentation System for Palliative Patients (MIDOS). The target population has always been people in general and specialist palliative care services [12], whose needs may significantly differ from those of people with dementia living in LTCFs [1]. With nine core symptoms, ESAS-r is significantly shorter than IPOS-Dem. Essentially, The version of ESAS-r used in Switzerland is essentially a symptom list with 0–10 numeric rating scales. Although ESAS-r was conceptualised to enable the longitudinal plotting of symptom burden to monitor people regarding symptoms [10], this mode of use has not been widely utilised in Swiss LTCFs, where it has mainly been used for palliative care screening [9]. One of the advantages of IPOS-Dem is that it is specific to older people with dementia, expands on the symptoms in ESAS-r and can easily be integrated into dashboards and serve as an outcome measure across settings and language regions [7, 13].

Our study aimed to determine the structural validity and internal consistency of the Swiss easy-read IPOS-Dem family member and frontline staff versions. Because of the vulnerability of the target population and the patient-reported outcome measure roots of IPOS-Dem, it and its parent measure—the Integrated Palliative Outcome Scale (IPOS)—are reduced instruments (i.e. the various constructs are not overdetermined, being measured by one item each); therefore, unidimensionality was not expected. However, the parent measure, IPOS, was designed based on a reflective model, with the underlying construct being palliative care-related concerns [14]. Because adaptation to the target population of people with dementia added several constructs [1, 9] to the measure, an exploratory approach was taken to describe its internal structure.

Methods

This study is a secondary data analysis from a multicentre study with 15 time periods (T0, T1 … T14), where data were collected as outlined in the main studyreport [15]. The primary study is a stepped-wedge cluster randomised trial of monthly IPOS-Dem assessment. After cross-over to the intervention, the LTCFs added monthly person profiles, in which frontline staff, family members and clinical nurse specialists discussed their IPOS-Dem findings to develop person-centred care plans.

In the present analysis, IPOS-Dem assessments were analysed separately for family members and frontline staff, although the items do not differ conceptually. For the analysis, data from one period per person with dementia for each version were used. Family members assessed the person with dementia to whom they were related, while frontline staff were assigned to people with dementia according to convenience. People with dementia were assessed with IPOS-Dem by family members between 16 January 2021 and 9 January 2023. Staff versions were completed between 5 March 2021 and 16 July 2022.

IPOS-Dem administration

The study team assigned each of the participating LTCFs a clinical champion in collaboration with the LTCF leadership staff. The clinical champion was a full-time local employee of the respective LTCF who oversaw recruitment, data collection and general study coordination with the study team. This is further outlined in the main study protocol [16]. Frontline staff and family members completed the instruments for people with dementia on the paper version of the IPOS-Dem. For frontline staff, we chose to use the completed IPOS-Dem measures from T13T13, which was the last time period in which no concurrent measurement instruments had to be completed, and the frontline staff were theorised as having considerable experience with the measure. Due to attrition and practical considerations for data collected by family members, the baseline data (T0) were included in our analysis. Specifically, our case selection algorithm most readily identified baseline assessments, and family member participation in the intervention condition declined significantly over the 15-month study period, particularly in cluster groups randomised to sequences where the intervention commenced after six or nine months [15].

Data collection procedures

Sociodemographic and clinical details of those with dementia were derived from their respective LTCF's Minimum Data Set (MDS) into Research Electronic Data Capture (REDCap), hosted at the HES-So University of Applied Science and Arts of Western Switzerland's Data Acquisition Unit in the Canton of Valais [17, 18]. The sociodemographic and clinical details collected included age, gender, dementia type and severity (if diagnosed). "Immediately after a training session for the main study, frontline staff and family members completed a survey designed to collect their sociodemographic data. This training also included instructions on how to complete the IPOS-Dem. The clinical champions entered the IPOS-Dem data into REDCap, which is browser-based software that provides continuous feedback to its users [17]. Automated tests run by REDCap check the data for plausibility and completeness [17].

Sample size

This overarching trial determined the sample size in which IPOS-Dem was captured. For this trial, between September 2020 and February 2023, we aimed to enrol 220 people with dementia living in 22 LTCFs [16]. Regarding the frontline staff, a total rater population of 440 people was targeted. In contrast, no target number of family members was defined because of demographic realities (i.e. many older people living in Swiss LTCFs do not have visiting relatives). Together with us, the LTCFs determined the sample of people with dementia assessed after screening all residents for inclusion and exclusion criteria (i.e. a convenience sample). We included people with dementia living in the LTCF with a diagnosis of Alzheimer's or vascular dementia or with symptoms indicating dementia, as documented in the LTCF MDS. Sample size adequacy to conduct our analysis for both assessor groups was determined post hoc by calculating and interpreting the Kaiser–Meyer–Olkin criterion according to Kaiser and Rice [19].

Statistical analysis

The IPOS-Dem assessments were analysed separately for each rater population. First, we inspected common item characteristics. The overall and individual measures of sampling adequacy were interpreted according to Kaiser's guidance, which deems values below 0.5 as 'unacceptable'. Furthermore, we tested whether the item correlation matrix was an identity matrix using the methods described by Bartlett [20], here with a Type I error acceptance threshold of 5% ($\alpha = 0.05$). A visual inspection of the correlation matrix (using Pearson's correlation coefficient [21]) followed this to exclude multicollinearity issues (correlations > 0.9) and to double-check for insufficient correlations (correlations < 0.3) to conduct factor analysis.

The number of factors to extract was determined by conducting Horn's parallel analysis, as described by Hayton et al. [22]. Its implementation in the paran 1.5.2 R package [23] performs simulated factor extraction iterations based on random datasets with the same number of items. It contrasts the factor eigenvalues with the extracted eigenvalues for the original dataset [24]. All our analyses were carried out using R 4.2.2 in RStudio 2023.06.0 [25] on macOS 13.4 and various packages, such as tidyverse 2.0.0 [26] for data wrangling and psych 2.3.3 [27] for common calculations in classical test theory.

Exploratory factor analysis

We then proceeded to model solutions for the number of factors resulting from the parallel analysis by conducting an exploratory factor analysis (EFA) with a minimum residual solution and varimax rotation [27]. Next, we inspected the factor loadings onto the factors to guide our dimensionality optimisation. Items were then removed individually, with the factor solution re-estimated after each deletion. Items were removed based on their factor loadings, with the lowest loadings removed first.

Internal consistency

After dimensionality optimisation, the resulting subscales' interitem and item-total correlations were calculated and described. This was followed by calculating each subscale's total and Cronbach's α when the corresponding item was dropped. In this step, we also inspected the values to identify items that increased the subscale total Cronbach's α. Items identified in this manner were excluded from the model and solution in the same stepwise manner described in the dimensionality optimisation. Subscales were named by the authors based on the items loading onto them. The thematic grouping of IPOS-Dem items suggested by the developers [7] (i.e. physical symptoms; emotional, social and existential; family concerns) was omitted.

Missing data

Some people with dementia were lost to follow-up at T13 of the overarching study, and the last IPOS-Dem rating was carried forward. Regarding this loss to follow-up, IPOS-Dem measures were handled as one entity. For each item, only complete cases were modelled. For IPOS-Dem measures completed by family members, the baseline observation (T0) entered the analysis because there were no concurrent measures for them to complete, and attrition was hypothesised as being high. We conducted a sensitivity analysis using various classic imputation methods (best case (0), worst case (4), numeric marker (5), mean and median) to validate our procedure for handling missing data. The different solutions were compared using multiple absolute and relative fit indices, such as the root mean square error of approximation (RMSEA) with its 90% confidence intervals (90% CI), the Tucker–Lewis Index of factoring reliability (TLI) and the Bayesian information criterion (BIC) to order the various potential solutions.

Additional analysis

Regarding the sociodemographic information for people with dementia, the two rater populations were analysed and reported using common descriptive statistical methods to describe central tendencies (i.e. mean [M] or median [Med]), frequencies (number [n] and percentages [%]) and dispersion (standard deviation [SD], minima and maxima [min-max]) of the sociodemographic data. Basic item characteristics (M score, score SD, % per response option, n of complete cases per item) and additional item characteristics (Med, trimmed M, Med absolute deviation, min-max, range, skew, kurtosis, standard error, interquartile range and item difficulty (mean/4)) were calculated for the family member version and frontline staff version of IPOS-Dem separately.

Results

Participants and characteristics

Frontline staff assessed $n = 257$ people with dementia, of whomom 118 had family members who also completed and submitted the respective IPOS-Dem. On average, the people with dementia were 86 years old. Despite meeting our inclusion criteria, nearly a third (28.4%) did not have a dementia diagnosis in their records. Of those where dementia severity was documented in the MDS, 62.6% had advanced dementia, but about half of the people with dementia had only low dependency in their activities of daily living, according to the Resident Assessment

Instrument for Nursing Homes Activities of Daily Living Short-Form Scale [28]. More details and the differences in the sample as assessed by family members and staff are illustrated in Table 1.

The 27 IPOS-Dem items are described in Table 2, as scored by frontline staff, and in Table 3, as scored by family members. Most IPOS-Dem items in both versions showed floor effects, with more than 15% of responses falling into the lowest category [29]. However, in the family member version, only four out of the 27 items—'Able to interact', 'Drowsiness', 'Inner peace' and 'Weakness'—did not show floor effects. For additional item characteristics, please refer to Additional File 1.

Swiss easy-read IPOS-Dem for frontline staff

Exploratory factor analysis

With the solution after structural optimisation, 22 of the original 27 IPOS-Dem items were retained, and no item exhibited substantial cross-loading (> 0.3) onto multiple factors. Factor 1, termed 'Dementia Physical and Interaction Impact' (DPII), encompassed items related to functional, social and physical needs, while Factor 2, named 'Dementia Emotional and Behavioural Impact' (DEBI), focused on the behavioural and psychological symptoms of dementia (BPSD).

The final fitted factor model from an EFA was conducted for 22 items with orthogonal rotation (varimax) and a minimum residual solution. The Kaiser–Meyer–Olkin measure verified the sampling adequacy for the analysis, iMSA = 0.78 ('middling', according to Kaiser, 1974), and all iMSA values for individual items were > 0.53, just above the acceptable limit of 0.5. Bartlett's test of sphericity, $\chi^2(351) = 2363.878$, $p < 0.001$, indicated that correlations between items were sufficiently large for EFA. A parallel analysis was run to obtain the adjusted eigenvalues for each factor in the data. Two factors had adjusted eigenvalues above 0 and together explained 32% of the variance. The factor loadings are shown in Fig. 1.

This model did not achieve an acceptable fit (< 0.06 according to Hoyle [30]), with an RMSEA of 0.09 and a 90% confidence interval of 0.082 to 0.098. RMSEA, however, has been considered sensitive to sample sizes below 200 and in small models [30]. Furthermore, the Tucker–Lewis Index of factoring reliability (TLI), which is considered insensitive to small n while penalising model complexity, also indicated poor fit, with the model at 0.707, below its cut-off of 0.95 [30]. A sensitivity analysis was performed to check whether the model fit would differ with various imputation methods to replace the missing responses. However, no improvements in fit were found.

Internal consistency

The two IPOS-Dem subscales—DPII and DEBI—appeared to be internally consistent, with the DPII subscale demonstrating a Cronbach's α value of 0.83 and the DEBI subscale exhibiting a Cronbach's α value of 0.81. Individual item statistics are provided in Table 4.

Swiss easy-read IPOS-Dem for Family Members

Exploratory factor analysis

After structural optimisation, we retained 25 of the original 27 items in the model, which mainly differentiated between physical symptoms that are hard to assess by visiting family members, functional symptoms, psychosocial symptoms and concerns and physical symptoms that are easier to assess by visiting family members.

According to this solution, we suggested four subscales, which were in the same vein as the frontline staff version but split DPII into three tentative subscales: Dementia Physical Impact Hard to Assess (DPIh), Dementia Physical Impact Easy to Assess (DPIe) and Dementia Interaction Impact (DII). However, when determining internal consistency, we identified issues with items that seemed to increase Cronbach's α of their respective scales, that is, DII and DEBI, when deleted from it.

After additional item removals, 21 of the original 27 items were retained. These mainly differentiated between physical symptoms that would be hard to assess by visiting family members, functional symptoms, psychosocial symptoms and concerns and physical symptoms that

Table 1 People with dementia's sociodemographic data

Variable	Staff version	Family version[a]
People with dementia (n1)	257	118
Female (n, [%])	179 [69.6%]	84 [73%]
Age (mean [± SD])	86.4 [± 7.5]	87.0 [± 6.8]
Dementia diagnosis in MDS (n, [%])	184 [71.6%]	90 [78.3%]
Alzheimer's' dementia (n, [%])	84 [32.7%]	49 [42.6%]
Vascular dementia (n, [%])	19 [7.4%]	9 [7.8%]
Other dementia type (n, [%])	81 [31.5%]	32 [27.8%]
Dementia severity in MDS (n, [%])	187 [72.8%]	96 [81.4%]
Mild dementia ((n, [%])	5 [2.7%]	1 [1.0%]
Moderate dementia (n, [%])	65 [34.8%]	29 [30.2%]
Advanced dementia (n, [%])	117 [62.6%]	66 [68.8%]
Dependency[b]		
Low dependency (n, [%])	135 [52.5%]	72 [61.0%]
Medium dependency (n, [%])	53 [20.6%]	14 [11.9%]
Completely dependent (n, [%])	60 [23.3%]	25 [21.2%]
Dependency data missing (n, [%])	8 [3.1%]	7 [5.9%]

[a] People with dementia assessed by family members from the same population as those assessed by staff, but at different time points during the trial

[b] Based on the Activities of Daily Living (ADL) Hierarchy Scale

Table 2 IPOS-Dem item characteristics staff version

Item		Cannot assess		Not at all (0)		Slightly (1)		Moderately (2)		Severely (3)		Overwhelmingly (4)	
Pain [a]	n (%)	12	4.70%	79	32.20%	79	32.20%	56	22.90%	25	10.20%	6	2.40%
Shortness of breath [a]	n (%)	4	1.60%	213	84.20%	26	10.30%	10	4%	2	0.80%	2	0.80%
Weakness [a]	n (%)	3	1.20%	65	25.60%	80	31.50%	57	22.40%	35	13.80%	17	6.70%
Nausea [a]	n (%)	16	6.20%	212	88%	18	7.50%	5	2.10%	5	2.10%	1	0.40%
Vomiting [a]	n (%)	9	3.50%	229	92.30%	11	4.40%	4	1.60%	2	0.80%	2	0.80%
Poor appetite [a]	n (%)	10	3.90%	131	53%	64	25.90%	33	13.40%	10	4%	9	3.60%
Constipation [a]	n (%)	14	5.40%	139	57.20%	66	27.20%	24	9.90%	10	4.10%	4	1.60%
Sore or dry mouth [a]	n (%)	17	6.60%	183	76.20%	28	11.70%	21	8.80%	6	2.50%	2	0.80%
Drowsiness [a]	n (%)	2	0.80%	61	23.90%	80	31.40%	70	27.50%	29	11.40%	15	5.90%
Poor mobility [a]	n (%)	1	0.40%	106	41.40%	41	16%	44	17.20%	35	13.70%	30	11.70%
Sleeping problems [a]	n (%)	11	4.30%	151	61.40%	54	22%	30	12.20%	5	2%	6	2.40%
Diarrhoea [a]	n (%)	9	3.50%	197	79.40%	36	14.50%	10	4%	3	1.20%	2	0.80%
Dental problems [a]	n (%)	10	3.90%	182	73.70%	32	13%	20	8.10%	9	3.60%	4	1.60%
Swallowing problems [a]	n (%)	6	2.30%	183	72.90%	32	12.70%	14	5.60%	12	4.80%	10	4%
Skin breakdown [a]	n (%)	5	1.90%	115	45.60%	73	29%	41	16.30%	19	7.50%	4	1.60%
Difficulty communicating [a]	n (%)	2	0.80%	83	32.50%	50	19.60%	50	19.60%	36	14.10%	36	14.10%
Hallucinations and/or delusions [a]	n (%)	18	7%	148	61.90%	47	19.70%	30	12.60%	7	2.90%	7	2.90%
Agitation [a,b]	n (%)	2	0.80%	72	28.20%	60	23.50%	66	25.90%	37	14.50%	20	7.80%
Wandering [a]	n (%)	4	1.60%	144	56.90%	40	15.80%	36	14.20%	21	8.30%	12	4.70%
Anxious or worried [a,b]	n (%)	3	1.20%	54	21.30%	55	21.70%	87	34.30%	46	18.10%	12	4.70%
Family anxious or worried [a,b]	n (%)	50	19.50%	69	33.30%	38	18.40%	52	25.10%	23	11.10%	25	12.10%
Felt depressed [a,b]	n (%)	26	10.10%	64	27.70%	58	25.10%	75	32.50%	29	12.60%	5	2.20%
Lost interest [a,b]	n (%)	37	14.40%	95	43.20%	54	24.50%	38	17.30%	24	10.90%	9	4.10%
Inner peace [a,b,c]	n (%)	40	15.60%	38	17.50%	84	38.70%	62	28.60%	27	12.40%	6	2.80%
Able to interact [a,b,c]	n (%)	5	1.90%	82	32.50%	44	17.50%	54	21.40%	46	18.30%	26	10.30%
Irritable or aggressive [a,b]	n (%)	3	1.20%	68	26.80%	67	26.40%	90	35.40%	23	9.10%	6	2.40%
Practical matters [a,b,c]	n (%)	19	7.40%	76	31.90%	92	38.70%	48	20.20%	10	4.20%	12	5%

[a] Items with a floor effect (more than 15% of responses in the lowest category)

[b] Frequency scale: Not at all (0) to Always (4)

[c] Inverted scale

would be easier to assess by visiting family members. The items that substantially loaded onto two or more of the factors (>0.3), that is, 'Constipation', 'Weakness', 'Drowsiness', 'Poor appetite', 'Swallowing problems', 'Family anxious or worried', 'Poor mobility', 'Able to interact' and 'Lost interest', were assigned to the factor they loaded onto the most.

The final fitted factor model from an EFA was conducted for 21 items with orthogonal rotation (varimax) and a minimum residual solution. The Kaiser–Meyer–Olkin measure verified the sampling adequacy for the analysis, iMSA = 0.86 ('meritorious' according to Kaiser, 1974), and all iMSA values for individual items were > 0.73, which is well above the acceptable limit of 0.5. Bartlett's test of sphericity, $\chi2(351) = 1270.148$, $p < 0.001$, indicated that the correlations between items were sufficiently large for EFA. A parallel analysis was run to obtain the adjusted eigenvalues for each factor in the data. Four factors had adjusted eigenvalues above 0 and explained 59% of the variance. The factor loadings are shown in Fig. 2.

The final model also did not achieve an acceptable fit, with an RMSEA of 0.173 (90% CI: 0.16–0.188). TLI also indicated poor fit, with the model at 0.533. A sensitivity analysis was undertaken to check whether the model fit would differ with various imputation methods to replace the missing responses. However, no improvements in fit were observed.

Internal consistency

Item-wise and subscale correlations and statistics for the IPOS-Dem for family members are shown in Table 5. The four IPOS-Dem subscales in the family member version—DPII, DPIe, DPIh and DEBI—appeared internally

Table 3 IPOS-Dem item characteristics family version

Item		Cannot assess		Not at all (0)		Slightly (1)		Moderately (2)		Severely (3)		Overwhelmingly (4)	
Pain [a]	n (%)	12	10.20%	34	32.10%	34	32.10%	26	24.50%	12	11.30%	0	0%
Shortness of breath [a]	n (%)	11	9.30%	72	67.30%	26	24.30%	6	5.60%	3	2.80%	0	0%
Weakness	n (%)	6	5.10%	9	8%	23	20.50%	43	38.40%	23	20.50%	14	12.50%
Nausea [a]	n (%)	32	27.10%	76	88.40%	8	9.30%	2	2.30%	0	0%	0	0%
Vomiting [a]	n (%)	33	28%	81	95.30%	4	4.70%	0	0%	0	0%	0	0%
Poor appetite [a]	n (%)	17	14.40%	53	52.50%	25	24.80%	11	10.90%	6	5.90%	6	5.90%
Constipation [a]	n (%)	67	56.80%	33	64.70%	12	23.50%	3	5.90%	2	3.90%	1	2%
Sore or dry mouth [a]	n (%)	33	28%	51	60%	21	24.70%	7	8.20%	4	4.70%	2	2.40%
Drowsiness	n (%)	9	7.60%	11	10.10%	34	31.20%	33	30.30%	20	18.30%	11	10.10%
Poor mobility [a]	n (%)	8	6.80%	17	15.50%	27	24.50%	27	24.50%	16	14.50%	23	20.90%
Sleeping problems [a]	n (%)	53	44.90%	32	49.20%	17	26.20%	14	21.50%	2	3.10%	0	0%
Diarrhoea [a]	n (%)	72	61%	33	71.70%	9	19.60%	2	4.30%	2	4.30%	0	0%
Dental problems [a]	n (%)	22	18.60%	50	52.10%	19	19.80%	18	18.80%	5	5.20%	4	4.20%
Swallowing problems [a]	n (%)	17	14.40%	54	53.50%	23	22.80%	12	11.90%	6	5.90%	6	5.90%
Skin breakdown [a]	n (%)	21	17.80%	41	42.30%	25	25.80%	23	23.70%	7	7.20%	1	1%
Difficulty communicating [a]	n (%)	4	3.40%	23	20.20%	16	14%	26	22.80%	26	22.80%	23	20.17%
Hallucinations and/or delusions [a]	n (%)	24	20.30%	43	45.70%	15	16%	21	22.30%	10	10.60%	5	5.30%
Agitation [a,b]	n (%)	7	5.90%	30	27%	33	29.70%	33	29.70%	14	12.60%	1	0.90%
Wandering [a]	n (%)	24	20.30%	65	69.15%	8	8.50%	16	17%	5	5.30%	0	0%
Anxious or worried [a,b]	n (%)	8	6.80%	19	17.30%	33	30%	46	41.80%	9	8.20%	3	2.70%
Family anxious or worried [a,b]	n (%)	3	2.50%	20	17.40%	23	20%	39	33.90%	19	16.50%	14	12.20%
Felt depressed [a,b]	n (%)	9	7.60%	23	21.10%	19	17.40%	52	47.70%	12	11%	3	2.80%
Lost interest [a,b]	n (%)	8	6.80%	17	15.50%	9	8.20%	32	29.10%	38	34.50%	14	12.70%
Inner peace [b,c]	n (%)	12	10.20%	12	11.30%	53	50%	25	23.60%	14	13.20%	2	1.90%
Able to interact [b,c]	n (%)	2	1.70%	14	12.10%	35	30.20%	25	21.60%	28	24.10%	14	12.10%
Irritable or aggressive [a,b]	n (%)	5	4.20%	45	39.80%	33	29.20%	33	29.20%	2	1.80%	0	0%
Practical matters [a,b,c]	n (%)	33	28%	22	25.90%	29	34.10%	20	23.50%	4	4.70%	10	11.80%

[a] Items with a floor effect (more than 15% of responses in the lowest category)

[b] Frequency scale: Not at all (0) to Always (4)

[c] Inverted scale

consistent, with the DII subscale demonstrating a Cronbach's α value of 0.83 and the DEBI subscale exhibiting a Cronbach's α value of 0.86. The Dementia Physical Impact subscales DPIe and DPIh showed Cronbach's α values of 0.84 and 0.77, respectively.

Discussion

Our study aimed to determine internal consistency and explore the structural validity of the Swiss easy-read IPOS-Dem. A two- and four-factor solution has been described for the frontline staff and family member versions of the measures. The resulting subscales show Cronbach's α values within acceptable intervals. For the frontline staff version, the DEBI showed a Cronbach's α of 0.83, and the second subscale, DPII, showed a Cronbach's α of 0.81. The family member version of DPII was split into hard-to-measure and easy-to-assess symptoms and concerns (DPIh and DPIe) and the interaction impact (DII). The four subscales' Cronbach's α ranged between 0.77 and 0.86. However, the fitted two- and four-factor models were not optimal regarding the absolute goodness-of-fit measures, and neither reached thresholds deemed acceptable, with RMSEAs of 0.173 for the family member version and 0.09 for the frontline staff version of IPOS-Dem.

The systematic use and integration of instruments like IPOS-Dem have been shown to be beneficial for individuals with dementia [15]. IPOS-Dem can feasibly assess palliative care-related symptoms and concerns [7, 9, 31]. By involving family members and staff in the care process, IPOS-Dem fosters a person-centred approach, even in advanced dementia or in LTCFs where professional staff experience high turnover [31]. Evidence from specialist palliative care indicates that integrating outcome

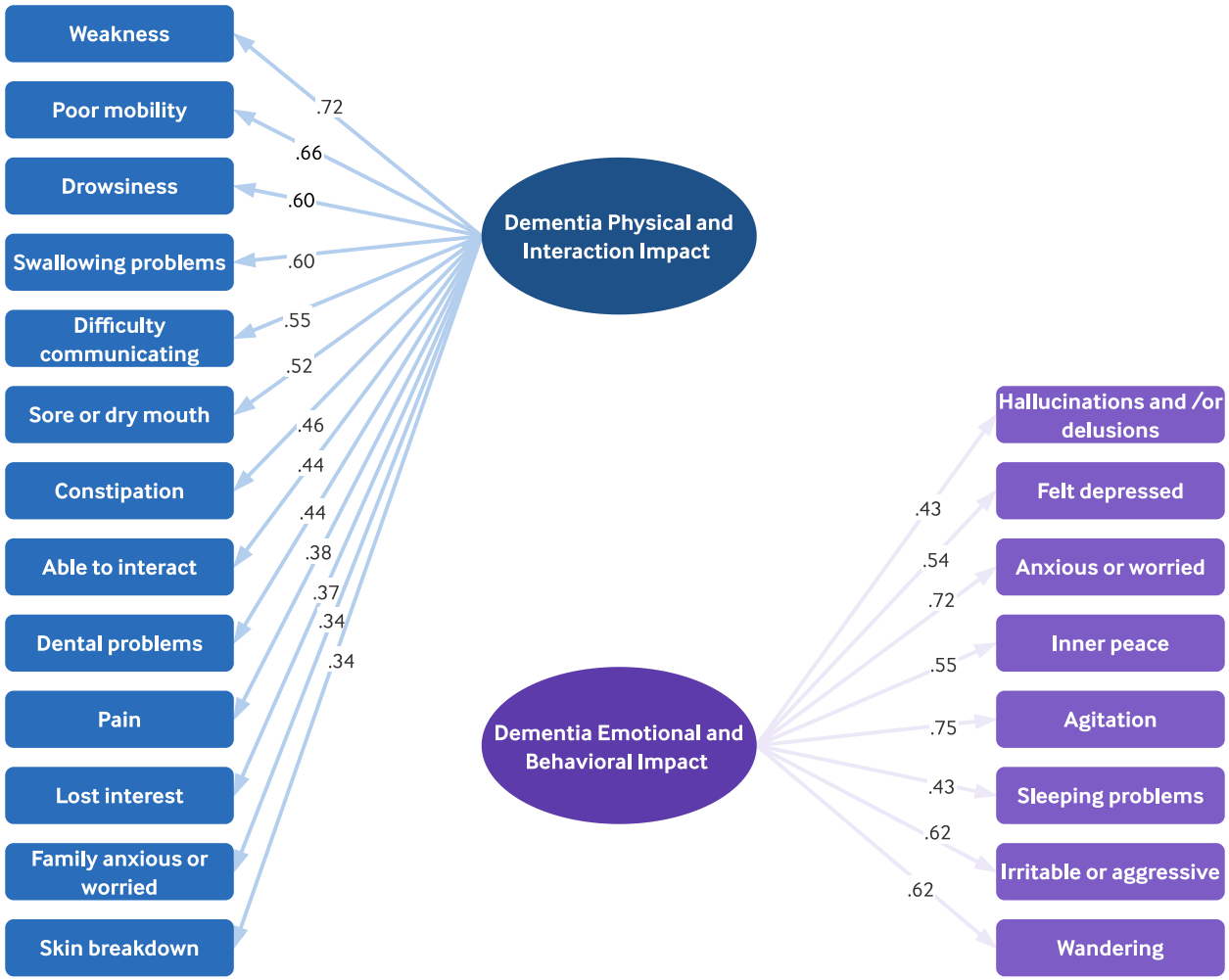

Fig. 1 Rotated factor loadings for the IPOS-Dem staff versions ($n = 257$): two tentative subscales

measures like the IPOS-Dem supports person-centred care planning, counteracting overly task-based care practices [32, 33]. Furthermore, the IPOS-Dem enhances communication, teamwork and systematic care planning by including multiple perspectives and facilitating collaborative assessments [7, 15, 31]. Its use in LTCFs supports holistic monitoring and care provision, while empowering informal caregivers, increasing their engagement in care and improving communication between care providers [7].

We observed differences in the internal structure of the family member and staff versions of IPOS-Dem. While the items still load onto subscales that are similar, it is the emotional and behavioural items—hallucinations or delusions, irritability and aggressiveness, sleeping problems and wandering—that did not meet the criteria for inclusion in the DEBI scale in the family member version of IPOS-Dem. The other main difference, as reflected in our naming of the split DPI subscales, seems to arise from the relatively shorter observation intervals used by family members compared to frontline staff, which they supposedly rely on to make their ratings. It is unsurprising that perceptions and ratings differ, as this has also been described in proxy ratings of people with dementia's quality of life [34, 35]. Robertson pointed out that differences between staff and family member ratings may stem from multiple dimensions: differences in experiences that shape varying focuses, coping mechanisms related to distinct roles in quality of life, the process of adjusting to and coping with loss, and variations in understanding and insight. The main reason we believe contributes to these differences, in addition to the lack of 24-h presence with the person with dementia, is that family members may evaluate based on the person's past and what has been lost, while staff may lack insight into the person's previous experiences but often equate quality of life with quality of care, potentially leading to more positive evaluations.

Table 4 Subscale and individual item statistics for the IPOS-Dem frontline staff version

Dementia Physical and Interaction Impact subscale statistics			Cronbach's α	Guttman's λ 6	Average interitem correlation	M	SD
			0.83	0.85	0.26	1.08	0.67
Item	**n**	**Item-total correlation**	**Item-total correlation** [a]	**Item-total correlation** [b]	**Item-total correlation** [c]	**M**	**SD**
Pain	245	0.47	0.47	0.4	0.36	1.18	1.07
Weakness	254	0.73	0.72	0.72	0.65	1.44	1.2
Poor appetite	247	0.63	0.65	0.61	0.55	0.79	1.06
Constipation	243	0.52	0.53	0.47	0.43	0.66	0.93
Sore or dry mouth	240	0.53	0.56	0.52	0.45	0.4	0.82
Drowsiness	255	0.64	0.64	0.62	0.56	1.44	1.14
Poor mobility	256	0.7	0.67	0.65	0.6	1.38	1.43
Dental problems	247	0.47	0.5	0.45	0.39	0.47	0.91
Swallowing problems	251	0.61	0.6	0.56	0.51	0.54	1.06
Skin breakdown	252	0.43	0.44	0.37	0.32	0.9	1.03
Difficulty communicating	255	0.65	0.63	0.6	0.55	1.58	1.43
Family anxious or worried	207	0.47	0.45	0.39	0.34	1.5	1.37
Lost interest	220	0.5	0.49	0.44	0.4	1.08	1.19
Able to interact	252	0.55	0.53	0.47	0.43	1.56	1.37
Dementia Behavioural and Emotional Impact subscale statistics			**Cronbach's α**	**Guttman's λ 6**	**Average interitem correlation**	**M**	**SD**
			0.81	0.81	0.35	1.17	0.74
Item	**n**	**Item-total correlation**	**Item-total correlation** [a]	**Item-total correlation** [b]	**Item-total correlation** [c]	**M**	**SD**
Sleeping problems	246	0.54	0.55	0.44	0.4	0.62	0.95
Hallucinations and/or delusions	239	0.56	0.56	0.46	0.41	0.65	1
Agitation	255	0.79	0.77	0.76	0.68	1.5	1.26
Wandering	253	0.67	0.65	0.61	0.53	0.88	1.21
Anxious or worried	254	0.77	0.75	0.73	0.65	1.63	1.14
Felt depressed	231	0.65	0.64	0.57	0.5	1.36	1.08
Inner peace	217	0.63	0.64	0.56	0.51	1.44	1.01
Irritable or aggressive	254	0.67	0.68	0.61	0.55	1.34	1.04

[a] When items are standardised

[b] When the items are standardised and correlations are corrected for item overlap

[c] When an item is dropped from the scale

Strengths and limitations

For the primary study, a considerable sample of people with dementia, family members and frontline staff in LTCFs was engaged. The easy-read IPOS-Dem is a promising person-centred measure for analysing the outcomes of older people with dementia living in LTCFs. The IPOS-Dem's particular strengths lie in the availability of proxy versions for family members and frontline staff, with a self-report version still in early development. This paper is one of the first publications to evaluate the psychometric properties of the IPOS-Dem in a larger sample. In this secondary analysis of trial data using exploratory factor analysis, several limitations must be highlighted. Our sample of people with dementia may be limited in several ways. Sampling bias is a significant concern when conducting research in LTCFs, particularly in the context of convenience sampling. This type of bias may have been introduced by selecting LTCFs based on their availability or convenience rather than ensuring they were representative of the entire population. Although 435 LTCFs in German-speaking Switzerland were contacted, only a small number were able to participate and provide data. As a result, the findings from our sample may not accurately reflect the broader population of people with dementia living in nursing homes.

Another form of bias, known as self-selection bias, can impact research in LTCFs. This bias may have occurred because participants and their legal representatives were

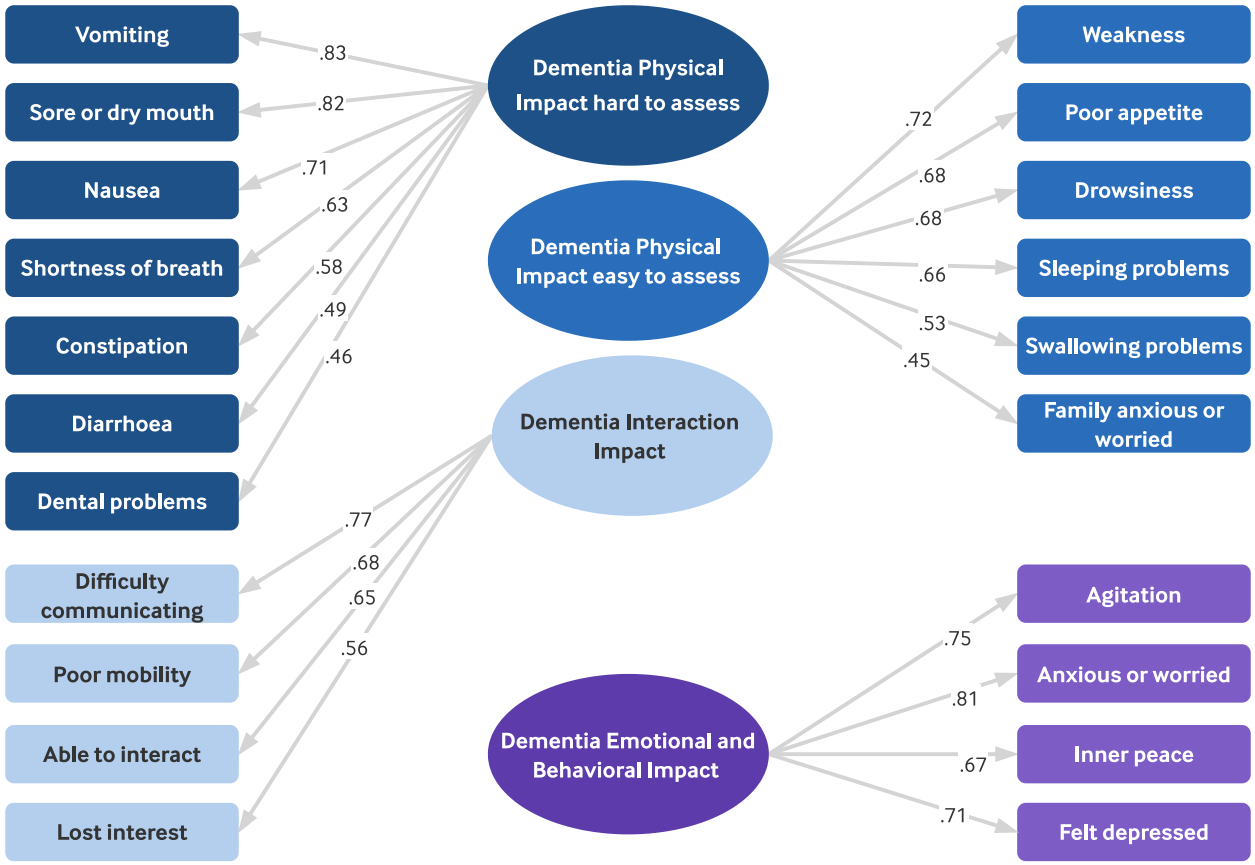

Fig. 2 Rotated factor loadings for the IPOS-Dem family member versions ($n = 118$): four tentative subscales

free to decide whether they wanted to participate. Consequently, individuals more interested in the study's topic may have been more inclined to participate, potentially skewing the sample.

To address these limitations in future research, it would be beneficial to aim for a larger and more representative sample of people with dementia, recruiting participants from a diverse range of facilities. This broader approach could help minimise the influence of sampling bias and enhance the generalisability of the findings. Furthermore, collecting data on participants' cognitive impairment levels and co-occurring health conditions would be valuable. Although we collected data on dementia severity and type, concerns arose regarding the accuracy and timeliness of information obtained from the minimum dataset of nursing homes. Improving the accuracy and comprehensiveness of data collection on dementia severity and other comorbid diagnoses would strengthen our ability to account for sampling bias and heterogeneity.

In the present study, it is worth noting that a substantial sample of 23 Swiss-German LTCFs was included, providing a reasonable breadth of representation. However, to further enhance the robustness of the findings, expanding recruitment efforts to include a larger number of LTCFs may be beneficial, as this could increase the diversity and representativeness of the sample.

Comparison with other instruments

We compare our results to the IPOS, from which the IPOS-Dem was derived. IPOS underwent confirmatory factor analysis for its 17 scorable items, with 376 participants [36]. However, IPOS was validated in English and German palliative care settings, which primarily dealt with oncologic primary diagnoses and typically cared for younger people compared with our study [36]. Murtagh et al. proposed a three-factor solution grouping the 10 physical symptoms, four emotional symptoms and a third factor with three items related to communication and practical issues. The three subscales showed Cronbach's α values between 0.58 and 0.70, with a total scale Cronbach's α of 0.77. We suggest that the difference in population and additional item measures contributed to the difference in the number of subscales. Interestingly, the IPOS confirmatory factor analysis with one-, two- and three-factor solutions was only undertaken for the self-assessment version of IPOS. Although inter-rater

Table 5 Subscale and individual item statistics for the IPOS-Dem family member version

Dementia Interaction Impact subscale statistics			**Cronbach's α**	**Guttman's λ 6**	**Average interitem correlation**	**M**	**SD**
			0.83	0.79	0.54	2.06	1.07
Item	**n**	**Item-total correlation**	**Item-total correlation** [a]	**Item-total correlation** [b]	**Item-total correlation** [c]	**M**	**SD**
Poor mobility	110	0.79	0.79	0.67	0.61	2.01	1.36
Difficulty communicating	114	0.86	0.86	0.81	0.73	2.09	1.41
Lost interest	110	0.8	0.81	0.72	0.64	2.21	1.23
Able to interact	116	0.79	0.79	0.68	0.62	1.94	1.23
Dementia Physical Impact Easy to Assess subscale statistics			**Cronbach's α**	**Guttman's λ 6**	**Average interitem correlation**	**M**	**SD**
			0.84	0.84	0.48	1.52	0.94
Item	**n**	**Item-total correlation**	**Item-total correlation** [a]	**Item-total correlation** [b]	**Item-total correlation** [c]	**M**	**SD**
Weakness	112	0.83	0.86	0.86	0.78	2.09	1.11
Poor appetite	101	0.76	0.74	0.65	0.6	0.88	1.19
Drowsiness	109	0.82	0.84	0.82	0.75	1.87	1.14
Sleeping problems	65	0.71	0.71	0.62	0.56	0.78	0.89
Swallowing problems	101	0.77	0.7	0.6	0.56	0.88	1.19
Family anxious or worried	115	0.7	0.68	0.58	0.54	1.86	1.24
Dementia Physical Impact Hard to Assess subscale statistics			**Cronbach's α**	**Guttman's λ 6**	**Average interitem correlation**	**M**	**SD**
			0.77	0.86	0.4	0.55	0.74
Item	**n**	**Item-total correlation**	**Item-total correlation** [a]	**Item-total correlation** [b]	**Item-total correlation** [c]	**M**	**SD**
Shortness of breath	107	0.79	0.71	0.66	0.59	0.44	0.73
Nausea	86	0.7	0.7	0.63	0.51	0.14	0.41
Vomiting	85	0.7	0.79	0.78	0.66	0.05	0.21
Constipation	51	0.7	0.75	0.75	0.56	0.55	0.92
Sore or dry mouth	85	0.89	0.8	0.78	0.75	0.65	0.98
Diarrhoea	46	0.65	0.57	0.47	0.39	0.41	0.78
Dental problems	96	0.73	0.57	0.46	0.42	0.9	1.14
Dementia Behavioural and Emotional Impact subscale statistics			**Cronbach's α**	**Guttman's λ 6**	**Average interitem correlation**	**M**	**SD**
			0.86	0.84	0.61	1.46	0.83
Item	**n**	**Item-total correlation**	**Item-total correlation** [a]	**Item-total correlation** [b]	**Item-total correlation** [c]	**M**	**SD**
Agitation	111	0.84	0.84	0.77	0.7	1.31	1.03
Anxious or worried	110	0.88	0.89	0.86	0.79	1.49	0.96
Felt depressed	109	0.84	0.84	0.76	0.7	1.57	1.03
Inner peace	106	0.8	0.81	0.7	0.65	1.44	0.93

[a] When the items are standardised

[b] When items are standardised and correlations are corrected for item overlap

[c] When an item is dropped from the scale

reliability was acceptable for most items, it would be interesting to explore whether the internal structure remains similar depending on the rater type. The ability to administer IPOS with different proxies (staff, family members) and in self-assessment is considered one of IPOS's greatest strengths compared with other health-related quality-of-life measures and measures of symptom burden used in clinical practice and research [36].

The IPOS-Dem, with its list of symptoms and concerns, aims to capture the impact of the health situation on the person with dementia in a multidimensional way. The multidimensionality reflected in IPOS and IPOS-Dem arises from the philosophy of palliative care on which it was based, recognising that relevant needs can be physical, psychological, social and spiritual [1]. Conceptually, the IPOS-Dem appears to be more closely aligned with clinical

screening instruments that determine the absence or presence of specific symptoms or their intensity, such as the revised Edmonton Symptom Assessment System (ESAS-r) and its officially validated German translation, 'Minimales Dokumentationssystem' (MIDOS^2), which is the Swiss standard for symptom assessment [11, 37]. Measures developed for palliative care self-assessment are often reduced to minimise the burden on patients, meaning that psychometric approaches developed for overdetermined measures (i.e., where multiple items measure the same construct) may not be suitable [37]. In MIDOS^2, the authors reported three factors. The first one, calculated from four items, indicates existential and psychosocial suffering. The second factor describes the intensity of the physical symptom burden using four items. The last factor, with three items, can be interpreted as an indicator of disease progression.

Conclusion

The IPOS-Dem provides a person-centred outcome measure for people with dementia that is easy to use in LTCFs. The findings from this study offer evidence of the internal consistency and structural validity of the Swiss easy-read IPOS-Dem. For each proxy rater population, frontline staff and family members described comparable internal structures. Internal consistency indices between 0.77 and 0.86 indicated acceptable to good internal consistency for the subscales. This evidence supports the use of the reduced instrument in clinical practice and clinical decision-making processes. However, further research into the psychometric properties of the Swiss easy-read IPOS-Dem is required. To improve the IPOS-Dem, additional efforts targeting rating and observation procedures may be beneficial. One of the theorised strengths of the Swiss easy-read IPOS-Dem was its potential to mitigate contextual barriers to the effective implementation of palliative and person-centred care in Swiss-German LTCFs. These barriers include low incentives for professional staff development, high frontline staff turnover and the supersaturation of methods and instruments for dementia and aged care. [38, 39]

Based on our results, the Swiss easy-read IPOS-Dem DPII and DEBI mean scores may be used in future research involving frontline staff as proxy raters for symptoms and concerns in people with dementia. However, we also recommend tracking how the impact of symptoms and concerns evolves on an individual level. Future research could focus on inter-rater reliability between the two instrument versions for family members and frontline staff at both the subscale and individual symptom levels. Further psychometric analyses on test–retest reliability, concurrent validity and responsiveness are also necessary. Additional publications on its psychometric validation, IPOS-Dem language, setting-specific versions and further resources are available at http://pos-pal.org/.

Abbreviations

BIC	Bayesian information criterion
DEBI	Dementia Emotional and Behavioural Impact
DII	Dementia Interaction Impact
DPIe	Dementia Interaction Impact Easy-to-Assess Symptoms and Concerns
DPII	Dementia Physical and Interaction Impact
DPIh	Dementia Interaction Impact Hard-to-Measure Symptoms and Concerns
EFA	Exploratory factor analysis
ESAS-r	Edmonton Symptom Assessment System - revised
iMSA	Measure of sampling adequacy
IPOS	Integrated Palliative Care Outcome Scale
IPOS-Dem	Integrated Palliative Care Outcome Scale for People with Dementia
LTCF	Long-term care facility
M	Mean
MDS	Minimum data set
Med	Median
2	Minimales Dokumentationssystem für Patienten in der Palliativmedizin (Minimal Documentation System for Palliative Patients)
n	Number
REDCap	Research Electronic Data Capture
RMSEA	Root mean square error of approximation
SD	Standard deviation
TLI	Tucker–Lewis index of factoring reliability

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-025-01691-9.

Additional file 1.

Acknowledgements

We want to thank the frontline staff who were involved in this study. Furthermore, we wish to thank the clinical champions who participated: A. Beqiri, R. Benz, M. Bonaconsa, A. Brunner, A. Conti, M. Deflorin, D. Deubelbeiss, L. Ebener, S. Egger, E. Eichinger, D. Elmer, A. Ermler, M. Fuhrer, C. Grichting, M. Havarneanu, H. Hettich, E. Hoffmann, E. Imgrueth, R. Juchli, I. Juric, K. Knöpfli, S. Kuonen, F. Laich, H. Meiser, N. Mergime, B. Michel, C. Ming, F. Müller, C. Niederer, G. Parkes, P. Piguet, A. Repesa, C. Ritz, B. Santer, A. Schallenberg, C. Schweiger, M. Spitz, and R. Strunck. We also extend our thanks to F. Murtagh, W. Sermeus, T. v. Achterberg and L. v.d. Block and Th. Volken for their discussions on the results and IPOS-Dem in general with us.

Authors' contributions

André Meichtry: Data curation, Formal analysis, Methodology, Validation, Visualisation and Writing - review & editing. Andrea Koppitz: Conceptualisation, Funding acquisition, Investigation, Project administration, Resources, Supervision and Writing - review & editing. Frank Spichiger: Conceptualisation, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Visualisation, Writing - original draft and Writing - review & editing. Philip Larkin: Conceptualisation, Funding acquisition, Resources, Software, Supervision and Writing - review & editing.

Funding

This work was supported by the Swiss Academic Medical Society, the Gottfried and Julia Bangeter-Rhyner Foundation, the HES-SO University of Applied Science and Arts Western Switzerland Bureau d'Appui et de Coordination de la Formation Doctorale and the Socratic Care Academy of Switzerland.

Data availability

The full dataset and R-code for reproducing the data are available at: Spichiger, F., Koppitz, A. L., Meichtry, A., Larkin, P., HES-SO Fribourg, & University of Lausanne. (2025). Internal consistency and structural validity of the Swiss easy-read Integrated Palliative Care Outcome Scale for Dementia: A secondary exploratory factor analysis [Data set]. Zenodo.https://doi.org/10.5281/zenodo.14789065.

Declarations

Ethics approval and consent to participate

All participants were required to provide informed consent and sign a consent form before data collection. The consent form and study materials were approved by the relevant Ethics Committee of the Canton of Zürich. The trial was approved by the Swiss Regional Ethics Committee of the Canton of Zürich on 12 November 2019, serving as the leading ethics committee for the involved regions, with clearance certification number BASEC2019-01847. The main study and secondary analysis were registered with the German Clinical Trials Register (DRKS00022339). Full registration details can be accessed online at http://www.drks.de/DRKS00022339. The trial was planned and conducted in accordance with the European Medicines Agency Good Clinical Practice Guidelines [38], which are based on the Declaration of Helsinki [39].

Consent for publication

All participants provided informed consent for publication via an informed consent form before data collection.

Competing interests

AK and FS are the translators/developers of the Swiss easy-read IPOS-Dem. The Swiss easy-read IPOS-Dem is a secondary outcome measure in a trial, where AK is the principal investigator. AM and PL have no conflicts of interest to disclose.

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Received: 12 October 2023 Accepted: 13 February 2025
Published online: 22 February 2025

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