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Citation: Johansson, T., Bujacz, A., Kowalski, L., Tishelman, C., Nierop-van Baalen, C. A., Eriksson, L. E., Groot, M., Olsson, Å., Vanderstichelen, S., Cohen, J. & et al (2025). Measurement invariance of the Death Literacy Index across Flemish Belgium, The Netherlands, and Sweden. Death Studies, pp. 1-9. doi: 10.1080/07481187.2025.2468162

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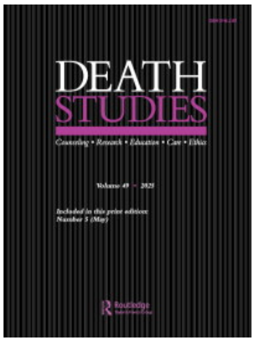

Death Studies

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/udst20

Measurement invariance of the Death Literacy Index across Flemish Belgium, The Netherlands, and Sweden

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To cite this article: Therese Johansson, Aleksandra Bujacz, Leo Kowalski, Carol Tishelman, Corine A. Nierop-van Baalen, Lars E. Eriksson, Marieke Groot, Åsa Olsson, Steven Vanderstichelen, Joachim Cohen & Ida Goliath (25 Feb 2025): Measurement invariance of the Death Literacy Index across Flemish Belgium, The Netherlands, and Sweden, Death Studies, DOI: 10.1080/07481187.2025.2468162

To link to this article: https://doi.org/10.1080/07481187.2025.2468162

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https://doi.org/10.1080/07481187.2025.2468162

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Measurement invariance of the Death Literacy Index across Flemish Belgium, The Netherlands, and Sweden

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ABSTRACT
Death literacy is a construct conceptualizing experience-based knowledge and skills for end-of-life care, which is operationalized as a six-factor model in the 29-item Death Literacy Index (DLI). The DLI has gained international interest, but its validity across countries is yet unknown. This cross-sectional study therefore assessed its measurement invariance (psychometric equivalence), across Flemish Belgium, the Netherlands, and Sweden. Translated and adapted country-specific DLI versions were developed and completed by 1516 participants in total. Results from a series of multigroup confirmatory factor analyses showed that the DLI met the conditions for configural, scalar, and metric invariance. The findings demonstrate that the DLI measures death literacy in an invariant (equivalent) way across the national samples without systematic contextual bias. Our study provides support for cross-national use of the DLI. Its potential as an appropriate instrument for comparing and evaluating impact of community competence-building interventions is discussed.

Background

Due to global trends of prolonged dying, numerous high-income countries face a considerable increase in people with end-of-life (EOL) care needs. Provision of EOL care has therefore been identified as a public health challenge that extends beyond the confines of specialized palliative care and necessitates a shift in the delivery of basic care from in-patient facilities toward primary care, social care, and community settings (Morin et al., 2017; Sleeman et al., 2019; Tanuseputro et al., 2017). These changes to EOL care provision increase responsibility on professional and family caregivers in the community, which calls for strengthening ability and preparedness for engaging in EOL care broadly in society (Bone et al., 2018; Collins et al., 2021).

The ongoing shift in EOL care provision also coincides with increased interest for health promotion strategies and public health approaches to palliative and EOL care. These approaches often characterize dying, death, and loss not solely as medical phenomena within the remit of healthcare professionals but as shared social processes that extend EOL care to a broader context that recognizes potential contributions of individuals, social networks, communities, and societies (Johansson, D'Eer, et al., 2024; Sallnow et al., 2016, 2022). Public health palliative care generally involve interventions that comprise a range of both formal and informal stakeholders, and aim to promote death literacy development, community engagement for EOL care and social capital to improve wellbeing for those experiencing dying, death, and loss (Peeler et al., 2023).

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/07481187.2025.2468162.

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Death literacy is a research-based concept about community-based EOL care provision developed in Australia (Horsfall et al., 2012). It is a multi-dimensional theoretical construct that encompasses four facets (knowledge, skills, experiential learning, and social action), and concerns the relationship between having knowledge about and being prepared to engage in situations related to the EOL, including care provision (Leonard et al., 2021; Noonan et al., 2016). Research shows that death literacy usually develops based on direct experiences with the end of life, e.g., through caring for a dying person, supporting a bereaved person, having conversations around death and dying, such as advance care planning (Johansson, Tishelman, et al., 2024). Higher levels of death literacy mean that people or communities have a context-specific understanding of the care system and the death system, and are better equipped to engage in situations related to the EOL and accessing services necessary for high-quality end-of-life (Noonan et al., 2016).

Death literacy is operationalized in the *Death Literacy Index* (DLI), a self-report instrument developed by Leonard et al. (2021). The intended use of the DLI is to evaluate and compare the impact of public health palliative care interventions in terms of individual and community capacity for care and support around the end of life, and to study factors associated with death literacy in groups or communities (Leonard et al., 2021). The DLI may also make possible comparative evaluations of interventions in different settings and with different target populations, which would benefit the death literacy evidence base and enable exploration of core aspects for building EOL-related preparedness. Moreover, there are numerous social and cultural differences that can impact access to services and experiences of the dying process (Oliviere et al., 2011). For example, cultural values and spiritual beliefs are known to affect people's views on dying and preferences for EOL communication and care (Hayes et al., 2020; Ohr et al., 2017). The DLI may also allow studies to better capture and understand social and cultural differences in preparedness for engaging with EOL in general and death literacy in particular. To the best of our knowledge, no such studies yet exist.

Thus far, the English-language DLI has demonstrated good internal consistency reliability, with Cronbach's alphas of scales ranging above 0.8, in the original Australian context (Leonard et al., 2021) and the United Kingdom (Graham-Wisener et al., 2022). Similarly, the Swedish-language DLI has been found to have similarly satisfactory psychometric properties (Johansson, 2022; Johansson et al., 2023). Factor analyses of DLI scores have suggested a six-factor DLI model. Support for this six-factor model has been found in national validation studies in several countries, including Australia (Leonard et al., 2021), Sweden (Johansson, 2022; Johansson et al., 2023), Turkey (Semerci et al., 2022), and China (Che et al., 2023). A modified, but conceptually similar model has also been evaluated in the UK (Graham-Wisener et al., 2022). These results suggest that the DLI might retain its psychometric properties in across national contexts.

For DLI scores to be meaningfully compared, however, empirical evidence is needed confirming that death literacy is understood and measured in a comparable manner across groups, i.e., that there is *measurement invariance* (cross-national psychometric equivalence) (Putnick & Bornstein, 2016). Measurement invariance must be established before it can be assumed that scores generated using an instrument are comparable across groups, i.e., that there is equivalence of the measured construct (Leitgöb et al., 2023). Failing to establish measurement invariance indicates response bias for one or several items, thereby biasing inferences made about differences between groups (Putnick & Bornstein, 2016). The DLI has not yet been tested for measurement invariance, and it is not known whether there might be bias in its measurement of death literacy. The aim of this study was therefore to provide evidence of psychometric equivalence for translated and adapted versions of the DLI in Flemish Belgium, the Netherlands, and Sweden by examining the measurement invariance of the six-factor DLI model across the three national samples.

Methods

Materials

The DLI consists of 29 statement-form items distributed over six scales that relate to the facets of the theoretical death literacy model. Items are answered using ordered category responses on a 5-point ordered categories scale. *Practical knowing* is measured in two scales, *Talking support* (4 items) and *Hands-on care* (4 items), which ask about respondents' self-perceived ability to engage in conversations about the EOL or provide practical care tasks (1 = *not able at all* and 5 = *very able*). Items in the remaining scales use a response scale ranging from 1 = *do not agree at all* to 5 = *strongly agree*. The scale *Learning from Experience* (5 items) asks about possible insight from prior EOL encounters. *Factual knowledge* (7 items) concerns knowledge about systems related to dying, death, and loss. *Community capacity* is measured using the scales

Accessing help (5 items) and *Community support groups* (4 items), which ask about awareness of where to receive support for EOL care provision in the community (Leonard et al., 2020, 2021).

The country-specific DLI versions were developed using a mixed-methods multistep process of translation, adaptation, and validation (the steps of which are reported elsewhere (Johansson, 2022; Johansson et al., 2023)). Instructions and items from the original Australian DLI and the country-specific versions (translated to English) are provided in Supplement Table 1.

Participants

Participants were recruited via an independent European data collector for market research, Norstatpanel (https://www.norstatpanel.com/en), with volunteer survey panels in 15 European countries, including Belgium, the Netherlands, and Sweden. Inclusion criteria were being aged 18 or older and a resident of the country of the specific panel in which the DLI was administered. No exclusion criteria were used. To ensure enough data and power for the confirmatory factor analyses, the minimum sample size was set to 500 per country (Mundfrom et al., 2005), i.e., a minimum total sample size of 1500 participants. We used quota sampling stratified based on gender and age (2 gender × 4 age groups) in each panel to generate samples reflecting the general demographic distribution of the country.

Procedure

Swedish data were collected in September–October 2021. Flemish and Dutch data were collected in September 2022. Eligible panel members received personal invitations to the study. If a panel member declined the invitation or did not complete the questionnaire, additional invitations were sent to panel members in the corresponding stratum. Data were collected using the country-specific DLI versions followed by socio-demographic questions. All participants were informed about the aim, topic, and procedure of the study, as well as their right to withdraw at any time. Participants provided informed consent before being able to access the questionnaire. All data were pseudonymized by Norstatpanel before being accessed by the researchers. Participants were compensated for their time by receiving credits, at the rate of 1 credit (equivalent to €0,10 or 1 SEK) per minute, which panel members can accumulate and cash in for gift cards or vouchers.

We received ethical approval for the study from the Swedish Ethics Review Authority (ref: 2021-00915), the Medical Ethics Committee at Vrije Universiteit Brussel, Belgium (ref: BUN 1432021000566), and the Medical Ethics Review Committee at Erasmus University Medical Center, the Netherlands (ref: MEC-2021-0575). We conducted the research in accordance with the ethical standards set out in the Declaration of Helsinki and its amendments (World Medical Association [WMA], 2013). Though the study topic can be perceived as sensitive, research finds that survey questions about the EOL are unlikely to cause lasting harm (Labott et al., 2013) and overall risk of harm to participants is low.

Data analysis

We performed the statistical analyses in SPSS (IBM, version 28) and using the *lavaan* and *semTools* package in R (version 4.1.1) (Jorgensen et al., 2016). Item- and scale-level scores were calculated using descriptive statistics. We used multigroup confirmatory factor analysis to assess measurement invariance by testing the six-factor DLI model to data collected from the three national samples (Leitgöb et al., 2023; Van De Schoot et al., 2012). To ascertain measurement invariance, the DLI factor structure should meet at least three conditions using a stepwise approach (Leitgöb et al., 2023; Wu & Estabrook, 2016). The same number of factors should be demonstrated in all groups referring to the same underlying constructs (*configural invariance*), i.e., the six-factor model should fit data well across groups. Factor loadings should be equivalent across groups (*metric invariance*). Finally, patterns of item intercepts or thresholds should be similar across groups (*scalar invariance*). Fit criteria for each invariance model must be met to proceed with the next step of testing.

As DLI responses are collected on an ordinal (ordered categories) response scale, we followed the recommended procedure for invariance testing outlined by Svetina et al. (2020). The order of steps in this procedure differs slightly from the traditional process used for continuous data. First, we tested model fit for the baseline six-factor model separately for each group, which is a precondition for the multigroup confirmatory factor analysis. We then tested configural invariance by fitting the same unconstrained model across groups. Scalar invariance was tested by imposing equality constraints for thresholds, i.e., cutoffs for each section of the underlying distribution of values, rather than item intercepts due to the ordinal nature of data (Bowen & Masa, 2015).

Finally, we tested metric invariance by constraining both thresholds and factor loadings to be equal across groups. We tested comparative fit between the nested configural, scalar, and metric invariance models, expecting that the model fit would not worsen statistically significantly compared to the previous model (Leitgöb et al., 2023).

We used Hu and Bentler (1999) conventional thresholds for fit statistics, with CFI and TLI ≥0.95, RMSEA ≤0.06, and SRMR ≤0.08 demonstrating good fit. For evaluating changes in model fit, we used the criteria proposed by Chen (2007) in addition to the traditional $\Delta\chi^2$ test: ΔCFI≥ −0.01 and ΔRMSEA ≥ 0.15. Since the $\Delta\chi^2$ test has been found to inflate over-rejection of model fit (type 1 error), particularly with sample sizes ≥ 300 (Leitgöb et al., 2023; Svetina et al., 2020), we interpreted acceptable changes to model fit indices as adequate regardless of the $\Delta\chi^2$ test results. Weighted least square mean and variance adjusted (WLSMV) was used as estimator for the analyses as this is more appropriate for ordinal data (Svetina et al., 2020).

Results

The total sample included 1516 participants. The Belgian sample comprised 502 participants, ages 18–94 ($M = 48.11$, $SD = 16.19$). The Dutch sample consisted of 511 participants, ages 18–85 ($M = 50.51$, $SD = 16.49$). Finally, the Swedish sample comprised 503 participants, aged 18–86 years ($M = 49.95$, $SD = 17.92$). Full sociodemographic characteristics for each national sample are presented in Supplement Table 2. As we used quota sampling, the groups were comparable in terms of age and gender composition. The three samples were not statistically significantly different in terms of professional care experience but did differ in relation to some personal EOL experiences (experiencing the death of a close relative or friend; supporting a bereaved person; caring for a relative at the EOL; and volunteering with people at the EOL or grieving people).

There were no missing values because the online survey required all questions to be answered, however, non-response due to non-completion of the questionnaires is unknown. In all three samples, item responses covered the entire response range, demonstrating expected spread in item ratings at the group-level. No sample demonstrated high skewness or kurtosis (Hair et al., 2017). Means and standard deviations for item and scale scores are presented in Supplement Table 3. The different scales showed satisfactory internal consistency reliability in each of the sampled countries. Reliability statistics are provided in Supplement Table 4 together with the transformed mean scores on scale-level. The six-factor death literacy model demonstrated good fit with data from each national sample, upholding the precondition for assessing measurement invariance. Fit indices for each country are shown in Table 1.

The multigroup confirmatory factor analysis showed that the six-factor configural model fit the data well. Factor loadings were explored to identify differences in the strength of the relationship between items and their corresponding scale across groups. Overall, all but 1 item had strong (> 0.60) factor loadings. Six items (4, 7, 8, 12, 15, and 21) were initially identified as having variable factor loadings between groups (differing by at least 0.1), but none of these differences were large enough to warrant a rejection of an invariant CFA model. A full list of factor loadings across groups is provided in Supplement Table 5.

Fit indices for each model and comparative fit for each step of the multigroup confirmatory factor analyses are shown in Table 2. In the threshold (scalar invariance) model, between-group equality constraints were imposed on the thresholds. This model also had good fit and comparative fit met the cutoff criteria (see Δ indices in Table 2), meaning that there was

Table 1. Fit indices of the six-factor death literacy model across the national samples.

	χ^2	*df*	*p*	CFI	RMSEA (95% CI)	SRMR
Belgium	1038.754	362	<0.001	0.996	0.061 (0.057–0.065)	0.051
Netherlands	721.824	362	<0.001	0.997	0.044 (0.039–0.059)	0.045
Sweden	1107.631	362	<0.001	0.993	0.064 (0.060–0.068)	0.054

Notes. CFI: Comparative Fit Index; RMSEA: Root Mean Square Error of Approximation; SRMR: Standardized Root Mean Square Residual.

Table 2. Fit indices for each invariance model tested in the multigroup confirmatory factor analysis.

Invariance model	χ^2	*df*	*p*	CFI	TLI	RMSEA	$\Delta\chi^2$	ΔCFI	ΔRMSEA
Configural	3875.066	1108	<0.001	0.968	0.964	0.071			
Threshold (scalar)	4072.336	1202	<0.001	0.967	0.966	0.069	153.81*	−0.001	−0.003
Factor loadings (metric)	4050.603	1248	<0.001	0.968	0.968	0.067	67.903*	0.001	−0.002

Notes. CFI: Comparative Fit Index; TLI: Tucker-Lewis Index; RMSEA: Root Mean Square Error of Approximation; SRMR: Standardized Root Mean Square Residual.

minor reduction in fit for the threshold model compared to the previous configural model. In the metric model, constraints of equality across groups for factor loadings were imposed in addition to threshold constraints. The metric model also demonstrated good fit, and the changes in model fit between the threshold and metric model were below the cutoff criteria.

Discussion

To our knowledge, this is the first study to explore the cross-national equivalence of death literacy as operationalized in the DLI. Through multigroup confirmatory factor analysis on data from Flemish Belgian, Dutch, and Swedish participants, we found that the DLI met the conditions for strong (i.e., scalar) measurement invariance. Despite its complexity and large number of parameters, the 29-item six-factor model demonstrated good fit in each national sample. Ascertaining configural invariance shows that the same six-factor structure of death literacy can be found across Belgium, the Netherlands, and Sweden. Demonstrating scalar invariance indicates that response options in the DLI were used equivalently across the national samples. Establishing metric invariance suggests that the DLI items are functioning in a comparable way across country-specific versions, signifying that items are similarly influenced by the death literacy construct. This finding is important since items that systematically over- or under-estimate the construct in one setting can introduce bias to inferences when comparing scores across groups. As both scalar and metric invariance was confirmed, it can be assumed that group differences in DLI scores are likely attributable to actual differences in death literacy and not to systematic bias of the instrument. Overall, this study demonstrates that the DLI total scores, and its scales, can be reliably compared across the three groups tested in this study. These findings provide initial support the generalizability of the DLI as a measurement and death literacy as a theoretical model for capturing and conceptualizing EOL competence.

The DLI has already been found to be psychometrically sound in several countries and previous findings show that the six-factor death literacy model is stable, despite linguistic, cultural, and healthcare system-related differences between the tested settings (Che et al., 2023; Graham-Wisener et al., 2022; Johansson et al., 2023; Semerci et al., 2022). With this study, we add to the existing evidence by demonstrating that the DLI does not appear to be significantly influenced by linguistic translation and adaptation of items in measuring death literacy. It can therefore be surmised that death literacy constitutes a cross-culturally valid concept for EOL care competence and preparedness. A non-invariant instrument would risk introducing bias through differently functioning items, which would threaten the validity of comparative studies. Having established strong measurement invariance is useful for future studies that may wish to use the DLI to explore death literacy development or to evaluate interventions that aim to build EOL competence and preparedness in the community.

Public health palliative care interventions in particular are often complex and involve several social, behavioral, cultural, and political factors, which require consideration to the context during planning, implementation, and evaluation. The multidimensionality of death literacy corresponds well to this complexity and, in light of this study, the DLI appears promising for assessing and comparing impact between complex community interventions in different geographical, cultural, and national contexts. The DLI might thus be useful to generate a stronger evidence base for initiatives such as compassionate communities, which are often tailored to the context in question (Dumont et al., 2022). It could also be suitable for evaluating impact of EOL-related policy changes in different countries.

Even though our results support using the DLI to make international comparisons, we recognize that there are nuances in how death literacy may be conceptually understood across cultures and care systems. The DLI was designed to measure EOL knowledge and skills in relation to the current death system of which the respondent is part. Therefore, any changes to the death system might introduce a need to modify DLI items accordingly. This is important to note, since some public health palliative care interventions strive for systemic and cultural change. The objective of this study, however, was not to determine a final, standardized measure of death literacy, but to assess support for comparable use across nations and death systems through testing measurement invariance. Still, exploring differences in how items function across groups is a useful way of identifying potentially non-invariant items and guide how measurements might be revised for better model fit (Van De Schoot et al., 2012). While the DLI was found to be invariant across national samples, exploring the functioning of specific items can provide insights into how to improve the DLI to better avoid unnecessary contextual influence. To exemplify, item 15 (*I feel confident in knowing what documents you need to complete in* *planning for death*) was found to have the lowest factor loading overall, and to load much less strongly in the Swedish sample compared to the Flemish and Dutch samples. In-depth comparison of the translations of item 15 against the English-language original showed that item content differed across languages. In practice, this means that respondents in different countries answered slightly different questions. At the same time, adaptations to context were necessary for the item to make sense in relation to variable national policies and systems for palliative and death care. Finding a balance between semantic equivalence and conceptual equivalence is a known challenge in instrument validation (Beck et al., 2003). It should also be noted that since we aimed to assess the measurement invariance of the six-factor DLI model, all items were retained in the country-specific versions in this study regardless of item functioning.

The main strengths of this study include relatively large sample sizes with comparable age and gender distributions in all three countries, lack of missing data, and an excellent model fit of the six-factor model when replicated across the national samples. These study characteristics create good conditions for measurement invariance testing by minimizing sampling biases. Although it should be noted that the Swedish data were collected a year prior to the Belgian and Dutch data, we expect minimal impact of this on our results as we did not aim to compare death literacy scores in the different populations in the current study and the findings should not be interpreted as such.

The use of non-probability sampling could increase risk of bias, as participants recruited from online volunteer panels might not be readily representative of the general population (Fricker, 2017). However, not using random sampling does not pose a problem for study validity since we sought theoretical generalization (Pasek, 2016; Polit & Beck, 2010), i.e., to generate evidence that the Flemish, Dutch and Swedish operationalisations of the Death Literacy Index result in scores that can reliably be compared with each other. We did not seek statistical generalization about Death Literacy in three national populations. Accordingly, while we found support for measurement invariance, our data cannot be used to make inferences about the observed differences between group mean DLI scores as these might be related to varying panel compositions rather than population differences due to the use of non-probability sampling.

Since the DLI employs a 5-point ordered categories response scale, the data could possibly be analyzed using standard approaches for continuous variables (Rhemtulla et al., 2012). The choice to treat data as ordinal in the current analysis may be considered a limitation, since the results are slightly more difficult to interpret and compare with other studies. The order of steps in the measurement invariance testing procedure with ordinal data differ from the traditional process of testing configural, metric, and lastly scalar invariance that is used for continuous measurement. However, our use of weighted least square mean and variance adjusted estimation may have led to less biased results, especially in terms of more accurate factor loadings (Li, 2016). In general, the procedures for testing measurement equivalence with ordinal data are not fully developed (Counsell et al., 2020), leading to possibly higher uncertainty when interpreting the results of the current study.

Finding support for the DLI as a valid instrument to measure death literacy in an equal way across national samples is important, since it provides a basis for future research to estimate and compare levels of death literacy in and across populations. It must be stressed, however, that this study assessed the cross-cultural equivalence of the DLI across three European high-income countries. In addition, the DLI versions tested here were developed using the same translation and adaptation procedure (see Johansson, 2022; Johansson et al., 2023), with repeated meetings with the full international team to highlight and discuss problematic items, which might mean that these DLI versions are more equivalent than would otherwise be the case with three separate development processes. Future research should further examine the cross-cultural validity by looking at how the DLI performs across other, possibly more diverse, national and cultural contexts.

The DLI was designed to capture a diverse range of knowledge and skills that develop from experience. One of its intended key uses has been said to be measurement of outcomes of initiatives targeting public education related to the EOL. However, it is likely that various public health palliative care interventions might target the dimensions of death literacy differently, e.g., focusing on building communicative competence or informing about community-based support for people providing EOL care at home (Mills et al., 2020; Patterson et al., 2022). Therefore, it would be valuable if future studies sought to validate the different constructs of the scales in the DLI, as these might be used independently as outcome measures for different kinds of initiatives. In addition, while there is growing support that death literacy has a primarily experiential basis (Johansson, Tishelman, et al., 2024; Li et al., 2023), little is yet known about change processes for death literacy over time or its relevance for conceptualizing EOL competence at the individual level. For example, more research is needed to better understand associations between DLI scores and behavior in practice (see for example Ng et al. (2024)).

Conclusion

This study found that, overall, the six-factor death literacy model that is operationalized in the DLI demonstrates measurement invariance when tested with participants from Flemish-speaking Belgium, the Netherlands, and Sweden, meaning that the DLI measured death literacy equivalently and without systematic contextual bias. Our results indicate that the DLI can be used to generate comparable measurements of death literacy across national groups and add to the existing evidence-base that has hitherto only demonstrated nation-specific validity. While this study provides initial support for the DLI as a stable and appropriate instrument for measuring and comparing death literacy, further research is needed to better understand how the death literacy construct pertains to more varied national and cultural contexts.

Acknowledgements

The authors would like to thank Rosemary Leonard and Kerrie Noonan for permission to use the DLI in this study and their input during the study process. We also acknowledge the contribution of Terese Stenfors during the translation of the Swedish DLI.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by the Strategic Research Area Health Care Science (SFO-V), Karolinska Institutet; the Doctoral School in Health Care Sciences, Karolinska Institutet; Swedish Research Council for Health, Welfare and Working Life (FORTE) under Grant number 2014-04071; Stockholm City Elder Care Bureau; and Stockholm Gerontology Research Center, and the Flemish Research Fund (FWO) under Grant number 1200424N. The funders had no part in, nor influence on, the study design, data collection, analysis, interpretation, or writing of results.

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