

Progressing the Death Literacy Index: the development of a revised version (DLI-R) and a short format (DLI-9)

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Abstract

Background: Since the development of the Death Literacy Index (DLI) in 2019 in Australia, subsequent internationally validated versions have prompted rewording and refinement of the original survey questions. Use of the DLI in the community has also resulted in requests for a short format.

Objectives: To examine and report on the psychometric properties of a revised version of the DLI-R and develop a short format DLI-9.

Design: A cross-sectional national survey was conducted for the validation of the revised DLI.

Methods: The DLI items were revised by the research team using the international literature. DLI data were collected from a representative online non-probability panel of 1202 Australian adults, based on age, gender, and geographical location. Confirmatory factor analysis (CFA) was conducted to ensure the revised version (DLI-R) was consistent with the original. To develop a short format version of the DLI (DLI-9), items were first removed based on face validity, followed by an exploratory factor analysis (EFA) and CFA. The internal reliability of the DLI-R and the DLI-9 was assessed using Cronbach's alpha. The intraclass correlation coefficient was calculated to examine the inter-rater reliability between the DLI-R and DLI-9.

Results: Twenty-four questions in the DLI were reworded for clarity. A CFA on the 29 items of this modified version of the DLI indicated a good model fit (Tucker-Lewis Index (TLI): 0.93; Comparative Fit Index (CFI): 0.93; root mean square of approximation (RMSEA): 0.06; standardized root mean residual (SRMR): 0.06), with six latent variables and an underlying latent variable "death literacy." For the DLI-9, an EFA identified a nine-item, two-factor structure model (DLI-9). A subsequent CFA in a separate sample demonstrated a good model fit for the DLI-9 (TLI: 0.92; CFI: 0.94; RMSEA: 0.089; SRMR: 0.07). Excellent inter-rater reliability (0.98) was observed between DLI-9 and DLI-R. Cronbach's alpha coefficients for DLI-R scales and subscales and the DLI-9 all exceeded 0.8, indicating high internal consistency.

Conclusion: The DLI-R and the DLI-9 were found to have acceptable psychometric properties. The development of a shorter version of the DLI provides a valid measure of overall death literacy.

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Plain language summary

Progressing the Death Literacy Index: the development of a revised version (DLI-R) and a short format (DLI-9)

The Death Literacy Index (DLI) is used to measure the knowledge and skills people about death and dying. Multiple countries have made their own versions, which helped improve the original questions. Community members also asked for a shorter version of the DLI. The research team updated the DLI questions using information from other studies around the world. Data was collected from 1202 Australian adults. A method called Confirmatory

Factor Analysis (CFA) was used to check if the new version (DLI-R) was similar to the original. To make a shorter version, some questions were removed first, then Exploratory Factor Analysis (EFA) and CFA were used. Reliability of both versions was tested using a test called Cronbach's alpha, and the short version was compared to the DLI-R to see if results were similar. Twenty-four questions were reworded to make them clearer. The revised 29-question version (DLI-R) worked well and showed a good fit with six main ideas under the main topic of "death literacy." Nine questions were chosen for the shorter version (DLI-9) and were found to be closely related to the longer version. Both versions showed high reliability, meaning the questions consistently measured what they were supposed to. Both the DLI-R and the DLI-9 worked well and were found to be reliable survey tools.

Keywords: compassionate communities, death literacy, Death Literacy Index, population studies, public health palliative care

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Introduction

The death literacy concept is defined as the knowledge and skills that make it possible to understand and act upon the end-of-life and death care options.¹ Death literacy has been described as encompassing four key components: knowledge, skills, experiential learning, and social action.¹ Skills and knowledge are usually acquired by providing personal care, having conversations around death and dying, negotiating with health and other service providers, and care and disposal of the body. Experiential learning describes the way attitudes and beliefs can be transformed by the experience of caring at the end of life, including a greater acceptance of death as part of life. Social action describes the way people share information about services and support.¹ People with higher death literacy have knowledge about health services and policies, medical, or care procedures, and EOL planning through their involvement in caring networks.²

The Death Literacy Index (DLI) was developed to enable an evidence-based approach to evaluating public health palliative care (PHPC) and compassionate community initiatives and indicate appropriate revisions to interventions.³ Unlike other death-related instruments that measure individual competency or anxiety, the DLI was developed for understanding the death literacy concept in the national and regional populations.⁴ In the Australian context, for example, the national mean scaled scores are used as a benchmark for providing a common ground for researchers and community groups to compare and contrast their findings. Benchmarking can

provide an evidence-based approach to project planning, enable progress tracking, and measure impact.⁵ Updating the benchmark data is crucial to ensure that researchers and evaluators have access to contemporary information.

A report by Leonard et al.³ presented three cases of using the DLI to monitor and measure impact. In one project, community members initiated the development of several social functions, community meetings, and the development of an end-of-life sign-posting initiative.³ Another project, the "Greater Choices at End of Life" initiative,⁶ is using the DLI to evaluate the collective impact of multiple community education initiatives.

As interest in death literacy has grown, translated versions have also been developed in Australia and internationally. A recent study in Western Sydney used the DLI to examine death literacy in culturally diverse communities and translated the DLI into three community languages Mandarin, Hindi, and Arabic.⁷ This study found that higher death literacy for these cultural groups was strongly related to being present at time of death, feeling comfortable communicating about death and dying, and the number of years people had lived in Australia. The authors concluded differences in death literacy were not intrinsic to culture, but instead related to familiarity with the Australian health system.⁷

Several international studies have also validated the DLI in various cultural contexts. The original DLI has 29 items and a six-factor scale was found to have good validity and internal consistency.³

Table 1. Item 20 of the DLI: original DLI, Chinese, Swedish, and UK versions.

DLI version	Item 20
Original	I know about the contribution the cemetery staff can make at end of life
Chinese	I know what the funeral/cemetery staff can help at end of life
Swedish	I am aware of different ways that cemetery staff can be of help around funerals
UK	I know about the contribution the funeral home staff can make at end of life
DLI, Death Literacy Index.	

The United Kingdom was first to validate the DLI outside of Australia, finding the overall scale and the subscales to be valid and reliable in the British context.⁸ Semerci *et al.*⁹ showed a Turkish version to be valid and reliable, and Johansson *et al.*¹⁰ reported similar results for the Swedish version, with some indications of potential differences in the community capacity subscales. Che *et al.*¹¹ confirmed the validity and reliability of a southern Chinese version, which was found to be invariant across genders and experiences of parental death. Flemish and Dutch DLI versions have also been developed, with validation testing ongoing. Moreover, the DLI has been used in community and professional education¹² and as a tool for collaboration with consumers.¹³ Further, studies using the DLI have demonstrated that higher death literacy is associated with end-of-life caregiving experiences.^{10,14}

Both the Swedish and southern Chinese studies followed the WHO translation guidelines including forward translations and back translation, pretesting, and cognitive interviews.^{10,11} These validation studies highlighted challenges with item wording to suitably adapt DLI item content to reflect the local death system and cultural context. One example of cultural adaptation is the changes to item 20, which forms part of the Factual Knowledge subscale (see Table 1) and was altered in both the Swedish and southern Chinese versions. The Swedish DLI also partially adapted the instructions for the practical knowledge and subscale using “How prepared would you be to talk about the following?” instead of “Please rate how difficult or easy you would find the following talking support,” and for the Experiential Knowledge scale “To what extent do you agree with the following?” instead of “Please rate how much each of the below statements sound like you.” Overall, the reported rewording of items and instructions was

determined as necessary for ensuring cultural applicability without impacting the validity of the country-specific versions, and all studies concluded that the DLI was a valid and reliable tool suitable for use in their respective national setting. In light of this, the authors, including Leonard, Noonan, and Grindrod of the original DLI developers, reviewed the international adaptations to utilize the international insights to revise the original DLI for improved readability without fundamentally altering the factor structure of the original DLI.

Furthermore, the authors have worked with several research and community groups using the DLI and requesting a shorter format of the DLI. Many surveys exist in both a long and short format. Short formats are frequently developed in the social and health sciences,^{15,16} as they make it easier for respondents to complete with less likelihood of missing data and allow space in a survey to address and explore relationships to other concepts. As noted above, the DLI was developed to foster meaningful community participation in community discussions and program planning, and developing a short format of the DLI will address this requested need from community groups.

The aims of this methodological study were to:

- (1) Examine and report on the psychometric properties of a revised version of the DLI.
- (2) Develop a short format of the DLI.

Materials and methods

Study design

A cross-sectional national survey was conducted for the validation of the revised DLI.

The reporting of this study conforms to the STARD statement (see Checklist in Supplemental File 4).

Study setting and sample

Data was collected from two population groups. A national representative group and a state-based sample from the Australian Capital Territory (ACT). The data in this study were sourced from Online Research Unit (ORU),¹⁷ a research company that collects information from a national online Australian panel. The ORU panel consists of over 300,000 Australians and is representative of the Australian population by state and by metro/regional. A proportionate representative sample of Australian adults stratified by age, gender, and geographical region was selected from the ORU panel. The sampling frame used an equal number of men and women across six age groups. Sample quotas were also established for each state to ensure that states with smaller populations were not excluded. A sample size of 1200 was determined adequate to achieve a 95% confidence level with a 3% confidence interval using the Australian Bureau of Statistics sample size calculator.¹⁸ Invited ORU panel members could choose to opt in or opt out and were invited to “Please click the forward arrow if you consent to participate.” Incentives were offered for survey completion, but there was no obligation to respond to the invitation. Participants could withdraw at any point. The median survey completion time was 12 min.

Data collection took place in December 2023. The data collected from ACT sample was collected during the same survey period using the same recruitment procedure.

Measures

Data were collected using a self-administered structured questionnaire consisting of demographic questions and the DLI-R (revised version).

The DLI consists of four scales and 29 items in total.⁴ The four scales are *Practical Knowledge* (8 items), *Experiential Knowledge* (5 items), *Factual Knowledge* (7 items), and *Community Knowledge* (9 items). *Practical Knowledge* includes two subscales—*Talking support* (4 items) and *Doing hands-on care* (4 items). Similarly, *Community Knowledge*

includes *Others can help me provide end-of-life care* (5 items) and *Support groups in my community* (4 items) subscales. All items in the scale are rated using a Likert-type scale ranging from 1 to 5.

The authors compared the original DLI and its back-translated versions from other countries and reached a collective agreement to revise each item in the updated DLI (DLI-R). Table 2 provides the wording of the original DLI items and the revised items, specifically highlighting:

1. Rewording of 23 items to enhance the comprehensibility of the items in the index for the heterogeneous population of Australia and worldwide.
2. Reworded instructions on four subscales.

Data analysis

Data were analyzed using IBM SPSS version 29.0 and AMOS version 29.0. Statistical significance was set as $p \leq 0.05$.

Psychometric testing of the DLI-R

Descriptive analyses were conducted to identify the characteristics of the study participants. Scaled-mean scores were calculated for the DLI-R, scales, and subscales. Distribution indicators such as skewness and kurtosis of the DLI-R, in both scale-level and item-level, were assessed before factor analysis.

A confirmatory factor analysis (CFA), utilizing the maximum likelihood estimator,¹⁹ was conducted to assess the relationship between observed items and latent variables and test whether the six-factor model of the original DLI fits the data collected using DLI-R. The Tucker-Lewis Index (TLI), the Comparative Fit Index (CFI), the standardized root mean residual (SRMR), and the root mean square of approximation (RMSEA) were assessed for the model fit. Chi-square was not appropriate given the large sample size. The acceptable criteria for model fit were set at $TLI > 0.95$, $CFI > 0.95$, and $SRMR < 0.08$.²⁰ The cut-off value for RMSEA was set at ≤ 0.10 .^{21,22} Each scale and subscale were also tested to see if they could be used as stand-alone scales.

Internal consistency of the DLI-R and its scales and subscales was examined using Cronbach's

Table 2. The Death Literacy Index—the original and the revised version with changes in bold/underlined.

Original DLI	DLI-revised
Practical knowledge	
<p>Talking support (1) Please rate how difficult or easy you would find the following talking support (on a scale of 1–5 between <i>Not at all able</i> and <i>Very able</i>)</p> <ol style="list-style-type: none"> 1. Talk about death, dying, or grieving to a close friend 2. Talk about death, dying, or grieving to a child 3. Talk to a newly bereaved person about their loss 4. Talk to a GP about support at home or in their place of care for a dying person 	<p>Talking support (1) Conversations about dying, death, or grief. How able are you to have the following conversations, where 1 = not at all able to 5 = very able</p> <ol style="list-style-type: none"> 1. Talking about death, dying, or grief to a close friend 2. Talking about death, dying, or grief to a child 3. Talking to a grieving person about their loss 4. Talking to a health professional about getting support for a dying person where they live
<p>Doing hands-on care (2) Please rate how difficult or easy you would find the following hands-on support. <i>Undertake the following care duties for the dying</i> (on a scale of 1–5 between <i>Not at all able</i> and <i>Very able</i>)</p> <ol style="list-style-type: none"> 5. Feeding a person or assisting them to eat 6. Bathing a person 7. Lifting a person or assisting to transfer them 8. Administering injections 	<p>Providing hands-on care (2) How able are you to do the following, where 1 = not at all able to 5 = very able</p> <ol style="list-style-type: none"> 5. Feed or help a person to eat 6. Wash a person 7. Lift a person or help them move 8. Administer injections
Experiential knowledge	
<p>Please rate how much each of the below statements sounds like you <i>My previous experience of grief, loss, or other significant life events has</i> (on a scale of 1–5 between <i>Very untrue of me</i> and <i>Very true of me</i>)</p> <ol style="list-style-type: none"> 9. Increased my emotional strength to help others with death and dying processes 10. Led me to re-evaluate what is important and not important in life 11. Developed my wisdom and understanding 12. Made me more compassionate toward myself 13. Provided me with skills and strategies when facing similar challenges in the future 	<p>To what extent do you agree with the following? Indicate your response on a scale from 1 to 5, where 1 = do not agree at all and 5 = strongly agree <i>Previous experiences of grief, losing someone, or other important life events have. . .</i></p> <ol style="list-style-type: none"> 9. Made me more emotionally prepared to support others with death, dying, and bereavement 10. Made me think about what is important and not important in life 11. Developed my wisdom and understanding 12. Made me more compassionate toward myself 13. Made me better prepared to face similar challenges in the future
Factual knowledge	
<p>Please rate how much each of the below statements sound like you (on a scale of 1–5 between <i>Strongly disagree</i> and <i>Strongly agree</i>)</p> <ol style="list-style-type: none"> 14. I know the law regarding dying at home 15. I feel confident in knowing what documents you need to complete in planning for death 16. I know how to navigate the healthcare system to support a dying person to receive care 17. I know how to navigate funeral services and options 18. I know how to access palliative care in my area 19. I have sufficient understanding of illness trajectories to make informed decisions around medical treatments available and how that will shape quality of end of life 20. I know about the contribution that cemetery staff can make at end of life 	<p>To what extent do you agree with the following? Indicate your response on a scale of 1–5, where 1 = do not agree at all and 5 = strongly agree.</p> <ol style="list-style-type: none"> 14. I know the rules and regulations when a person dies at home 15. I know what documents are needed when planning for death 16. I know enough about the healthcare system to find the support that a dying person needs 17. I know enough to make decisions about funeral services and options 18. I know how to access palliative care in my area 19. I know enough about how illnesses progress to make decisions about medical treatments at end of life 20. I know about the ways that cemetery staff can be of help around funerals

(Continued)

Table 2. (Continued)

Original DLI	DLI-revised
Community knowledge (two subscales)	
<p>Others can help me provide end-of-life care (1) Please rate your level of agreement with the following statements <i>If I were to provide end-of-life care for someone, I know people who could help me</i> (on a scale of 1–5 between <i>Strongly disagree</i> and <i>Strongly agree</i>)</p> <p>21. Access community support 22. Provide day-to-day care for the dying person 23. Access equipment required for care 24. Access culturally appropriate support 25. Access emotional support for myself</p>	<p>Others can help me provide end-of-life care (1) Please rate your level of agreement with the following statements <i>If I were to provide end-of-life care for someone, I know people who could help me</i> (on a scale of 1–5 between <i>Strongly disagree</i> and <i>Strongly agree</i>)</p> <p>21. To get support in the area where I live, for example, from clubs, associations, or volunteer organizations 22. To get help with providing day-to-day care for a person at the end of life 23. To get equipment that is required for care 24. To get support that is culturally appropriate for a person 25. To get emotional support for myself</p>
<p>Support groups in my community (2) Please rate your level of agreement with the following statements. <i>There are support groups in my community for</i> (on a scale of 1–5 between <i>Strongly disagree</i> and <i>Strongly agree</i>)</p> <p>26. People with life-threatening illnesses 27. People who are dying 28. Carers for people who are dying 29. People who are grieving</p>	<p>Support groups in my community (2) Please rate your level of agreement with the following statements. There is support in my community for (on a scale of 1–5 between <i>Strongly disagree</i> and <i>Strongly agree</i>)</p> <p>26. People with life-threatening illnesses 27. People who are nearing the end of their lives 28. People who are caring for a dying person 29. People who are grieving</p>
GP, general practitioner.	

alpha coefficient. The α value ≥ 0.9 was considered excellent, ≥ 0.8 as good, ≥ 0.7 as acceptable, and ≥ 0.5 as questionable.²³

Scaled-mean scores were calculated to provide death literacy benchmark scores for health practitioners as well as paid workers and volunteers in the palliative care sector in Australia.⁴ An independent sample *t*-test was conducted to determine whether there is a significant statistical difference in the death literacy scores between Australian population in 2019 and 2023, using previously collected survey data for comparison.³

Development of a short format of the DLI

As a first step, the research team carried out a virtual workshop to select two to five items from each scale and subscale, drawing upon their experience in death literacy, the administration of the DLI, and public health approach to palliative and end-of-life care.^{15,24} This deliberative process resulted in the selection of 16 from the 29 items that covered central theoretical facets of death literacy. An exploratory factor analysis (EFA)¹⁹ using principal axis factoring with oblimin

rotation was conducted (using the same survey data used to examine the psychometric properties of the DLI-R) to remove those items with loadings less than 0.65 from the 16 that were initially chosen. The suitability of the dataset for factor analysis was determined based on a Kaiser-Meyer-Olkin (KMO) value greater than 0.5 and a *p*-value < 0.05 obtained from Bartlett's test of sphericity.²⁵ After the item-removal step, the data was factored again to provide the underlying factor structure of the shorter version of the scale.^{26,27}

A CFA was conducted using data from an additional sample collected for the ACT to verify the factor structure of the short format in a separate population. Model fit was tested using CFI, TLI, RMSEA, and SRMR.^{20–22} The cut-off value for RMSEA was set at ≤ 0.10 as RMSEA is less sensitive for small degrees of freedom and the value increases as the number of items in the scale decreases.^{21,22} Model re-specification by removing an item with a high modification index value was done to achieve an acceptable model fit.

Internal reliability was assessed using Cronbach's alpha. The inter-rater reliability of the short

Table 3. Fit statistics and Cronbach's alpha values of the DLI-R and its scales and subscales.

Models	TLI	CFI	RMSEA	SRMR	Cronbach's alpha
DLI-R	0.927	0.933	0.064	0.065	0.957
Practical knowledge	0.922	0.947	0.105	0.050	0.874
Talking support	0.958	0.986	0.116	0.023	0.867
Hands-on care	0.964	0.988	0.094	0.023	0.818
Experiential knowledge	0.986	0.993	0.070	0.014	0.916
Factual knowledge	0.949	0.966	0.111	0.030	0.931
Community knowledge	0.976	0.983	0.069	0.025	0.932
Accessing help	0.993	0.996	0.051	0.010	0.918
Community support	0.957	0.986	0.150	0.017	0.926

CFI, Comparative Fit Index; DLI-R, Death Literacy Index—Revised Version; RMSEA, root mean square of approximation; SRMR, standardized root mean residual; TLI, Tucker-Lewis Index.

format version with DLI-R was evaluated using the intraclass correlation coefficient (ICC), employing an absolute agreement type and two-way mixed method model.²⁸ ICC value less than 0.5 indicates poor reliability, 0.5–0.75 as moderate reliability, 0.75–0.90 as good reliability, and value over 0.90 indicates excellent reliability.²⁸

Results

A non-probability sample of 1202 was used for the analysis of the DLI-R. Of the participants, 56.4% were female and 43.6% were male; there was no participation from the other genders. Participants aged 18–24 years comprised 8.6% of the sample, and 5.8% were aged 80 years or over. Nearly 60% of the participants had undergraduate or higher level of education, one-third had completed formal schooling.

Nearly 70% of the participants were employed and 16% were retired workers. 7.6% of all participants were working as a health or medical practitioner. One in 10 participants (10.4%) had paid work experience in caring for people at the end of life, while similar proportion of people had paid work experience in supporting people through grief and loss (9.6%). Further, 6.7% of participants had volunteered for people at the end of life and 8.3% volunteered to support people going through grief and loss. Please refer to Supplemental File 1 for additional details.

Psychometric testing of the DLI-R

Descriptive statistics. The scaled-mean score of DLI-R was 4.83 ± 0.06 . The kurtosis value of the full scale was 0.11 ± 0.14 , while the skewness was -0.10 ± 0.07 . The kurtosis and skewness of the scales, subscales, and individual items were also between +1 and -1, indicating the normal distribution.

Confirmatory factor analysis. As shown in Table 3, the TLI and CFI demonstrated excellent fit of the six-factor DLI-R model and the individual scales and subscales within DLI-R. The RMSEA and SRMR values were within the acceptable range. Please refer to the path diagram for the DLI-R model in Supplemental File 2—Figure 1.

Internal reliability. The Cronbach's alpha coefficients of the DLI-R, scales, and subscales exceeded 0.8, indicating high internal reliability (Table 3).

Benchmarks of DLI-R scores

The benchmark scaled-mean scores for DLI-R and each of the scales and subscales for the Australian population, health and medical practitioners, and other paid workers in end-of-life care, grief, and bereavement support are found in Table 4 and while the benchmark scores for volunteers are presented in Table 5.

Table 4. Scaled means, F statistics, and eta square for the DLI-R, scales and subscales of the health and palliative care professionals.

DLI-R, scales and subscales	All participants	Health or medical practitioner		Paid job in end-of-life care			Paid job in grief and bereavement			
	Mean DLI (±SE)	Mean DLI (±SE)	F statistic	Eta square	Mean DLI (±SE)	F statistic	Eta square	Mean DLI (±SE)	F statistic	Eta square
DLI-R	4.83 (±0.06)	6.51 (±0.20)	78.61*	0.061	6.49 (±0.15)	112.10*	0.085	6.75 (±0.15)	139.26*	0.104
Practical knowledge	5.04 (±0.06)	6.74 (±0.20)	61.73*	0.049	6.88 (±0.16)	104.83*	0.800	7.01 (±0.16)	111.05*	0.085
Talking support	5.46 (±0.07)	6.83 (±0.21)	31.49*	0.026	6.96 (±0.17)	54.76*	0.044	7.14 (±0.17)	63.14*	0.050
Hands-on care	4.62 (±0.07)	6.66 (±0.25)	67.20*	0.053	6.79 (±0.20)	111.25*	0.085	6.89 (±0.20)	111.25*	0.085
Experiential knowledge	5.90 (±0.07)	6.87 (±0.22)	17.74*	0.015	7.10 (±0.17)	39.57*	0.032	7.35 (±0.17)	52.70*	0.042
Factual knowledge	3.79 (±0.07)	6.13 (±0.26)	87.63*	0.068	5.91 (±0.21)	102.88*	0.079	6.22 (±0.20)	125.24*	0.095
Community knowledge	4.60 (±0.06)	6.29 (±0.10)	60.39*	0.048	6.08 (±0.17)	65.96*	0.052	6.42 (±0.18)	93.00*	0.072
Accessing help	4.15 (±0.07)	6.11 (±0.26)	64.63*	0.051	6.02 (±0.19)	84.71*	0.066	6.27 (±0.18)	99.92*	0.077
Community support	5.06 (±0.07)	6.46 (±0.23)	36.25*	0.029	6.14 (±0.16)	30.06*	0.024	6.57 (±0.16)	55.10*	0.044

*Significance at *p*-value <0.001.
DLI-R, Death Literacy Index—Revised Version.

Table 5. Scaled means, F statistics, and eta square for the DLI-R, scales, and subscales of volunteers.

DLI, scales, and subscales	Volunteering experience in End of Life Care			Volunteering experience in grief and bereavement		
	Mean DLI (±SE)	F statistic	Eta square	Mean DLI (±SE)	F statistic	Eta square
DLI-R	6.64 (±0.18)	80.00*	0.062	6.59 (±0.16)	96.59*	0.074
Practical knowledge	6.73 (±0.20)	52.21*	0.042	6.61 (±0.18)	57.80*	0.046
Talking support	6.90 (±0.22)	30.33*	0.025	6.89 (±0.19)	38.26*	0.031
Hands-on care	6.56 (±0.23)	51.88*	0.041	6.33 (±0.23)	51.67*	0.051
Experiential knowledge	7.31 (±0.20)	33.28*	0.027	7.21 (±0.17)	36.53*	0.030
Factual knowledge	6.13 (±0.26)	74.94*	0.059	6.10 (±0.24)	94.79*	0.073
Community knowledge	6.41 (±0.20)	60.53*	0.048	6.42 (±0.18)	79.15*	0.062
Accessing help	6.23 (±0.23)	62.97*	0.050	6.31 (±0.21)	88.58*	0.069
Community support	6.59 (±0.21)	37.75*	0.030	6.53 (±0.20)	44.46*	0.036

*Significance at *p*-value <0.001
DLI-R, Death Literacy Index—Revised Version.

Table 6. Items retained in DLI-9.

DLI-9 (original DLI item number)	Items
Factor 1	
1 (3)	How able are you to talk to a grieving person about their loss?
2 (5)	How able are you to feed or help a person to eat?
3 (9)	Previous experiences of grief, losing someone, or other important life events have made me more emotionally prepared to support others with death dying and bereavement.
4 (13)	Previous experiences of grief, losing someone, or other important life events have made me better prepared to face similar challenges in the future.
Factor 2	
5 (15)	To what extent do you agree that you know what documents are needed when planning for death?
6 (16)	To what extent do you agree that you know enough about the healthcare system to find the support that a dying person needs?
7 (18)	To what extent do you agree that you know how to access palliative care?
8 (24)	If I were to provide end-of-life care for someone, I know people who could help me to get support that is culturally appropriate for a person.
9 (28)	There is support in my community for people who are caring for a dying person.

The scaled-mean score of DLI-R and its subscales were significantly higher among health and medical practitioners, those with paid job experience working in end-of-life care, as well as those who were supporting people during grief and bereavement. The mean score was higher among those who worked in grief and bereavement support. The eta-square statistics shows the power of relationship was mostly medium for all scales and subscales. The effect size was particularly high in *Factual Knowledge* (0.068) among health and medical practitioners, while it was greater in *Hands on Care* and *Factual Knowledge* for paid workers working in end-of-life care (≥ 0.068) or in providing grief and bereavement support (≥ 0.085 ; Table 4). The scaled-mean scores for DLI-R, scales, and subscales were also significantly higher among volunteers than in the general Australian population (Table 5). Scaled-mean scores for the full DLI-R (p -value 0.018) and scales *Factual Knowledge* (p -value 0.021) and *Hands on Care* (p -value < 0.001) were found to be significantly higher in the 2023 sample than in the 2019 sample.

Development of the short format of the DLI

Establishing face validity as the first step, 16 items were chosen from the DLI-R—four items from *Practical Knowledge* (two items each from subscales *Talking support* and *Hands on care*), two from *Experiential Knowledge*, four from *Factual Knowledge*, and six items from *Community Knowledge* (four from subscale *Others can help me provide end of life care* and two from *Support groups in my community*; refer to Supplemental File 3).

Factor analysis for item removal and psychometric testing of the short version was conducted using an ACT sample. The sample consisted of 114 participants, with 56% being female. Equal proportions (4.4%) were from the age groups 18–24 years and 80+ years. A 67.5% of participants had an undergraduate or higher level of education. Nearly 60% were employed and 2% were working as health or medical practitioners. Over 6% had paid work or volunteer experience in end-of-life care, while 8% had experience supporting people through grief. Please refer to Supplemental File 1 for detailed numbers.

The KMO Measure of Sampling Adequacy value (>0.5) and Bartlett's test of sphericity ($p < 0.001$) indicated that the 16 DLI items were appropriate for factor analysis in ACT sample.

EFA and CFA

EFA suggested retaining 10 items with factor loadings greater than 0.65 and two-factor model.

A CFA of the 10-item, two-factor model was conducted using the ACT sample. However, the fit indices did not meet the cut-off criteria. The modification indices showed that the item "*There is support in my community for people who are grieving*" had high residuals with five other items, and upon removal of this item, the fit of the model was acceptable: TLI (0.921), CFI (0.943), SRMR (0.068), and RMSEA (0.089).

Thus, the short version of the DLI comprises nine items, four in factor 1 and five in factor 2 (Table 6). Factor 1 includes items from the *Practical Knowledge and Experiential Knowledge* scales of the DLI-R, while Factor 2 includes items from the *Factual Knowledge and Community Knowledge* scales. The short version of DLI is abbreviated as DLI-9. Please refer to Supplemental File 2—Figure 2 for the path diagram illustrating the DLI-9 model conducted in the ACT sample population.

The item "*There is support in my community for people who are caring for a dying person*" (Item-9) showed lower factor loading in the final path diagram of DLI-9. However, CFA analyses with and without this item indicated that the model fit indices were good when Item-9 was included. Moreover, this item was deemed theoretically essential for the construct.

These two factors could be interpreted as Factor 1 addressing the private sphere and Factor 2 addressing the public sphere. However, unlike the subscales of the DLI-29, they are not concepts that have been developed from the literature and rigorous qualitative research. We will be recommending that the DLI-9 be used as a single scale.

Internal reliability and validity

The Cronbach's alpha coefficients of the DLI-9 was 0.879, while the α value was 0.820 for factor

1 and 0.872 for factor 2, indicating high internal reliability.

The ICC between the DLI-R and DLI-9 was 0.987 (95% confidence interval 0.985–0.988) with p -value < 0.001 , showing strong inter-rater reliability between the DLI-9 and DLI-R. Scores for the DLI-R and DLI-9 also showed a strong positive correlation among the medical and healthcare practitioners (0.986).

Discussion

The DLI was designed to be utilized in PHPC research and for evaluating compassionate community initiatives. It has also been useful for fostering community participation and meaningful engagement in project planning and codesign activities. The DLI-R includes improved instructions and item wording derived from recently published validation research from several countries. Considering the evolving international scholarship in death literacy using the index, the authors made minor adjustments to the wording of the instructions and items to increase the clarity of the scale and facilitate its use in other settings and languages.

Consistent with the published international adaptations, the rewording did not significantly impact the psychometric qualities of the DLI-R, which were found to be comparable to the original DLI,^{8–11} with Cronbach's alpha found to be slightly higher for the DLI-R. Further, the subscales of the DLI-R continue to be valid for use as individual scales that can provide useful insights into different dimensions of death literacy if researchers or community initiatives have reason to focus on subscale data.

The revisions to the original DLI also provided an opportunity for the research team to respond to requests to develop and validate a short format DLI. The subsequent DLI-9 was found to have satisfactory psychometric properties and provides a valid alternative measure of death literacy with the benefit of being simpler to administer and complete, which in turn might increase the uptake of DLI in community initiatives. Although the DLI-9 has been shown to have two factors, we recommend it is used as a single nine-item scale. The strong correlation between the DLI-R and DLI-9 means that there is a choice of two reliable and valid measurements of death literacy in future

studies or community projects, depending on the scale and scope of the project. Importantly when using the DLI-9 for community engagement activities, the total DLI-9 scaled-mean score can be reliably compared to the overall score of the DLI-R.

The study also provides updated death literacy benchmarks for use in the Australian population, for the general population, health professionals, and those working or volunteering in the palliative and end-of-life care sector. Consistent with the 2019 Australian Death Literacy study, death literacy scores were higher for health professionals and volunteers than for the general population. The authors encourage researchers and community groups to use these updated tables for comparison. In practice, benchmarks provide a standardized frame of reference and promote evidence-based interventions.^{5,29} Further, from a public health perspective, using benchmarks enables death literacy in the Australian community to be tracked over time. This highlights the importance of using the updated benchmarks for the general and health professional/volunteer communities, because experience with dying, death, and caregiving continues to be a key predictor of higher death literacy.

It has been 4 years since the previous benchmarks were published and the overall death literacy scores and scores on the *Factual Knowledge* and *Hands on Care* were found to have increased since 2019. Future publications will report on the variables that contributed to these changes, in particular, the role of the COVID-19 pandemic, and the introduction of the Voluntary Assisted Dying (VAD) laws in Australia.

Limitations

This research utilized an Australian research panel to collect data from a non-probability sample.³⁰ Research panels provide incentives to support participation and consist of people who are experienced at completing online surveys and self-select participation based on the topic.¹⁷ People more comfortable with loss and death may have chosen to complete the survey in greater numbers. Though stratified sampling was used to mitigate this limitation. Similarities between the 2019 and 2023 scaled-mean benchmarks are reassuring, and previous research using convenience sampling through community surveys and snowball sampling tends to result in recruiting

people with higher death literacy, suggesting that some of the biases that can occur in a non-random representative sample may have been mitigated by stratified sampling.^{3,30} Research using case studies and other behavioral measures will however add to our understanding of the death literacy concept. Further, the development of the DLI-9 is promising for community settings and testing in community settings with diverse community groups will be required to learn more about how it performs as an assessment and community engagement tool.

Future directions

The DLI is a useful instrument for researchers, community sectors, and organizations. It is sensitive to change and identifies differences between and within population groups. Because the DLI-R is highly correlated with the original DLI, the DLI-R can be used in future research even when comparisons in death literacy levels over time are the research focus. Nevertheless, further research is needed to examine death literacy levels using the DLI-R in nationally representative samples internationally. Using benchmarking enables community organizations to take a snapshot of death literacy in a meaningful and cost-effective way and is a useful evaluation tool in PHPC initiatives.

The addition of the DLI-9 provides a validated shorter format for the PHPC sector. The authors recommend the DLI-9 is used in community settings where brevity and ease of survey completion is central, and where more detailed analysis of subscales is not practical or required. There are projects underway in Australia and internationally that may wish to further validate this new tool by testing it in their communities. Likewise, there are plans for validation studies in Culturally and Linguistically Diverse (CALD) communities in Australia, in end-of-life community caring networks across Australia (HELP App Network-Centred Care DLI Study).³¹

Conclusion

This is the first published study revising the DLI to align with learnings from several international translation, adaptation, and validation studies. The DLI continues to be a useful instrument to investigate death literacy in populations, and to measure the impact of PHPC interventions, such as compassionate communities and public education initiatives. International collaborative

death literacy research, coupled with practical feedback from diverse community organizations have informed the refinement of the survey questions outlined in this study. Importantly, researchers can utilize the DLI-R, knowing it will perform comparably with the original survey.

Declarations

Ethics approval and consent to participate

This study was approved by the Human Research Ethics Committees of Western Sydney University and La Trobe University (H12185).

Consent for publication

Informed consent for publication was provided by the participants.

Author contributions

Kerrie Noonan: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Supervision; Writing – original draft; Writing – review & editing.

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Sora Lee: Formal analysis; Methodology; Validation; Writing – review & editing.

Rosemary Leonard: Methodology; Supervision; Writing – review & editing.

Therese Johansson: Investigation; Methodology; Writing – review & editing.

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Competing interests

The authors declare that there is no conflict of interest.

Availability of data and materials

Available supplementary data has been provided. The raw data are not publicly available due to the conditions of institutional ethics approval.

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Supplemental material

Supplemental material for this article is available online.

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