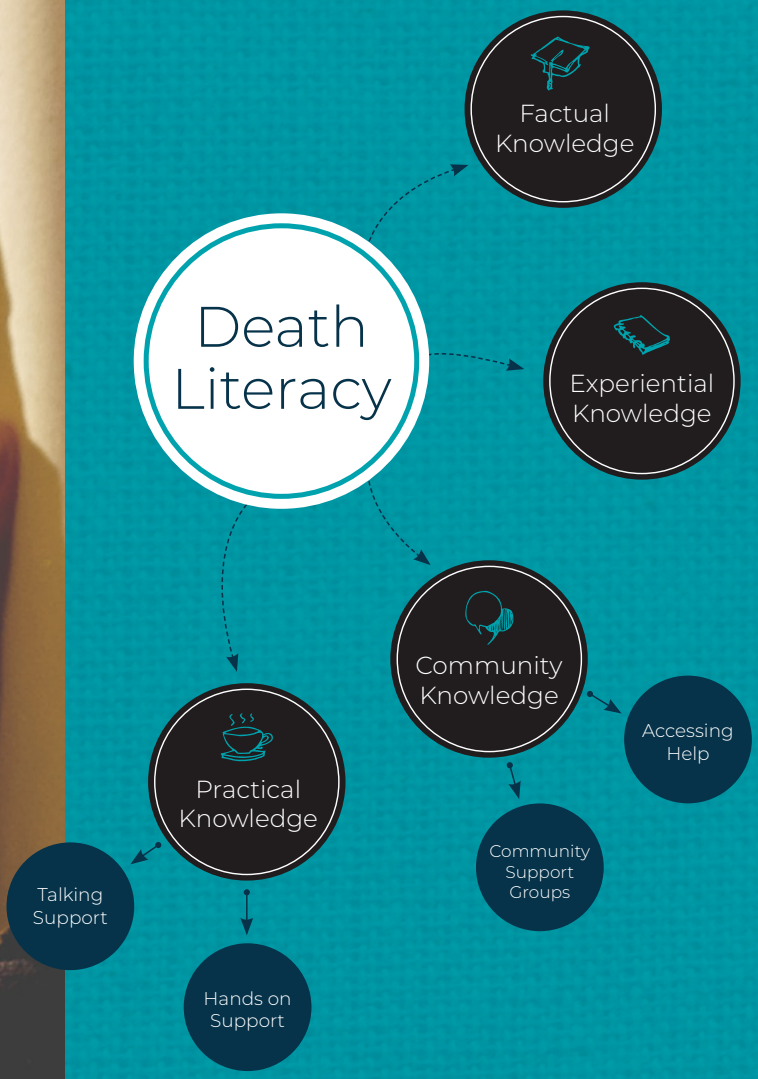

DEATH LITERACY INDEX: A REPORT ON ITS DEVELOPMENT AND IMPLEMENTATION

WESTERN SYDNEY UNIVERSITY
THE GROUNDSWELL PROJECT
THE WICKING TRUST
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The research was developed in partnership between The GroundSwell Project and the *Caring at End of Life* research team, led by Prof. Debbie Horsfall at Western Sydney University. Over a decade of collaborative, community-informed, social research about end-of-life care and the public health approach to end of life forms the bedrock of the death literacy concept and the Death Literacy Index.

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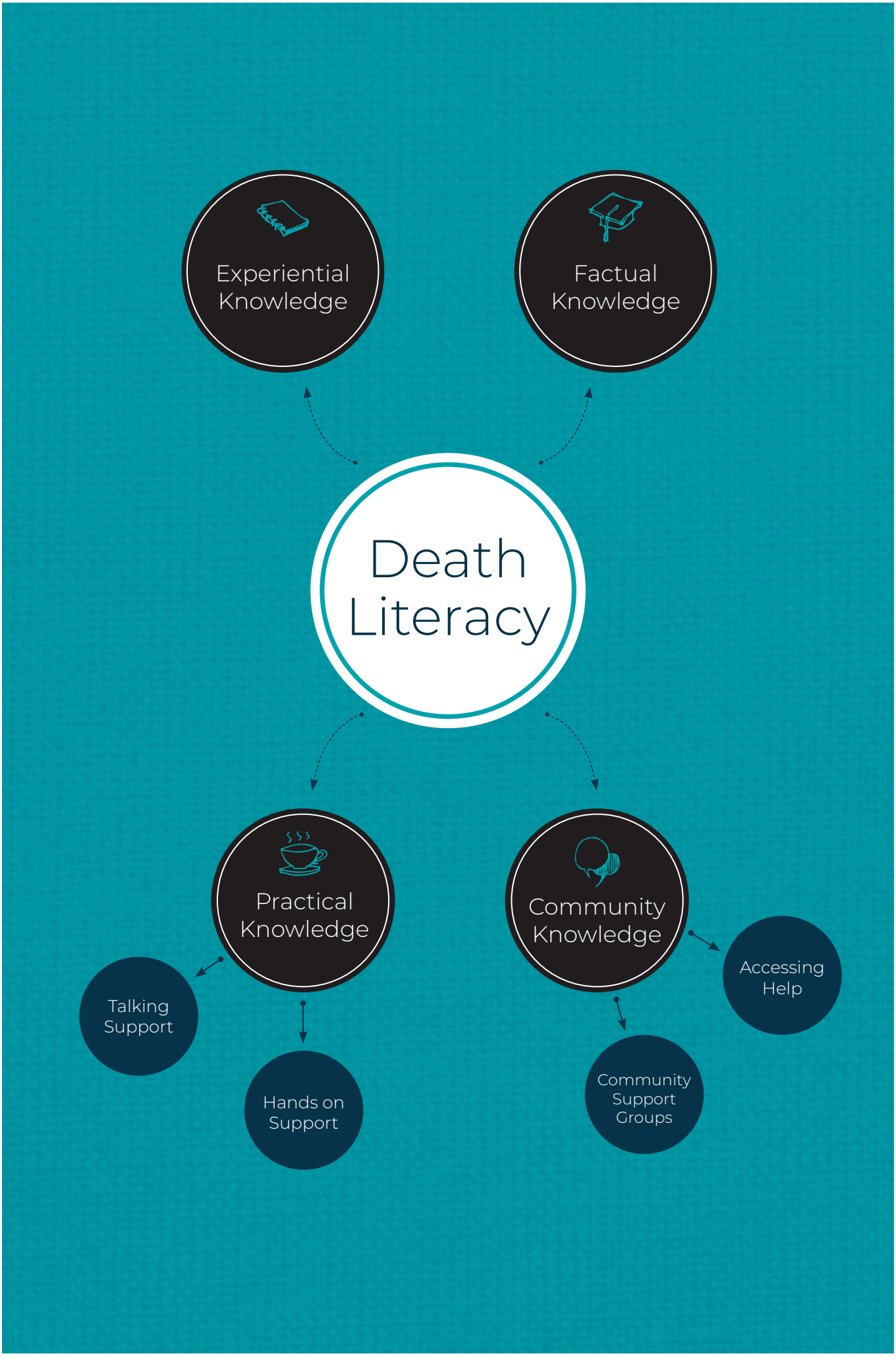
Experiential Knowledge
Factual Knowledge
Death Literacy
Practical Knowledge
Community Knowledge
Talking Support
Hands on Support
Accessing Help
Community Support Groups

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DEATH LITERACY IS ...

... the knowledge and skills that people need to make it possible to gain access to, understand, and make informed choices about end of life and death care options. People and communities with high levels of death literacy have context specific knowledge about the death system and the ability to put that knowledge into practice.

BACKGROUND TO THE DEATH LITERACY INDEX

The Death Literacy Index (DLI) provides a means to measure and research public health palliative care initiatives, including those under the umbrella of Compassionate Communities, by exploring the ways in which community members' knowledge and practice are enhanced through these initiatives. Within public health palliative care, the Compassionate Communities approach views the community as equal partners in the long and complex task of providing quality health care at end of life(1). Over the past decade there has been growing acknowledgement that communities have been marginalised in the increasingly professionalised EOL care service sector. In contrast Compassionate Communities draw upon the social connections, reciprocity and trust available when social capital is present in a community(2-5). Thus, the DLI is designed to be used by community practitioners and researchers alike.

This report provides an overview of the concept of death literacy and the development of the DLI. The DLI was developed from personal narratives of carers, with input from a wide range of professionals and experts and was tested on a national sample of Australians. The report includes detailed information about the development of the Index, reliability and validity statistics, four case studies demonstrating the uses of the DLI and a series of data tables for understanding the norms and baseline data about death literacy in Australia.

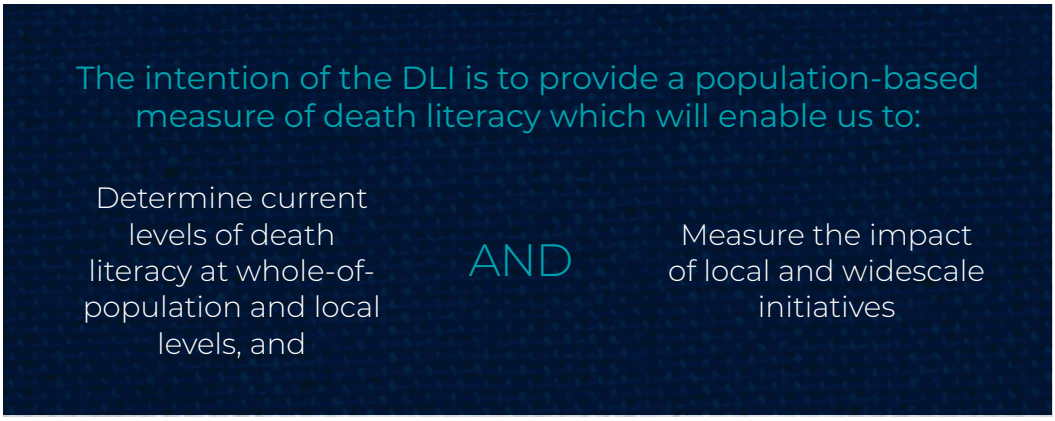
The emergence of the concept of death literacy

The idea of death literacy developed from a body of research from the Caring at End of Life research team at Western Sydney University. Qualitative research into social and caring networks found evidence that caring and being involved in end-of-life (EOL) care, while difficult at times, can also be a learning experience(6). Carers and their networks were invited to come together in focus groups and interviews to talk about their experiences of caring for a person in their home. They told visual and oral stories about the nature, quality and effect of social networks on caring for a person dying at home, including how caring networks were established or strengthened. Over six years of research, 308 people provided in-depth personal and collective narratives. The act of EOL caregiving was a catalyst for learning about EOL caring, navigating the health system and the death system. The outcome of this learning process was labelled death literacy (7-9).

There was also some evidence that enhancing death literacy strengthens capacity for future caregiving. Carers and people who participated in care networks were not only learning from each other but sharing their learning with others. These findings led to further investigation of the death literacy concept (7) and to the development of the Death Literacy Index(10).

Why develop an index?

Social interventions such as those undertaken in community development are often long term and focused on mobilising and supporting the existing assets in a community to address community determined need.



With representative sampling, the DLI can be used as a tool for determining the current level of death literacy in a community, organisation, or nation, to help in the targeting of interventions to address gaps in death literacy and/or build on existing strengths.

The DLI can potentially demonstrate the impact of interventions designed to increase the death literacy of communities, organisations, and even whole nations. This can contribute to knowledge of successful strategies and interventions in the EOL field. Through using the DLI before and after interventions, it can potentially be used as a tool to help track the impact of social interventions *within* a particular group, organisation, or community. It can also provide data for making comparisons *across* organisations or communities.

Used in this way, the DLI can contribute to scholarly, policy, practice and public knowledge and debate on successful EOL strategies and interventions.

INDEX DEVELOPMENT AND NATIONAL SURVEY

DLI development

Building on existing research and practice relationships, Western Sydney University (WSU) and The GroundSwell Project (GSP) formed a partnership in 2017 to develop a benchmarking tool (that is, an 'index') to measure death literacy(7). A steering group was formed, comprising of the Caring at End of Life research team, representatives from La Trobe University, Queensland University of Technology, and The GroundSwell Project to oversee and guide the development of the tool. This research received ethics approval from the three university Human Research Ethics Committees of the researchers (The approval numbers were: Western Sydney University H12185; QUT 1700000854; La Trobe University H12185)

The development of the DLI occurred in two stages. The project used a mixed methods approach with qualitative methods for content development, followed by a national survey and quantitative analyses to identify a reliable measure of death literacy.

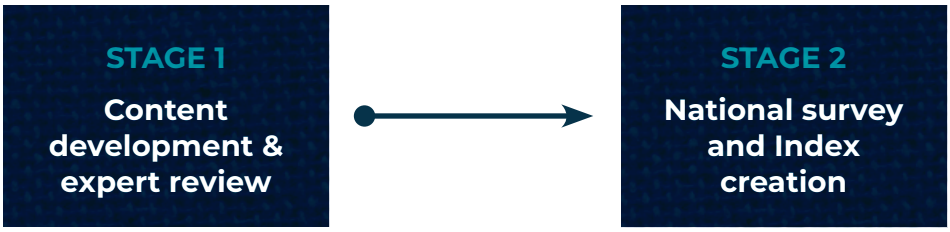


Figure 1: Stages of DLI development

In Stage 1, a preliminary questionnaire consisting of 252 questions was developed from the literature and existing instruments. Heron and Reason (11) ways of knowing was a useful framework for ensuring that the questions represented a range of knowledge such as having practical skills or the understanding that comes from experience, not knowledge in the usual sense. These questions were presented to three focus groups and six interviewees, all key informants selected for their experience (in a paid or voluntary capacity) in the EOL sector for five years or more. Participants were familiar with the fields of health promoting palliative care or death literacy. They included palliative care service providers, funeral directors, community-based service providers and academics in palliative care or sociology. The input provided by these industry experts was used to further refine the questionnaire.

This questionnaire was subsequently administered in an online format (via computer, iPad or mobile phone) by the Online Research Unit(12) (a company with population-based survey research expertise). Demographic questions included age, gender, income, education, location, postcode, employment status, household type, marital status, parental status, religious background, religious practice, ancestry, and belief in an afterlife.

The questionnaire aimed to collect data from an online panel which aimed to be representative of Australian adults based on age, gender and location. A sample size of 1200 was chosen to give a 95% confidence level with a 3% confidence interval. We aimed for a demographic spread with an equal number of women (600) and men (600), across six age groups 18-24 (76 of each sex), 25-36 (110 of each sex), 35-44 (112 of each sex), 45-54 (108 of each sex), 55-64 (91 of each sex) and 65 plus (103 of each sex). Quotas were also set by State and Territory to ensure those with smaller populations were included: New South Wales (396), Victoria (300), Queensland (240), South Australia (84), Western Australia (120), Tasmania (24), Australian Capital Territory (24) and Northern Territory (12). In the final sample there was a 4% over-representation of women overall and a 6% under-representation of men aged 18 to 25. No one identified an alternative gender. Subsequent tests showed that Age but not Gender was significantly positively related to the DLI, so the final DLI mean for Australia might be slightly inflated. There was a 6% over-representation of people from Victoria and similar under-representation of people from New South Wales. However subsequent tests showed that State was not significantly related to the DLI.

For the published peer reviewed article on the DLI development please see: Leonard et al (2020 under review)

Developing a Death Literacy Index

Death Studies

The quantitative analysis, which involved exploratory and confirmatory factor analyses and structural equation modelling, is presented in detail in Leonard et al (2020). It resulted in a 29-item survey with four scales and two subscales as shown in Figure 2.[1] (See list of questions for each scale in Appendix 2.1)

Characteristics of the DLI

The DLI contains 29 items and consists of four subscales:

1. Practical Knowledge
    a. Talking Support
    b. Hands-on Care
2. Experiential Knowledge
3. Factual Knowledge
4. Community Knowledge
    a. Community Support Groups
    b. Accessing Help

1 For those wanting more detailed information about the development and structure of the DLI, we have provided the standardised coefficients which indicate the predictive strength of each latent variable on the observed variables and the fit statistics, Cronbach's alpha and Means for the DLI and Subscales in the Appendix 1, Table A1

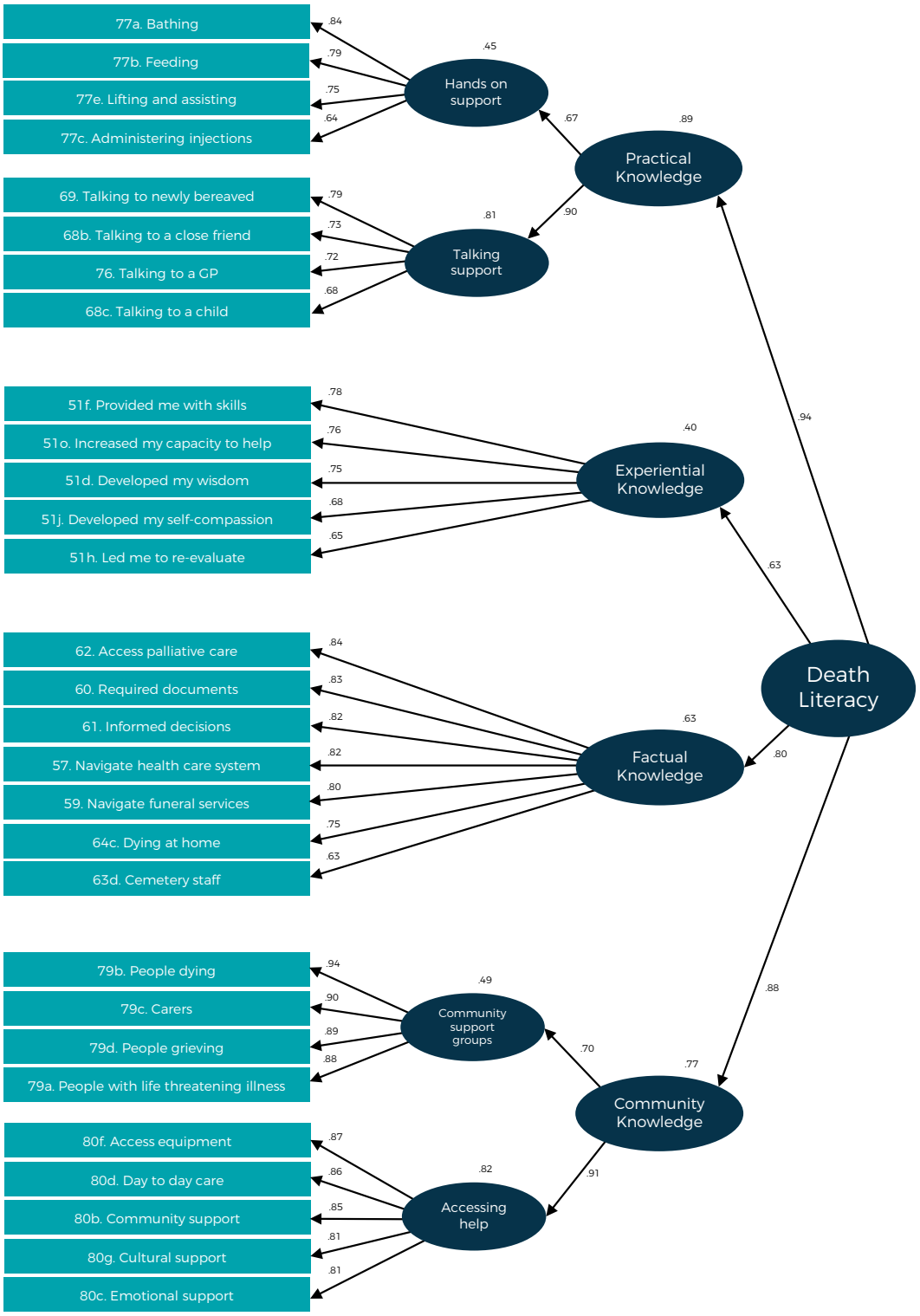


Figure 2: The structure of the DLI showing its subscales and indications of the items in each

Notes:

1. The numbers show the strength of the relationships indicated by the arrows
2. A full list of items is presented in Appendix 2.1
3. This figure with the error terms is presented in Appendix 1 Figure A1
4. Based on the 2018 DLI National survey

Practical Knowledge

Practical Knowledge refers to how well a person perceives they can talk with their friends and family about dying, death and loss and contribute to hands-on care when someone is dying. The *Practical Knowledge* scale has two subscales: *Talking Support* and *Hands-On Support*. Each subscale has four items. *Talking Support*, for example, has questions about how able a person feels talking to a close friend, or child about dying, death and grief, while *Hands-On Support* asks directly about some of the tasks of physical care such as bathing, feeding and administering injections.

Experiential Knowledge

Experiential Knowledge (learning from experience) refers to the wisdom and skills learnt from direct EOL experiences with caring and/or death education. There are five items that ask the respondent to reflect on their previous experiences with loss, grief and death.

Factual Knowledge

Factual Knowledge refers to people's knowledge about the death system, particularly information needed to plan well for dying, caregiving and death. There are seven items that include questions about access to palliative care, completing EOL documents and funeral plans, and decision making related to dying at home, and body disposal.

Community Knowledge

Community Knowledge refers to knowledge of services and other EOL and grief supports that exist within the community. There are nine items with two subscales - Accessing Help and Support Groups. Accessing Help refers to knowing where to access equipment, physical and emotional support while Community Support Groups has questions about accessing local support for dying people, carers and when grieving. Overall this scale paints a picture of what services are understood to be available in their local community.

PSYCHOMETRIC PROPERTIES OF THE DEATH LITERACY INDEX

The psychometric properties of the DLI indicate how effective it is as a measurement instrument. The DLI has good psychometric properties as expressed through its structure, reliability, and validity, so users of the DLI can feel confident that the DLI is measuring a single concept: death literacy. The structure presented in Figure 2 shows strong relationships between the DLI and its subscales. Most importantly, it shows that the single underlying concept of death literacy unites the disparate subscales.

Reliability refers to how stable or consistent the questions in the DLI are with the concept of death literacy. All the scales and subscales of the DLI have high reliability as indicated by Cronbach's alpha scores ranging from .818 to .947 (details in Appendix 1 Table A1).

In an initial assessment of the validity of the DLI, the survey asked about respondents' attitudes and actions around death, dying and bereavement. For construct validity, people who report a high level of positive attitudes and past actions around dying and death would be expected to score more highly on the DLI. To look at this, we grouped 111 of survey questions about people's attitudes and actions around EOL into nine topics and analysed how they related to the DLI. It is important to distinguish between actions and attitudes, and death literacy. Death literacy is the knowledge and understanding one has gained from past actions; people could, for example, be present at a death but not learn anything about the death system. (See Appendix 2.2 for questions included in the Attitudes and Actions scales)

Table 1 shows the nine topics that were positively related to death literacy. Questions related to 'avoiding thinking about death and dying' had a negative correlation, further supporting the validity of the DLI. Having personally provided care at EOL had the strongest relationship, but discussing death and dying, and having been present at a death were also important. (Statistical details in Appendix 1 Table A2)

Notably, there has been a strong emphasis on Advance Care Planning in recent years(13). In this survey, 'planning for one's own end of life' was positively – but not strongly – related to death literacy. Less emphasis has been placed on cultural experiences such as films, novels, and documentaries, however these results suggest that many people have engaged in cultural experiences related to death and dying and such engagement was more strongly related to the DLI than EOL planning.

Table 1: Relationship of Measures of Attitudes and Actions to the DLI on 2019 National sample

Attitude and Action scales	Effect size
Provided care at EOL	Large
Been present at someone's death	Large
Discussed death and dying with family and community	Large
Helped a caregiver with emotional support	Large
Helped a caregiver with practical support	Large
Had a variety of cultural experiences around death and dying	Large
Avoided thinking about death and dying	Large
Felt supported around a recent death	Large
Made plans for own EOL	Medium

Notes:

1. ^ The effect size shows the power of the relationship between the variables. It is calculated using Eta Sq. where .01 small; .06 medium; .14 large
2. Based on the 2018 DLI National survey

Another step in validating the DLI was to examine whether people who work in EOL and thus would be expected to have higher death literacy, have higher scores on the DLI. Table 2 shows that, as expected, people who have worked in the EOL sector, volunteered or completed training in dying, death and grief were all found to score higher on DLI than people who had not, with volunteers scoring just as high as paid workers.

Table 2: Relationships between four Formal Roles and the DLI scale and subscales

DLI scales and subscales	I work or have worked with people at end of life (including volunteering)	I work or have worked in a job where I support/ed people through grief and loss (including volunteering)	I have attended training on helping people with dying, grief or bereavement	I have been involved in caring for a person while they were dying in the home
	Effect size^	**Effect size**	**Effect size**	**Effect size**
Practical Knowledge	Medium	Medium	Medium	Medium
Talking support	Small	Small	Small	Small
Hands on care	Medium	Medium	Medium	Small
Experiential Knowledge	Small	Small	Small	Small
Factual Knowledge	Small	Medium	Small	Medium
Community Knowledge	Small	Small	Small	Small
Others help	Small	Small	Small	Small
Support groups	Small	Small	Small	Small
DLI	Medium	Medium	Medium	Medium
Number of respondents involved in these activities	173	149	121	230

Notes:

1. ^ The effect size shows the power of the relationship between the variables. It is calculated using Eta Sq. where .01 small; .06 medium; .14 large
2. Based on the 2018 DLI National survey
3. Details of the statistics provided in Appendix 1 Table A3

Further validation included understanding the relationship between the DLI and other well-researched measures relating to death and dying. A second national survey administered in 2019 included two measures – one of Death Competence - Bugen's *Coping with Death*

Scale (11) of 30 items, and one on death anxiety - the Collett-Lester *Fear of Death Scale* which has four subscales each of eight items: *Fear of one's own death, Fear of others death, Fear of one's own dying,* and *Fear of others dying*. The *Coping with Death Scale* is closest to the DLI in that it measures skills and competencies, however its psychometric properties were not well tested, and it does not ask about each respondent's community. Neimeyer (14) noted that the scales are sensitive to different interventions; for example, those that focus on fear and anxiety (such as the *Fear of Death Scale*) are useful measures of interventions that involve affective learning, but find no changes resulting from more didactic interventions (14). Bugen's *Coping with Death Scale* was sensitive to changes resulting from volunteer experience in EOL care (14).

Our analysis found that the DLI and its subscales relate strongly to the *Coping with Death Scale*. There is a significant but low negative correlation with being disturbed by *Others Death or Dying* (i.e. death literacy might make a person less disturbed or anxious about the deaths of others) but not at all to *Fear of Own Death or Dying*. The only positive correlation for the fear scales was between DLI *Experience* subscale and *Being Disturbed by Own Dying,* but note the types of questions in the *Experience* subscale are about being stronger because of an experience; if people felt weaker because of their experience, it would make sense that it correlates with fear of death (details in Appendix 1 Table A4).

A final check was to correlate DLI scores with a set of test questions to assess people's objective knowledge of the death system. There were significant positive correlations between test scores and DLI and subscale scores, but the relationships were not strong. Once again this emphasizes that DLI is about more than simply knowledge. (details in Appendix 1 Table A4 with test items in Table A4A).

DEATH LITERACY IN AUSTRALIA

Mean scores for the Australian population on DLI and its subscales

Two national surveys have now been completed examining the death literacy of Australians. The second survey in 2019 had a better representation of the population, so the data presented in this section relate to that survey. An examination of the scaled mean DLI scores for Australians shown in Table 3, revealed that, relative to the other subscales, they scored highest in Experiential Knowledge or learning from experience (scaled mean=5.9) and appear to have an ability to talk about issues of death and dying (talking support subscale scaled mean= 5.5). This finding is consistent with recent community surveys which indicate that over 70% of Australians report they are comfortable talking about death and that they think talking about death is important (13,14). The findings also reveal that Australians feel less confident of their ability to provide *Hands on Care* (scaled mean= 4.4) and the scored lowest on *Factual Knowledge* (scaled mean= 3.1) about the legal and administrative processes associated with end of life planning and death care.

Table 3: Mean scores for the Australian population on DLI and its subscales

DLI scales and subscales	Australian population Mean (N=1200)
Practical Knowledge (TOTAL 8 items)	**4.9**
Talking Support (4 items)	5.5
Hands On Care (4 items)	4.4
Experiential Knowledge (5 items)	**5.9**
Factual Knowledge (7 items)	**3.1**
Community Knowledge (TOTAL 9 items)	**4.6**
Accessing Help (5 items)	4.2
Support Groups (4 items)	5.0
Total DLI (29 items)	**4.7**

Notes:

1. Based on the 2019 DLI National survey
2. All scales ranged 0-10

Sources of death literacy

Questions were also asked about where people obtained their knowledge about death and dying; Table 4 shows that personal experience and family connections were most important, then cultural sources (books and films) and finally formal organisations such as churches, schools, workplaces. These results indicate that knowledge of death and dying in mainly part of the private sphere.

Table 4: Means and ranking (highest to lowest) of factors contributing to knowledge about death and dying

Contribution to knowledge about death and dying	Australian population Mean (N=1200)
Personal experience	3.5
Family/Kinship group	2.7
Fiction books, films, theatre, television	2.5
Factual/autobiographical books or documentaries	2.2
Faith community or practice	2.1
Work experience	2.0
Community activities	1.8
School	1.7

Notes:

1. Scales ranged from 1-5
2. Based on the 2019 DLI National survey

Demographic variation within the Australian population

To examine the demographic variability in the DLI, bivariate analyses were conducted for each of the demographic variables. Table 5 shows that the relationships which were significant and had small effect sizes. There were no demographics that had medium or high effect sizes which demonstrate a low level of demographic variability in the DLI. (See Appendix 1 Table A5 for a full list of the demographic variables including those with non-significant relationships to the DLI and those with negligible effect sizes.

The strongest significant demographic predictors mostly related to age (and related variables such as being widowed or retired) or religiosity (having a religious background or practice of any sort, or beliefs about an afterlife). This investigation indicates that the minimal levels of demographic variability suggest it will be useful across a wide variety of social contexts. The usual indicators of socioeconomic status were very weakly or not at all predictors of DLI scores suggesting that death literacy is not related to class.

Table 5: Strongest significant Relationships between the DLI and Demographic Variables

Demographic variables	Nature of the relationship to DLI
Age	Older people had higher DLI scores
Relationship status	Widowed people had higher DLI scores than other categories
Language spoken at home	Higher DLI scores were associated with speaking English at home followed by speaking mainly English and then those speaking other languages
Employment status	
Retired	Retired people had higher DLI scores
Employed F/T	Those employed full-time had lower DLI scores
Do you have children of any age?	Those with children had higher DLI scores
Do you have adults who are dependent on you?	Those with adults dependent on them had higher DLI scores
Do you believe in an afterlife?	People who believed in an after-life had higher DLI scores
No Religious or spiritual background	People without any religious or spiritual background had lower DLI scores
No Current religious or spiritual practice	People without any current religious or spiritual practice had lower DLI scores
Ancestry	Retired
English	People of English ancestry had higher DLI scores
Irish	People of Irish ancestry had higher DLI scores

Notes:

1. All these variables had a small effect size see Appendix 1 Table A5 for details
2. Based on the second DLI survey in 2019
3. Demographic categories were based on the Australian Bureau of Statistics categories (ABS, 2016)

The DLI is also designed to be sensitive to people's embeddedness in their community so we included two questions about their social connections in the first survey in 2018.

Table 6: Social connections as predictors of DLI

Social variables	Direction of the relationship to DLI	Power of the relationship
How often do you talk to your neighbours?	Positive	Medium
Do you have someone you can call on for help?	Positive	Small

Note: Based on the 2019 DLI National survey

Table 6 shows that having social connections from talking to neighbours and having someone to call if needing help were both positive predictors of DLI scores (Details in Appendix 1 Table A6). They were stronger predictors than the demographic variables. Indeed, talking to one's neighbours was as strong a predictor as having worked, trained, or volunteered in EOL care (see Table 2).

The results for the Australian population suggest that people using the DLI in future should think about the sample they are obtaining. Given the DLI is a new tool, in addition to the usual variables such as age, gender, and parental status, users would benefit from collecting extra demographic data on work, training or volunteering at EOL, religiosity and social connections. Collection of such data will provide further insights into the social and demographic factors important to the development of death literacy. Appendix 2.3 lists suggested demographic questions and response options.

IMPLEMENTATION OF THE DEATH LITERACY INDEX

These four case studies where people have used the DLI are presented in this section, providing insights into how people are likely to use the DLI, the best way to use it, and how to work with the results.

Case Study 1: The Blue Mountains, NSW

This case is an example of a community who wanted to take a snapshot of death literacy. This is a peri-urban community in NSW who are developing Compassionate Communities projects. This community is slightly older than average in NSW and recent social research found that the population is ageing at a higher rate than the rest of NSW. The community is known for its focus on art and alternative lifestyles. The Blue Mountains rates higher than both the NSW, and Australian averages when it comes to voluntary work, community work and unpaid care (15).

The *End of Life Key Leaders Group* overseeing the Compassionate Communities work in the region chose to use the DLI to take a snapshot of the community they were working with, and to measure any changes in death literacy as a result of the intervening Compassionate Communities work. This was based on recommendations made in the *Caring for People at End of Life* report (16) produced by the same group that identified that the development of death literacy through a Compassionate Communities approach in this region would benefit both people at EOL and the health professionals looking after them. Further to the DLI, the local project has been connecting people, organisations and services across traditional networks through social functions, community meetings and shared platforms to cultivate a whole of community approach to EOL. This has resulted in a centralised resource for all that is now an online directory of EOL supports. To further spread knowledge, access and awareness, community members have developed a signposting initiative and a health connector is working with people one-on-one from a General Practice (17).

In early 2019, the DLI was sent out across the Blue Mountains. People heard about the survey via leaflet handouts, social media, multiple mailing lists and networks, local newspaper

and face-to-face. Of 139 people who took the survey, there were 134 completed questionnaires.

The results of the survey are discussed below. This first survey gave the group a sense of the audience they were working with and a more detailed understanding of strengths and weaknesses in death literacy. The second survey is currently being distributed (early 2020), the results of this survey post intervention will begin to measure if and in what areas the Compassionate Communities work has made an impact on death literacy.

Further to the DLI, the local project has been connecting people, organisations and services across traditional networks through social functions, community meetings and shared platforms to cultivate a whole of community approach to EOL.

Case Study 2: The South Western Sydney Primary Health Network

The South Western Sydney Primary Health Network (SWSPHN) ran Compassionate Communities workshops and EOL education sessions. Everyone was welcome, although SWSPHN particularly invited community leaders, carers, local elders, community groups, people who have experienced loss, dying and grieving, seniors, local council staff, health and community professionals, and local business owners.

These workshops aimed to engage and educate people to find ways to promote emotional, social, physical and spiritual wellbeing for people who are frail, experiencing loss, are ageing, dying or grieving. The workshops enabled participants to understand and identify practical approaches to establishing and maintaining networks to support people in their community experiencing dying and grief. They assisted interested local people to come together to build community partnerships, and ultimately, a compassionate community.

There were 31 attendees across two workshops (Camden: 19; Campbelltown: 12) Through email contact with these attendees, they explained the DLI research and invited people to complete the questionnaire online.

SWSPHN also held three education sessions of two hours each around dementia, palliative care and advance care planning for *Dying to Know Day* and *Dementia Awareness Week*. The flyer promoting the sessions said:

> *"Today, I feel good, healthy and capable of doing everything I want to... But what about tomorrow? Or next year? What should I know and do before I go? Too many of us are dying in a way not consistent with our values or wishes. Too often, we feel ill-equipped to support loved ones. Death takes all of us! Let's create a world where we can talk about what we want for our future and what to do when someone is dying, caring and grieving. The future is unknown territory and we don't know what is in store for us, but we can plan for possible future challenges! Whether you have a medical condition which is life limiting or you feel fine, learn what to know and how to plan before you go. This is how you can care for yourself and others! "*

The topics covered included *What is palliative care and why it isn't only about dying or cancer? Advance care planning* and *Dementia* (including what it is and how it can affect future decision making).

The DLI was distributed via email from the poll of registered participants after the sessions. People attending the education sessions were informed of the purpose of the study and the DLI approach. The Education Sessions had 74 attendees over three sessions (Macquarie Fields 15: Liverpool 19: Campbelltown 40)

In total, 32 attendees from the information and education sessions completed the DLI questionnaire.

Case Study 3: The St Nicholas Hospice Care project in Mildenhall, Suffolk, United Kingdom

St Nicholas Hospice Care conducted a pilot study in Mildenhall aiming to test new ways of working such as a public health approach to palliative care and using an Asset Based Community Development (ABCD) approach. The hospice developed programs based on the concepts of Compassionate Communities, community connectors and networks of support.

Using these approaches and concepts, St Nicholas Hospice Care embarked on understanding the hospice's role in a community with the aim of improving death literacy. By working in new ways and testing different approaches they envisaged that a more sustainable model for EOL care can be realised to face expanding need and an aging population.

Early indications from the pilot suggested the key components in developing a compassionate community included:

1. A dedicated person who understands the approaches is essential in leading the work.
2. Hospice branding can be used to promote local initiatives such as death cafes.
3. Identifying key people (e.g. Parish Nurse) and places in the community and making links with them at the beginning enables effective connections within the community.
4. Engaging, working, and building relationships with statutory partners straight away, for example councils and GP surgeries, enables the work to reach a wider audience.

The key learning and next steps from testing the concepts in the pilot were:

1. Community connectors need more time to develop, more testing is needed to understand their role in a community, for example within GP surgeries.
2. Community groups have worked well and continue to thrive. These relationships should be maintained and nurtured to facilitate further development of a compassionate community.
3. Developing compassionate companies needs a different approach with the community, not necessarily through fundraising.
4. Hospice education is an asset within the public health and ABCD approaches. The team should continue to develop and grow their training and education packages based on community feedback.
5. Individual network resources need to be tested further, directly involving patients and the public to understand if they are effective.

They concluded that a sustainable model of EOL care would be one where the hospice offers a supportive and enabling role that equips people, rather than one providing direct care as a default. As an organisation, St Nicholas Hospice Care therefore needs to be comfortable in letting communities develop ownership of their approach to supporting dying, death, bereavement and grief, with public health and ABCD approaches being essential to achieving such sustainability.

This description of the Mildenhall project was provided by Hulbert (2019) from their report on their pilot study. St Nicholas Hospice Care administered the DLI and related questions as an online survey to the Mildenhall community where 106 people responded.

Case Study 4: Care Beyond Cure, Tasmania

Care Beyond Cure Inc is a local charity and Compassionate Community based in North West Tasmania. Their vision is to relieve the suffering and distress of individuals with a diagnosed progressive life limiting illness and their family carers through the provision of practical assistance. To this end, Care Beyond Cure Inc work to establish and develop programs which include the Care Beyond Cure fortnightly program, a Community Coffin Club inclusive of Arts and Death Literacy and the Weavers Dementia Carer Peer Support program.

Care Beyond Cure began with a "Taster Day" for the target group in 2015. In 2016 they gained funding for eight fortnightly pilot programs across three areas of the Cradle Coast Community through which the need for a Community Coffin Club was identified. They became incorporated in 2017 and a charity in 2018. For the past two years, they have been part of the *GroundBreaker*s initiative of The GroundSwell Project. Care Beyond Cure Inc are currently working with their community to establish Tender Funerals Tasmania.

Results for the four community samples

There were some strong similarities among the four community samples, so they are considered together and contrasted with the Australian population survey.

Table 7 shows that the community samples all attracted a much higher percentage of people who had worked, trained or volunteered in end of life care.

Table 7: Percentage who have worked volunteered or trained in EOL in the Australian population and the four case studies

Work in end of life	Australian Population (N=1200)	Blue Mountains (N=134)	SWSPHN (N=32)	St Nicholas Hospice Care, community sample (N=106)	Care Beyond Cure, TAS (N=121)
Percentage of all work training or volunteering in EOL	18%	59%	41%	42%	73%
Percentage of EOL paid work	10%	41%	34%	32%	43%
Percentage of EOL volunteer work	9%	28%	16%	21%	41%

Note: Based on the second DLI survey in 2019

The 2019 Australian National Survey was undertaken by 1200 people representative of the Australian population, whereas the community surveys were undertaken by anyone who chose to participate. This tells us that people with work/volunteer/training experience were more likely to take the local survey than those who did not have those experiences. As working, volunteering or training in EOL care can increase understanding of EOL issues and the ability to contribute, it is not surprising that in each case the community samples had higher DLIs (Table 8).

Table 8: Comparison of DLI and subscales for the four community samples in comparison with the Australian population

DLI scales and subscales	Australian Population Mean (N=1200)	Blue Mountains Mean (N=134)	SWSPHN Mean (N=32)	St Nicholas Hospice Care, community sample Mean (N=106)	Care Beyond Cure, TAS Mean (N=121)
Practical Knowledge	**4.9**	**6.8***	**6.2***	**6.7***	**7.0***
Talking support	5.5	8.1*	7.1*	7.5*	6.8*
Hands on care	4.4	5.5*	5.2	5.8*	7.2*
Experiential Knowledge	**5.9**	**7.7***	**7.2***	**7.3***	**7.4***
Factual Knowledge	**3.1**	**4.4***	**3.8**	**4.6***	**5.3***
Community Knowledge	**4.3**	**5.9***	**5.1**	**5.1**	**6.1***
Accessing help	4.2	6.0*	4.9	5.0*	6.4*
Community groups	5.0	5.8*	5.3	5.1	5.7*
DLI	**4.7**	**6.2***	**5.5***	**5.9***	**6.4***

Notes:

1. *Indicates community sample means that are statistically higher than the Australian average
2. All scores ranged 0 to 10
3. Based on the second DLI survey in 2019

To overcome the problem that the community samples had larger numbers of respondents with work, training or volunteer experience, the comparison was repeated with only those who had worked, volunteered or trained in EOL care across the four groups (Table 9) and for those who had not worked, volunteered or trained in EOL care across the four groups (Table 10).

Table 9: Comparison of DLI and subscales across the four groups for those who have had Experience as Workers or Volunteers or Training in EOL

DLI scales and subscales	Australian Population Mean (N=213)	Blue Mountains Mean (N=73)	SWSPHN Mean (N=13)	St Nicholas Hospice Care, community sample Mean (N=44)	Care Beyond Cure, TAS Mean (N=88)
Practical Knowledge	**6.4**	**7.3***	**7.0**	**7.2***	**7.6***
Talking support	6.6	8.3*	7.5	7.6*	8.3*
Hands on care	6.1	6.3	6.5	6.8	6.8*
Experiential Knowledge	**7.0**	**8.2***	**7.7**	**7.6**	**7.9***
Factual Knowledge	**4.7**	**5.2**	**4.5**	**5.1**	**6.1***
Community Knowledge	**6.0**	**6.5***	**6.3**	**6.0**	**6.5***
Accessing Help	6.1	6.7*	6.2	6.2	7.0*
Community Groups	6.0	6.3	6.4	5.7	6.0
DLI	**6.0**	**6.8***	**6.4**	**6.5**	**7.0***

Notes:

1. * Indicates community sample means that are statistically higher than the Australian average
2. All scores ranged 0 to 10
3. Based on the second DLI survey in 2019

Table 10: Comparison of DLI and Subscales across the four groups for those who do NOT have Experience as Workers or Volunteers or Training in EOL

DLI scales and subscales	Australian Population Mean (N=982)	Blue Mountains Mean (N=52)	SWSPHN Mean (N=18)	St Nicholas Hospice Care, community sample Mean (N=61)	Care Beyond Cure, TAS Mean (N=32)
Practical	**4.6**	**6.1***	**5.5**	**6.3***	**5.5***
Talking support	5.3	7.9*	6.7*	7.5*	6.3*
Hands on care	4.0	4.3	4.3	5.1*	4.7
Experiential	**5.7**	**7.1***	**6.8**	**7.1***	**6.2**
Factual	**2.8**	**3.2**	**3.3**	**4.2***	**3.0**
Community	**4.3**	**5.0***	**4.2**	**4.4**	**4.9**
Accessing Help	3.8	4.9*	3.9	4.1	4.8
Community Groups	4.8	5.1	4.5	4.6	5.0
DLI	**4.4**	**5.3***	**4.9**	**5.5***	**4.9**

Notes:

1. *Indicates community sample means that are statistically higher than the Australian average
2. All scores ranged 0 to 10
3. Based on the second DLI survey in 2019

By separately examining those who have had experience working, volunteering or training in EOL and those who have not, there are fewer differences among the five groups, nevertheless, almost all the means in Tables 9 and 10 are higher than the Australian population – whether or not those differences were significant was often dependent on the number of respondents. Overall it is worth noting the strong performance of all groups on the Practical Knowledge scale suggesting that people who chose to respond to the survey had a practical connection to the issue.

1. The Blue Mountains sample was significantly higher than the Australian population on three of the four subscales both for those with experience and those without. Both experienced and inexperienced respondents were similar to the population on Factual knowledge. Their generally strong performance on the DLI could relate to qualities of the Blue Mountains community such as being older and rating higher than the Australian average when it comes to voluntary work, community work and unpaid care (15). Given the project was in early stages of development, it might also indicate that the DLI was completed by people who were involved in the project.
2. For SWSPHN, the small number of respondents meant that there was little opportunity to show significant differences from the Australian population, however they did perform better on Talking support.
3. For St Nicholas Hospice Care, people with experience only performed significantly better on Practical knowledge but those without experience performed better on all scales except the Community scales.

4. In the Care Beyond Cure sample, those with experience, were significantly higher than the Australian population on all scales except Community groups. Care Beyond Cure has been providing programs for over four years and it would be not surprising that they have promoted higher levels of death literacy in their community. However, for those without experience the only scale for which they performed better than the population was Practical knowledge, particularly Talking support.

Comparing the Attitudes and Actions of community samples with the Australian population

Comparing the Attitudes and Actions across the five groups, it is clear the participants in the four community samples have more experiences related to death and dying and are less likely to avoid the topic than the Australian population (Table 11). In particular, the community samples had more experience with caring at EOL and supporting other people to care. They were also more likely to have been present at the time of a death. This is consistent with the community samples having higher numbers of people who had worked or volunteered in EOL. Despite their care for others, people in the community samples were not more likely to have felt supported around a recent death.

Table 11: Comparison of the community surveys and Australian population 2019 survey on the Attitudes and Actions

Attitudes and Actions scales	Australian Population Mean (N=1200)	Blue Mountains Mean (N=134)	SWSPHN Mean (N=32)	St Nicholas Hospice Care, community sample Mean (N=106)	Care Beyond Cure, TAS Mean (N=121)
Caring at EOL	2.9	5.0*	6.5*	6.5*	6.3*
Emotional Support to Carer	5.9	8.6*	8.6*	8.1*	8.9*
Practical Support to Carer	2.3	3.7*	4.7*	3.7*	4.6*
Present at Death	3.7	5.8*	6.1*	6.6*	6.6*
Planning for EOL	2.5	5.0*	4.2*	2.9	5.9*
Cultural Experiences	2.0	5.7*	NA	3.5*	5.5*
Discusses D&D	4.0	5.0*	4.6	4.5	5.0
Avoidance of D&D	4.4	1.8^	2.7^	2.4^	1.9^
Feeling supported around a recent death	5.9	5.9	4.8	4.4^	6.0
Expressing knowledge about D&D	1.5	1.9*	1.2	1.1	1.4

Notes:

1. *Significantly higher than Australian population
2. ^significantly lower than Australian population
3. Based on the second DLI survey in 2019
4. All scores ranged 0 to 10

Table 12: Comparison of the community samples and the Australian population on sources of knowledge about Death and Dying

Sources of knowledge about death and dying	Australian Population Mean (N=1200)	Blue Mountains Mean (N=134)	SWSPHN Mean (N=32)	St Nicholas Hospice Care, community sample Mean (N=106)	Care Beyond Cure, TAS Mean (N=121)
Personal experience	1st	1st	1st	1st	1st
Family/Kinship group	2nd	5th	Equal 2nd	2nd	3rd
Fiction books, films, theatre, television	3rd	3rd	6th	5th	5th
Factual/ autobiographical books or documentaries	4th	2nd	5th	3rd	2nd
Faith community or practice	5th	6th	4th	7th	7th
Work experience	6th	4th	Equal 2nd	4th	4th
Community activities	7th	7th	7th	6th	6th
School	8th	8th	8th	8th	8th

Note: Based on the second DLI survey in 2019

Table 12 shows that there was agreement across the five groups that personal experience was rated as the most important source of knowledge about death and dying, and school was the least important. For three of the four groups, family and kinship was the second most important source of knowledge, but it is interesting that they were not important for the Blue Mountains sample. With the higher number of people who had worked trained or volunteered in EOL it was not surprising that work experience was more important in the community samples than the Australian population.

Post-tests

For the Blue Mountains and St Nicholas Hospice Care there were post-tests after the community interventions. Links to the on-line survey were distributed to the community broadly with no requirement that people had attended any of the interventions.

Unfortunately, the response rates were low in both cases so there was little chance of identifying a significant change over time. It is worth noting that in both cases they were trying to collect the information at the time when the COVID 19 fears were at their height (March - April 2020) and it is likely that people had other concerns.

In the Blue Mountains, 74 people responded of whom 26 had attended a relevant community event. There were no significant differences between scores in the DLI scales or subscales

from the first and second surveys. However, there was some indication that people who had attended relevant events had improved their death literacy. The improvements in the Knowledge, Experience and Obtaining Help subscales were the most marked and when these were grouped they showed a significant change [M attendees = 19.7, S.D.= 5.6; M non-attendees = 17.3, S.D. = 4.8; F(1,72) =3.83, p=.05] This is not a strong result but it does suggest death literacy in the Blue Mountains is trending in a positive direction.

For St Nicholas Hospice Care the number of responses was much lower with 37 post-test respondents of which only 9 had attended a relevant community event. With these low numbers it was not surprising that there were no significant differences between Surveys 1 and 2. Nor were there any significant differences between those who had attended events and those who had not.

The Care Beyond Cure sample is also a post-test because the program has been well-established and well-known in a small community for some years. I had the most consistently high DLI scores for those with experience of work volunteering or training in EOL. But did not perform so well for those without experience.

Discussion of the case studies

There were only four case studies, but a pattern of results emerged whereby the SWSPHN case study which had surveyed prior to their interventions had lower DLI scores than the ones that had started their interventions, Blue Mountains and St Nicholas Hospice Care. The most established program, Care Beyond Cure, had the highest DLI scores.

Coordinators of the programs in case studies one to three recognised the challenge of hearing from people who are not so comfortable and confident about talking about death and dying.

The Blue Mountains coordinator reflected:

> *I would want to take this snapshot to a reference group or community meeting that includes all stakeholders and ask for their responses and ideas. I would like to use Asset Based Community Development (ABCD) principles to look at what strengths or assets we have and how they might support building up the less confident end of Death Literacy.*

Coordinators for SWSPHN reported on the limitations of sending out the survey link and the need to survey people when they attended a workshop or information session in order to capture responses of those without formal training or experience, particularly those less comfortable with internet surveys.

Coordinator for Case Study 3 reflected on the fact that they had already been working in Mildenhall for some time before the DLI was administered and decided to survey a new area prior to the commencement of their program there.

Results for case study 4 were only recently received, so we have not yet had time to discuss them with the coordinator.

Aiming for community change and measuring it through an impersonal community survey is challenging. It would be worthwhile for users of the DLI to ask about the participants' connection to or learning from the program, project or hospice directly. The results also highlight the challenges of using the DLI as a pre and post measure. Designed as a population-based measure, the use of the DLI as a pre and post measure in short term interventions is likely limited given that many social interventions are long term in nature. Ongoing research is needed to address this.

CONCLUSION

The key finding is that there is a valid and measurable construct that can be labelled death literacy. The component subscales are diverse but are all part of this core concept. The *Experiential* subscale suggests death literacy is about making the most of life experiences. Higher scores on the *Community Knowledge* subscale do not require hands on experience but rather knowledge of local community groups and engagement in community networks. The *Factual Knowledge* subscale requires familiarity with legal and administrative processes which could be acquired without personal experience of death and dying. The *Practical Knowledge* subscale as with all practice knowledge is the one that has the greatest reliance on direct personal experience.

A comparison of the mean scores for each of the subscales indicates that, relative to other death literacy knowledge, Australians report comparatively higher levels of learning through experience and ability to talk about issues of death and dying. On the other hand, people are less confident of their ability to provide hands on care and their weakest aspect is their factual knowledge about legal and administrative processes. It is important to remember that these figures are probably higher than the actual mean if we could survey everyone in Australia. Any survey around death and dying will not be completed by people who have a strong aversion to engaging with death. Though it is worth noting that community surveys have also indicated that only 3.9 percent of people aged over 55 feel 'very uncomfortable' talking about death and dying (18). We have the greatest difficulty obtaining responses from young men and can only speculate that they are not engaging with the reality of death to allow them to avoid fear.

The main finding from the four case studies is further evidence that ***death literacy develops as a result of experience.***

The four case studies showed some positive signs of the effectiveness of Compassionate Communities interventions. A pattern of results emerged whereby the case study which had

surveyed prior to their interventions had lower DLI scores than the ones that had started their interventions. The most established program, Care Beyond Cure, had the highest DLI scores for those with experience and it is the nature of their program that it allows people to develop experience. Also, there were signs that interventions in the Blue Mountains had a positive influence on knowledge from experience and obtaining help and factual knowledge. However, obtaining clearly significant results was hampered by the difficulty of recruiting sufficient participants from an on-line survey especially responses of those without formal training or experience in EOL and those who are less comfortable with internet surveys.

The main finding from the four case studies is further evidence that death literacy develops as a result of experience. This was consistent across all the studies. If the DLI is going to be helpful for communities, this finding around experience seems important. Any community group considering developing death literacy through compassionate communities' projects, may benefit greatly from initiatives that bring to life the knowledge of the experienced people in their communities.

The DLI could be used by groups and communities as a framework for developing capacity further. The DLI identifies ways of knowing that are well-developed, and others that might benefit from further attention. In so far as death literacy is a community characteristic, the DLI suggests the domains in which assets should be identified and mobilised if that community is to develop effective capacity to respond to their EOL needs. Thus, if an initial survey demonstrates deficits in certain domains, community members or, if necessary, outsiders who can reduce these deficits might be recruited. We should hasten to add that this is not suggested as a strategy for increasing DLI scores per se. As Fischer (19) argues, there is a beneficial effect in using standardised tools for the process of enquiry, not for the numerical result. Therefore, we would argue that there can be a beneficial effect from the process of using the DLI rather than as a rating tool.

How could we support people in, and provide opportunities for, people to ***learn about providing practical hands-on support?***

A Compassionate Communities approach suggests that the recruitment of community members is preferable to bringing in outsiders however community members are often unaware of the contribution they could make to the community and social dimensions of EOL care unless this is explored with them: They may see EOL care as the responsibility of health services, not everyone's business (20). The DLI result can also be used by outsiders, for example, it might provide information for health services, wanting to understand more about the existing assets in the communities they work in.

The findings from the case studies could prompt questions for the community, for example, starting up a discussion amongst community members and health services about what this might mean for service delivery in the area.

How can we tap into the wisdom of people with experiences of EOL to learn from their knowledge and access their skills? Can we harness and coordinate this expertise without placing any further caring burden on women? We could share their stories about the wisdom and skills gained from their experience. Is there something to be learned from those who believe in an afterlife or have a religious or spiritual practice that is more broadly relevant?

We can also ask what types of interventions might be best suited to improving the various aspects of death literacy? When are community education programs, experiential enquiry, or expert consultation useful? When is it more effective to provide formal programs about navigating the health and death systems or more useful to have support or mentors available when people are facing problems with the systems? No doubt all are useful and there will be

individual differences in learning preferences. Ideally a range of supports are available within a community so the appropriate intervention can be selected.

The results also raise the question of whether there is a larger pool of volunteers to be harnessed. The higher scores for *Talking support* than *Hands on care* suggest that programs could be developed to assist those willing to talk to carers to move into more hands on and much needed assistance. How could we support people in, and provide opportunities for, people to learn about providing practical hands-on support? How can we do this in a way that doesn't exploit or overburden carers or community members?

Could death literacy be improved through increasing cultural experiences around EOL or death literacy education in schools? The results showed consistently that school was the least likely place for respondents to learn about EOL. However, there is already a positive example from Calvary Bethlehem's *School Health Promotion project "Embracin*g Life" which aims to enable discussion by lessening community fear of death and dying. (https://www.calvarycare.org.au/blog/2016/01/12/embracing-life/). The evaluation by La Trobe University (21) found that the program influenced career choice toward healthcare professions and improved support of fellow students experiencing bereavement.

The findings to date on the DLI contribute to the growing body of research in Australia that is attempting to understand more about the attitudes and beliefs about death and dying and how these attitudes are related to behaviour change (22-24). As we address the questions raised by these results, we can use the DLI to further increase our understanding of how to develop Compassionate Communities.

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APPENDICES

APPENDIX 1 Detailed Tables for the Statistical Results

Figure A1: Structural Equation Model for the fitting model for the DLI with error terms

Table A1: Fit statistics, Chronbach's alpha, and Means for the DLI scales and Subscales

Table A2: Descriptions of Measures of Attitudes and Actions and Relationship to the 2018 DLI

Table A3: Relationships between four Formal Roles and the DLI Scale and Subscales

Table A4: Correlations between the 2019 DLI and Death Competence, Fear of Death and Knowledge test scores

Table A4A: Test questions to assess people's objective knowledge of the death system

Table A5: Bivariate Relationships of the DLI to the demographic variables

Table A6: Relationship between Social Connection Variables and DLI

APPENDIX 2 DLI Scale Items and Supplementary Scales

APPENDIX 2.1 Death Literacy Index

APPENDIX 2.2 Attitudes & Actions Scales

APPENDIX 2.3 Demographic & Social Variables

APPENDIX 1 - Detailed Tables for the Statistical Results

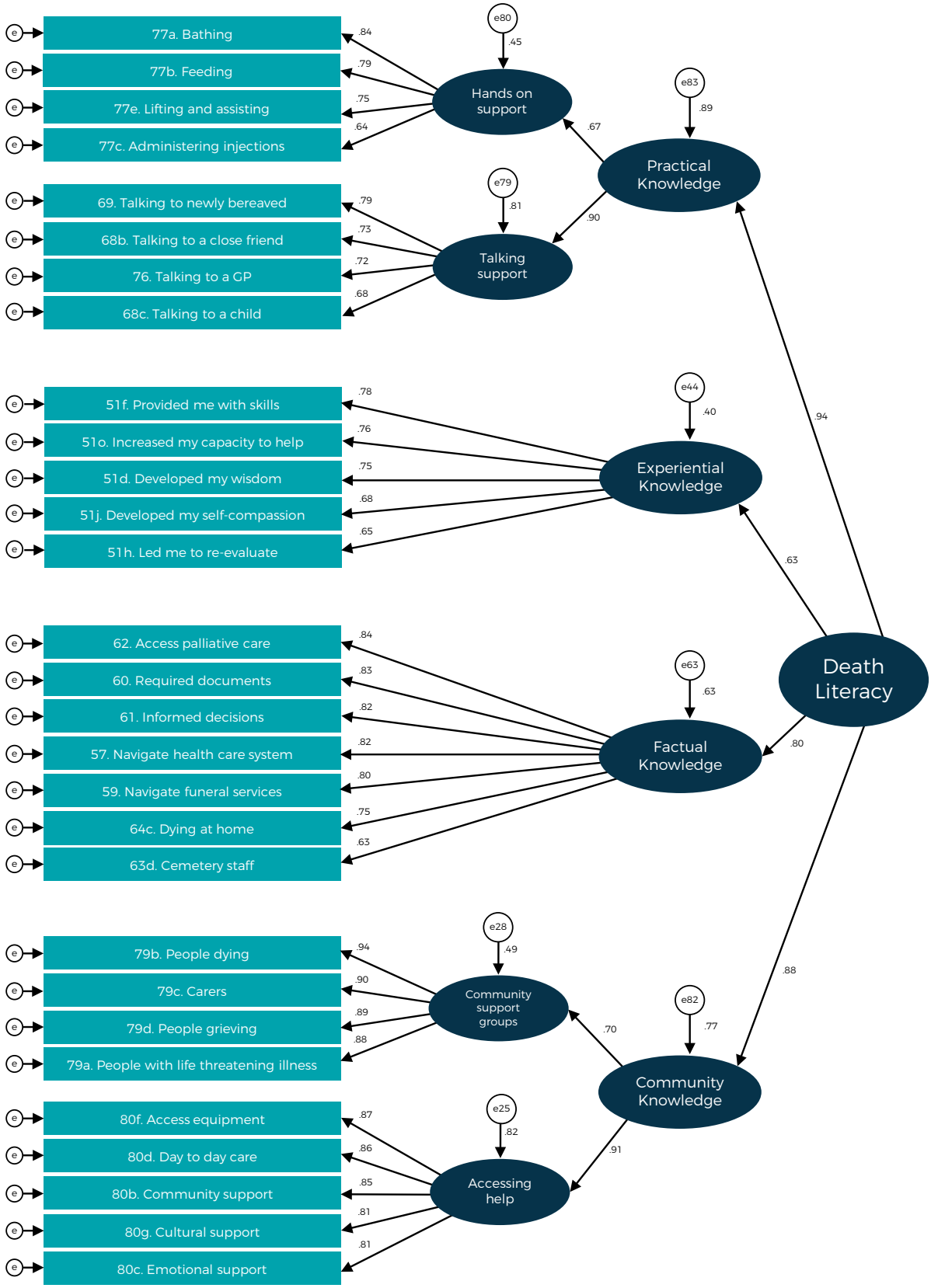

Figure A1: Structural Equation Model for the fitting model for the DLI with error terms

Table A1: Fit statistics, Chronbach, alpha and Means for the DLI Scales and Subscales

DLI Scale and Subscales	TLI	CFI	Rmsea	Chi Sq	DF	CMIN	Chronbach's Alpha	Mean (S.D.)
Total DLI Model 29 items	0.950	0.955	0.049	1556.4	406	4.218	0.946	48.4 (18.4)
Practical Knowledge (Total model 8 items)	0.950	0.966	0.078	171.7	19	9.036	0.856	48.9 (21.3)
Talking support (4)	0.973	0.991	0.079	18.5	2	9.245	0.818	55.2 (22.9)
Hands on care (4)	0.990	0.997	0.051	8.8	2	4.428	0.840	42.6 (26.2)
Experiential Knowledge (5 items)	0.965	0.983	0.082	49.528	5	9.906	0.848	58.9 (20.9)
Factual Knowledge (7 Items)	0.971	0.98	0.079	131.1	14	9.361	0.918	39.6 (24.5)
Community Knowledge (Total model 9 items)	0.976	0.983	0.073	212.2	26	8.161	0.931	48.8 (23.4)
Accessing help (5)	0.969	0.985	0.106	80.2	5	16.047	0.923	48.8 (26.4)
Support groups (4)	0.988	0.996	0.089*	22.9	2	11.485	0.947	49.1 (25.8)

Notes on Fit statistics and criteria

Fit indices	Fit criteria	Comments	Used
TLI – Tucker-Lewis Index	> .95	Widely used fit statistic	Yes
CFI – Comparative Fit Index	> .95	Widely used fit statistic	Yes
RMSEA – Root Mean-Square Error of Approximation	< .08	Widely used fit statistic but not sensitive with small degrees of freedom	Yes
Chi Sq	Non-significant at .05	Chi Sq does not work for sample sizes over 200 so is not appropriate for this study	No
Cmin (Chi Sq/df)		No agreed upon criterion	No

Table A2: Descriptions of Measures of Attitudes and Actions and Relationship to the 2018 DLI

Attitudes and Actions scales	No. of items	Chronbach's Alpha	Correlation with DLI
Provided care at EOL	4	0.74	.46***
Discussed death and dying with family and community	2	0.75	.43***
Been present at someone's death	4	0.72	.43***
Had a variety of cultural experiences around death and dying	7	0.70	36***
Helped a care-giver with practical support	7	0.76	.35***
Made Plans for own EOL	3	0.82	.31***
Helped a care-giver with emotional support	5	0.77	.30***
Avoided thinking about death and dying	4	0.84	-.28***
Felt supported around a recent death	3	0.90	.19***

Notes *** p<.0005

From the first DLI national survey 2018

Table A3: Relationships between four Formal Roles and the DLI Scale and Subscales

DLI Scale and Sub-scales	I work or have worked with people at end of life (including volunteering)		I work or have worked in a job where I support/ed people through grief and loss (including volunteering)		I have attended training on helping people with dying, grief or bereavement		I have been involved in caring for a person while they were dying in the home	
	F statistic	^Eta sq	F statistic	^Eta Sq	F statistic	^Eta Sq	F statistic	^Eta Sq
Practical Knowledge	83.4***	.059	85.4***	.060	91.0***	.064	77.8***	.055
Talking support	38.0***	.028	46.1***	.034	52.3***	.038	63.5***	.046
Hands on care	88.6***	.063	81.4***	.058	82.8***	.059	53.3***	.039
Experiential Knowledge	72.7***	.052	62.4***	.045	66.8***	.048	38.7***	.028
Factual Knowledge	61.9***	.045	92.9***	.067	68.4***	.049	95.5***	.067
Community Knowledge	33.7***	.025	95.5***	.047	52.2***	.038	38.2***	.028
Accessing help	37.7***	.029	72.0***	.051	57.2***	.041	35.8***	.026
Support groups	16.4***	.012	34.8***	.026	27.9***	.021	25.2***	.019
DLI	97.7***	.069	124.9***	.086	110.9***	.077	97.6***	.068
N involved	173		149		121		230	

Notes *** p<.0005: ^ Eta Sq. (Cohen 1988) .01 small; .06 medium; .14 large

From the first DLI national survey 2018

Table A4: Correlations between the 2019 DLI and Death Competence, Fear of Death, and Knowledge test scores

	Factual knowledge Scale	Experiential Knowledge Scale	Practical Knowledge Scale	Community Knowledge Scale	DLI
Fear of Death subscale Disturbed Own Death	-.068*	.062*	-.114**	-.040	-.050
Fear of Death subscale Disturbed by Own Dying	-.054	.150**	-.024	-.010	.020
Fear of Death subscale Disturbed by Others Death	-.163**	.054	-.121**	-.060*	-.093**
Fear of Death subscale Disturbed by Others Dying	-.170**	.007	-.214**	-.121**	-.158**
Bugen's Coping with Death Scale	.550**	.445**	.578**	.520**	.673**
Knowledge Test score	.168**	.084**	.121**	.093**	.150**

Notes: *p<.05 **p<.005

From the second DLI national survey 2019

Table A4A: Test questions to assess people's objective knowledge of the death system

Question	Response options with correct answers in bold
It is legally permitted to die at home?	No **Yes** Only under the supervision of a G.P.
What is the role of an enduring guardian/healthcare proxy?	Take complete control of my finances **Act in my best interest when I can't make decisions for myself** Make decisions for me
What percentage of deaths in Australia is from a sudden illness or accident?	**0-10% 11-20%** 21-30% 31-40% 41-50% 51-60% 61-70% 71-80% 81-90% 91-100%
Of the people who die in Australia, how many people die at home?	0-10% **11-20%** 21-30% 31-40% 41-50% 51-60% 61-70% 71-80% 81-90% 91-100%
What is palliative care?	Care received only by people in the last few weeks or days of life Care for people aged over 85 **Care that improves the quality of life of people with a life-threatening illness**
An advance care directive is:	A legal document about managing your financial affairs About making sure you stay out of a nursing home **A written record of a person's preferences for their care**

Table A5: Bivariate Relationships of the DLI to the demographic variables

Demographic Variables	Direction of the relationship to DLI	F	sig	Eta Sq	Power of the relationship^
Age	positive	10.27	.000	.049	small
Gender	NS	2.74	.098	.002	
What is your total annual household income before tax?	negative	7.37	.007	.006	negligible
What is the highest level of education you have completed?	NS	1.45	.192	.007	
Employment status					
Employed F/T	negative	17.77	.000	.015	small
Employed P/T	positive	4.851	.028	.004	negligible
Casual	NS	3.379	.066	.003	
Not working	negative	5.015	.025	.004	negligible
Retired	positive	40.126	.000	.033	small
Actively seeking work	NS	.337	.562	.000	
Student	NS	.009	.926	.000	
State in which you live	NS	1.139	.336	.007	
Location (Urban, Suburban Regional, Rural)	NS	2.444	.063	.006	
Relationship status	Widowed were higher than others	6.224	.000	.035	small
Do you have school-aged children?	NS	.157	.692	.000	
Do you have children of any age?	positive	25.996	.000	.021	small
Do you have adults who are dependent on you?	positive	13.652	.000	.011	small
Language spoken at home (English, Mainly English, Other language)	Positive relationship to speaking English	19.667	.000	.032	small
Ancestry					
English	positive	16.473	.000	.014	small
Irish	positive	13.387	.000	.011	small
Scottish	positive	5.986	.015	.005	negligible
Italian	NS	1.893	.169	.002	
German	NS	.366	.545	.000	

Chinese	negative	11.244	.001	.009	negligible
Australian	positive	5.516	.019	.005	negligible
Indigenous status	NS	.029	.993	.000	
Do you believe in an afterlife?	Positive	10.742	.000	.018	small
Religious or spiritual background					
None	negative	18.790	.000	.016	small
Catholic	NS	1.939	.164	.002	
Anglican (Church of England)	positive	8.144	.004	.007	negligible
Presbyterian	positive	8.861	.003	.007	negligible
Uniting Church	NS	.422	.516	.000	
Buddhism	NS	.538	.463	.000	
Baptist	NS	.295	.587	.000	
Islam	NS	.010	.922	.000	
Greek Orthodox	NS	.104	.747	.000	
Hinduism	NS	.435	.510	.000	
Spiritual	positive	11.193	.001	.009	negligible
Current religious or spiritual practice					
None	negative	11.531	.001	.010	small
Catholic	NS	.031	.860	.000	
Anglican (Church of England)	positive	8.299	.004	.007	negligible
Presbyterian	positive	5.077	.024	.004	negligible
Uniting Church	NS	.492	.483	.000	
Buddhism	negative	4.959	.026	.004	negligible
Baptist	NS	.001	.975	.000	
Islam	NS	.033	.856	.000	
Greek Orthodox	NS	.051	.822	.000	
Hinduism	NS	.581	.446	.000	
Spiritual	positive	10.008	.002	.008	negligible

Notes: NS – no significant relationship

^ Eta Sq. (Cohen 1988) .01 small; .06 medium; .14 large

From the second DLI national survey 2019

Table A6: Relationship between Social Connection Variables and DLI

Social Connection Variables	Frequency (N=1330)	Direction of the relationship to DLI	F	sig	Eta Sq	Power of the relationship^
Do you talk to your neighbours? (1 not at all to 5 a lot)	179 never speak to their neighbours	positive	173.295	.000	.115	medium
Do you have someone you can contact if you need help? (yes/No)	1120 had someone to contact	positive	70.822	.000	.051	small

Notes ^ Eta Sq. (Cohen 1988) .01 small; .06 medium; .14 large

From the first DLI national survey 2018

APPENDIX 2 – DLI Scale Items and Supplementary Scales

Appendix 2.1: Death Literacy Index

PRACTICAL KNOWLEDGE (2 Subscales)

Talking support (1)

PLEASE RATE HOW DIFFICULT OR EASY YOU WOULD FIND THE FOLLOWING TALKING SUPPORT (on a scale of 1-5 between *Not at all able* to *Very able*)

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

Doing hands on care (2)

PLEASE RATE HOW DIFFICULT OR EASY YOU WOULD FIND THE FOLLOWING HANDS ON SUPPORT. *Undertake the following care duties for the dying* (on a scale of 1-5 between *Not at all able* to *Very able*)

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

EXPERIENTIAL KNOWLEDGE

PLEASE RATE HOW MUCH EACH OF THE BELOW STATEMENTS SOUND LIKE YOU. *My previous experience of grief, loss or other significant life events has* (on a scale of 1-5 between *Very untrue of me* to *Very true of me*)

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

FACTUAL KNOWLEDGE

PLEASE RATE HOW MUCH EACH OF THE BELOW STATEMENTS SOUND LIKE YOU (on a scale of 1-5 between *Strongly disagree* to *Strongly agree*)

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 health care 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 the cemetery staff can make at end of life

COMMUNITY KNOWLEDGE (2 Subscales)

Others can help me provide end of life care (1)

PLEASE RATE YOUR LEVEL OF AGREEMENT WITH THE FOLLOWING STATEMENTS. *If I were to provide end of life care for someone, I know people who could help me* (on a scale of 1-5 between *Strongly disagree* to *Strongly agree*)

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

Support groups in my community (2)

PLEASE RATE YOUR LEVEL OF AGREEMENT WITH THE FOLLOWING STATEMENTS. *There are support groups in my community for* (on a scale of 1-5 between *Strongly disagree* to *Strongly agree*)

26. People with life threatening illnesses
27. People who are dying
28. Carers for people who are dying
29. People who are grieving

Appendix 2.2: Attitudes & Actions Scales

When designing a survey, it is useful to consider which of these background questions to include, partly to understand the previous experiences of respondents and partly to give an indication of where interventions might be effective in a particular community**.**

Cultural Experience of death & dying

WE ARE INTERESTED IN CULTURAL EXPERIENCES RELATING TO DEATH AND DYING. PLEASE ANSWER THE FOLLOWING (rate as *Yes* or *No*)

1. I have read or discussed a book on death, dying or bereavement
2. I have read an autobiographical account of a person's dying or bereavement
3. I have learnt about end of life issues through school (including death, dying and grief)
4. I have participated in community events or activities related to death or dying
5. I have seen an art exhibition which has featured works about dying, death or bereavement
6. I have attended a play or film which deeply explored dying, death or bereavement
7. I have had a conversation with a dying person about their death

Discuss death & dying

PLEASE RATE YOUR LEVEL OF AGREEMENT WITH THE FOLLOWING STATEMENTS (on a scale of 1-5 between *Strongly disagree* to *Strongly agree*)

1. In my community we discuss death and dying
2. In my family we discuss death and dying

Avoidance of death & dying

PLEASE RATE YOUR LEVEL OF AGREEMENT WITH THE FOLLOWING STATEMENTS (on a scale of 1-5 between *Strongly disagree* to *Strongly agree*)

1. I usually avoid the topic of death and dying
2. I usually avoid people who are grieving
3. I tend to avoid conversations about dying and death to avoid upsetting people
4. I tend to avoid conversations about dying and death because it makes me feel uncomfortable

Feeling supported at time of death

WE ARE INTERESTING IN YOUR PERSONAL EXPERIENCES. PLEASE ANSWER THE FOLLOWING (on a scale of 1-5 between *Strongly disagree* to *Strongly agree* or *N/A – I have not experienced death*)

1. Considering your most recent experience of someone's death, please rate your experience as follows:
    a. I felt supported prior to their death
    b. I felt supported at the time of their death
    c. I felt supported after their death

Plans for end of life

WE ARE INTERESTED IN END OF LIFE PLANNING. PLEASE ANSWER THE FOLLOWING (rate as *Yes* or *No*)

1. Have you made any plans for the end of your life?
    a. Will
    b. Appointed someone to make decisions regarding your health or wellbeing e.g. Enduring guardianship/ Health care proxy
    c. Appointed someone to make decisions regarding finances or property e.g. Enduring Power of Attorney/ Legally appointed substitute decision maker
2. I have helped someone to make plans for end of life e.g. advance care plans, funerals etc.

Caring at end of life

WE ARE INTERESTED IN YOUR CARING EXPERIENCE, PLEASE RESPOND TO THE FOLLOWING (rate as *Yes* or *No*)

1. I am currently the main carer of someone who might die within 12 months
2. I have contributed to the hands-on care of a person who is dying
3. I have given medications to a person who is dying
4. I have provided emotional support to a person who was dying

Supporting a carer

WE ARE INTERESTED IN YOUR EXPERIENCE SUPPORTING A CARER, PLEASE RESPOND TO THE FOLLOWING (rate as *Yes* or *No*)

1. I have helped someone who is supporting a dying person by:

    Providing emotional help to carer

    a. Making contact to show I am concerned
    b. Giving emotional support
    c. Supporting them with grief and bereavement
    d. Being available to talk

e. Communicating with friends and family

Providing practical help to carer

f. Helping to access informal support
g. Raising money
h. Helping out with the children such as taking them to school
i. Buying essential items
j. Taking them food
k. Sitting with a person dying
l. Organising care

Present at death

WE ARE INTERESTED IN YOUR EXPERIENCE OF BEING WITH SOMEONE AT THE TIME OF THEIR DEATH. PLEASE RESPOND TO THE FOLLOWING (rate as *Yes* or *No*)

1. I have kept someone company who is near death
2. I have witnessed the death of another person
3. I have spent time with a person after their death
4. I have helped care for a dead body

Contribution to knowledge of death & dying

WE ARE INTERESTED IN THE CONTRIBUTION TO YOUR KNOWLEDGE OF DEATH AND DYING. PLEASE RESPOND TO THE FOLLOWING (rate on a scale of 1-5 between *Not at all* and *A great deal*)

1. To what extent have the following experiences contributed to your knowledge of death, dying and bereavement?
    a. Factual/autobiographical books or documentaries
    b. Fiction books, films, theatre, television
    c. Community activities
    d. Personal experience
    e. Work experience
    f. Family/Kinship group
    g. School
    h. Faith community or practice

Expression

PLEASE RESPOND TO THE FOLLOWING ABOUT YOUR EXPRESSION (on a scale of 1-5 between *Strongly disagree* to *Strongly agree*)

1. I express what I know about death and dying through
    a. Social media
    b. Art making
    c. Music or dance
    d. Performing

Work in end of life

PLEASE RESPOND TO THE FOLLOWING ABOUT YOUR WORK AND TRAINING EXPERIENCES (rate as *Yes* or *No*)

1. I do paid work or have done paid work with people at end of life

2. I volunteer or have volunteered with people at end of life
3. I do paid work or have done paid work in a job where I support/ed people through grief and loss
4. I volunteer or have volunteered in a job where I support/ed people through grief and loss
5. I have attended training on helping people with dying, grief or bereavement

Appendix 2.3: Demographic & Social Variables

Appendix 2.3 lists the demographic and social variables that have been used in the various surveys. We would particularly recommend including those that have a strong relationship to the DLI (see Tables, 2, 5 & 6) in any survey. However, we would also recommend including other demographic questions, that although did not correlate with death literacy, help to describe the sample population (e.g. gender, location).

1. Age:
   - 18 - 24 years
   - 25 - 34 years
   - 35 - 44 years
   - 45 - 54 years
   - 55 - 64 years
   - 65 - 79 years
   - 80+ years

2. Gender:
   - Female
   - Male
   - Non-binary (specify)

3. What is the highest level of education you have completed?
   - Year 9 or below
   - Year 10 or equivalent
   - Year 12 or equivalent
   - Certificate or Diploma
   - Undergraduate degree
   - Postgraduate degree
   - Other (specify)

4. Employment status (select the most appropriate):
   - Employed - full time
   - Employed – part time
   - Casual
   - Not working
   - Retired
   - Actively seeking work
   - Student

5. Postcode (please specify)

6. Location:
   - Urban area
   - Semi-urban area
   - Regional area
   - Rural area
   - Remote area

7. Relationship status (select the most appropriate response):
   - Married/defacto
   - Never married/defacto
   - Widowed
   - Divorced
   - Separated but not divorced
   - Partnered but not living together
   - Single
   - Other (specify)

8. Do you have children?
   - Yes
   - No

9. Do you have someone you can contact if you need help?
   - Yes
   - No

10. Do you talk to your neighbours?
    - Yes
    - No

11. Language spoken at home:
    - English
    - Mainly English
    - Other language (please specify)

12. Ancestry (please specify)

13. Australian First Nations status:
    - Non-Aboriginal or Torres Strait Islander
    - Aboriginal
    - Torres Strait Islander
    - Both Aboriginal and Torres Strait Islander

14. Do you have a religious or spiritual background?
    - Yes (please specify)
    - No

15. Do you have a current religious or spiritual practice?
    Yes (please specify)
    No

16. Do you believe in an afterlife?
    Yes
    No

17. Do you have a disability or long-term health condition?
    Yes
    No

18. Are you currently living with a terminal illness?
    Yes
    No

19. Have you attended an event about end of life in your community?
    Yes (please specify)
    No