## Supplement file 1. Original version of the Death Literacy Index (Leonard et al., 2021)

### 1. Practical knowing

#### 1.1. Conversations about dying, death, or grief

*How prepared would you be to talk about the following? Indicate your response on a scale of 1-5, where 1=not prepared at all and 5=very prepared*

1. Talk about dying, death, or grief with a close friend

2. Talk about dying, death, or grief to a child

3. Talk to a bereaved person about their loss

4. Talk to care staff about support for a person who will die, at home or in their place of care

#### 1.2 Providing practical care

*How prepared would you be to perform the following? Indicate your response on a scale of 1-5, where 1=not prepared at all and 5=very prepared*

5. Feeding someone or helping them eat

6. Wash someone

7. Lifting someone or helping to move them

8. Administering injections

### 2. Learning from experience

*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.*

*Previous experience of grief, losing someone, or other significant life events has…*

9. Made me more emotionally prepared to support others with processes related to death and dying

10. Made me reflect on what is important and not important in life

11. Made me wiser and given me new understanding

12. Increased my compassion toward myself

13. Given me preparedness to face similar challenges in the future

### 3. Knowledge about processes and systems related to the end of life

*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.*

14. I know about regulations regarding deaths at home

15. I know that there are documents that can help a person plan for death

16. I know enough about how [the health care system] operates to support a person to receive care at the end of life

17. I know how the funeral process works, where to turn and the various options available

18. I know how to access palliative care in the area where I live

19. I know enough to make decisions about medical treatments and understand how they may shape the quality of life at the end of life

20. I know about different ways that cemetery staff can be of service around funerals

### 4. Knowledge about the community where you live

#### 4.1 How others can help me with end-of-life care provision

*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.*

*If I were to care for someone at the end of life, I know where to turn for:*

21. Access to support in the area where I live, e.g., from associations or volunteer organizations

22. Help with providing day to day care for a person at the end of life

23. Access equipment that are required for care

24. Access support that is culturally appropriate for a person

25. Access emotional support for myself

#### 4.2 Support groups in my community

*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.*

*I know that there are support groups for:*

26. People with illnesses that might lead to death

27. People who are at the end of their lives

28. People who care for someone who is dying

29. People who are grieving

## Supplement file 2. The Swedish-language DLI (DLI-S) with back-translation to English.

**Death Literacy Index-S**

Detta frågeformulär undersöker kunskaper och förmågor som rör livets slut. Frågeformuläret kan användas av alla, oavsett om du har tidigare erfarenhet av livets slut eller inte. I frågeformuläret kommer du att få svara på hur väl olika påståenden stämmer in på dig. Det finns inget rätt eller fel svar, utan vi är intresserade av din uppfattning så som den ser ut idag.

**1. Praktisk kunskap**

**1.1. Samtal om att dö, döden eller sorg**

*Hur beredd skulle du vara att prata om följande?*

*Ange ditt svar på en skala mellan 1-5, där 1=inte alls beredd och 5=mycket beredd*

1. Att prata om att dö, döden eller sorg med en nära vän

2. Att prata om att dö, döden eller sorg med ett barn

3. Att prata med en sörjande person om hens förlust

4. Att prata med vårdpersonal om stöd till en person som kommer att dö i hemmet eller på den plats där hen får vård

**1.2. Ge praktisk omvårdnad**

*Hur beredd skulle du vara att göra följande?*

*Ange ditt svar på en skala mellan 1-5, där 1=inte alls beredd och 5=mycket beredd*

5. Mata någon eller hjälpa någon att äta

6. Tvätta någon

7. Lyfta någon eller hjälpa till vid förflyttning

8. Ge injektioner

**2. Erfarenhetsbaserad kunskap**

*Hur stämmer följande för dig?*

*Ange ditt svar på en skala mellan 1-5, där 1=stämmer inte alls och 5=stämmer mycket väl*

***Tidigare erfarenheter av sorg, att förlora någon eller andra viktiga händelser i livet har...***

9. Gjort mig mer känslomässigt förberedd att ge stöd till andra i processer kring döden

**DLI-S back-translated to English**

This survey investigates knowledge and skills related to the end of life. The survey can be used by anyone, no matter if you have previous end-of-life experiences or not. In the survey you will rate the extent to which you agree with different statements. There are no right or wrong answers, we are only interested in your views as they are today.

**1. Practical knowledge**

**1.1. Conversations about dying, death, or grief**

*How prepared would you be to talk about the following?*

*Indicate your response on a scale of 1-5, where 1=not prepared at all and 5=very prepared*

1. Talk about dying, death, or grief with a close friend

2. Talk about dying, death, or grief to a child

3. Talk to a bereaved person about their loss

4. Talk to care staff about support for a person who will die, at home or in their place of care

**1.2 Providing practical care**

*How prepared would you be to perform the following?*

*Indicate your response on a scale of 1-5, where 1=not prepared at all and 5=very prepared*

5. Feeding someone or helping them eat

6. Wash someone

7. Lifting someone or helping to move them

8. Administering injections

**2. Experiential knowledge**

*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*

***Previous experience of grief, losing someone, or other significant life events has…***

9. Made me more emotionally prepared to support others with processes related to death and dying

10. Fått mig att fundera på vad som är viktigt och mindre viktigt i livet

11. Gjort mig mer klok och gett mig ny förståelse

12. Ökat min medkänsla för mig själv

13. Gett mig beredskap att klara av liknande utmaningar i framtiden

**3. Kännedom om processer och system relaterade till livets slutskede**

*Hur stämmer följande för dig?*

*Ange ditt svar på en skala mellan 1-5, där 1=stämmer inte alls och 5=stämmer mycket väl*

14. Jag känner till de regelsystem som rör dödsfall i hemmet

15. Jag känner till att det finns dokument som kan hjälpa en person att planera inför döden

16. Jag vet tillräckligt mycket om hur vård och omsorg fungerar för att kunna stödja en person att få vård i livets slut

17. Jag känner till processen inför begravning, vart jag kan vända mig och vilka val som finns

18. Jag känner till hur jag får tillgång till palliativ vård i området där jag bor

19. Jag vet tillräckligt för att kunna ta beslut om medicinska behandlingar och förstå hur de kan påverka livskvaliteten i livets slut

20. Jag känner till olika sätt som personal vid begravningsplatser kan vara till hjälp vid begravning

**4. Kunskaper om samhället där du bor**

***4.1. Hur andra kan hjälpa mig med vård i livets slut***

*Hur stämmer följande för dig?*

*Ange ditt svar på en skala mellan 1-5, där 1=stämmer inte alls och 5=stämmer mycket väl*

***Om jag skulle ta hand om en person i livets slut, så känner jag till var jag kan vända mig för:***

21. Att få stöd i området där jag bor, exempelvis från föreningar eller frivilligorganisationer

22. Att få hjälp med att ge en person daglig vård under livets sista tid

10. Made me reflect on what is important and not important in life

11. Made me wiser and given me new understanding

12. Increased my compassion toward myself

13. Given me preparedness to face similar challenges in the future

**3. Knowledge about processes and systems related to the end of life**

*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*

14. I know about regulations regarding deaths at home

15. I know that there are documents that can help a person plan for death

16. I know enough about how [the health care system] operates to support a person to receive care at the end of life

17. I know how the funeral process works, where to turn and the various options available

18. I know how to access palliative care in the area where I live

19. I know enough to make decisions about medical treatments and understand how they may shape the quality of life at the end of life

20. I know about different ways that cemetery staff can be of service around funerals

**4. Knowledge about the community where you live**

**4.1 How others can help me with end-of-life care provision**

*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*

***If I were to care for someone at the end of life, I know where to turn for:***

21. Access to support in the area where I live, e.g., from associations or volunteer organizations

22. Help with providing day to day care for a person at the end of life

23. Att skaffa hjälpmedel som behövs för vård

24. Att få tillgång till stöd som passar personens kultur

25. Att få tillgång till eget känslomässigt stöd

**4.2. Stödgrupper**

*Hur stämmer följande för dig?*

*Ange ditt svar på en skala mellan 1-5, där 1=stämmer inte alls och 5=stämmer mycket väl*

***Jag känner till att det finns stödgrupper för:***

26. Personer som har en sjukdom som kan leda till döden

27. Personer som inte har långt kvar att leva

28. Personer som tar hand om någon som är döende

29. Personer som sörjer

23. Access equipment that are required for care

24. Access support that is culturally appropriate for a person

25. Access emotional support for myself

**4.2 Support groups in my community**

*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*

***I know that there are support groups for:***

26. People with illnesses that might lead to death

27. People who are at the end of their lives

28. People who care for someone who is dying

29. People who are grieving

## Supplement file 3. English translations of survey questions for sociodemographic, health and experience-based variables.

|  |  |  |  |
| --- | --- | --- | --- |
| **Variable** | **Question** | **Response alternatives** | **Recoded responses in regression** |
| **Age** | What is your age? |  |  |
| **Gender** | What gender are you? | * Man * Woman * Non-binary * Transgender * Do not wish to answer | Man/Woman |
| **Education level** | What is your highest level of completed education? | * No education or primary school not finished * Primary education (e.g. primary school, elementary school) * Lower secondary education (e.g. middle school, junior high school) | Lower secondary or less |
| * Upper secondary education, general or vocational (e.g. gymnasium, high school) * Post-secondary education (e.g. vocational certificate) * Higher general or vocational education (e.g., higher education diploma) | Upper secondary |
| * Higher education, bachelor’s level or equivalent * Higher education, master’s level or equivalent * Higher education, doctorate level or equivalent * Other education, please specify | Tertiary education, diploma or higher |
| **Health status** | How would you describe your overall health? | * Excellent * Very Good * Good * Fair * Poor * Do not wish to answer | Dummy coded |
| **Household composition** | What is your relationship status? (Please choose the alternative(s) that best describe(s) your situation) | * Single * In a relationship but not co-habiting * Married/co-habiting with partner * Widowed * Other (please specify) * Do not wish to answer | Widowed recoded as a separate dichotomized variable |
| Do you have children? | * Yes, I have children living in the household * Yes, but they do not live in the household * No |  |
| **Religious belief** | Which of these statements comes closest to your beliefs? | * I believe there is a God * I believe there is some sort of spirit of life force | Religious/ spiritual |
| * I don’t know what I believe | Agnostic |
| * I don’t believe there is any sort of God or life force | Atheist |
| **Professional care background** *(current or prior)* | Do you currently work, or have you worked, in any of the following sectors? (Choose all that apply) | * Health care * Social care * No | Dummy coded |
| **Working with people at the EOL** | Have you worked for pay with people who are at their end of life? | * No | No |
| * Yes, currently * Not currently but within the past 2 years * Not currently but more than 2 years ago | Yes |
| Have you worked as a volunteer with people who are at their end of life? | * No | No |
| * Yes, currently * Not currently but within the past 2 years * Not currently but more than 2 years ago | Yes |
| **Grief support** | Have you worked for pay to support people through grief and loss? | * No | No |
| * Yes, currently * Not currently but within the past 2 years * Not currently but more than 2 years ago | Yes |
| Have you worked as a volunteer to support people through grief and loss? | * No | No |
| * Yes, currently * Not currently but within the past 2 years * Not currently but more than 2 years ago | Yes |
| Have you ever had any of the following experiences? | * Experience of supporting a person who has lost a family member or friend |  |
| **Loss** | Have you ever had any of the following experiences? (choose all that apply) | * Experience of a family member’s, close relative’s, or friend’s death * Experience of a relative’s or an acquaintance’s death |  |
| **Life-threatening illness** | Have you ever had any of the following experiences? (choose all that apply) | * Experience of own life-threatening illness * Experience of supporting a person with life-threatening illness |  |
| **EOL care provision** | Have you ever had any of the following experiences? (choose all that apply) | * Experience of caring for a relative at the end of life * Professional experience of caring for a person at the end of life |  |
| **EOL education** | Have you completed any formal training focused on the end of life, palliative care, death, dying and bereavement, as an adult? | * No | No |
| * Yes, training encompassing less than 1 week * Yes, training encompassing 1-10 weeks * Yes, training encompassing more than 10 weeks   *(Please specify)* | Yes |
| **Attending EOL-related event** | Have you attended an event about the end of life, death, dying, or bereavement? | * Yes *(please specify)* * No |  |

## Supplement file 4. Summary of the procedure of constructing the directed acyclic graph

The construction of the directed acyclic graph by the first author in this study was guided by the protocol set out by Ferguson et al. (2020). The main steps of this procedure, and decisions made, are summarized here.

First, in what Ferguson et al. call the Mapping stage, a diagram was created with death literacy as the outcome node and all variables retained from the bivariate regression analysis as exposure nodes. Assumed relationships, “directed edges”, were drawn between nodes. This allowed us to identify potential confounder variables to control for and possible mediated paths. For example, Age, Gender and Educational level were identified as potential confounders, i.e., associated with both the outcome and several of the predictor variables. The Mapping stage resulted in the creation of an “implied graph”, serving as a template that helped identify important parameters for building the hierarchical regression model.

Moving to the Translation stage, the assumed relationships and their reverses were assessed according to three criteria: *Chronology*, whether the assumed cause precedes the effect; *Face validity*, whether the assumed relationship is plausible at face value; and *Theory*, whether the assumed relationship is supported by theory.

In the subsequent Synthesis stage, the retained relationships from the Translation stage were merged with the implied graph from the Mapping stage to produce an integrated model illustrating the potential links between exposure node(s) and the outcome node as well as possible confounder and mediator relationships (Figure 3).

To increase the readability of the explanatory model, the following, conceptually linked, variables were combined in the Recombination stage:

* Professional experience working in healthcare and working in social care were combined as *Care background*
* Professional and personal end-of-life care experiences were combined as a *EOL care*
* Paid work and volunteering with dying and/or grieving people were combined as *EOL work/volunteering*

Arguably, all experiential nodes could have been combined as a single node of direct end-of-life experiences. However, given the aim of the study, it was important to maintain some distinction between facets of end-of-life experiences as these were assumed to possibly have differential associations with the outcome. Thus, nodes that were considered to encompass different components of end-of-life-related situations were retained as separate nodes.

## Supplement file 5. Matrix showing paired correlation coefficients (Spearman’s Rho) between explanatory variables retained from bivariate regression analysis.

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Spearman's rho correlation coefficients** | **Age** | **Female** | **Widow** | **Upper Secondary education** | **Tertiary education** | **Religious** | **Agnostic** | **Not Religious** | **Excellent Health** | **Very Good Health** | **Good Health** | **Fair Health** | **Poor Health** | **Prof Healthcare** | **Prof Social Care** | **EOL education** | **Paid EOL work** | **EOL volunteering** | **Close Loss** | **Own Illness** | **Support Illness** | **Support Bereaved** | **Personal EOL care** | **Professional EOL care** | |
| **Age** | -- |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Female** | 0,01 | -- |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Upper secondary education** | -0,10\* | -0,01 | -- |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Tertiary education** | 0,04 | 0,02 | -0,85\*\* | -- |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Widow** | 0,14\*\* | 0,07 | 0,03 | -0,06 | -- |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Religious** | 0,15\*\* | 0,16\*\* | -0,02 | -0,02 | -0,04 | -- |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Agnostic** | -0,15\*\* | -0,02 | 0,02 | -0,02 | 0,05 | -0,52\*\* | -- |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Not Religious** | -0,01 | -0,15\*\* | 0,00 | 0,05 | -0,01 | -0,54\*\* | -0,43\*\* | -- |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Excellent Health** | -0,07 | -0,15\*\* | -0,03 | 0,06 | -0,05 | -0,04 | -0,04 | 0,08 | -- |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Very Good Health** | -0,13\*\* | 0,03 | -0,03 | 0,09\* | 0,03 | -0,01 | 0,03 | -0,02 | -0,24\*\* | -- |  |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Good Health** | 0,04 | -0,04 | 0,05 | -0,09 | -0,02 | 0,00 | 0,00 | 0,00 | -0,24\*\* | -0,52\*\* | -- |  |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Fair Health** | 0,17\*\* | 0,09\* | 0,00 | -0,05 | 0,01 | 0,02 | 0,03 | -0,05 | -0,14\*\* | -0,32\*\* | -0,31\*\* | -- |  |  |  |  |  |  |  |  |  |  |  |  | |
| **Poor Health** | 0,00 | 0,07 | 0,02 | -0,02 | 0,03 | 0,01 | -0,05 | 0,04 | -0,08 | -0,17\*\* | -0,17\*\* | -0,10\* | -- |  |  |  |  |  |  |  |  |  |  |  | |
| **Health care professional** | 0,00 | 0,17\*\* | -0,08 | 0,13\*\* | -0,02 | 0,06 | 0,02 | -0,09\* | -0,06 | 0,05 | -0,04 | -0,04 | 0,11\* | -- |  |  |  |  |  |  |  |  |  |  | |
| **Social care professional** | -0,09\* | 0,19\*\* | 0,06 | -0,02 | -0,05 | 0,04 | 0,06 | -0,10\* | -0,02 | -0,08 | 0,04 | 0,05 | 0,04 | 0,09\* | -- |  |  |  |  |  |  |  |  |  | |
| **EOL education** | -0,09\* | 0,21\*\* | -0,01 | 0,07 | -0,02 | 0,06 | 0,01 | -0,07 | -0,06 | -0,01 | -0,07 | 0,03 | 0,17\*\* | 0,56\*\* | 0,25\*\* | -- |  |  |  |  |  |  |  |  | |
| **Paid EOL work** | 0,00 | 0,18\*\* | -0,08 | 0,15\*\* | -0,03 | 0,09\* | -0,04 | -0,06 | -0,07 | -0,05 | -0,01 | 0,06 | 0,08 | 0,54\*\* | 0,33\*\* | 0,60\*\* | -- |  |  |  |  |  |  |  | |
| **EOL volunteering** | 0,04 | 0,03 | -0,04 | 0,06 | -0,05 | 0,07 | -0,06 | -0,01 | -0,06 | 0,03 | -0,02 | 0,00 | 0,02 | 0,09\* | 0,10\* | 0,22\*\* | 0,26\*\* | -- |  |  |  |  |  |  | |
| **Close personal loss** | 0,21\*\* | -0,01 | -0,08 | 0,06 | 0,07 | -0,01 | 0,01 | 0,01 | -0,05 | -0,07 | 0,07 | 0,02 | 0,04 | 0,03 | 0,00 | -0,01 | 0,01 | -0,02 | -- |  |  |  |  |  | |
| **Own life-threatening illness** | 0,17\*\* | -0,03 | -0,03 | 0,07 | -0,05 | 0,04 | -0,02 | -0,02 | -0,04 | -0,12\*\* | 0,07 | 0,03 | 0,11\* | 0,01 | 0,10\* | 0,03 | 0,12\*\* | 0,14\*\* | 0,04 | -- |  |  |  |  | |
| **Support illness** | 0,09\* | 0,22\*\* | -0,10\* | 0,11\* | 0,05 | 0,09\* | 0,00 | -0,09\* | -0,07 | -0,07 | 0,03 | 0,02 | 0,15\*\* | 0,22\*\* | 0,14\*\* | 0,27\*\* | 0,24\*\* | 0,21\*\* | 0,13\*\* | 0,14\*\* | -- |  |  |  | |
| **Supporting a bereaved person** | -0,03 | 0,21\*\* | -0,06 | 0,08 | 0,06 | 0,07 | 0,00 | -0,07 | -0,06 | -0,10\* | 0,08 | -0,01 | 0,15\*\* | 0,09\* | 0,08 | 0,23\*\* | 0,19\*\* | 0,22\*\* | 0,19\*\* | 0,07 | 0,44\*\* | -- |  |  | |
| **Personal EOL care** | 0,04 | 0,11\* | -0,09\* | 0,09 | 0,02 | 0,01 | -0,05 | 0,04 | -0,05 | -0,05 | 0,04 | -0,02 | 0,12\*\* | 0,22\*\* | 0,06 | 0,23\*\* | 0,20\*\* | 0,31\*\* | 0,14\*\* | 0,16\*\* | 0,33\*\* | 0,25\*\* | -- |  | |
| **Professional EOL care** | 0,01 | 0,22\*\* | -0,05 | 0,09 | -0,01 | 0,08 | 0,03 | -0,12\*\* | -0,10\* | 0,00 | -0,04 | 0,02 | 0,14\*\* | 0,55\*\* | 0,25\*\* | 0,60\*\* | 0,64\*\* | 0,17\*\* | 0,00 | 0,04 | 0,21\*\* | 0,20\*\* | 0,21\*\* | -- | |
| \*\*Correlation is significant at the 0.01 level (2-tailed). | | | | | | | | | | | | | | | | | | | | | | | | |
| \*Correlation is significant at the 0.05 level (2-tailed). | | | | | | | | | | | | | | | | | | | | | | | | |