Original Article

Discomfort With Suffering and Dying, a Cross-Sectional Survey of the General Public

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Abstract

Context. Death and the process of dying have become increasingly medicalized and professionalized. The associated cultural estrangement from death may affect how comfortable we feel about death and dying. This study examines the general public's discomfort with another person's suffering and dying, and whether these feelings are associated with specific personal characteristics or experiences.

Objectives. Cross-sectional survey in a random sample of people aged 16 or older in four municipalities in Flanders, Belgium (*N*=4400). We used the self-developed construct *Discomfort with someone's suffering and dying*. A directed acyclic graph guided the development of a multivariable regression model which explored the effect of different variables on the main outcome measure.

Results. A total of 2008 completed questionnaires were returned (response rate: 45.6%). Average discomfort with someone's suffering and dying was 3.74 (SD = 0.89). Being female or currently mourning a loss were associated with more discomfort. Not being religious, having better knowledge about palliative care, having worked in healthcare, having been with someone else at the time of their death and having been culturally exposed to death and dying were associated with less discomfort.

Conclusion. A considerable level of discomfort is present within the general public about the suffering and dying of others and this may increase social stigma and a tendency to avoid seriously ill people and their social surroundings. Our findings suggest that interventions may help shift this societal discomfort if they incorporate a focus on cultural and experiential exposure and increasing knowledge about palliative care. J Pain Symptom Manage 2023;66:529−540. © *2023 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).*

Key Words
Palliative care, end-of-life, death discomfort, public health

Key Message

This cross-sectional survey of the general public showed that a considerable level of discomfort is present within the general public. This discomfort is associated with different personal experiences, characteristics, knowledge about palliative care, and cultural exposure to death, and dying.

Background

Death and the process of dying have become increasingly medicalized and professionalized over recent decades, as is evidenced by the intensified use of healthcare resources and the reliance on professional care services prior to death.[1−5] As a result, societies around the world are becoming largely estranged from

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death as a social event, to the extent that it is often considered unfamiliar and a failure of healthcare systems, as opposed to the last inevitable step in our life cycle.[5−7] In high-income or urban settings, many older people are cared for in nursing or care homes, people are hospitalized when unwell and the majority of deaths occur in institutions.[8,9] This professionally integrated social management of illness, care, and death often takes place hidden from public view, further contributing to our cultural attitudes towards these topics and, therefore, to shaping how comfortable populations feel about death and dying. Considering that a person's health is influenced and shaped by cultural and social norms, the contemporary care delivery model — centralized around professionalized care — needs to align care delivery with societal health evolutions.[10] New public health approaches to palliative care aim to address this by accepting death as a natural part of life, health, and well-being and integral to the community in which it takes place.[11] Addressing how comfortable populations feel about suffering and dying could be part of the action domains of public health policies aiming to change how we approach serious illness, caring and dying as a society.

When people feel uncomfortable about death and dying, feelings of fear, and anxiety may be evoked.[7,12] Becker[13] stated that a person's self-awareness about their mortality prompts a desire to live which in turn can trigger fear and anxiety. Fear of dying in itself is not abnormal and serves as self-preservation, preventing us from crossing a busy highway, for instance. How uncomfortable we feel about suffering and death is not only expressed with regard to our own mortality though but can also be reflected in feelings about the dying of others. These feelings may become detrimental when people feel uncomfortable around seriously ill or dying people as this may lead to an increase in social stigma and the avoidance of these people or their close social surroundings.[6,14−20] However, when people feel more comfortable about the dying of others, seriously ill people may feel more socially connected, which can positively affect their well-being.[21] Moreover, being around seriously ill and dying people or being exposed to these topics through other means (e.g., by watching someone giving testimony about their illness), could open the door towards building new knowledge, developing skills for caregiving, or changing attitudes towards these topics.[22−26] A number of initiatives have been described in the literature which aim to foster the potential of communities through the establishment of community-based mutual support models around serious illness, death, dying, and loss. However, the impact of these initiatives remains largely understudied.[27,28] Nonetheless, communities that feel more comfortable about death and dying could leverage more community engagement in health provision, which has shown

potential in unburdening healthcare professionals and cutting healthcare expenditure.[29−34]

Although death anxiety has been studied in varying populations with differing results, existing studies largely focus on feelings of fear about one's own death and conclude that this is generally low to moderate.[6,35−39] Until now, very few studies have considered people's discomfort with the suffering or dying of others and those that did exclusively focus on healthcare professionals' perceptions when caring for a dying person.[40−42] No population-based studies have been performed on this topic nor has it been explored if factors such as personal characteristics or experiences with care, illness and death are associated with people's discomfort with the suffering and dying of others.

This study aims to examine the discomfort of the general public with the suffering and dying of others and whether these feelings are associated with personal characteristics or experiences such as having worked in healthcare or having had a family care experience. Specific research questions are:

(1) How uncomfortable do people feel about the suffering and dying of others?
(2) Are personal experiences with care, illness and death, and demographic characteristics and religiousness, associated with how uncomfortable people feel?

Methods

Design, Participants and Setting

We conducted a cross-sectional survey in a random sample of people aged 16 or older in four municipalities in Flanders, Belgium: Bruges (urban center city of 118,000 inhabitants), Herzele (semi-urbanized municipality of 18,500 inhabitants), Sint-Niklaas (urban center city of 80,000 inhabitants) and Gavere (semi-urbanized municipality of 12,000 inhabitants). The surveys were part of a baseline measurement (i.e., preintervention) in which the municipalities of Bruges and Herzele are undergoing a public health intervention around the topics of serious illness, death, dying, and bereavement. The impact of these interventions on people's discomfort with the suffering and dying of others is being explored in separate papers, and is not the aim of this study. To be able to evaluate the interventions in a later stadium and to minimize bias when attributing the observed changes to the interventions, it was decided to also distribute the survey in two control municipalities of which each is comparable to one of the intervention cities concerning their urbanization grade.[43] Since people in Flanders mostly live in semi-urbanized municipalities or urban cities, the selected municipalities are representative for the majority of the Flemish

population. Results from this baseline measurement give insight into the assets and needs of the local population which then help to create a bespoke approach. More information on this intervention can be found in the published study protocol.[44] CROSS guidelines were followed to report on this survey study.[45]

Sampling

In every municipality, a civil servant who had access to the population register drew a random sample of the general population using simple random sampling. In Bruges, we disproportionately oversampled family carers by a factor of six because we expected that the public health intervention, with its focus on serious illness, death, dying and bereavement, might specifically target them as a group. Hence, we aimed at better statistical power for this subgroup in view of improved generalizability of findings. In Bruges (and not in the other municipalities), family carers, defined as anyone caring for someone who is heavily care dependent, are registered for them to receive a municipal financial compensation. Analyzing the sample from Bruges, we found a deviation from the population's age distribution and therefore weighted to correct this imbalance. Weighting factors ranging between 0.58 and 2.42 were calculated using the a priori available demographic data to correct for sampling error, the oversampling of family carers and for nonresponse by age.[46] Within each municipality we aimed for a 95% confidence interval with a width of ±5%, with alpha set at 0.05 to estimate proportions (with the most conservative estimation for heterogeneity at 50%). Based on literature and by applying a conservative approach, a response rate of 35% was anticipated.[47] This led to an estimated required initial sample size of 1100 potential participants in each municipality (4400 across all four).

Data Collection Procedure

A civil servant in each of the municipalities, supported by a data collector from the research team, sent out the questionnaire and accompanying introduction letters to all individuals in the sample in the first semester of 2021. Measures to improve the response rate as suggested in Dillman's total design method were implemented.[48] This included a follow-up mailing procedure with up to three reminder mailings. Respondents had the option to fill out the questionnaire on paper and mail it using an included pre-paid envelope or online using Limesurvey, a secure open-source survey tool. Participants were not offered incentives to participate. Completed questionnaires were sent directly to the researcher who communicated the respondent's unique, pseudonymized number to the data collector, so as to prevent these respondents erroneously receiving a reminder. Through this mailing procedure, responses to the questionnaires could at no point be

linked to the individual. All answers on paper were entered into Limesurvey.

Questionnaire and Measures

All measures studied in this questionnaire relate to serious illness, care, death, loss or grief and can be found in the published study protocol.[44] Some of the measures used in this survey study are based on background questions from the now validated Death Literacy Index which had not been published when we designed this survey.[34] Through contact with researchers from the Death Literacy Index, we obtained input into the development of several of our used measures. For some measures in the questionnaire, we asked respondents to reflect on their situation prior to the COVID-19 pandemic. Reflecting on their then current situation would have influenced results pertaining to measures about social networks or community participation.

Main Outcome Measure. We developed a nonvalidated Dutch adaptation based on the subconcept *Dying of others* from the Revised Collett-Lester Fear of Death Scale.[49] It is a well-known scale with which to assess people's fear of death and dying, where dying is regarded as the degenerative process preceding a predictable death. We changed the original question *"How disturbed or made anxious are you by the following aspects"* to *"How uncomfortable would you feel in the following situations"* after discussion with a literacy service which argued that the inclusion of two concepts within one question could lead to confusion. Additionally, we changed the direction of the response categories as per recommendation in Likert scale development and to create consistency among all other scales used in this questionnaire.[50] We altered the sixth item in this scale from *"Not knowing what to do about your grief at losing the person when you are with him/her"* to *"You are with someone who is dying and this person is grieving"*. We did this since its original phrasing concerns the respondent's emotional suffering rather than the suffering and dying of someone else. The developed scale comprises eight items which are scored on a five-point Likert scale ranging from (1) not uncomfortable to (5) very uncomfortable, hence higher scores indicate higher levels of discomfort. Total scores range between a minimum of 8 and a maximum of 40. Our alterations to the original *Dying of others* scale have thus resulted in a new scale which we named *Discomfort with someone's suffering and dying*, hence the original scale's proofs of validity are not applicable to the operationalization of our scale.

Personal Experience Measures. Personal experiences were measured via different constructs. The measure *Cultural exposure to death and dying* was composed of eight items coming from two questionnaires. As a response to the cultural estrangement many societies experience

with death and dying, public health initiatives aim to create visibility through cultural activities and integrate the end-of-life into everyday life. This can be achieved through various means, such as visiting an art exhibition on death or witnessing a testimony. Additionally, we registered whether respondents had a family care experience with care, illness and death, had worked in healthcare, had experience as a volunteer around serious illness, death, dying or grief in the year preceding the COVID-19 pandemic initiation and whether they had been with someone at the time of their death. The exact composition of these measures can be found in Appendix I.

Demographic Characteristics, Religiousness, and Other Measures. The following personal characteristics were surveyed: age, sex, highest degree of education, working situation, whether respondents were volunteers, religious orientation, whether they live in a long-term care residence (nursing home, service flat, institution), whether they have a chronic illness, and whether they considered themselves to be mourning someone who had died. A number of variables, considered as mediators or moderators for this study, were additionally measured: knowledge of palliative care using a validated Dutch translation of the *Palliative Care Knowledge Scale*[51]; subjective estimation of palliative care knowledge (*self-estimated palliative care knowledge)* using a self-developed item. The exact composition of both palliative care knowledge scales can be found in Appendix I. Lastly, we asked whether respondents had already undertaken any actions around their own end of life such as having discussed end-of-life preferences or having filled out advance directives.[34]

Translation and Testing of the Questionnaire

The constructs *Cultural exposure to death and dying* and *Palliative Care Knowledge Scale* were translated following EORTC guidelines.[52] A cognitive testing approach was followed to assess content (face) validity, language, and understandability.

Data Preparation and Data Analyses

Missing scores for individual items of the main outcome measure were imputed with the mean score. We calculated both factor scores and average sum scores for the dependent variable *Discomfort with someone's suffering and dying* but, after consultation with a statistician, decided to only use the factor score for the multivariable analysis since that gave a more normal distribution. Prior to performing the factor analysis, we confirmed the subject-to-item ratio which was 247.5.[53] Internal consistency was assessed and showed a reliable factor structure. These analyses can be found in Tables I to III in Appendix I. The independent variables *Cultural exposure to death and dying, Family care experience with*

care, illness, and death, having worked in healthcare, experience as a volunteer around serious illness, death, dying, or mourning, and *being with someone else at the time of their death* are all different types of experiences with care, illness, and death. A factor analysis — used to explore if any of the variables could be combined into an underlying variable — identified two different components. We examined the internal consistency of the one component which contained the required minimum of three variables. This showed an unreliable factor structure. Therefore, all independent variables are regarded separately. Variable *Family care experience with care, illness and death* did not have a significant effect on the outcome variable. The analyses can be found in Tables IV to VII and in Figs. 1-5 in Appendix I.

Respondents who filled out fewer than six out of eight questions from the main outcome measure *Discomfort with someone's suffering and dying* were withheld from further analysis. This led to the exclusion of 118 cases, leaving 1890. Fig. 1 provides an overview of how the number of questionnaires used for data analysis was obtained. Weighting factors were activated prior to data analyses.

To examine how personal experience measures and the additional measures are associated with people's discomfort with a person's suffering and dying, we performed a bivariate correlation analysis with the factor score of this dependent variable. To inform the construction of the multivariable statistical model and appropriate deconfounding (i.e., clearly distinguishing between confounders and mediators) we used a directed acyclic graph to make our assumptions explicit — based on previous findings about death anxiety[6,7,12,37] and plausibility — about the causal relationship between the different variables (Fig. 2).[54] Pearson correlation coefficients ($P < 0.05$, one tailed) were then calculated to determine the actual correlations of the relationships specified in the model, which can be found in Appendix I. Next, we expanded our multivariable regression model by controlling for the effect of confounding variables (step 1), entering the variables that were significantly associated with the dependent variable (step 2) and entering variables identified as possible mediators (step 3).

Ethics

Approval for this study was obtained from the Medical Ethics Committee of the University Hospital Brussels with reference B1432020000186 on 16 September 2020.

Results

From the 4400 questionnaires sent, 2135 were returned. After removing duplicate questionnaires and questionnaires with more than 80% missing data on
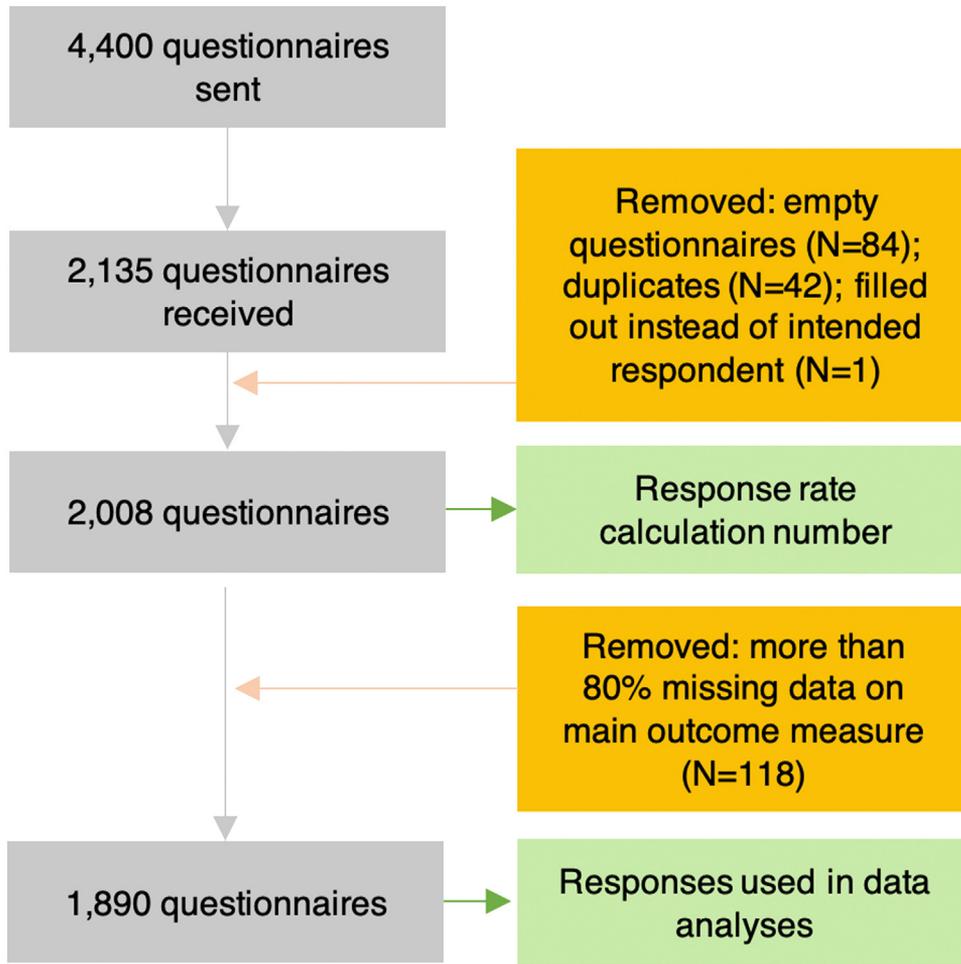
Fig. 1. Flowchart of how final number of questionnaires for data analysis was obtained.

the main outcome measure, 2008 questionnaires were considered as valid responses (response rates were 49.7% for Bruges, 44.1% for Sint-Niklaas, 38.3% for Herzele, and 42.5% for Gavere).[55]

Characteristics of the Study Population

A total of 38.2% of respondents had a higher education degree, 52.1% were female, 49.3% were employed, and 57.6% identified as Catholic; 34.9% had had a
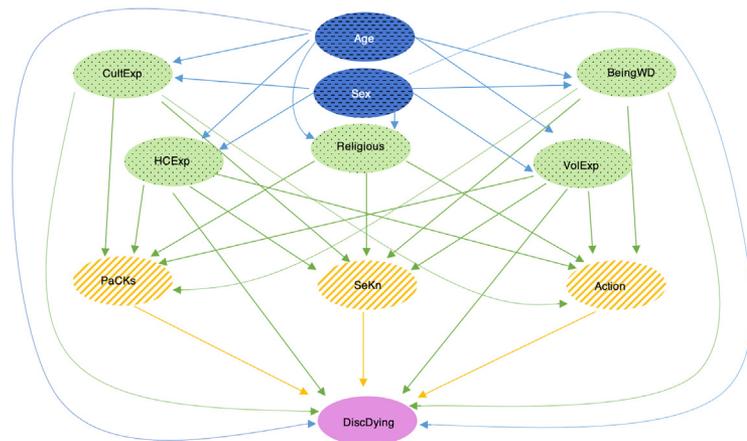

Fig. 2. Directed acyclic graph of the hypothesized causal relationships between the predictor variables and dependent variable "discomfort with someone's suffering and dying."

Table 1
Characteristics of the Study Population

Place N = Respondents	Total N = 2008	Bruges N = 561	Sint-Niklaas N = 515	Herzele N = 441	Gavere N = 491
1. Demographic characteristics					
Age	N (%)	N (%)	N (%)	N (%)	N (%)
16−24	178 (9)	65 (11.8)	40 (7.9)	44 (10.1)	29 (6)
25−34	233 (11.7)	77 (13.9)	68 (13.4)	41 (9.4)	47 (9.7)
35−44	257 (13)	72 (13)	68 (13.4)	68 (15.6)	49 (10.1)
45−54	327 (16.5)	84 (15.2)	80 (15.7)	75 (17.2)	88 (18.2)
55−64	378 (19.1)	94 (17.0)	95 (18.7)	79 (18.2)	110 (22.7)
65−74	335 (16.9)	78 (14.1)	81 (15.9)	76 (17.5)	100 (20.7)
>74	273 (13.8)	83 (15)	77 (15.1)	52 (12)	61 (12.6)
Sex					
Female	1034 (52.1)	262 (47.1)	256 (50.3)	235 (53.9)	281 (57.9)
Highest degree of education					
Primary school or lower	200 (10.2)	40 (7.4)	75 (15)	38 (8.8)	47 (9.8)
Secondary school, first 3 yrs	309 (15.7)	78 (14.1)	83 (16.6)	68 (15.7)	80 (16.6)
Secondary school finished	677 (34.5)	186 (33.9)	168 (33.6)	167 (38.6)	156 (32.4)
College	488 (24.9)	152 (27.7)	108 (21.6)	111 (25.6)	117 (24.3)
University or higher	262 (13.3)	87 (15.8)	56 (11.2)	45 (10.4)	74 (15.4)
Other	27 (1.4)	6 (1.1)	10 (2)	4 (0.9)	7 (1.5)
Working situation					
Student	137 (7)	44 (8.1)	31 (6.1)	35 (8.1)	27 (5.6)
Unemployed	40 (2.1)	17 (3.2)	16 (3.2)	3 (0.7)	4 (0.8)
On (work) disability	88 (4.4)	23 (4.1)	32 (6.3)	22 (5.1)	11 (2.3)
Working	972 (49.3)	276 (50.2)	222 (43.8)	224 (51.7)	250 (51.8)
Retired	658 (33.4)	173 (31.5)	176 (34.7)	138 (31.9)	171 (35.4)
Homemaker	66 (3.4)	14 (2.6)	26 (5.1)	9 (2.1)	17 (3.5)
Other	11 (0.7)	2 (0.3)	4 (0.8)	2 (0.5)	3 (0.6)
Did you move in the last 10 yrs?					
Yes	693 (36.4)	234 (44.4)	209 (43)	120 (28.3)	130 (28)
I am a volunteer					
Yes	379 (19.1)	117 (21)	83 (16.5)	73 (16.7)	106 (21.7)
2. Religious orientation					
Catholic	1125 (57.6)	262 (48.0)	272 (53.9)	294 (69.0)	297 (62.5)
Islam	92 (4.7)	6 (1.0)	77 (15.2)	5 (1.2)	4 (0.8)
Secular humanism	83 (4.3)	38 (7.0)	18 (3.6)	12 (2.8)	15 (3.2)
Atheism	598 (30.6)	215 (39.3)	126 (25.0)	106 (24.9)	151 (31.8)
Other religion	40 (2.0)	19 (3.4)	8 (1.6)	6 (1.4)	7 (1.5)
Other nonreligious	16 (0.8)	8 (1.4)	4 (0.8)	3 (0.7)	1 (0.2)
3. Personal experiences with care, illness and death					
I take care of a person in need as a family carer	371 (18.5)	108 (19.3)	91 (17.7)	100 (22.7)	72 (14.7)
I took care of a person in need as a family carer in the past	420 (20.9)	106 (18.9)	107 (20.8)	107 (24.3)	100 (20.4)
I have a family care experience	700 (34.9)	185 (33)	182 (35.3)	179 (40.6)	154 (31.4)
I have undertaken volunteer tasks around serious illness, death, dying or grief in the past year before the COVID pandemic	165 (8.3)	58 (10.4)	40 (7.9)	29 (6.6)	38 (7.8)
I have worked in healthcare	278 (13.8)	92 (16.4)	61 (11.8)	55 (12.5)	70 (14.3)
I live in a long-term care residence (nursing home, service flat, institution…)	17 (0.8)	6 (1)	5 (1)	0 (0)	6 (1.2)
I have a chronic illness	220 (11)	72 (12.9)	70 (13.6)	44 (10)	34 (6.9)
I mourn for someone I have lost	441 (22)	135 (24.1)	115 (22.3)	102 (23.1)	89 (18.1)
Culturally exposed to death and dying	1168 (65.8)	358 (70.8)	289 (67.7)	257 (63.1)	264 (60.7)

family care experience and 65.8% had been exposed to cultural events around death and dying (Table 1).

Discomfort With the Suffering and Dying of Others

Overall, people scored an average of 3.74 (SD = 0.89) on a scale from 1 to 5. People felt most uncomfortable if they had to *watch the person suffer from pain* (4.24; SD = 1.01) and *have to be the one to tell the person that he/she is dying* (4.37; SD = 1.01). They felt least uncomfortable in the situation where they *have the person want to talk about death with them* (2.91, SD = 1.35) (Table 2).

Univariable correlation analysis (Table 3) showed that being female or mourning a loss is associated with feeling more uncomfortable about the dying of others. People felt more comfortable about the suffering and dying of others when they were not religious, when they were volunteers or had volunteered around serious illness, death, dying, or grief, had experience as a family carer or as a healthcare worker, or had already undertaken some action about their own end of life, had been with someone at the time of their death, had been culturally exposed to death and dying, had better knowledge about palliative care or higher self-estimated knowledge of palliative care.

Table 2
Discomfort With Someone's Suffering and Dying

	Total[a] $N = 2008$ Average Sum Score (Standard Deviation)	Bruges[b] $N = 547$ Average Score[c] (Standard Deviation)	Sint-Niklaas[b] $N = 485$ Average Score (Standard Deviation)	Herzele[b] $N = 421$ Average score (Standard Deviation)	Gavere[b] $N = 468$ Average Score (Standard Deviation)
Discomfort with someone's suffering and dying	3.74 (0.89)	3.68 (0.87)	3.77 (0.90)	3.81 (0.89)	3.73 (0.89)
Being with someone who is dying	3.32 (1.33)	3.25 (1.32)	3.35 (1.35)	3.43 (1.35)	3.26 (1.32)
A dying person wants to talk about death with you	2.91 (1.35)	2.80 (1.31)	2.98 (1.39)	3.00 (1.35)	2.89 (1.36)
Watching a dying person suffer from pain	4.24 (1.01)	4.15 (1.03)	4.29 (0.98)	4.27 (1.03)	4.27 (1.00)
Having to be the one to tell the person that he/she is dying	4.37 (1.01)	4.34 (0.98)	4.38 (1.00)	4.41 (1.04)	4.38 (1.05)
Seeing the physical degeneration of the person's body	3.93 (1.09)	3.85 (1.08)	3.95 (1.09)	3.98 (1.08)	3.96 (1.08)
Being with a person who is dying and grieving	3.92 (1.20)	3.80 (1.21)	3.97 (1.17)	4.00 (1.21)	3.92 (1.21)
Watching the deterioration of the person's mental abilities	3.94 (1.10)	3.91 (1.09)	4.00 (1.08)	4.00 (1.09)	3.88 (1.12)
You realise that you too can someday die in this way	3.53 (1.33)	3.48 (1.32)	3.51 (1.33)	3.61 (1.34)	3.55 (1.32)

[a]Cases that filled out a minimum of six out of eight items. 5.9% missing values.
[b]Depending on municipality and item, missing values lay between 5.4% and 10.1%. Missing data are completely at random.
[c]Values ranging from 1 (not uncomfortable) to 5 (very uncomfortable).

Table 3
Bivariate Analysis of Variable Correlations With Discomfort With Someone's Suffering and Dying

Variable *(Reference Category)*	Discomfort People Feel About Someone's Suffering and Dying, 1 Tailed[a] (Pearson Correlation[b]) *Higher R Values Indicate More Discomfort*
Age	$R = 0.031$ ($P = 0.09$)
Sex *(Female)*	$R = 0.049$ ($P < 0.05$)
Religious *(No)*	$R = -0.068$ ($P < 0.01$)
Volunteer *(Yes)*	$R = -0.150$ ($P < 0.001$)
Experience as a volunteer around serious illness, death, dying or grief *(Yes)*	$R = -0.123$ ($P < 0.001$)
Family care experience with care, illness and death *(Yes)*	$R = -0.043$ ($P < 0.05$)
Worked in healthcare *(Yes)*	$R = -0.205$ ($P < 0.001$)
Mourning *(Yes)*	$R = 0.064$ ($P < 0.01$)
Cultural exposure to death and dying *(Yes)*	$R = -0.183$ ($P < 0.001$)
Been with someone at the time of their death *(Yes)*	$R = -0.174$ ($P < 0.001$)
Action undertaken around own end of life *(Yes)*	$R = -0.121$ ($P < 0.001$)
Palliative Care Knowledge Scale	$R = -0.169$ ($P < 0.001$)
Self-estimated palliative care knowledge	$R = -0.250$ ($P < 0.001$)

[a]Significance at $P < 0.05$ level.
[b]Pearson correlation coefficient is a parametric test used to measure the degree of correlation between two variables. Values range between 1 and -1, the more a value leans towards 1 or -1, the stronger the correlation.

After controlling for confounders in a hierarchical multivariable linear regression analysis, cultural exposure to death, and dying ($r = -0.136$; $P < 0.001$), having worked in healthcare ($r = -0.162$; $P < 0.001$), having been with someone else at the time of their death ($r = -0.107$; $P < 0.001$), having experience as a volunteer around serious illness, death, dying, and mourning ($r = -0.084$; $P < 0.001$) and not being religious ($r = -0.064$; $P < 0.01$) were associated with feeling more comfortable about someone's suffering and dying. When we added the identified mediator variables (i.e., knowledge of palliative care, self-estimated palliative care knowledge, and having undertaken action around one's own end of life), the associations became less strong but remained significant for all variables but religiousness (Table 4).

Some age groups significantly differed in discomfort when compared using the Mann-Whitney U test, which can be consulted in Appendix I.

Multivariable Linear Regression Analysis of Variables Associated With People's Discomfort With Someone's Suffering and Dying

Independent variable	Model 1 Adjusted R^2 = 0.002		Model 2[a] Adjusted R^2 = 0.091		Model 3 Adjusted R^2 = 0.116	
	Standardized β	Significance[a]	Standardized β	Significance[a]	Standardized β	Significance[a]
Age	0.034	$P = 0.144$	−0.023	$P = 0.339$	0.001	$P = 0.956$
Sex *(Female)*	0.051	$P < 0.05$	0.088	$P < 0.001$	0.100	$P < 0.001$
Cultural exposure to death and dying *(Yes)*			−0.136	$P < 0.001$	−0.090	$P < 0.001$
Worked in healthcare *(Yes)*			−0.162	$P < 0.001$	−0.119	$P < 0.001$
Being with someone else at the time of their death *(Yes)*			−0.107	$P < 0.001$	−0.093	$P < 0.001$
Experience as a volunteer around serious illness, death, dying or grief *(Yes)*			−0.084	$P < 0.001$	−0.074	$P < 0.001$
Religious *(No)*			−0.065	$P < 0.01$	−0.037	$P = 0.100$
Self-estimated palliative care knowledge					−0.129	$P < 0.001$
Palliative Care Knowledge Scale					−0.045	$P = 0.077$
Action undertaken around own end of life *(Yes)*					−0.070	$P < 0.01$

[a]Model 2 presents the total effect size after controlling for confounders but not mediators.

Discussion

This cross-sectional survey study shows that people on average feel somewhat uncomfortable about a person's suffering and dying. People feel most uncomfortable in situations where they have to be the one to tell someone that he or she is dying and where they have to watch the dying person suffer from pain, and least uncomfortable when they need to talk about death with a dying person. People feel more comfortable when they have been culturally exposed to topics around death and dying, worked in healthcare, have been with someone at the time of their death, have had a volunteer experience around serious illness, death, dying or grief, and when they (believe themselves to) have more knowledge about palliative care.

This study has several strengths and limitations. The random samples using full population registers in four purposively selected municipalities makes our findings about people's discomfort with someone's suffering and dying statistically generalizable to the full populations within these municipalities, although possibly not generalizable nationwide or globally due to cultural and social differences in populations. While response rates were satisfactory, some selection bias due to nonresponse cannot be ruled out. The cross-sectional study design, in which outcomes and exposure are investigated coincidently, makes it impossible to examine temporal relations and infer causal associations when studying hypotheses.[56] We used the subscale *Dying of others* from the Collett-Lester Fear of Death scale, which has been validated for use in populations. While we had to use a nonvalidated Dutch adaptation of the instrument, we performed additional cognitive testing of the instrument to ascertain content validity and minimize measurement bias. Based on the insights of our cognitive testing we deliberately chose to refrain from the

original formulation of "anxious and disturbed" because of its negative and directing connotation and opted for the more neutral formulation of "uncomfortable." Our obtained results offer valuable insights; however, to enhance the reliability and construct validity of the scale, future research should be conducted. The threatening nature of questions about death and dying may also introduce bias.[6] People may have denied how uncomfortable they really feel or may have refrained from filling out the questionnaire overall due to their high discomfort with death and dying, which would induce bias in our findings.

Our findings on how people feel about the suffering and dying of others deviate somewhat from results in previous research on death anxiety.[6,35−39] We found a larger prevalence of discomfort with someone's suffering and dying in the general public compared with results from death anxiety studies. This may be because of the more neutral formulation of "uncomfortable" compared to the much stronger formulation of "anxious or disturbed". People may feel uncomfortable about death and suffering, but may not necessarily feel anxious or disturbed by it. The concepts of comfortability and anxiety are semantically distinct and not necessarily interconnected; feeling uncomfortable does not unequivocally lead to anxiety. The paucity of literature on discomfort with death explains why we compared our study with literature relating to death anxiety.

A number of personal experiences on cultural, professional, and informal levels are associated with lower discomfort with someone's suffering and dying. This corresponds to previous studies which showed that changing attitudes to death and dying through exposure (i.e., experiential learning) is indeed possible.[23,24,57,58] Instilling these feelings of comfort can facilitate the provision of care by lay people, an

essential component of good care at the end of life, and can also support overburdened healthcare systems worldwide.[10,59,60] Involving social networks (i.e., family, friends) of people facing an illness early on in the illness trajectory and facilitating their access to information about palliative care may increase awareness about the expected physical or mental decline, thereby decreasing these networks' discomfort with death and dying. Naturally, this can only succeed if realistic information is applied and the inescapabilty of death and the probability of adversity (e.g., increased care dependency) are not avoided.[61] When more social networks take up caring tasks, countries benefit from the economic savings on care expenditure; something difficult to calculate but hard to overestimate.[33,62] For countries to invest in this strategic approach to care delivery may become a necessity due to the growing number of people with complex care needs who live in the community. This may stimulate societies to rethink their traditional service-focused approach to healthcare provision.[2,26]

In addition to personal experiences, we found knowledge about palliative care to be associated with feeling more comfortable about the suffering and dying of others. Increasing people's knowledge about palliative care can be part of a proactive and preventive strategic approach to increasing population health in all societies. Healthcare organizations that provide accessible information can influence people's discomfort about suffering and dying, which contributes to the new public health aim of empowering care in and by the community.[2,63] Additionally, the act of performing informal care has been shown to be an important impetus to the creation of the carer's knowledge, skills and attitudes.[64,65] This approach facilitates people's ability to navigate the local care system and creates opportunities to make informed decisions about their own health and end of life care options, thereby minimizing preventable harm.

Policy makers and civic administrative institutions, which aim to address current and future societal challenges related to ageing and the increasing presence of people with complex care needs who live in the community, can apply our study findings by making both professional and informal care provision more appealing (e.g., by financially compensating informal carers' lost workdays). Promoting cultural activities around death and dying in collaboration with civic societies is already a valued component in a number of public health interventions which have the explicit or implicit aim to normalize death as part of life.[27,28] Such interventions foster community-based support models which have shown potential in reducing emergency hospital admissions and healthcare expenditure,[32] increasing support networks of those at the end-of-life,[66,67] and increasing death literacy.[34] It can be argued that they provide opportunities for people to access information on death and dying, develop new caregiving skills, or change attitudes and misconceptions on caregiving and illnesses.[22−26] Although religiosity was only moderately associated with people's discomfort, religion has a strong influence on culture and thus cultural activities with a religious component could be considered in religious societies to enhance impact. A retrospective look at discrimination against people facing dementia or COVID-19 shows that changing attitudes about death and dying can have a positive effect on social stigma of seriously ill people and their social surroundings.[68−70] Concerning future research, we recommend the use of longitudinal studies and quasi-experimental interventions to assess whether decreases in people's discomfort about the suffering and dying of others can indeed be achieved through increasing experiences, exposure and knowledge building, and whether this ultimately has an effect on patient and care outcomes.

Conclusions

This study shows that people generally feel considerably uncomfortable in situations that revolve around the suffering and dying of others. People feel more comfortable when they have previously been exposed to death and dying (culturally, professionally, or in an informal context) or when they have more knowledge about palliative care. A diverse group of stakeholders, both formal and informal, can address people's death and dying avoidance through interventions on cultural, professional and informal levels and thereby change their attitudes towards these topics. This heightened exposure may create more awareness and knowledge about death and dying and lead to decreased social stigma around seriously ill people. Fostering increased comfort about death and dying could eventually aid in normalizing support and care delivery by lay people and, as such, increase care by and not exclusively for communities.

Authors' Contributions

All listed authors contributed to this paper and gave permission for publication.

Consent for Publication

Not applicable.

Availability of Data and Materials

All data is backed up and locked with a code on a secured, system encrypted storage server of the Vrije Universiteit Brussel. In accordance with Good Clinical

References

1. Omran AR. The epidemiologic transition: a theory of the epidemiology of population change. Milbank Q 1971;83:731–757.

2. Baum F. The new public health. 4th ed. Oxford: Oxford University Press; 2015.

3. Rosen G. A history of public health. Baltimore: Johns Hopkins University Press; 2015. p. 370.

4. Cohen J, Deliens L. A public health perspective on end of life care editors. Oxford: Oxford University Press; 2012.

5. Sallnow L, Smith R, Ahmedzai SH, et al. Report of the lancet commission on the value of death: bringing death back into life. The Lancet 2022;399:837–884, 10327.

6. Kastenbaum R, Moreman CM. Death, society, and human experience. 12th Ed New York: Routledge; 2018. p. 1.

7. Menzies RE, Menzies RG. How the fear of death shaped human society. Crows Nest. Allen & Unwin; 2021. p. 448.

8. Pivodic L, Pardon K, Morin L, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. J Epidemiol Community Health 2016;70:17–24.

9. Seitz K, Cohen J, Deliens L, et al. Place of death and associated factors in 12 Latin American countries: a total population study using death certificate data. J Glob Health 2022;12:04031.

10. Abel J, Walter T, Carey LB, et al. Circles of care: should community development redefine the practice of palliative care? Palliat Care 2013;7:383–388.

11. Stjernswärd J. Palliative care: the public health strategy. J Public Health Policy 2007;28:42–55.

12. Walter T. Why different countries manage death differently: a comparative analysis of modern urban societies. Br J Sociol 2012;63:123–145.

13. Becker E. The denial of death. New York: Free Press; 1973.

14. Smith RJ, Sherman MF, Sherman NC. The elderly's reactions toward the dying: the effects of perceived age similarity. OMEGA - J Death Dying 1983;13:319–331.

15. Chapple A, Ziebland S, McPherson A. Stigma, shame, and blame experienced by patients with lung cancer: qualitative study. BMJ 2004;328:1470.

16. Rose S, Paul C, Boyes A, Kelly B, Roach D. Stigma-related experiences in non-communicable respiratory diseases: a systematic review. Chron Respir Dis 2017;14:199–216.

17. Sleeth C, Drake K, Labiner DM, Chong J. Felt and enacted stigma in elderly persons with epilepsy: a qualitative approach. Epilepsy Behav 2016;55:108–112.

18. Lebel S, Devins GM. Stigma in cancer patients whose behavior may have contributed to their disease. Future Oncol 2008;4:717–733.

19. Kang Y. Why are dying individuals stigmatized and socially avoided? Psychological explanations. J Soc Work End −Life Palliat Care 2021;17:317–348.

20. Wube M, Horne CJ, Stuer F. Building a palliative care program in ethiopia: the impact on HIV and AIDS patients and their families. J Pain Symptom Manage 2010;40:6–8.

21. Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. PLoS Med 2010;7.

22. Carr M, Merriman MP. Comparison of death attitudes among hospice workers and health care professionals in other settings. OMEGA - J Death Dying 1996;32:287–301.

23. Anderson WG, Williams JE, Bost JE, Barnard D. Exposure to death is associated with positive attitudes and higher knowledge about end-of-life care in graduating medical students. J Palliat Med 2008;11:1227–1233.

24. Kolb DA. Experiential learning: experience as the source of learning and development. 2nd ed Upper Saddle River, New Jersey: Pearson Education, Inc; 2015. p. 390.

25. Horsfall D. Developing compassionate communities in Australia through collective caregiving: a qualitative study exploring network-centred care and the role of the end of life sector. Ann Palliat Med 2018;7(S2):S42–S51.

26. Barrett P, Hale B, Butler M. Family care and social capital: transitions in informal care [Internet]. .Dordrecht: Springer Netherlands; 2014. [Accessed July 26, 2022]. Available from: http://link.springer.com/10.1007/978-94-007-6872-7.

27. Quintiens B, D'Eer L, Deliens L, et al. Area-Based compassionate communities: a systematic integrative review of existing initiatives worldwide. Palliat Med 2022;36:422–442.

28. Dumont K, Marcoux I, Warren É, et al. How compassionate communities are implemented and evaluated in practice: a scoping review. BMC Palliat Care 2022;21:131.

29. O'Mara-Eves A, Brunton G, McDaid D, et al. Community engagement to reduce inequalities in health: a systematic review, meta-analysis and economic analysis. Public Health Res 2013;1:1–526.

30. Reeves D, Blickem C, Vassilev I, et al. The contribution of social networks to the health and self-management of patients

with long-term conditions: a longitudinal study Ozakinci G, editor PLoS ONE 2014;9:e98340.

31. Cyril S, Smith BJ, Possamai-Inesedy A, Renzaho AMN. Exploring the role of community engagement in improving the health of disadvantaged populations: a systematic review. Glob Health Action 2015;8:29842.

32. Abel J, Kingston H, Scally A, et al. Reducing emergency hospital admissions: a population health complex intervention of an enhanced model of primary care and compassionate communities. Br J Gen Pract 2018;68:e803–e810.

33. Reinhard SC, Feinberg LF, Houser A, Choula R, Evans M. Valuing the invaluable: 2019 update: charting a path forward [Internet]. AARP Public Policy Institute 2019. [Accessed July 27, 2022]. Available from: https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html.

34. Leonard R, Noonan K, Horsfall D, et al. Death literacy index: a report on its development and implementation. 2020 [Accessed May 11, 2023]; Available from: https://researchdirect.westernsydney.edu.au/

35. Tomer A, Eliason G. Beliefs about self, life, and death: testing aspects of a comprehensive model of death anxiety and death attitudes. Death attitudes and the older adult Theories concepts and applications. New York: Brunner-Routledge; 2000.

36. Depaola SJ, Griffin M, Young JR, Neimeyer RA. Death anxiety and attitudes toward the elderly among older adults: the role of gender and ethnicity. Death Stud 2003;27:335–354.

37. Russac RJ, Gatliff C, Reece M, Spottswood D. Death anxiety across the adult years: an examination of age and gender effects. Death Stud 2007;31:549–561.

38. Thiemann P, Quince T, Benson J, Wood D, Barclay S. Medical students' death anxiety: severity and association with psychological health and attitudes toward palliative care. J Pain Symptom Manage 2015;50:335–342.e2.

39. Soleimani MA, Bahrami N, Allen KA, Alimoradi Z. Death anxiety in patients with cancer: a systematic review and meta-analysis. Eur J Oncol Nurs 2020;48:101803.

40. Frommelt KHM. The effects of death education on nurses' attitudes toward caring for terminally ill persons and their families. Am J Hosp Palliat Med 1991;8:37–43.

41. Kvale J, Berg L, Groff JY, Lange G. Factors associated with residents' attitudes toward dying patients. Fam Med 1999;31:691–697.

42. Cevik B, Kav S. Attitudes and experiences of nurses toward death and caring for dying patients in Turkey. Cancer Nurs 2013;36:E58–E65.

43. Dimick JB, Ryan AM. Methods for evaluating changes in health care policy: the difference-in-differences approach. JAMA 2014;312:2401.

44. Quintiens B, Smets T, Chambaere K, et al. Researching two compassionate cities: study protocol for a mixed-methods process and outcome evaluation. Palliat Care Soc Pract 2022;16. https://doi.org/10.1177/26323524221137601.

45. Sharma A, Minh Duc NT, Luu Lam Thang T, et al. A consensus-based checklist for reporting of survey studies (CROSS). J Gen Intern Med 2021;36:3179–3187.

46. Vlaamse Statistische Autoriteit. Structuur van de bevolking [Internet]. 2021 [Accessed January 13, 2023]. Available from: https://statistieken.vlaanderen.be

47. Baruch Y, Holtom BC. Survey response rate levels and trends in organizational research. Hum Relat 2008;61:1139–1160.

48. Hoddinott SN, Bass MJ. The dillman total design survey method. Can Fam Physician 1986;32:2366–2368.

49. Lester D. The collett-lester fear of death scale: The original version and a revision. Death Stud 1990;14:451–468.

50. Limesurvey. The likert scale: enhance your survey data [Internet]. 2020 [Accessed June 8, 2023]. Available from: https://www.limesurvey.org/blog/20-blog/108-likert-scale-how-to-properly-scale-your-survey-responses

51. Kozlov E, Carpenter BD, Rodebaugh TL. Development and validation of the palliative care knowledge scale (PaCKS). Palliat Support Care 2017;15:524–534.

52. Degroot AMB, Dannenburg L, Vanhell JG. Forward and backward word translation by bilinguals. J Mem Lang 1994;33:600–629.

53. Osborne JW, Costello AB. Sample size and subject to item ratio in principal components analysis. Pract Assess Res Eval 2004;9.

54. Shrier I, Platt RW. Reducing bias through directed acyclic graphs. BMC Med Res Methodol 2008;8:70.

55. The American Association for Public Opinion Research. Standard definitions: final dispositions of case codes and outcome rates for surveys. 9th edition AAPOR; 2016.

56. Grimes DA, Schulz KF. An overview of clinical research: the lay of the land. The Lancet 2002;359:57–61.

57. Shi H, Shan B, Zheng J, et al. Knowledge and attitudes toward end-of-life care among community health care providers and its influencing factors in China: A cross-sectional study. Medicine (Baltimore) 2019;98:e17683.

58. Feifel H, Strack S. Thanatologists view death: a 15-year perspective. OMEGA - J Death Dying 2001;43:97–111.

59. Vanderstichelen S, Houttekier D, Cohen J, et al. Palliative care volunteerism across the healthcare system: a survey study. Palliat Med 2018;32:1233–1245.

60. D'Eer L, Quintiens B, Van den Block L, et al. Civic engagement in serious illness, death, and loss: a systematic mixed-methods review. Palliat Med 2022: 625–651.

61. Menzies RE, Menzies RG, Iverach L. Cognitive and behavioural procedures for the treatment of death anxiety. Curing the dread of death: theory, research and practice. Samford Valley, QLD: Australian Academic Press; 2018. p. 273.

62. European Commission. Directorate General for Employment, Social Affairs and Inclusion., London School of Economics and Political Science (LSE). Informal care in Europe: exploring formalisation, availability and quality. .Publications Office; 2018. [Internet][Accessed March 8, 2022]. Available from: https://data.europa.eu/doi/10.2767/78836.

63. World Health Organization. The Ottawa charter for health promotion. [Internet]. 1986 [Accessed August 1, 2022]. Available from: www.who.int/healthpromotion/conferences/previous/ottawa/en/

64. Noonan K, Horsfall D, Leonard R, Rosenberg J. Developing death literacy. Prog Palliat Care 2016;24:31–35.

65. Horsfall D, Yardley A, Leonard R, Noonan K, Rosenberg J. End of life at home: co-creating an ecology of care. Sydney: Western Sydney University; 2015.

66. Leonard R, Horsfall D, Noonan K. Identifying changes in the support networks of end-of-life carers using social network analysis. BMJ Support Palliat Care 2015;5:153–159.

67. Aoun SM, Richmond R, Gunton K, et al. The compassionate communities connectors model for end-of-life care: implementation and evaluation, 16. Palliat Care Soc Pract; 2022:263235242211396.

68. Rewerska-Juśko M, Rejdak K. Social stigma of people with Dementia. J Alzheimers Dis 2020;78:1339–1343.

69. United Nations (UN). Policy brief: the impact of COVID-19 on older persons [Internet]. 2020 [Accessed July 1, 2022]. Available from: https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2020/05/COVID-Older-persons.pdf

70. Bhanot D, Singh T, Verma SK, Sharad S. Stigma and discrimination during COVID-19 pandemic. Front Public Health 2021;8:577018.

71. Onyx J, Bullen P. Measuring social capital in five communities. J Appl Behav Sci 2000;36:23–42.

Appendix I to article: Discomfort With Suffering and Dying, a Cross-Sectional Survey of the General Public

Table I, Table II, Table III, Table IV, Table V, Table VI and Table VII.

1. Calculation of Sum and Factor Scores of Main Outcome Measure: Discomfort With Someone's Suffering and Dying

1. A. Calculation of sum score

- For every case we made a sum score of all eight items out of which the main outcome measure existed. This resulted in a total score ranging between 8 and 40.

1. B. Factor analysis of the main outcome variable

- We present the Dutch translation of each item with the corresponding original English formulation in Italic.
- Missing scores were replaced with the mean score and we used Varimax rotation
- Calculation of subject to item ratio: 1980/8 = 247.5
- Assessment of internal consistency
- Factor analysis

2. Factor Analysis of the Independent Variables Which Are Different Types of Exposures to Sickness, Death, and Dying to See if Any Overarching Concept Can Be Identified

- Independent variables are: Cultural exposure to death and dying, Professional experience with care, illness, and death, being with someone else at the time of their death and family care experience with care, illness and death, experience as a volunteer around serious illness, death, dying or mourning
- Reliability analysis of variables in Component 1
- Unreliable factor structure, variables regarded independently
- Component 2 does not have the minimum requirement of three variables
- Multivariable regression analysis of independent variables' effect on outcome measure
- The variable Family care experience with care, illness and death did not have a significant effect on the outcome measure in a multivariable regression analysis which is why it was not withheld.

3. Main Outcome Measure: Discomfort With Someone's Suffering and Dying

The original question "How disturbed or made anxious are you by the following aspects of death and dying" was translated to "How uncomfortable would you feel in the following situations" *(in Dutch: Hoe oncomfortabel zou u zich voelen in de volgende situaties).*

4. Personal Experience Measures

Cultural exposure to death and dying

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.[34] The eighth question was derived from a question from the subconcept *Participation in the local community* from the Social Capital survey[68,71]: How many events/activities have you attended in your city in the year preceding the COVID-crisis which relate to the themes serious illness, death, dying or mourning (e.g., art exhibition, a play, film, a testimony). The answers to all eight questions were combined and binary coded for every respondent to: (0) no cultural exposure to death and dying and (1) cultural exposure to death and dying.

Family care experience with care, illness, and death

1) Do you take up a caring task for a person in need (i.e., family carer); 2) Did you take up a caring task for a person in need (i.e., family carer)

Having worked in healthcare

1) Did you work in a healthcare domain (now or in the past)

Experience as a volunteer around serious illness, death, dying, or mourning

1) How often did you perform volunteering tasks for an organization focused around serious illness, death, dying, or mourning in the year preceding the COVID-19 pandemic?

Being with someone else at the time of their death

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. Results were recorded to (0) has not been with dead or dying people and (1) has been with dead or dying people.

5. Palliative Care Knowledge Scales
Palliative Care Knowledge Scale (PaCKS)

- We present the Dutch translation of each item with the corresponding original English formulation in Italic.

Palliatieve zorg heeft onder meer tot doel psychologische problemen aan te pakken die ontstaan bij een ernstige ziekte	*One goal of palliative care is to address any psychological issues brought up by serious illness*
Stress ten gevolge van een ernstige ziekte kan aangepakt worden door palliatieve zorg	*Stress from serious illness can be addressed by palliative care*
Palliatieve zorg kan mensen helpen om de bijwerkingen van hun medische behandelingen onder controle te krijgen	*Palliative care can help people manage the side effects of their medical treatments*
Wanneer mensen palliatieve zorg krijgen, moeten ze hun andere dokters opgeven	*When people receive palliative care, they must give up their other doctors*
Palliatieve zorg is uitsluitend voor mensen die in de laatste zes maanden van hun leven zijn	*Palliative care is exclusively for people who are in the last six months of life*
Palliatieve zorg is specifiek voor mensen met kanker	*Palliative care is specifically for people with cancer*
Mensen moeten in het ziekenhuis zijn om palliatieve zorg te krijgen	*People must be in the hospital to receive palliative care*
Palliatieve zorg is specifiek bedoeld voor oudere volwassenen	*Palliative care is designed specifically for older adults*
Palliatieve zorg is een teambenadering van zorg	*Palliative care is a team-based approach to care*
Palliatieve zorg heeft onder meer tot doel mensen te helpen hun behandelingsopties beter te begrijpen	*One goal of palliative care is to help people better understand their treatment options*
Palliatieve zorg stimuleert mensen om de behandelingen gericht op de genezing van hun ziekte stop te zetten	*Palliative care encourages people to stop treatments aimed at curing their illness*
Palliatieve zorg heeft onder meer tot doel mensen beter in staat te stellen om deel te nemen aan dagelijkse activiteiten	*One goal of palliative care is to improve a person's ability to participate in daily activities*
Palliatieve zorg helpt de hele familie om met een ernstige ziekte om te gaan	*Palliative care helps the whole family cope with a serious illness*

Self-estimated palliative care knowledge

Hoe goed kent u het begrip 'palliatieve zorg'?	*How well do you know the concept 'palliative care'?*
Hoeveel denkt u dat u weet over palliatieve zorg?	*How much do you think you know about palliative care?*
Hoe goed kan u aan iemand uitleggen wat palliatieve zorg is?	*How well can you explain to someone what palliative care is?*

6. Directed Acyclic Graph of Independent Variables' Effect on the Main Outcome Measure
Fig. 1, Fig. 2, Fig. 3, Fig. 4 and Fig. 5.

3. Mann-Whitney U Test to Test Differences in Discomfort With Someone's Suffering and Dying When Comparing Age Groups

Age group	16−24 N = 160	25−34 N = 220	35−44 N = 229	45−54 N = 316	55−64 N = 372	65−74 N = 363	74< N = 280
16−24		$Z = -3.957$ $P = < 0.001$	$Z = -3.540$ $P < 0.001$	$Z = -2.317$ $P < 0.05$	$Z = -2.777$ $P < 0.01$	$Z = -2.615$ $P < 0.01$	$Z = -4.217$ $P < 0.001$
25−34	$Z = -3.957$ $P = < 0.001$		$Z = -0.365$ $P = 0.715$	$Z = -1.997$ $P < 0.05$	$Z = -1.392$ $P = 0.164$	$Z = -1.807$ $P = 0.071$	$Z = -0.60$ $P = 0.953$
35−44	$Z = -3.540$ $P < 0.001$	$Z = -0.365$ $P = 0.715$		$Z = -1.519$ $P = 0.129$	$Z = -1.043$ $P = 0.297$	$Z = -1.363$ $P = 0.173$	$Z = -0.459$ $P = 0.646$
45−54	$Z = -2.317$ $P < 0.05$	$Z = -1.997$ $P < 0.05$	$Z = -1.519$ $P = 0.129$		$Z = -0.603$ $P = 0.546$	$Z = -0.282$ $P = 0.778$	$Z = -2.101$ $P < 0.05$
55−64	$Z = -2.777$ $P < 0.01$	$Z = -1.392$ $P = 0.164$	$Z = -1.043$ $P = 0.297$	$Z = -0.603$ $P = 0.546$		$Z = -0.343$ $P = 0.731$	$Z = -1.592$ $P = 0.111$
65−74	$Z = -2.615$ $P < 0.01$	$Z = -1.807$ $P = 0.071$	$Z = -1.363$ $P = 0.173$	$Z = -0.282$ $P = 0.778$	$Z = -0.343$ $P = 0.731$		$Z = -2.001$ $P < 0.05$
74<	$Z = -4.217$ $P < 0.001$	$Z = -0.60$ $P = 0.953$	$Z = -0.459$ $P = 0.646$	$Z = -2.101$ $P < 0.05$	$Z = -1.592$ $P = 0.111$	$Z = -2.001$ $P < 0.05$	

Table 1
KMO and Bartlett's Test of Sphericity of the Main Outcome Measure

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		0.893
Bartlett's Test of Sphericity	Approx. Chi-Square	7462.67
	Degrees of freedom	28
	Significance	<0.001

Table II
Internal Consistency Assessment of the Main Outcome Measure

Cronbach's alpha	N of items
0.877	8

Table III
Factor Analysis of the Items of the Main Outcome Measure

Item	Component 1
U bent bij iemand die gaat sterven en die heeft verdriet. *Being with someone who is dying and who is grieving.*	0.840
U ziet iemand die gaat sterven lichamelijk achteruitgaan. *Seeing the physical degeneration of the person's body.*	0.832
U ziet iemand die gaat sterven mentaal achteruitgaan. *Watching the deterioration of the person's mental abilities.*	0.827
U bent bij iemand die aan het sterven is. *Being with someone who is dying.*	0.724
U moet aan iemand vertellen dat die gaat sterven. *Having to be the one to tell the person that he/she is dying.*	0.723
U ziet een stervende persoon pijn lijden. *Watching a dying person suffer from pain.*	0.723
Een persoon die gaat sterven, wil met u praten over de dood. *A dying person wants to talk about death with you.*	0.671
U beseft dat ook u ooit kan sterven op deze manier. *You realize that you too can someday die in this way.*	0.646

Table IV
KMO and Bartlett's Test of Sphericity of the Main Outcome Measure

Kaiser-Meyer-Olkin Measure of Sampling Adequacy		0.573
Bartlett's Test of Sphericity	Approx. Chi-Square	388.440
	Degrees of freedom	10
	Significance	<0.001

Table V
Component Matrix

	Component	
	1	2
Cultural exposure to death and dying	0.537	−0.312
Professional experience with care, illness, and death	0.590	−0.559
Being with someone else at the time of their death	0.683	0.008
Family care experience with care, illness, and death	0.426	0.717
Experience as a volunteer around serious illness, death, dying or mourning	0.511	0.364

Table VI
Internal Consistency Assessment of the Main Outcome Measure

Cronbach's Alpha	N of Items
0.420	4

Table VII
Effect of Independent Variables on Main Outcome Measure

| Model		Unstandardized Coefficients		Standardized Coefficients Beta	t	Significance
		B	Std Error			
1	(Constant)	−0.248	0.099		−2.516	0.012
	Age	0.002	0.001	0.034	1.462	0.144
	Sex	0.102	0.046	0.051	2.211	0.027
2	(Constant)	0.028	0.106		0.267	0.789
	Age	−0.001	0.001	−0.017	−0.697	0.486
	Sex	0.179	0.045	0.090	3.958	<0.001
	Professional experience with care, illness, and death	−0.465	0.067	−0.163	−6.918	<0.001
	Being with someone else at the time of their death	−.295	0.066	−0.105	−4.452	<0.001
	Cultural exposure to death and dying	−.287	0.050	−0.135	−5.725	<0.001
	Family care experience with care, illness, and death	−.035	0.050	−0.017	−0.694	0.487
	Religious	.136	0.048	0.065	2.843	0.005
	Experience as a volunteer around serious illness, death, dying, or mourning	−.297	0.082	−0.082	−3.616	<0.001
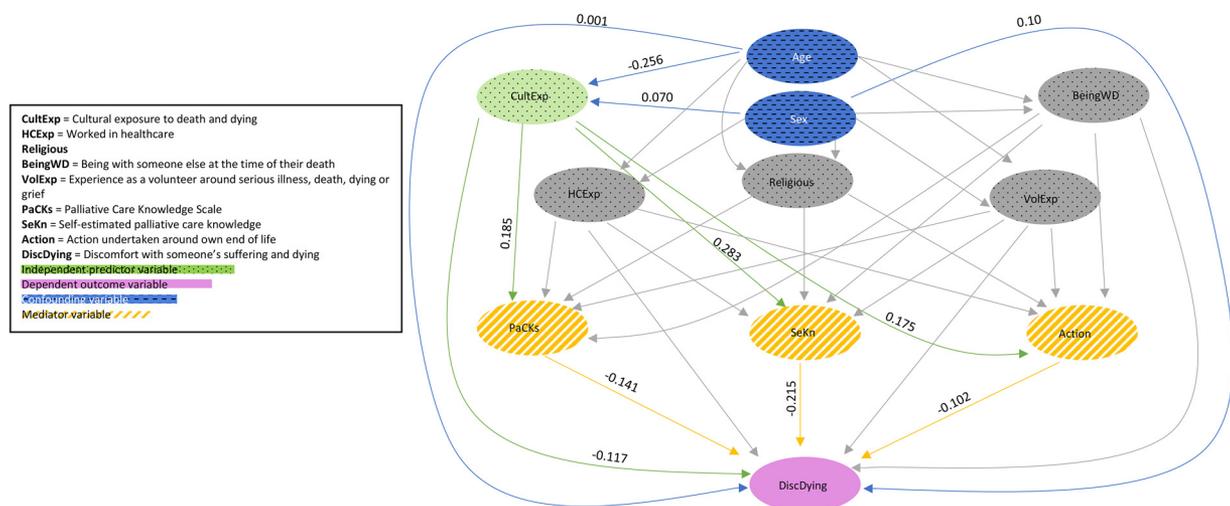
Fig. 1. Effect of cultural exposure to death and dying on discomfort with someone's suffering and dying.
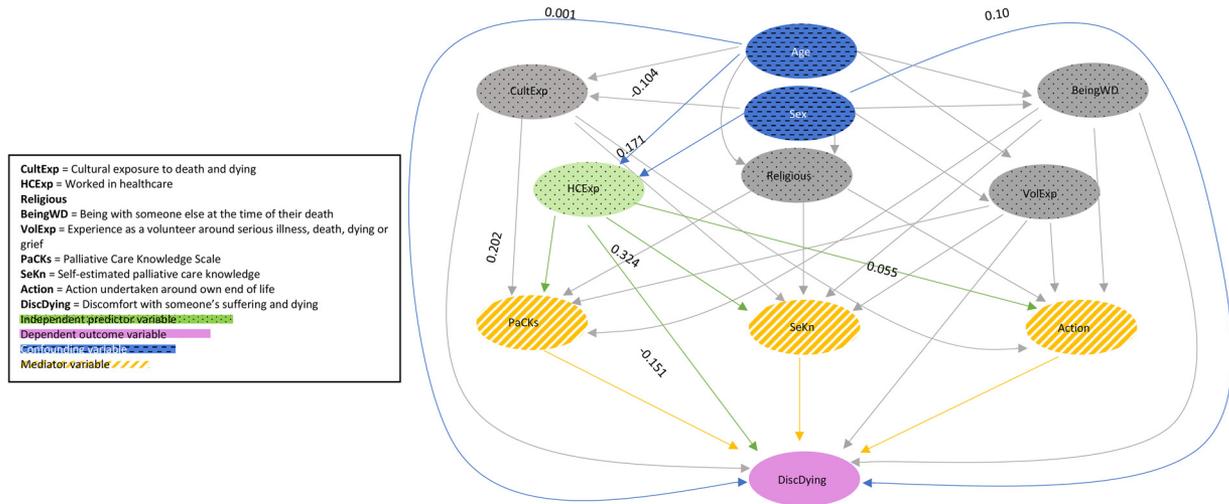
Fig. 2. Effect of having worked in healthcare on discomfort about someone's suffering and dying.
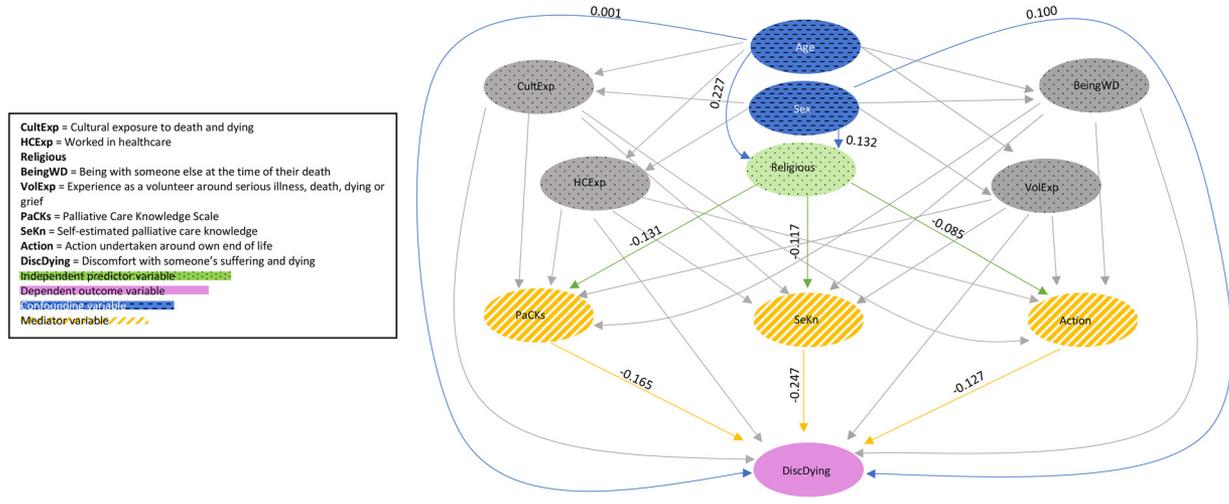

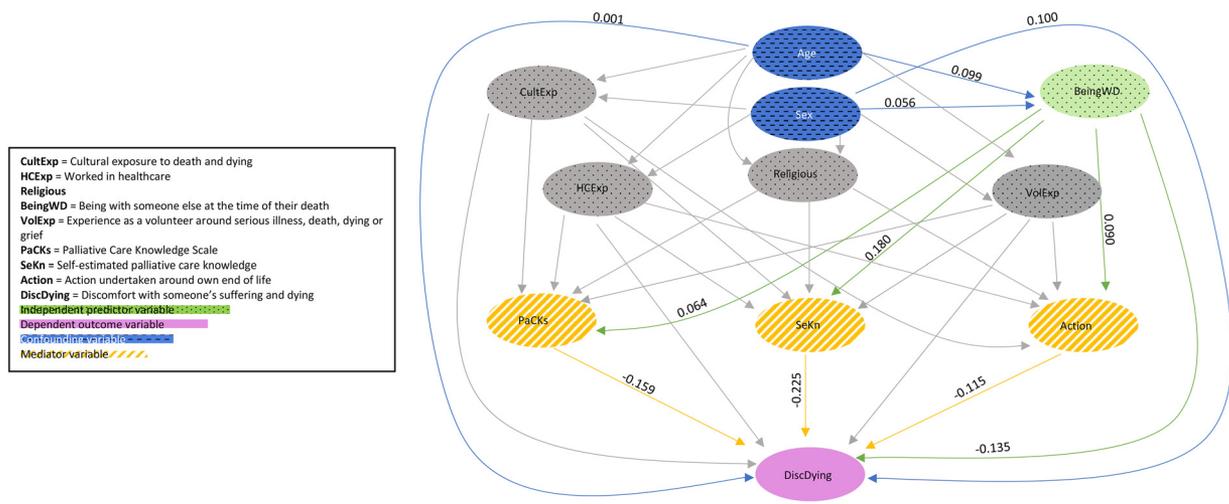Fig. 3. Effect of being religious on discomfort with someone's suffering and dying.

Fig. 4. Effect of being with someone else at the time of their death on discomfort with someone's suffering and dying.
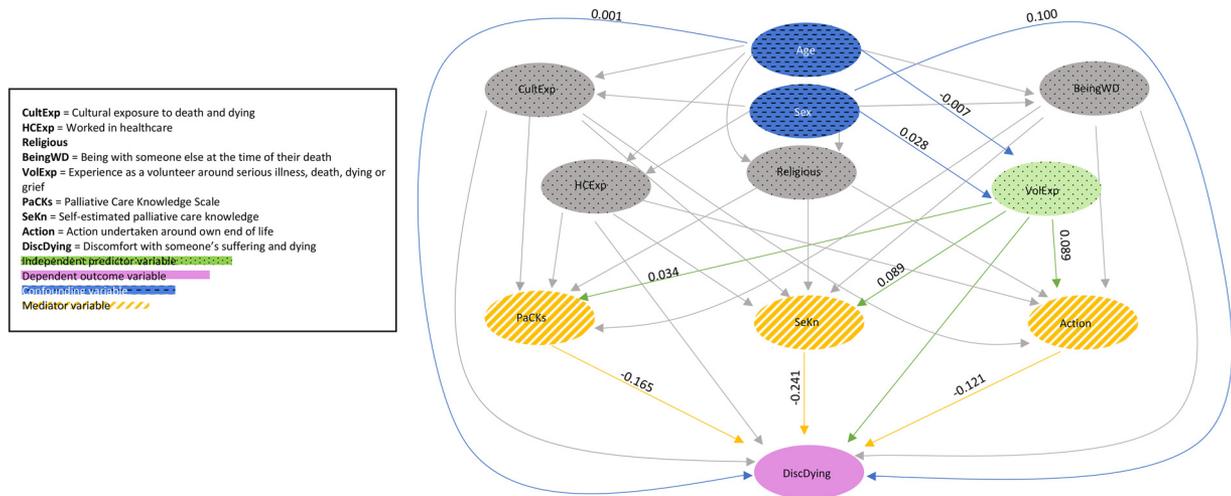
Fig. 5. Effect of having experience as a volunteer around serious illness, death, dying, or mourning on discomfort with someone's suffering and dying.