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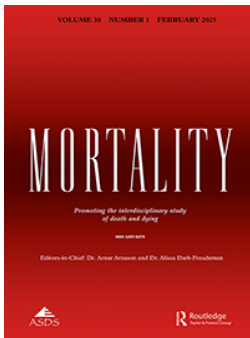
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# Citizens with a caregiving experience in the past year are more likely to participate in neighbourhood activities regarding serious illness, death or loss: a cross-sectional survey study

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## ABSTRACT


While death literacy is believed to foster social connections around serious illness, death and loss, limited evidence exists on whether it stimulates neighbourhood participation concerning these topics. This study measured the association between personal experiences with serious illness, death or loss in the past year and neighbourhood participation around these topics, and whether citizens' self-perceived capacity, skills and self-efficacy developed from previous experiences, strengthens this association. A questionnaire was sent to a random sample of 2,324 citizens aged 18+ in two neighbourhoods in Flanders, Belgium, between February and April 2021; 714 citizens responded (31% response rate). Hierarchical linear regression analysis showed that people with caregiving experience in the past year were more likely to participate in neighbourhood activities regarding serious illness, death or loss ( $\beta = 0.161$ ; CI = 0.378–1.276) than those without such experience. This association strengthened ( $\beta = 0.193$ ; CI = 0.588–1.393) when adding self-perceived capacity and skills developed from previous experiences to the analysis, indicating increased participation among those who felt they gained capacity and skills. We recommend that researchers look into other aspects of death literacy which might be better mediating predictors, and explore the mechanisms behind the associations we measured.

## KEYWORDS


Neighbourhood participation; compassionate communities; cross-sectional survey; hierarchical linear regression; death literacy

## Introduction

Experiencing serious illness, caregiving, dying or loss involves several challenges and needs that cannot be met only with a reliance on palliative care and other healthcare

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services (Abel et al., 2018). There is increasing recognition that social and community approaches that include salutogenic perspectives, focusing on the overall well-being of people rather than on the medical aspect of illness, are additionally needed (Kellehear, 2009). Salutogenesis, as coined by Antonovsky (2002) implies a focus on the various aspects that support human health and well-being, rather than on factors that cause illness it emphasises people's and communities' strengths and abilities to cope with these topics (Lindström, 2005). Salutogenic approaches advocate for interdisciplinary strategies that consider not just the individual, but also the interaction between individuals and societal structures in addressing health challenges (Antonovsky, 2002; Lindström, 2005). This focus on individual and collective resources within societal structures resonates strongly with the principles of Compassionate Communities (Care et al., 2020).

*'Compassionate Communities are places and environments in which people, networks, and institutions actively work together and are empowered to improve the circumstances, health, and well-being of those facing serious illness, death, dying, or loss'* (Vanderstichelen et al., 2022). One way for community members to be involved in Compassionate Communities is through civic engagement in which people take collective action to help improve connections between, or conditions for, people in the community who experience serious illness, death or loss (Adler & Goggin, 2005; Crowley, n.d.; Diller, 2001). In Compassionate Communities, civic engagement can be part of different community settings such as neighbourhoods, workplaces, schools, or cultural institutions (D'Eer et al., 2022; Quintiens et al., 2022). However, the neighbourhood is regarded as the setting par excellence for civic engagement in the areas of serious illness, caregiving responsibilities, or loss, henceforth called neighbourhood participation regarding serious illness, death or loss (Dury et al., 2023; Johansen & Van den Bosch, 2017).

Sense of coherence is an important concept for salutogenesis. It encompasses people's capacity to comprehend situations concerning serious illness, death, and loss, empowering them to take actions in response (Antonovsky et al., 1998; Lindström, 2005). Experience-based learning is seen as a means to extract meaning and understanding from individuals' experiences with serious illness, caregiving, death and loss, encouraging active engagement rather than passive acceptance of challenging circumstances (Acton & Kang, 2001). For example, personal experiences related to serious illness, caregiving, death, or loss can increase people's knowledge and skills and can foster connections between people within neighbourhoods, particularly when individuals with such experiences participate in peer support, caregiving, and bereavement groups (Acton & Kang, 2001). Furthermore, Leonard et al. (2022) discovered that people with caregiving experiences in the context of serious illness not only felt better equipped to offer support to people with serious illness but also felt confident in sharing the acquired caregiving knowledge and skills within their social network. These examples illustrate the potential for previous experiences with serious illness, death or loss to increase people's self-perceived capacity and skills and their engagement in social networks regarding these topics, thereby enhancing death literacy, which has been defined as *'the knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options'* (Noonan et al., 2016) and thereby stimulates participation around serious illness, death or loss (Johansson, 2022; Leonard et al., 2022; Noonan et al., 2016). These findings in the literature formed the basis of our assumption that there is an association between previous experiences with serious illness, death or loss in the last year and

neighbourhood participation relating to these topics and that this association may be mediated by self-perceived capacity, skills and self-efficacy developed from previous experiences with serious illness, death or loss. This aligns with theories on planned behaviour indicating people's belief in their capacity and skills to adopt health-promoting behaviour, influences whether or not they engage in this behaviour (Schwarzer et al., 1996; Terry & O'Leary, 1995; Williams & Rhodes, 2016). In this publication, neighbourhood participation concerning serious illness, caregiving, death, and loss is understood, in alignment with Onyx & Bullen's Social Capital Scale (2000) as all forms of formally or informally organised individual or collective engagement related to these topics. This includes activities such as volunteering, attending neighbourhood events, or participating in local community groups, such as bereavement support groups. A comprehensive list of the eight items used to measure this type of neighbourhood participation is provided in Appendix 1.

This study is part of a broader project aimed at developing and evaluating two neighbourhood civic engagement initiatives within the context of two Compassionate Cities. The study aligns with the overall objective of identifying development strategies by conducting a pre-development measurement of neighbourhood participation regarding serious illness, death or loss. Specifically, the present paper has two key aims: (1) to examine the association between having personal experiences with serious illness, death, or loss in the past year and neighbourhood participation in these areas, and (2) to explore whether the capacity, skills and self-efficacy individuals perceive they have gained from these experiences, enhance this association.

## **Methods**

### ***Study design***

We performed a cross-sectional survey among a random sample of adult citizens (18+) in two neighbourhoods in Flanders, Belgium.

### ***Setting***

This study is part of CAPACITY, Flanders Project to Develop Capacity in Palliative Care Across Society, which has the overarching aim of developing and evaluating innovative programmes that leverage existing resources and potential to promote communities' capacity development (Group E-o-LCR, 2024). In this study we aim to develop two Compassionate Neighbourhoods in Herzele and Sint-Kruis, the latter being a sub-municipality of Bruges. Both Herzele and Bruges are engaged to become Compassionate Cities. Together with city officials of Herzele, we selected two geographically defined neighbourhoods in a radius of 1.5 km around the local city centre, containing most of the organisations and shops in that area. In Sint-Kruis the neighbourhood coincides with the already existing geographic areas Sint-Kruis Centrum and Sint-Kruis Kruispoort, in Herzele the selected neighbourhood is demarcated as the area close to the local service centre. Both neighbourhoods are peri-urbanised and constitute around 4,000 inhabitants (Verzekeringen, 2018).

### ***Sampling procedure***

In both Herzele and Sint-Kruis, a city representative with access to the population register took a random sample of residents who were eighteen years or older. In the two neighbourhoods, we aimed for a 95% confidence interval with a width of  $\pm 5\%$ , with alpha set at 0.05 to estimate the proportions. Following a conservative approach, with the conservative estimation for heterogeneity set at 50%, we anticipated a response rate of 35%. This led to an estimated required initial sample size of 1,177 potential respondents for Sint-Kruis and 1,147 potential respondents for Herzele, 2,324 potential respondents in total. With the expected 35% response rate, we anticipated obtaining approximately 813 respondents.

### ***Data collection***

The survey took place between February and April 2021. We applied the principles of Dillman's Total Design method (Hoddinott & Bass, 1986) in the design of the questionnaire, the accompanying letters and the mailing procedures. We sent up to three reminders for non-responders to the questionnaire with two weeks in between each reminder (Hoddinott & Bass, 1986). Each questionnaire was accompanied by a cover letter, providing information on the study and information on how to complete the questionnaire and send it back to the researchers. Respondents could choose to fill in the questionnaire on paper using a prepaid return envelope or they could complete it online via Lime Survey. The researcher (LDEE) entered the data from the paper questionnaires into LimeSurvey as soon as possible after receipt of the questionnaire. An independent double data entry was performed by the researcher (LDEE) and a data collector for 10% of the data. None of the questionnaires required re-entry in its entirety as none of them had an error rate exceeding 3%. After data entry, data were transported from Lime Survey to SPSS. We used syntaxes to be able to retrace each step in the data-cleaning process.

### ***Confidentiality***

The data were processed in compliance with European and Belgian data protection regulations (Belgian Government, 2018). Each questionnaire was provided with a unique code which served the double purpose of providing the respondent with a code to fill in the questionnaire online and guaranteeing confidentiality in tracking which questionnaires were sent back and which ones needed a reminder. The researcher (LDEE) and the PI of the project (JC) were the only ones with access to the online survey database and to the SPSS file. The original database is saved in a secured remote storage environment.

### ***Ethics***

Before the start of the study, we received ethical approval from the Ethics Committee of the Vrije Universiteit Brussel (case number B1432020000185).

## Questionnaire and measures

The questionnaire measured seven different themes, either by validated scales, by validated scales which were adapted by adding the topics of serious illness, death or loss to the original items, or by a self-developed scale created by following recommendations in the literature (Francis et al., 2004; Michie et al., 2011). An overview of the themes and the scales by which these themes were measured, can be found in Appendix 2. Each of the validated scales went through a process of forward-backward translation. This entailed that the original items in English were translated to Dutch by a professional translator, followed by a backward translation to English by another professional translator. The researcher compared the backward translation of the items to the original ones. Inconsistencies were resolved by adjusting the Dutch translation to a more accurate one. The process was repeated until all inconsistencies were resolved (Appendix 1).

*Neighbourhood participation around serious illness, death or loss* was measured with the Social Capital Measure (Onyx & Bullen, 2000) which we adjusted by adding the topics serious illness, death or loss to the original items, by replacing 'local community' with the neighbourhood, and by adding two items on helping neighbours. This resulted in eight items: 'Do you help in a neighbourhood group as a volunteer to support ill people, caregivers or people who have lost someone?', 'Have you attended an event in your neighbourhood around illness, caregiving or loss in the past six months (e.g. a benefit action to raise money)?', 'Are you an active member of an organisation or club in your neighbourhood that did something around illness, caregiving or loss (e.g. a memorial for someone who has died)?', 'In the past 3 years have you ever been involved in a local community initiative around illness, caregiving or loss in your neighbourhood (e.g. a bereavement group)?', 'Have you ever been part of a project to organise a new service in your neighbourhood for ill people, caregivers or people who have lost someone?', 'Do you belong to a digital neighbourhood group that does something for people who are ill, caregiving or people who have lost someone (e.g. WhatsApp, Facebook)?', 'Did you help an immediate neighbour (someone living next door) who was ill or in need of help?', 'Did you help anyone in your neighbourhood who was ill or in need of help?' An overview of all the items for neighbourhood participation around serious illness, death, caregiving or loss can be found in Appendix 1. Respondents could indicate for each item on a Likert scale from 1 to 4 whether they were active in this kind of participation; 1 meaning not active, 4 meaning very active. *Believed Capacity, skills and self-efficacy resulting from previous experiences with serious illness, death or loss* were measured by two different scales both containing five items measured on a Likert scale from 1 (totally disagree) to 5 (totally agree). The self-perceived capacity and skills to deal with serious illness, death or loss resulting from previous experiences were measured with the subscale 'experiential knowledge' of the Death Literacy Index, e.g. my previous experiences with serious illness, caring, death or loss provided me with skills and strategies when facing similar challenges in the future (Leonard et al., 2020). Self-efficacy to deal with serious illness, death or loss resulting from previous experiences was measured by 5 self-constructed items, which we developed by following specific recommendations in the literature on developing items around self-efficacy, e.g. my previous experiences with serious illness, caring, death or loss ensured I can talk to people in my neighbourhood who have lost someone (Francis et al., 2004; Michie et al., 2011). Furthermore, we developed items on being able to talk to

people in the neighbourhood about serious illness, caregiving or loss, talking to professional caregivers, and helping people who are seriously ill, caregivers or bereaved people based on previous experiences with these topics. Lastly, citizens' *previous experiences with serious illness, caregiving, death, or loss in the last year* were measured with four self-developed items: 'I was seriously ill', 'someone I knew very well died', 'a family member was seriously ill', and 'I was caregiver of a family member who was seriously ill', in the last year. Respondents could indicate yes or no for each of these items. Each of these items was employed independently in the analysis.

*Demographic characteristics* included sex (i.e. female, male, X), age as a continuous variable, highest degree obtained (i.e. primary education, lower secondary education, higher secondary education, university college, university), and living situation (i.e. living alone, living with a partner, living with children, living with a partner and/or with children, living with parent(s), living with other roommates). These variables were coded into fewer categories to conduct the analysis with; 65+ years versus being younger, lower education versus higher education and living alone versus living with other people. A full version of the questionnaire in Dutch, the language in which it was distributed, can be found in Appendix 3.

### **Statistical analyses**

We used descriptive statistics to analyse the demographic data, previous experiences with serious illness, death or loss in the last year and believed capacity, skills, and self-efficacy developed from previous personal experiences with these topics. To generalise the data to the entire population living in the two neighbourhoods together, we weighted the data for age and gender (Appendix 4).

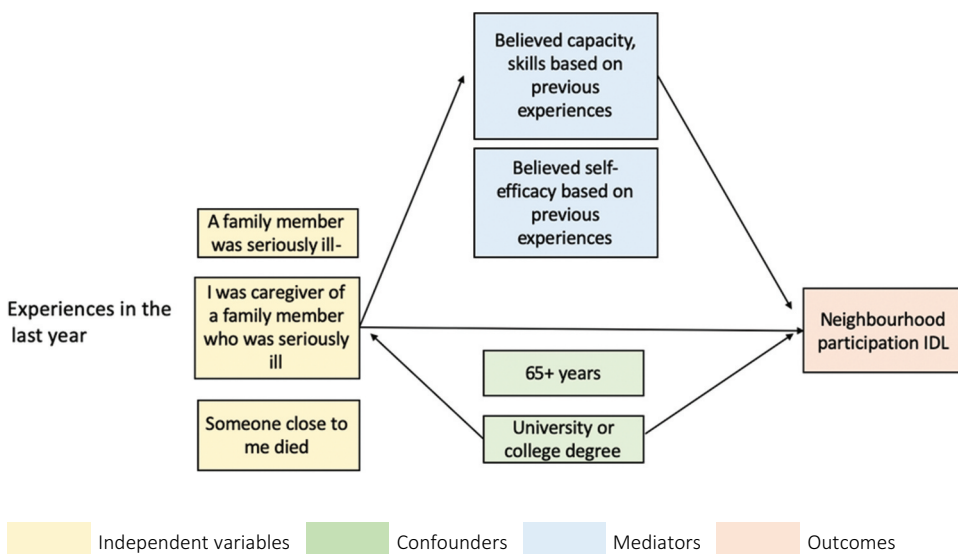
Before looking into the association effects, we calculated the sum score or factor score of the variables involved. Whether we collected a sum score or a factor score of a variable depended on the instructions of the original validated scale. If no instructions were provided, we preferred calculating the factor score because factors consider the shared variance among the variables (DiStefano et al., 2009). Based on the instructions from the Social Capital Measure (Onyx & Bullen, 2000) we calculated a sum score of the eight items on neighbourhood participation regarding serious illness, death or loss, with total scores ranging from 0 to 24. If 2 items or fewer (25% of all items) were missing, we replaced the value for that item with the sample average. When more than two items were missing, that value for that item was reported as missing. We performed a Principal Component Analysis (PCA) before calculating the factor score of the variable self-perceived capacity, skills and self-efficacy to deal with serious illness, death or loss and found that the factors loaded onto two distinct scales. The first scale represented self-perceived capacity and skills developed from previous experiences with serious illness, death or loss, while the second scale pertained to perceived self-efficacy in coping with these topics developed from previous experiences (Appendix 5). Consequently, we computed factor scores for each of these two scales and employed them separately in our subsequent analyses.

This analysis was developed from assumptions, grounded in existing literature (Johansson, 2022; Leonard et al., 2022; Noonan et al., 2016), that there is an association between previous experiences with serious illness, death or loss and neighbourhood participation regarding these topics and that this association may be mediated by self-



perceived capacity, skills and self-efficacy developed from previous experiences with serious illness, death or loss. Additionally, we identified retirement age (65+), living together with a partner or children, and having a college or university degree as potential confounding variables affecting the association between previous experiences with serious illness, death, or loss in the last year and neighbourhood participation regarding these topics (De Hart et al., 1999; Egerton, 2002; Van den Bogaard et al., 2014). To inform the multivariable analysis and more specifically the de-confounding strategies, we depicted the assumed causal interrelations in a Directed Acyclic Graph (DAG) model (Appendix 6). We calculated one-tailed Pearson correlation coefficients ( $p < 0.05$ ) to determine the correlations of the relationships specified in the model. These correlation coefficients were then filled into the DAG model (Appendix 6). Removing non-significant correlations, resulted in a simplified model, Figure 1, that served as a guide for our mediation analysis.

We conducted the mediation analysis via a hierarchical linear regression in which we first examined the association between each of our independent variables 'I was seriously ill', 'a family member was seriously ill', 'I was caregiver of a family member who was seriously ill' and 'someone I knew very well died' in the last year, and the dependent variable neighbourhood participation regarding serious illness, death or loss. Then we controlled for confounders by adding age (65+ vs. younger), sex (women vs. men, education (higher education vs. lower education) and living situation (living alone vs. living with other people) to the analysis. Subsequently, we added the mediating variables, perceived capacity and skills and perceived self-efficacy to deal with serious illness, death or loss, developed from previous experiences with these topics to the regression analysis. Non-significant variables were removed in each step. We reported on the standardised regression coefficient ( $p < 0.05$ ) the standardised R-squared change and the Confidence Interval (95%) for each step in the regression analysis. Additionally, we calculated the full mediation effect size and conducted a Sobel test to assess the significance ( $p < 0.05$ ) of our mediation model.



**Figure 1.** Simplified model illustrating the assumed association between previous experiences with serious illness, death or loss in the last year and neighbourhood participation regarding these topics.

## Results

A total of 714 respondents completed the survey (response rate 30.7%). Of the respondents, 59.4% lived in the neighbourhood in Sint-Kruis and 40.6% in the neighbourhood in Herzele. Overall, there were 53.7% women and 46.3% men who participated. A large proportion of respondents lived alone (29.1%), or lived with a partner and children (36.5%). Responding citizens were generally highly educated with a university or college degree (30.6%) or with a higher secondary school degree (34.9%).

If two or fewer items (25% or less of all items) were missing for neighbourhood participation regarding serious illness, death or loss, the value for those items was imputed using the sample average, resulting in the imputation of 72 items (10.1%). For cases where more than two items were missing, the values were coded as missing, which applied to 49 cases (6.9%). A sensitivity analysis was conducted to assess how missing data might impact the conclusions. The analysis revealed that the distribution of missing data was similar to that of the available data. This justified the use of a relatively simple imputation method, where missing values for the affected items could be replaced by the sample average without compromising the integrity of the results.

Experiences with being seriously ill, having a family member who was seriously ill, caregiving for a family member who was seriously ill, or having someone close who died in the last year, occurred in both neighbourhoods; 72.1% of citizens had at least one of these experiences in the last year. More than half of the citizens (57.1%) lost someone they knew well, 14.2% reported that they had been a caregiver for a family member who was seriously ill and 14.5% reported that they had been seriously ill in the last year. [Table 1](#) shows an overview of the characteristics of the study population per neighbourhood.

In terms of believed capacities and skills to deal with serious illness, death, or loss as a result of previous experiences with these topics ([Table 2](#)), 48.3% of the respondents found that their previous experiences gave them capacities and strategies to deal with similar challenges in the future (38% of the respondents neither agreed nor disagreed), although this was less often the case for citizens living in the neighbourhood in Sint-Kruis (43.6%) than for the citizens living in the neighbourhood in Herzele (55.4%). Furthermore, 47.0% of the responding citizens indicated that their previous experiences made them emotionally stronger to help others deal with death and dying. In terms of self-efficacy (35.5% neither agreed nor disagreed), 59.2% believed their previous experiences enabled them to talk with other people in their neighbourhood about loss (24.5% neither agreed nor disagreed; 44.1% believed their previous experiences enabled them to help people in their neighbourhood who lost someone (34.3% neither agreed nor disagreed), 39.3% believed their previous experiences enabled them to help someone who is ill or is a caregiver in their neighbourhood (36.9% neither agreed nor disagreed), and 33.4% believed their previous experiences enabled them to talk a doctor or professional caregiver about what ill people in the neighbourhood need (40.8% neither agreed nor disagreed).

We found a significantly positive association between having been a caregiver for a seriously ill family member in the last year and neighbourhood participation regarding serious illness, death or loss ( $\beta = 0.161$ ;  $CI = 0.378-1.276$ ), but not for other experiences with serious illness, death or loss ([Table 3](#)). Adding the assumed confounding variables to the analysis, we found a positive association between having a college or university degree and neighbourhood participation regarding

**Table 1.** Characteristics of the study population per neighbourhood.

	Neighbourhood in Sint-Kruis N = 424 (59.4%)	Neighbourhood in Herzle N = 290 (40.6%)	Total N=714 (%)
<b>Age:</b> Mean=63.19, SD=2.02			
18–24	31 (7.3)	11 (3.8)	42 (5.9)
25–49	83 (19.6)	69 (23.8)	152 (21.3)
50–64	109 (25.7)	82 (28.3)	191 (26.8)
65–79	114 (26.9)	81 (27.9)	195 (27.3)
80 (+)	87(20.5)	45 (15.5)	132 (18.5)
<b>Gender</b>			
Female	216 (51.2)	163 (57.4)	379 (53.7)
Male	206 (48.8)	121 (42.6)	323 (46.3)
<b>Living situation</b>			
Living alone	134 (31.9)	72 (25.1)	206 (29.1)
Living together with my partner	64 (15.2)	59 (20.6)	123 (17.4)
Living together with my child(ren)	32 (7.6)	22 (7.7)	54 (7.6)
Living together with my partner and child(ren)	154 (36.7)	104 (36.2)	258 (36.5)
I live with my parents	31 (7.4)	16 (5.6)	47 (6.6)
I live with other roommates	5 (1.2)	14 (4.9)	19 (2.7)
<b>Highest degree</b>			
Primary school	48 (11.6)	37 (13.2)	85 (12.2)
Lower secondary school	104 (25.1)	51 (18.1)	155 (22.3)
Higher secondary school	138 (33.3)	105 (37.4)	243 (34.9)
University College	87 (21.0)	58 (20.6)	145 (20.8)
University	38 (9.2)	30 (10.7)	68 (9.8)
<b>Previous experiences with serious illness, caregiving, death or loss</b>			
Someone I knew well, died	227 (56.4)	160 (58.2)	387 (57.1)
A family member was seriously ill	135 (34.6)	119 (43.3)	254 (38.2)
I was the caregiver of a family member who was seriously ill	60 (15.4)	34 (12.5)	94 (14.2)
I was seriously ill	59 (14.9)	39 (14.0)	98 (14.5)
<i>At least one of the above experiences</i>	317 (72.1)	216 (72.4)	533 (72.1)

Missing values for the variables in the table are respectively 0.7%; 1.1%; 1.0%; 2.5%; 5.8%; 5.3%; 6.9%; 7.2%.

serious illness, death or loss ( $\beta = 0.115$ ;  $CI = 0.080-0.420$ ). Living situation and sex were not significantly associated. In the third step, by adding the assumed mediators believed capacity, skills, and self-efficacy developed from previous experiences with serious illness, death, or loss to the analysis, the association between having been a caregiver for a seriously ill family member in the last year and neighbourhood participation regarding serious illness, death or loss slightly increased ( $\beta = 0.193$ ;  $CI = 0.588-1.393$ ). In contradiction to the believed capacity and skills to deal with serious illness, death or loss developed from previous experiences, believed self-efficacy was not significantly associated with neighbourhood participation regarding serious illness, death or loss. The initial model, which included experiences with serious illness, death or loss accounted for an R-squared of 0.049. Upon the addition of the mediator capacity and skills developed from previous experience, the R-squared increased to 0.069. This indicates that the inclusion of the mediator contributes to a 2.0% increase in the variance explained in the dependent variable, suggesting that self-perceived capacity and skills developed from previous experiences contribute to understanding the association between caregiving experiences in the past year and neighbourhood participation regarding serious illness, death and loss.

**Table 2.** Capacity, skills and self-efficacy to handle illness, death or loss resulting from previous experiences.

	Neighbourhood in Sint-Kruis (n= 424)			Neighbourhood in Herzele (n=290)			Total (n=714)		
	Disagree N (%)	disagree N (%)	Agree N (%)	Disagree N (%)	disagree N (%)	Agree N (%)	Disagree N (%)	disagree N (%)	Agree N (%)
1. Increased my emotional strength to help others with death and dying processes	65 (17.0)	142 (37.1)	176 (45.9)	48 (18.4)	86 (33.0)	126 (48.6)	113 (17.6)	228 (35.5)	302 (47.0)
2. led me to re-evaluate what is important and not important in life	49 (12.4)	98 (24.7)	248 (62.8)	65 (24.9)	114 (43.8)	82 (31.3)	114 (17.4)	212 (32.3)	329 (50.3)
3. Developed my wisdom and understanding	42 (10.9)	122 (31.2)	226 (57.9)	43 (16.9)	111 (43.4)	101 (39.6)	86 (13.3)	232 (36.0)	327 (50.7)
4. Made me more compassionate toward myself	58 (15.1)	164 (42.4)	164 (42.5)	32 (12.3)	100 (38.6)	127 (49.1)	90 (14.0)	264 (40.9)	291 (45.1)
5. Provided me with skills and strategies when facing similar challenges in the future	53 (13.7)	165 (42.8)	169 (43.6)	34 (13.2)	80 (31.3)	141 (55.4)	87 (13.5)	245 (38.2)	310 (48.3)
6. Enabled me to talk to people in my neighbourhood about illness, caregiving or dying	87 (22.2)	102 (25.9)	205 (51.9)	44(16.6)	80 (30.3)	140 (53.1)	131 (19.9)	182 (27.7)	345 (52.4)
7. Enabled me to talk to people in my neighbourhood about loss	74 (18.8)	95 (24.4)	222 (56.8)	33 (12.4)	65 (24.7)	166 (62.9)	106 (16.3)	161 (24.5)	388 (59.2)
8. Enabled me to help people who are ill, or caregiving, in my neighbourhood	103 (26.2)	143 (36.5)	146 (37.3)	52 (20.1)	96 (37.5)	109 (42.4)	154 (23.8)	239 (36.9)	255 (39.3)
9. Enabled me to help people in my neighbourhood who lost someone	95 (24.2)	136 (34.7)	160 (41.0)	45 (17.5)	87 (33.7)	126 (48.8)	140 (21.6)	223 (34.3)	286 (44.1)
10. Enabled me to talk to a doctor or professional caregiver about what people who are ill in my neighbourhood need	116 (29.4)	159 (40.6)	116 (29.6)	52 (19.9)	106 (41.0)	101 (39.1)	168 (25.8)	265 (40.8)	217 (33.4)

Missing values for the variables in the table are respectively: 10.1%; 8.3%; 9.7%; 9.5%; 10.2%; 7.8%; 8.3%; 9.2%; 9.1%; 8.9%.

## Discussion

### Main results

Our study found that a large proportion of responding citizens had experienced serious illness, caregiving, or loss in the past year (72.1%) with the most reported experience being someone they knew well who died (57.1% of citizens). We found that citizens who had been the caregiver for a seriously ill family member in the past year were more likely to participate in their neighbourhood around the topics of serious illness, death or loss

**Table 3.** Hierarchical linear regression analysis testing the assumed associations with neighbourhood participation around serious illness, death.

Predictor variables	DV= neighbourhood participation regarding serious illness, death and loss						MED variable= capacity & skills	
	R <sup>2</sup> change= 0.049		R <sup>2</sup> change= 0.058		R <sup>2</sup> change= 0.069		R <sup>2</sup> change= 0.020	
	$\beta$ (95% IC)	t-value	$\beta$ (95% IC)	t-value	$\beta$ (95% IC)	t-value	$\beta$ (95% IC)	t-value
ID = A family member was seriously ill	0.065 (-0.032–1.080)	1.850						
ID = I was the caregiver of a family member who was seriously ill	0.161*** (0.378–1.276)	3.620	0.197*** (0.615–1.409)	5.045	0.193*** (0.588–1.393)	4.838	0.143*** (0.133–0.436)	3.680
ID = someone I knew well died	0.044 (-0.190–0.638)	1.063						
CON = Highest degree			0.115** (0.080–0.420)	2.881	0.092* (0.034–0.367)	2.362		
CON = age			0.092* (0.001–0.008)	2.291				
MED = Capacity & skills					0.094* (0.046–0.447)	2.414		
MED = Self-efficacy					Redundant for the model			
Total mediating effect			0.143 x 0,193 = 0.028					
Sobel test			z = 2.929					

IV = Independent variable, CON = confounding variable, MED = mediating variable, DV = dependent variable.  
\* $p < 0.05$ ; \*\* $p < 0.01$ ; \*\*\* $p < 0.001$ .

( $\beta = 0.161$ ; CI = 0.378–1.276). The association between having been a caregiver for a seriously ill family member in the past year and neighbourhood participation regarding serious illness, death or loss strengthened slightly ( $\beta = 0.193$ ; CI = 0.588–1.393) when adding believed capacity and skills regarding serious illness, death or loss developed from previous experiences to the analysis.

### Strengths and limitations

This study is the first to investigate the association between previous experiences with serious illness, caregiving, death, or loss in the last year, people's self-perceived capacity, skills, and self-efficacy to deal with these topics developed from previous experiences, and neighbourhood participation around serious illness, death or loss. Furthermore, our response rate of 30.7%, ( $n = 714$ ) was below the conservatively anticipated 35.0% ( $n = 813$ ), which has reduced the statistical power of the analyses and may increase selection bias despite our efforts to mitigate this by weighing. Additionally, there is a possibility that those who filled in the survey were the ones who had a personal experience with serious illness, caregiving, dying or loss and were the ones who were willing to share this experience. Nevertheless, given the exploratory nature of this research, our findings still provide valuable preliminary insights. A possible explanation for this lower response rate could be that population-based surveys on sensitive topics can be perceived as too emotionally confrontational. People who are not currently experiencing these issues

may find it uninviting to engage with topics that seem distal from their daily life. Conversely, those who are dealing with illness or loss may find the subject too painful, choosing to avoid the emotional discomfort that comes with reflecting on their experiences.

Furthermore, although the response rate was lower than expected, it still provides some generalisability of the findings, especially since non-response bias is taken into account by weighting the data for age and gender. It is, however, important to acknowledge that the sample was limited to two purposefully selected neighbourhoods which possibly limits external validity, and thereby generalisability to other peri-urban regions in Flanders and beyond. Lastly, because the study was innovative in its focus on serious illness, death, or loss in neighbourhoods and communities, we could not rely on validated instruments. We reviewed and used many candidate instruments, but these instruments required adaptations for the specific context and focus of our study.

### **Interpretations**

Our study found that citizens who had been caregiver for a seriously ill family member in the past year were more likely to participate in neighbourhood activities regarding serious illness, death or loss such as helping close neighbours or volunteering for people in the neighbourhood. We did not find this association for any of the other experiences such as being seriously ill, having lost someone close or having a family member who was seriously ill in the last year. We suggest this can be linked to caregiving being a unique form of participation that induces caregivers' 'sense of coherence', a concept that is central to salutogenic approaches (Antonovsky et al., 1998; Lindström, 2005). Antonovsky defined sense of coherence as the confidence a person feels in handling health-related challenges, and he divided this concept into three key elements: manageability, meaningfulness and comprehensibility. We suggest that, manageability, which is in our study the ability to cope with the topics of serious illness, death and loss, is reinforced through caregiving as individuals gain confidence in their ability to support others in times of need (Antonovsky et al., 1998). Additionally, also the other way around, lacking this manageability can be an instigator for social bonding within neighbourhoods, as it may lead to seeking support from neighbourhood contacts that are in similar types of situations (Noguchi et al., 2020; Papastavrou et al., 2015). Meaningfulness, which refers to the sense of purpose gained from caregiving tasks, can inspire caregivers by allowing them to find value and fulfilment in their role, potentially making them more inclined to seek similar meaning through active participation in their neighbourhood around these topics (Antonovsky et al., 1998). Lastly, regarding comprehensibility, caregiving's hands-on nature helps individuals reduce chaos by providing a clear, actionable role in difficult situations. We suspect that the convergence of these three elements is present most prominently among caregivers, as they are uniquely positioned to transform their caregiving experiences into a coherent understanding of the topics of serious illness, death or loss. Additionally, former caregivers may be a particularly interesting group to identify, as they have time to reflect on their experience and may recognise the importance of engaging in neighbourhood activities regarding these topics (Larkin, 2009).

Furthermore, we found that the likelihood of participating in neighbourhood activities regarding serious illness, caregiving, death or loss of citizens who had been a caregiver for

a seriously ill family member in the past year increased if they believed they developed capacity and skills from their previous experiences with these topics. This finding coincides with a tendency towards leveraging learning from previous experiences with serious illness, death or loss as a means to bolster citizens' death literacy (Leonard et al., 2022). This death literacy is defined as '*a set of knowledge and skills that make it possible to gain access to understand and act upon end-of-life and death care options*' (Noonan et al., 2016) and provides people with a well-rounded understanding of palliative care and the social context in which it can be provided. Existing literature found that caregivers, since they have first-hand caring experiences, are inclined to share their knowledge and insights within their social network, thereby contributing to the development of death literacy in that network (Antonovsky et al., 1998). Based on our findings we suggest that encouraging caregivers to extend knowledge-sharing beyond the personal network and into the community and neighbourhood may foster collective death literacy building and strengthen social action regarding serious illness, death, or loss. However, it is essential to ensure that this encouragement is approached carefully, as some individuals may still be processing trauma or grief, which could be exacerbated by social expectations to participate in neighbourhood activities (Holtzlander et al., 2017). To mitigate these risks, we believe it is crucial to prioritise the voluntary nature of involvement, offering flexible participation options that are sensitive to each caregiver's comfort level. While the importance of boundaries and flexibility in caregiving has been well-documented in professional care settings (Abrams et al., 2019) this consideration has not yet been thoroughly examined in the context of civic neighbourhood participation on these sensitive topics. Furthermore, reflection is needed on when such participation shifts from being a potential trigger for negative emotional responses for caregivers to becoming a meaningful, enriching experience.

Furthermore, when measuring experiential knowledge, a rather large proportion of respondents provided neutral responses, selecting 'neither agree nor disagree' (ranging between 25% and 35% for each item). This rather unexpected finding suggests that individuals may be uncertain about how to evaluate their own experiential knowledge or how it translates into practical skills, highlighting that experiential learning alone may not be sufficient to extract meaning and understanding from these experiences with serious illness, caregiving, death and loss. Thus, while experiential learning is a potential strategy for fostering neighbourhood participation regarding serious illness, dying and loss, additional education, training, or community support may still be necessary to help individuals developing these skills from their experiences. Notably, the mediating effect of capacity and skills developed from their previous experiences with these topics was relatively small. This aligns with our initial expectations, recognising that complex social change processes—such as fostering participation in neighbourhood activities related to these sensitive topics—can only be explained by a myriad of factors, all intricately interwoven within a complex mechanism of change. Consequently, we hypothesise that besides capacity and skills, there may be other aspects of death literacy (e.g. knowledge of community resources, knowledge to provide hands-on support) that co-predict the association between having been a caregiver for a seriously ill family member in the last year and neighbourhood participation regarding serious illness, death or loss. Future longitudinal research is needed to further test the hypothesis of increasing the likelihood of



neighbourhood participation regarding serious illness, death or loss through developing death literacy, and potentially looking at other mediators for neighbourhood participation regarding serious illness, death, or loss.

## Conclusions

Our findings suggest that citizens who had a caregiving experience in the last year are more likely to participate in neighbourhood activities regarding serious illness, death or loss, and to an even greater extent if they believe they developed capacity and skills as a result of previous experiences with these topics. We recommend that researchers look into other aspects of death literacy, besides believed capacity and skills, which might be better mediating predictors for neighbourhood participation regarding serious illness, death or loss. Furthermore, we suggest future research should explore the mechanisms behind the associations we measured, with qualitative research seeming a particularly relevant approach. Lastly, we recommend policies and practices to facilitate the social capital of current and former caregivers by for instance organising social activities and support networks in their neighbourhood, that strengthen people's knowledge and understanding of serious illness and end-of-life matters.

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## Data availability statement

The data set and data syntax can be provided by contacting the corresponding author.

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