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How compassionate is your neighborhood? Results of a cross-sectional survey on neighborhood participation regarding serious illness, death, and loss

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ABSTRACT

We conducted a cross-sectional survey measuring the extent and nature of neighborhood participation regarding serious illness, death and loss and the factors that are associated with it. We distributed the survey to 2324 adult citizens in two neighborhoods in Flanders, Belgium, to which 714 citizens responded (response rate 30.7%). Of the respondents, 42.4% participated in at least one action in their neighborhood around serious illness, death, or loss, for 30.8% of them this participation was sporadic. Most of the respondents participated by helping neighbors (32.4%) or by volunteering (10.3%). We found a positive association between perceived neighborhood social cohesion ($\beta = 0.100$; CI = 0.003-0.040), previous experiences with serious illness, death, and loss ($\beta = 0.158$; CI = 0.204-0.586) and neighborhood participation around serious illness, death and loss. Future research should investigate strategies on how to move from death literacy developed through illness, caregiving and bereavement experiences to neighborhood participation around these topics.

KEYWORDS



Public health; palliative care; compassionate communities; neighborhood participation; informal participation

Background


Communities that are “passionate and committed to improving the experiences and well-being of individuals who are dealing with a serious health challenge, and those who are caregiving, dying, or grieving”, can be termed Compassionate Communities (Care, Canada, & Ontario, 2020). Compassionate Community networks can be developed through supportive policies, educating citizens about illness, dying, and loss (Kellehear, 2013) or via civic engagement (D'Eer et al., 2022). We define civic engagement as all collective action that is undertaken to help improve connections between or conditions for people in a community (Adler & Goggin, 2005; Crowley, n.d.; Diller, 2001). Thereby, we interpret civic engagement as an umbrella term for volunteering, informal caregiving, and all other types of

collective, community and neighborhood participation. Civic engagement can be performed in different sectors within a Compassionate Communities approach, such as in workplaces, schools, or cultural organizations. A systematic review of civic engagement initiatives regarding serious illness, death and loss worldwide illustrated that people are primarily involved in caring for people in their neighborhood, for instance by directing people with palliative care needs to existing neighborhood resources (D'Eer et al., 2022; Pesut et al., 2020).

Although neighborhood participation around serious illness, death and loss has been shown to build a more extensive support network for the people who participate in it (Aoun et al., 2022) and increases knowledge about palliative care (Salau et al., 2007), the actual extent and nature of this neighborhood

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participation around serious illness, death and loss have not been previously described. For instance, survey studies in Flanders, Sweden and the UK measured people's participation regarding serious illness, death and loss in palliative care settings (Vleminck et al., 2022), but did not measure this in a neighborhood setting. Since neighborhood participation around serious illness, death and loss has been suggested as an important means of fostering Compassionate Communities (Pesut et al., 2017), there is a need to develop insights into the current extent and nature of people's participation and the factors associated with it. Previous studies have identified neighborhood social cohesion as a facilitating factor for neighborhood participation (Dang et al., 2022; Parekh et al., 2018; Ziersch, 2011) but have also illustrated that barriers to helping those who are seriously ill or bereaved may be traced back to changing social relationships, for instance by being afraid to ask for or to offer support (Grindrod & Rumbold, 2017). Consequently, we assume social cohesion to be of particular relevance for supporting people around serious illness, death, and loss, and anticipate finding a positive association between citizens' perceived feelings of social cohesion and their neighborhood participation in serious illness, death and loss. By developing a strategy that considers potential mediating variables that influence the association between perceived neighborhood social cohesion and neighborhood participation regarding serious illness, death and loss, this study does not only want to look into the possible association between social cohesion and participation but also offers some careful assumptions as to the mechanisms underlying it. Thereby, this study aims to contribute to more scientifically supporting hypothesis-building around strengthening neighborhood participation regarding serious illness, death, and loss. Specifically, we posed the following research questions:

1. To what extent do citizens participate in actions around serious illness, dying and loss in their neighborhood?
2. Are citizens more likely to participate in actions around serious illness, dying and loss in their neighborhood when there is a higher level of perceived social cohesion in the neighborhood?

Methods

Study design

We conducted a cross-sectional survey of citizens in two neighborhoods in Flanders, Belgium, pre-implementation

of neighborhood civic engagement initiatives around serious illness, death and loss in these two neighborhoods.

Setting and participants

The survey was distributed in two neighborhoods in two peri-urban municipalities in Flanders, namely Sint-Kruis and Herzele (Verzekering, 2018). Sint-Kruis is a sub-municipality of the city of Bruges. Together with the two groups of municipality representatives, we defined a neighborhood in this study as the geographical area matching the city center that contains most of the services, organizations, shops, etc. in that neighborhood. Following this reasoning, the neighborhood in Sint-Kruis (henceforward called neighborhood S) was demarcated as the two geographically defined areas (i.e., Sint-Kruis Kruispoort and Sint-Kruis Centrum) and the neighborhood in Herzele (henceforward called neighborhood H) was chosen as the area that is located in a radius of 1 mile around the local service center. Both neighborhoods are constituted of approximately 4,000 inhabitants.

Sampling procedure & study size

We aimed for a 95% confidence interval with a width of +/- 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 resulted in a sample of 1,177 inhabitants for neighborhood S and 1,147 inhabitants for neighborhood H. A city official took a random selection of inhabitants in each neighborhood of 18 years or older. A total of 2,324 surveys were sent out.

Data collection

Questionnaires were distributed by post between February and April 2021. We used the Total Design method, sending up to three reminders for those not answering (Hoddinott & Bass, 1986). There was a two-week period between each round of sending questionnaires or reminders, in which citizens could complete the survey and send it back. Citizens were asked to fill in the questionnaire within two weeks of receipt and to return it by post via a prepaid envelope. They could also choose to complete the questionnaires online by using their unique respondent number. A cover letter was provided with each questionnaire stating the context and aim of the research and that citizens could participate without obligation. The paper questionnaires were

processed in compliance with the requirements of the European and Belgian data protection regulations ("Act of 30 July 2018 on the Protection of Natural Persons with Regard to the Processing of Personal Data," 2018). The data was entered as soon as possible after receipt of each questionnaire in the open-source web-based survey application Lime Survey. The lead researcher (LD) and an independent data collector performed an independent double data entry for 10% of the data. If the number of errors on any given survey exceeded 3%, the entire survey would be reentered, but this was not the case for any of the surveys. After data entry, the data was exported from LimeSurvey to SPSS. The lead researcher (LD) saved the original, exported file on a secured cloud, after which a second file for data cleaning was created. All data cleaning was conducted via syntaxes to ensure reproducibility by other researchers.

Ethics and confidentiality

Ethical approval to conduct the study was obtained from the Ethics Committee of the Vrije Universiteit Brussel (case number B1432020000185). To guarantee confidentiality, each participant received a unique respondent code. The lead researcher saved a file with names, addresses and respondent numbers on a secured cloud. This file was password-protected and only accessible by the lead researcher (LD).

Concepts measured

We developed a survey comprised of both validated and novel concepts, of which an overview can be found in the [online Supplementary Materials online](#). The five main concepts in this survey study with which we perform the regression analysis, are *perceived neighborhood social cohesion*; *general neighborhood participation*; *neighborhood participation around serious illness, death and loss*; *experiences with illness, caregiving, and loss over the past year*; and *perceived help from neighbors*. We refer to perceived neighborhood social cohesion as a category 1 variable that is measured with a validated scale (see [Supplementary Materials online](#)). The Neighborhood Cohesion Instrument consists of 18 statements (e.g., I feel like I belong in this neighborhood, I would be willing to work together with others on something to improve my neighborhood) on a five-point Likert scale ranging from *totally agree* (5) to *totally disagree* (1) (Buckner, 1988).

To general neighborhood participation and neighborhood participation around serious illness, death, and loss, we refer to category 2 variables which are

measured by an adjusted validated scale. Both concepts were measured with the subscale *participation in the local community* from the Social Capital Measure (Onyx & Bullen, 2000); respondents could indicate for each item on a Likert scale from 1 (not active) to 4 (very active) in this kind of participation. We adjusted the examples of participation to examples that exist in a Belgian context and added the topics of illness, death, and loss to the scale. All category 1 and 2 concepts were forward-backward translated, to provide a correct translation of the validated instrument, which can be found in the [online Supplementary Materials](#)). The remaining concepts are category 3 and 4 concepts which are self-developed. In the case of perceived help from neighbors the items are self-developed but based on the Medical Outcomes Study Survey (MOS) (Sherbourne & Stewart, 1991), resulting in 10 items going from (1) totally disagree to (5) totally agree. In the case of experiences with illness, caregiving, and loss the items are self-developed, resulting in four items on previous experiences for which respondents could indicate yes or no.

The demographic characteristics of the participants included age, sex (i.e., male, female, or X), highest degree (i.e., primary school, lower secondary school, higher secondary school, university college, university) and living situation (i.e., living alone, living with a partner, living with children, living with a partner and children, living with parent(s), living with other roommates).

We performed cognitive testing of our self-developed items by taking a sample of ten people from the neighborhood and gathering their feedback on the items. Thereby we were able to ensure that the test items did measure our intended construct and that they appeared valid to participants. An overview of all the items measured can be found in the questionnaire (see [Supplementary Materials online](#)).

Statistical analyses

The demographic characteristics of the respondents and their degree of neighborhood participation in illness, death and loss were analyzed using descriptive statistics. We weighted the data for age and gender for both neighborhoods to generalize the results to the entire population living in the two neighborhoods (see [Supplementary Materials online](#)). To conduct the regression analyses, we first calculated the sum scores, resulting in a score from 0 to 24 for *generic neighborhood participation and neighborhood participation regarding IDL*, 18 to 90 for *neighborhood social*

cohesion, 0 to 40 for *perceived help from neighbors*, and 0 to 3 for *personal experiences with illness, dying, and loss*; with higher values indicating better scores for each of the concepts. If a respondent filled in less than 20% of items for a particular scale, these items were reported as missing; if they filled in more than 20% of the items the missing items were replaced by the sample average.

This study is interested in the association between perceived neighborhood social cohesion, general neighborhood participation and neighborhood participation regarding serious illness, death, and loss. A review of relevant literature suggested that civic or neighborhood participation potentially plays a mediating role in the association between perceived social cohesion and collective action such as neighborhood participation regarding serious illness, death and loss (Carbone & McMillin, 2019). Subsequently, our study assumed that general neighborhood participation has a potentially mediating role in explaining the association effect between perceived neighborhood social cohesion and neighborhood participation regarding serious illness, death, and loss. The potential confounding variables are age (65+ vs. non-retirement age), gender (women vs. men), education (higher education vs. lower education), living situation (living alone vs. living with others), previous experiences with serious illness, caregiving, and loss in the last year and perceived help from neighbors were identified by consulting previous findings on the subject (Bovaird et al., 2015; Christensen & Læg Reid, 2005; Putnam, 2000). To inform the multivariable analysis, and more particularly the de-confounding strategies (i.e., the difference between confounders and the mediator), we created a Directed Acyclic Graph model, visualizing the potential causal interrelation between the different core concepts of perceived neighborhood social cohesion, general neighborhood participation and neighborhood participation regarding serious illness, death, and loss, which can be found in the [online Supplementary Materials](#). We calculated Pearson correlation coefficients ($p < 0.05$, one-tailed) to determine the correlations of the relationships specified in the model, which we then filled into the model. Based on these results we constructed a simplified directed acyclic graph, [Figure 1](#), guiding our mediation analysis.

We started the mediation analysis by conducting a hierarchical linear regression in which we first examined the association between the independent variable perceived neighborhood social cohesion and the dependent variable neighborhood participation regarding serious illness, death and loss. Following this, we

controlled for the confounding variables, and subsequently added the mediating variable, general neighborhood participation, to the analysis. Variables that were non-significantly associated with neighborhood participation in serious illness, death, and loss, were systematically removed. For each of the analyses, we reported the standardized regression coefficient ($p < 0.05$) the standardized R-squared change and the Confidence Interval (95%). By multiplying the standardized regression coefficients of on the one hand the association between perceived neighborhood social cohesion and general neighborhood participation and on the other hand the association between general neighborhood participation and neighborhood participation regarding serious illness, death, and loss, we were able to determine the full mediation effect size. Additionally, we conducted a Sobel test to tell whether our mediation model can be considered significant ($p < 0.05$).

Results

A total of 714 respondents completed the survey with a response rate of 30.7% (response rate neighborhood S = 37.8%, response rate neighborhood H = 27.5%). Ten respondents filled in none of the items of neighborhood participation around serious illness, death and loss and were hence removed from further analyses, meaning 704 respondents were retained for further analyses. Of the 704 respondents, 416 (59.1%; [Table 1](#)) lived in neighborhood S and 288 (40.9%) in neighborhood H. The majority of respondents were female (53.6%) in both neighborhoods, with a mean age of 63.2 years ($SD = 2.02$). Of the respondents, 30.9% were highly educated, 36.9% lived with a partner and children, and 28.8% lived alone.

Current neighborhood participation around serious illness, death or loss was reported by 42.4% of respondents, with 30.8% of respondents participating seldom or sometimes and 11.6% participating more often ([Table 2](#)). Of those participating, the majority occurred by citizens helping a close neighbor who was seriously ill or needed help (32.4%) or by participating as a volunteer for seriously ill people, dying people or people with a loss experience (10.3%). To a lesser extent, citizens participated in neighborhood projects such as community care, grief groups or other partnerships related to illness, death, or loss (6%), organizing a new service for ill people, dying people or people with a loss experience (6%) or being part of a digital neighborhood group (7.7%).

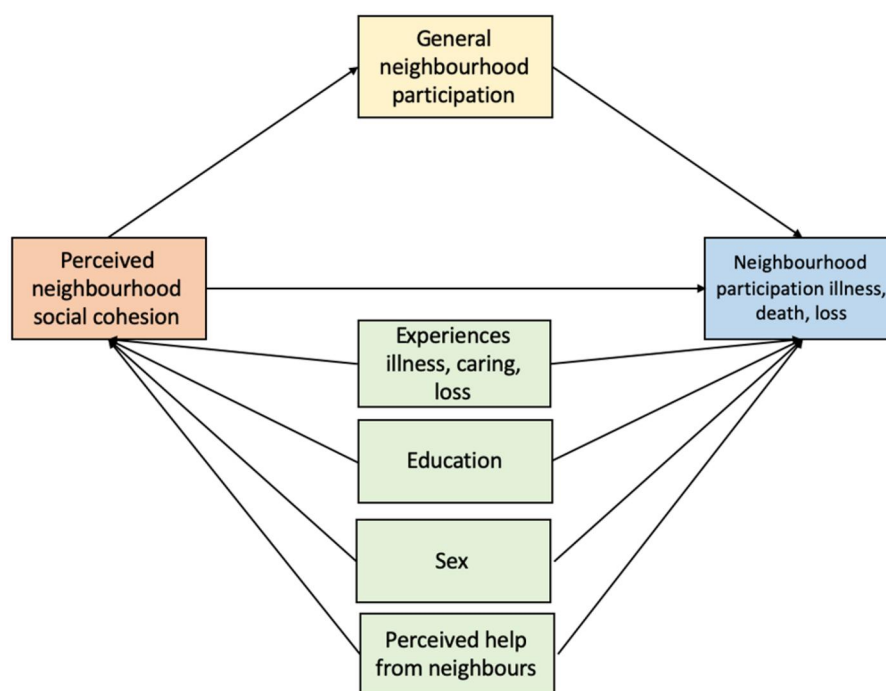


Figure 1. Simplified Directed Acyclic Graph of perceived neighborhood social cohesion and neighborhood participation regarding serious illness, death, and loss.

We found a positive but weak association between perceived neighborhood social cohesion and neighborhood participation around serious illness, death, and loss ($\beta = 0.171$; CI = 0.032-0.083), which was only slightly reduced $\beta = 0.100$; CI = 0.003-0.040) when adding general neighborhood participation to the analysis (Table 3). The other variables that were significantly positively associated with neighborhood participation around serious illness, death and loss were having had experiences with these topics in the last year ($\beta = 0.158$; CI = 0.204-0.586) and the perception that their neighbors would help them if they were seriously ill, caregiving or lost someone ($\beta = 0.134$; CI = 0.011-0.048). Our regression analysis revealed an R-squared value of 0.131, indicating that approximately 13% of the variability in the neighborhood participation regarding serious illness, death and loss can be explained by perceived neighborhood social cohesion and general neighborhood participation. By conducting a Sobel test, we found that the mediation model was significant ($z\text{-value} = 3.228$; $p < 0.01$) but with a small mediation effect of 0.032.

Discussion

This study found that 42% of the respondents participated in their neighborhood around the topics of serious illness, death, and loss at least once. This participation consisted primarily of helping close

neighbors or being involved in volunteering around these topics. Additionally, we found that people are more likely to participate in their neighborhood in activities around serious illness, death, and loss the higher their perception of the neighborhood's social cohesion is, and if they had an experience with illness, caregiving, or bereavement in the last year. This association remained after controlling for other variables such as general neighborhood participation.

Our results show that almost half of the residents of the neighborhoods (42.4%) participated in at least one activity around serious illness, death, and loss such as volunteering or helping a close neighbor, with only a smaller proportion participating regularly (11.6%). This finding shows that sporadic participation around illness, death and loss in the neighborhood predominates over frequent involvement. Besides time constraints (e.g., due to demanding work schedules) or changing circumstances (e.g., having children, moving, having health issues) that prevent people from committing to more intense commitments on a weekly or daily basis (Southby & South, 2016), people may find it emotionally challenging to deal with sensitive issues like illness, death and loss on a more frequent basis (Claxton-Oldfield, 2016). Since we found a positive association between perceived neighborhood social cohesion and neighborhood participation around serious illness, death, and loss, we suggest that social cohesion is a potential

Table 1. Characteristics of the study population per neighborhood.

	Neighborhood S N = 416 (59.1%)	Neighborhood H N = 288 (40.9%)	Total N = 704
Age: Mean = 63.19, SD = 2.02			
18-24	30 (7.2)	11 (3.8)	41 (5.8)
25-49	80 (19.2)	68 (23.8)	148 (21.1)
50-64	109 (26.2)	82 (28.7)	191 (27.2)
65-79	112 (26.9)	81 (28.3)	193 (27.5)
80 (+)	85 (20.4)	44 (15.4)	129 (18.4)
Sex			
Female	210 (50.7)	163 (57.8)	373 (53.6)
Male	204 (49.0)	119 (42.2)	323 (46.4)
Living situation			
Living alone	131 (31.8)	70 (24.6)	201 (28.8)
Living together with my partner	62 (15.0)	59 (20.7)	121 (17.4)
Living together with my child(ren)	31 (7.5)	22 (7.7)	53 (7.6)
Living together with my partner and child(ren)	153 (37.1)	104 (36.5)	257 (36.9)
I live with my parents	30 (7.3)	16 (5.6)	46 (6.6)
I live with other roommates	5 (1.2)	14 (4.9)	19 (2.7)
Highest degree			
Primary school	45 (11.0)	37 (13.3)	82 (11.9)
Lower secondary school	103 (25.2)	50 (17.9)	153 (22.3)
Higher secondary school	136 (33.3)	104 (37.3)	240 (34.9)
University College	86 (21.1)	58 (20.8)	144 (21.0)
University	38 (9.3)	30 (10.8)	68 (9.9)

Note. Missing values = age (0.3%), sex (1.1%), living situation (1.0%), degree (2.4%).

facilitator for participation around these topics. We can however wonder if a feeling of social cohesion is in itself sufficient enough to remedy emotional challenges that come with frequent informal participation in general and especially around deeply human topics such as serious illness, death and loss. This survey showed that people are more likely to help their close neighbor than to participate in general neighborhood activities around serious illness, death and loss where there is no personal connection with someone they know (e.g., involvement in events, clubs, organizations, digital groups), thereby confirming a previous finding that it is difficult to involve community members beyond neighbors or professional caregivers in support networks of care (Horsfall et al., 2015). Abel et al. (2013) coined the term “outer networks of care” to describe this subgroup lacking a deeply personal connection to the person in need of care. Both our findings and the study by Horsfall et al. (2015) suggest that by strengthening the neighborhood’s role in helping individuals faced with serious illness, death, and loss, these outer networks of care hold the potential to be activated and mobilized effectively.

Furthermore, we found that general neighborhood participation only slightly influenced the association between perceived neighborhood social cohesion and neighborhood participation around serious illness, death, and loss, suggesting that citizens who participate around illness, caregiving or loss are specifically triggered by these topics rather than by general neighborhood involvement. In line with this finding, we found a strong positive association between citizens’ experiences with illness, death and loss and their

participation in these topics in their neighborhood. A possible explanation could be that exposure to the topics of illness, death, and loss either through work experience, educational activities, or personal caring or loss experiences, enables citizens’ knowledge and skills to understand and act upon end-of-life and death care options (Noonan et al., 2016), also known as death literacy (Johansson, 2022; Leonard et al., 2022). For instance, Leonard et al. (2022) found that citizens with caregiving experiences felt better equipped than others to share knowledge and skills within their network, thereby enabling social action around illness, death, and loss. Combining these findings seems to suggest that citizens with previous illness, caring or bereavement experiences are not only the ones that can benefit from neighborhood participation around these topics, but they are an essential part of this neighborhood participation themselves. Future research should investigate strategies on how to move from death literacy developed through illness, caregiving, and bereavement experiences to neighborhood participation around these topics.

Implications and recommendations for research and practice

The findings of this research resonate with broader research looking into experience-based learning as one of the strategies for developing death literacy and stimulating social actions around serious illness, death, and loss. This study provides the first step in mapping the potential of citizens’ previous experiences with serious illness, caregiving, and loss with neighborhood

Table 2. The degree to which citizens in two neighborhoods in Flanders engage in neighborhood participation regarding serious illness, death or loss.

	Neighborhood S (n = 416)			Neighborhood H (n = 288)			Total (n = 704)		
	Not active N (%)	Seldom or Sometimes active N (%)	More active N (%)	Not active N (%)	Seldom or Sometimes active N (%)	More active N (%)	Not active N (%)	Seldom or Sometimes active N (%)	More active N (%)
1. Do you help in a neighborhood group as a volunteer to support ill people, caregivers or people who have lost someone?	361 (90.3)	34 (8.4)	5 (1.4)	253 (89.1)	24 (8.5)	7 (2.4)	614 (89.8)	58 (8.5)	12 (1.8)
2. Have you attended an event in your neighborhood around illness, caregiving, or loss in the six months before corona started (e.g., benefit action to raise money) ?	384 (96.6)	12 (3.0)	2 (0.5)	264 (95.8)	11 (4.2)	0 (0)	648 (96.2)	23 (3.5)	2 (0.3)
3. Are you an active member of an organization or club in your neighborhood that did something around illness, caregiving, or loss (e.g., memorial for someone who has died)?	391 (98.2)	5 (1.2)	3 (0.7)	226 (98.1)	3 (1.2)	2 (0.7)	616 (98.1)	7 (1.2)	4 (0.7)
4. In the past 3 years, have you ever been involved in a local-community initiative around illness, caregiving, or loss in your neighborhood (e.g., a bereavement group)?	378 (94.8)	17 (4.4)	3 (0.8)	256 (92.9)	19 (6.9)	1 (0.2)	634 (94.0)	36 (5.4)	4 (0.6)
5. Have you ever been part of a project to organize a new service in your neighborhood for ill people, dying people or people with a loss experience?	359 (95.0)	16 (4.2)	3 (0.8)	245 (91.7)	20 (7.6)	2 (0.7)	603 (93.6)	36 (5.6)	5 (0.8)
6. Are you a member of a digital neighborhood group on social media that does something for ill people, caregivers, or people with loss experience?	350 (90.0)	35 (9.0)	4 (1.0)	261 (95.5)	12 (4.1)	1 (0.4)	611 (92.2)	46 (7.0)	5 (0.7)
7. Did you help a neighbor (that lives next to you) who was ill or needed help?	274 (68.3)	102 (25.4)	25 (6.3)	182 (66.4)	81 (29.7)	11 (3.9)	456 (67.5)	183 (27.1)	36 (5.3)
8. Did you help someone in your neighborhood who was ill or needed help?	281 (69.6)	96 (23.8)	27 (6.6)	167 (64.9)	77 (30.2)	13 (4.9)	448 (67.7)	174 (26.3)	39 (5.9)
At least one of the above activities	230 (58.2)	116 (29.4)	49 (12.4)	153 (56.7)	89 (33.0)	28 (10.4)	38 (57.6)	205 (30.8)	77 (11.6)

Note. Missing values items 1-8: 2.9%; 4.3%; 10.8%; 4.2%; 8.5%; 5.8%; 4.1%; 6.0%; 5.5%.

Table 3. Hierarchical linear regression testing the assumed associations for neighborhood participation around serious illness, death, and loss.

Correlates	Dependent variable: general neighborhood part			Dependent variable: neighborhood participation regarding serious illness, death, and loss						
	Step 1			Step 2			Step 3			
	Adjusted R ² = 0.028	t-value	sr ²	Adjusted R ² = 0.040	t-value	sr ²	Adjusted R ² = 0.098	t-value	sr ²	Adjusted R ² = 0.131
IV = Perceived neighborhood social cohesion	0.171***	4.437	1.3%	0.204***	5.201	0.8%	0.128**	2.843	1%	0.100*
CON = Education (higher education)	(0.032-0.083)			(0.027-0.061)			(0.009-0.047)			(0.003-0.040)
CON = Experiences caring, dying, loss							0.161	3.959	8.7%	0.118
CON = Perceived help from neighbors							(0.174-0.518)	4.191	9.9%	(0.088-0.420)
CON = Women							0.166***			0.158***
							(0.211-0.611)			(0.204-0.586)
							0.142	3.198	1%	0.134**
							(0.012-0.050)			(0.011-0.048)
							-0.020	-0.501	19.6%	
							(-0.483-0.286)			
MED = General neighborhood participation										0.186***
Total mediating effect										(0.069-0.169)
Sobel test										4.706
										2.5%

Notes. *p < 0.05; **p < 0.01; ***p < 0.001; IV = Independent variable; CON = confounding variable; MED = mediating variable.

z = 3.228**
0.171 × 0.186 = 0.032

participation around these topics. We advise neighborhood workers to actively look into how these experiences can be lifted from the individual level to a neighborhood-wide level, for instance by organizing group activities. Future research has a role in mapping which specific experiences around serious illness, death and loss are associated with neighborhood participation and if these experiences are sufficient for citizens to participate in initiatives regarding serious illness, death, or loss or whether the development of death literacy is a necessary intermediate step. Additionally, neighborhood participation around serious illness, death and loss is in itself an experience that can develop citizens' death literacy and can thereby strengthen future participation. This insight challenges us to approach Compassionate Communities from a more circular perspective in which the outcomes of neighborhood participation are also a facilitator for future participation.

Strengths and limitations

This study is the first to measure the extent of neighborhood participation in serious illness, death, and loss in a population of neighborhood citizens, and to provide an insight into the type of neighborhood participation in which citizens are most involved. We recognize several limitations in this study. First, our cross-sectional data does not allow us to make causal claims. Second, our survey only measured a specific set of activities around serious illness, caregiving, death, and loss, thereby counting people who are involved in other potentially relevant activities as nonparticipating. We did not explore citizens' motivations for or experiences with neighborhood participation around serious illness, death, and loss. Furthermore, we measured citizens' previous experiences with serious illness, death and loss in the last year but did not measure how citizens experienced these encounters with serious illness, death, and loss and whether feelings of trauma or stigmatization were involved. Recognizing the complexity of Compassionate Communities as intricate social change processes, we note that besides perceived neighborhood social cohesion there are undoubtedly other potential predictors for actual 'compassion' in the form of neighborhood participation regarding serious illness, death, and loss to consider.

Conclusion

This survey showed that four out of ten residents in two neighborhoods in Flanders participated in activities in their neighborhood around serious illness,

death, and loss, though most participated infrequently. Furthermore, we identified that perceived neighborhood social cohesion and experiences with serious illness, caregiving and loss in the last year are both positively associated with neighborhood participation regarding serious illness, death, and loss. We recommend that neighborhood workers and policymakers prioritize the fostering of social cohesion and social ties when developing initiatives, and recommend future research to explore how previous experiences around serious illness, death and loss can be used as a means of building these social ties and stimulate neighborhood participation regarding serious illness, death and loss.

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Disclosure statement

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Data availability

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

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