

## Original Article

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**Author for correspondence:**

Vincent Van Goethem,  
End-of-Life Care Research Group,  
Ghent University and Vrije  
Universiteit Brussel, Corneel  
Heymanslaan 10, Ghent 9000, Belgium.  
E-mail: [vincent.vangoethem@ugent.be](mailto:vincent.vangoethem@ugent.be)

# Size and characteristics of family caregiving for people with serious illness: A population-based survey

Vincent Van Goethem, M.Sc.<sup>1,2,3</sup> , Sigrid Dierickx, M.Sc, Ph.D.<sup>1,2,3</sup>,

Luc Deliens, M.Sc, Ph.D.<sup>1,2,3</sup>, Aline De Vleminck, M.Sc, Ph.D.<sup>1,3</sup>, Lore Lapeire, M.D.<sup>1,4</sup>

and Joachim Cohen, M.Sc, Ph.D.<sup>1,3</sup>

<sup>1</sup>End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University, Ghent, Belgium;

<sup>2</sup>Department of Public Health and Primary Care, Ghent University, Ghent, Belgium; <sup>3</sup>Department of Family Medicine and Chronic Care, Vrije Universiteit Brussel (VUB), Brussels, Belgium and <sup>4</sup>Department of Medical Oncology, Ghent University Hospital, Ghent, Belgium

**Abstract**

**Objectives.** Family caregivers play a vital role in care for people with serious illness. Reliable population-level information on family caregiving is scarce. We describe the socio-demographic and family caregiving characteristics and experiences of family caregivers of people with serious illness in the adult population.

**Method.** We performed a secondary analysis of the cross-sectional population-based 19th Social-Cultural Changes survey. A random sample of 2,581 Dutch-speaking people aged 18–95, living in Flanders or Brussels, were contacted for participation in the survey between March and July 2014 using a stratified two-step sample. Differences between groups are described using Pearson chi-square tests and analysis of variance.

**Results.** Response rate was 58.7% (1,515/2,581). Over a 12-month period, 7.6% of respondents provided family care for someone with a serious illness ( $n = 114$ ). They were most often aged 55–74 (36.0%), women (57.9%), worked full-time (42.3%); 31.8% provided at least 10 h of family care each week. Family caregivers of people with serious illness, compared with family caregivers of people with other conditions, provided more medical and nursing care (33.3% vs. 22.5%,  $p = 0.027$ ), and experienced a higher burden of family caregiving ( $p = 0.038$ ) but a similarly high meaningfulness of family caregiving.

**Significance of results.** A considerable part of the adult working population provides family care for someone with serious illness. While family caregiving for someone with serious illness shows similarities with family caregiving for people with other conditions in terms of caregiver characteristics and the impact of caregiving on work-life balance and the meaning derived from it, it is also associated with increased burden.

**Introduction**

Slightly more than one in five adults (21.3%) provides family care in the US (Kent and Dionne-Odom, 2019; Prudencio and Young, 2020). Nevertheless, population-based studies describing the size and characteristics of family caregiving are scarce and are mainly conducted in the USA (Kent et al., 2016). Moreover, previous research has mainly focused on family caregivers' needs and roles and the economic value of family caregiving (Applebaum and Breitbart, 2013; Ferrell and Wittenberg, 2017; Rabarison et al., 2018).

Family caregivers are relatives, partners, friends, or neighbors who provide support in a non-contractual relationship that develops naturally and does not have formally agreed work hours, breaks, or holidays (Irlam and Bruce, 2002; Masuy, 2011; Grieve, 2016). Family care plays a pivotal role in care provision for people with serious illness with family caregivers providing practical help, personal care, and psychological support (Ornstein et al., 2017; Cengiz et al., 2021), which often makes family caregivers the main care providers (Emanuel et al., 1999; Lim et al., 2017). Through research four distinct family caregiver roles have been identified namely; as stated earlier, the role of the family caregiver as a care provider, (Harding, 2013; Nielsen et al., 2016; Li and Song, 2019), the family caregiver as a facilitator of care (Miller et al., 2016), the family caregiver as an expert on the patient's care (Emanuel et al., 1999; Colla and Bea, 2013), and the family caregiver as care recipient (Wang et al., 2018).

Care provided by family caregivers for people with serious illness can be described as informal palliative care due to its conformity to the definition of palliative care set forward by the World Health Organization (WHO) where palliative care “improves the quality of life of patients and that of their families who are facing challenges associated with life-threatening illness, whether physical, psychological, social or spiritual.” Furthermore, palliative care is

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not only for those imminently dying but also for those with a chronic condition, is embedded in the community and home-based care and supports care providers such as family and community volunteers (World Health Organization, 2019).

Different experiences between caregivers can be explained by the Model of Carer stress and Burden which posits that caregiver burden differs based on background and contextual factors, primary and secondary stressors, and exacerbating and mitigating factors. As patient characteristics and the tasks related to patient care are considered primary stressors, the unmet needs of family caregivers are likely to differ between family caregivers for people with serious illness and other types of family caregivers (Sørensen et al., 2006; Secinti et al., 2021). Disease progression and symptoms the patient experiences can also impact caregiver well-being due to a change in intensity of care tasks and possible behavioral changes in the patient such as irritability, depression, and anxiety (Keir et al., 2006; Chen et al., 2014). On the other hand, providing family care for people with serious illness can also have benefits for both the patient and the family caregiver, such as a stronger relationship and a sense of satisfaction, accomplishment, and personal growth (Kang et al., 2013; Li and Loke, 2013; Henriksson et al., 2015).

Describing the proportion, characteristics, and differences between non-, other family caregivers, and family caregivers for people with serious illness within the entire population can guide legislators on what direction to take to adequately support family caregivers that provide informal palliative care. Population-based representative findings allow policy makers to make decisions based on scientifically proven and divergent data (Cerdá, 2018). As such, this information is of vital importance to policy and practice. This study, therefore, aims to describe the numbers, characteristics, and experiences of family caregivers of people with serious illness using population-based data. We address the following research questions:

- 1) What proportion of the adult population, within a time period of 12 months, provide family care for a person with serious illness?
- 2) What are the socio-demographic characteristics of family caregivers of people with serious illness, compared with family caregivers of people with other conditions or disabilities and people not providing family care?
- 3) What are family caregiving characteristics of family caregivers of people with serious illness, compared with family caregivers of people with other conditions or disabilities?
- 4) How do family caregivers of people with serious illness experience being a caregiver compared with family caregivers of people with other conditions or disabilities?

## Methods

### Study design, setting, and participants

We performed a secondary analysis of data from the 19th Social-Cultural Changes survey (SCC) in Flanders conducted from March to July 2014 by the Study Service of the Flemish Government (Carton et al., 2015). The Social-Cultural Changes survey is a face-to-face computer-assisted cross-sectional survey that is repeated every year in a random sample of the Dutch-speaking adult population in Flanders and Brussels-Capital Region, Belgium to assess changes in beliefs and values. As such, the Social-Cultural changes survey is an

important instrument to measure the social-cultural environment in Flanders (Carton, 2021). The SCC survey contains a set of fixed topics which are repeated in each edition and varying topics that are not included in each edition. The 2014 Social-Cultural Changes survey was the most recent edition to contain an extensive module on family caregiving and was therefore chosen for analyses.

A random sample of 2,581 Dutch-speaking people between the ages of 18 and 95 living in Flanders (the northern Dutch-speaking part of Belgium) or Brussels (the Capital Region of Belgium) was selected from the national population register. People living in collective households such as hotels, hostels, hospitals, and nursing homes were excluded. The participants were selected using a stratified two-step sample. Clusters of postal sectors were the primary sampling unit. The number of clusters in each province was proportional to the total population size. For the second step, random clusters within postal sectors were formed depending on the population size of the postal sector. Participants were randomly recruited from these random clusters and contacted for participation by the Study Service of the Flemish Government (Carton et al., 2015, 2021).

### Questionnaire and measures

The questionnaire, originally developed in 1996, is revised annually by the Study Service of the Flemish Government and a scientific guidance committee consisting of survey-methodologists from several Flemish universities.

Socio-demographic measurements include age, gender, education, household composition, marital status, employment situation, and perception of net monthly income. The characteristics of family caregiving include relationship to the care provider, sex, age, living situation and proximity of the care recipient, and frequency, intensity, duration, and content of caregiving. Family caregiving experiences were measured using questions on the perceived physical or psychological impact of providing care, the impact of providing care on time for family or themselves and satisfaction with and meaningfulness of providing care, using a 5-point Likert scale (1 = completely disagree to 5 = completely agree). The extent to which participants experienced family caregiving as burdensome and felt appreciated for providing care was measured on a scale from 0 (not at all burdensome/not at all appreciated) to 10 (very burdensome/very appreciated). The extent to which family caregiving hindered the respondent's job demands or vice-versa was measured on a scale ranging from 1 (never) to 4 (always).

### Statistical analysis

Weighing of the data was done by the Study Service of the Flemish Government. They utilized a complex three-step procedure, generating a design weight, non-response weight and performing post-stratification. In the first step (design weight), the sample is corrected for the oversampling factor. For the non-response weight, a logistic regression is performed to estimate the response based on living situation, gender, marital status, age, and nationality. In the third step, the Study Service of the Flemish Government conformed the sample to variables within the sample, namely province, gender, age, and nationality to make it representative for the adult population of Dutch-speaking people in Flanders and Brussels. We divided participants into three groups: (1) family caregivers of people with serious illness, (2) family caregivers of people with other conditions or

disabilities, and (3) people not providing family care. We identified family caregivers using the question “Are you currently, or have you been during the past 12 months, supporting a sick, disabled or elderly family member, acquaintance or neighbor?” This question was framed to inquire about informal care provided, i.e., care not provided as part of a professional occupation or volunteering. People who answered “yes, I currently provide support” or “yes, I have provided support during the last 12 months but not currently” were identified as family caregivers. Those who indicated they provide/have provided support to someone with chronic and/or terminal illness were classified as “family caregivers of people with serious illness.” Those who indicated they provide/have provided support to someone with physical disability, mental disability, early stage dementia/cognitive decline, psychological difficulties, general decline due to old age, or acute illness/accidents were classified as “family caregivers of people with other conditions.” Participants who answered “no” were identified as people not providing family care. All data were analyzed using SPSS 27.0 (IBM).

We used descriptive statistics to report socio-demographic characteristics of family caregivers of people with serious illness, family caregivers of people with other conditions and people not providing family care. We conducted Pearson chi-square tests to compare (1) socio-demographic characteristics between family caregivers of people with serious illness vs. family caregivers of people with other conditions and people not providing family care and (2) family caregiving characteristics of people with serious illness vs. family caregivers of people with other conditions. We tested differences in experiences of family caregiving between those caring for people with serious illness and others using Mann–Whitney *U* tests. To reveal underlying structures of family caregiving experiences we performed a principal component analysis (PCA) with varimax rotation on all items concerning family caregiving experiences. Items loading higher than 0.70 on a component were retained in that component. Internal consistency of the items within the underlying constructs was checked using Cronbach’s  $\alpha$  (Table 1). To identify differences between the two family caregiver groups on the constructs revealed through the PCA, a preliminary one-way analysis of

variance (ANOVA) was conducted with the family caregiver group as a independent variable and the constructs identified through PCA as dependant variables. Means, mean difference, *F*-value, and *p*-value are reported. Constructs that were significantly associated with the family caregiver group ( $p < 0.05$ ) were included in multivariable ANOVA. We included the variables for which we found a statistically significant difference ( $p < 0.05$ ) between family caregiver groups as confounders. Mean, 95% confidence interval and *p*-value were reported on interaction effects between the family caregiver group and other independent variables.

### Ethical considerations

Participants were informed of the goal and content of the survey. Participants were free to refuse participation without any negative effects and were free to withdraw from the study at any time. Data used for this study were made available by the study service of the Flemish government. No further personal data were sought or collected, therefore ethical approval was not required.

### Results

Of the 2,581 participants who were contacted in Flanders or Brussels-Capital region, Belgium, a total of 1,515 completed the questionnaire resulting in a response rate of 58.7%. The most frequent reason for non-response was refusal to take part in the survey (Figure 1).

### Proportion that provides family care

Within a 12-month period, 114 (7.6%) of the respondents provided family care to someone with serious illness, 272 (18.1%) provided family care to a person with another condition, and 1,117 (74.3%) did not provide family care.

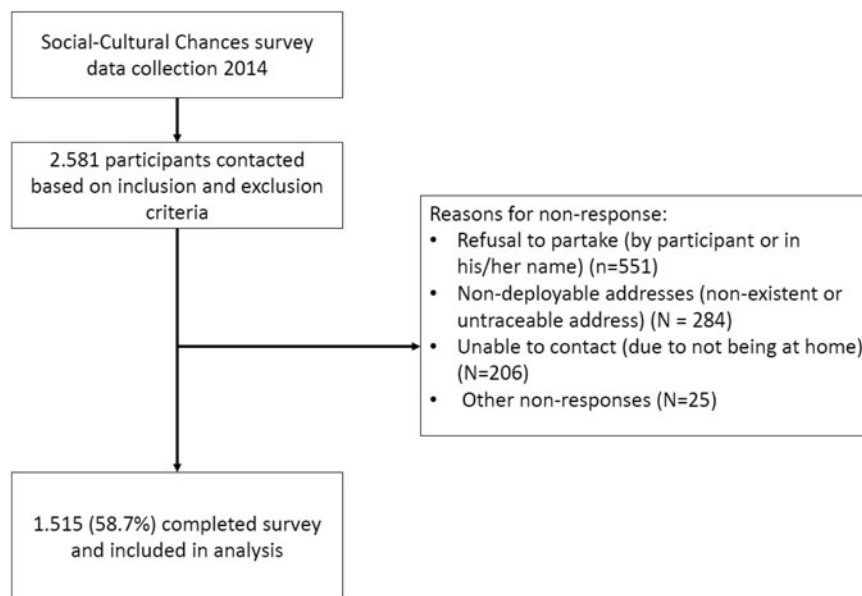
### Socio-demographic characteristics of respondents

More than one third of family caregivers were aged 35–54 or 55–74 (family caregivers of people with serious illness: 34.2% and 36.0%;

**Table 1.** Principal component analysis: component loadings

Item	Burden of family caregiving	Meaningfulness of family caregiving	Work-family conflict
The care I provide is physically demanding	0.744	–	–
The care I provide is psychologically demanding	0.798	–	–
I experience family care as meaningful	–	0.916	–
I get satisfaction from the care tasks I take on	–	0.932	–
I have insufficient time for myself due to the care I provide	0.787	–	–
I have insufficient time for my family due to the care I provide	0.705	–	–
How burdensome is providing family care to you?	0.808	–	–
How appreciated by society do you feel for providing family care <sup>a</sup>	–	–	–
Job demands hinder(ed) my family caregiving tasks	–	–	0.912
Family caregiving tasks hinder(ed) my job demands	–	–	0.914
Cronbach’s alpha	0.771	0.861	0.882
Number of items	5	2	2

<sup>a</sup>This item scored low on all components which is why we made the executive decision to remove it from the model.



**Fig. 1.** Flowchart of participation Social-Cultural Changes survey.

family caregivers of people with other conditions: 34.9% and 36.4%) (Table 2). Family caregivers of people with serious illness were more often women (57.9%) compared with people who did not provide family care (47.8%,  $p = 0.040$ ). About half of all participants attained secondary education (Family caregivers of people with serious illness: 46.5%, family caregivers of people with other conditions: 50.9%, and people not providing family care: 50.7%). More than one out of three family caregivers were full-time employed or self-employed (family caregivers of people with serious illness: 42.3%; family caregivers of people with other conditions: 35.4%) and 62.9% were married or legally cohabiting. A minority of participants reported that it was (very) hard to make ends meet with the current income (family caregivers of people with serious illness: 21.9%; family caregivers of people with other conditions: 12.9%, and people not providing family care: 17.2%).

### Family caregiving characteristics

Nearly half (47.8%) of the family caregivers of people with serious illness provided care to parents or parent in-law (Table 3). Compared with care recipients with other illness, those with serious illness were more often men (29.5% and 46.5%, resp.,  $p = 0.001$ ), aged 35–54 (6.6% and 13.0%, resp.,  $p < 0.001$ ) or aged 55–74 (19.2% and 36.5%, resp.,  $p < 0.001$ ) and more often lived with relatives other than the participating family caregiver (28.7% and 48.2%, resp.,  $p < 0.001$ ). Proximity to the care recipient was for about half of the participants between 1 and 15 min travelling time for both family caregivers of people with serious illness (50.0%) and family caregivers of people with other conditions (56.2%). Nearly one in three (32.5%) family caregivers of people with serious illness provided care on a daily basis and 44.7% provided family care one or more times a week; 31.8% provided care for more than 10 h a week and most provided family care for over 2 years (63.2%). Family caregivers of people with serious illness provided emotional support (92.1%), assistance in household chores (69.3%), transportation and guidance (64.0%), supervision (56.1%), assistance with administration (46.5%), and personal care (24.3%). Compared with family caregivers of people with other conditions, family caregivers of people

with serious illness more often provided medical and nursing care (33.3% and 22.5%, resp.,  $p = 0.027$ ).

### Family caregiver's experience of being a family caregiver

Among family caregivers of people with serious illness, 22.8% reported that the care they provided is physically demanding and 45.6% reported that it was psychologically demanding (Table 4). A minority of respondents felt that they did not have time for themselves (13.9%) or their family (9.0%) due to the care they provided, though providing family care did not interfere with their professional occupation (94.2%) or vice versa (87.1%). Compared with family caregivers of people with other conditions, they more often reported that providing care is psychologically demanding (45.6% and 28.7%, resp.,  $p = 0.001$ ) and meaningful (97.4% and 93.7%, resp.,  $p = 0.019$ ).

The PCA performed to identify underlying constructs in family caregiver experiences resulted in three components, i.e., burden of family caregiving (Cronbach's  $\alpha = 0.771$ ), meaningfulness of family caregiving (Cronbach's  $\alpha = 0.861$ ), and work-family conflict (Cronbach's  $\alpha = 0.822$ ).

Family caregivers of people with serious illness experienced higher burden than family caregivers of people with other conditions (mean difference  $-0.226$ ,  $p = 0.038$ ) but did not differ in experienced meaningfulness (mean difference  $0.159$ ,  $p = 0.138$ ) and work-life conflict (mean difference  $= 0.074$ ,  $p = 0.503$ ) (Table 5). Family caregivers of people with serious illness experienced increased burden independently of whether they provided medical and nursing care (mean  $= 0.261$  and  $0.116$ , resp., 95% CI  $= -0.211, 0.733$  and  $-0.283, 0.516$ , resp.). Family caregivers of people with other conditions experienced higher burden when providing medical and nursing care (mean  $0.400$ , 95% CI  $0.008, 0.793$ ) and lower burden if not providing medical and nursing care (mean  $= -0.290$ , 95% CI  $= -0.620, 0.039$ ;  $p = 0.026$ ; Table 6).

## Discussion

### Main findings

This population-based survey indicates that, within a period of 12 months, 7.6% of the respondents in Flanders or Brussels-Capital



**Table 2.** Characteristics of family caregivers of people with serious illness, family caregivers of people with other conditions, and people not providing family care

	A: Serious illness <i>n</i> (%)	B: Other conditions <i>n</i> (%)	C: Not providing family care <i>n</i> (%)	<i>P</i> -value for A vs. B <sup>a</sup>	<i>P</i> -value for A vs. C <sup>b</sup>
<i>Total</i>	114 (7.6%)	272 (18.1%)	1,117 (74.3%)		
<i>Characteristics</i>					
Sex				0.177	0.040
Woman	66 (57.9%)	137 (50.4%)	534 (47.8%)		
Man	48 (42.1%)	135 (49.6%)	583 (52.2%)		
Age				0.997	0.067
18–34	24 (21.1%)	55 (20.2%)	283 (25.3%)		
35–54	39 (34.2%)	95 (34.9%)	357 (32.0%)		
55–74	41 (36.0%)	99 (36.4%)	302 (27.0%)		
75+	10 (8.8%)	23 (8.5%)	175 (15.7%)		
Educational attainment				0.439	0.137
None	3 (2.6%)	6 (2.2%)	33 (3.0%)		
Primary school	10 (8.8%)	34 (12.5%)	167 (14.9%)		
Secondary school	53 (46.5%)	138 (50.9%)	567 (50.7%)		
Higher education	48 (42.1%)	93 (34.3%)	350 (31.3%)		
Other	0 (0.0%)	0 (0.0%)	1 (0.1%)		
Job situation				0.619	0.438
Full-time (self-)employed	47 (42.3%)	96 (35.4%)	430 (38.6%)		
Part-time (self-)employed	18 (16.2%)	52 (19.2%)	128 (11.5%)		
Unemployed	10 (9.0%)	36 (13.3%)	114 (10.2%)		
Retired	27 (24.3%)	67 (24.7%)	334 (30.0%)		
Other	9 (8.1%)	20 (7.4%)	108 (9.7%)		
Perception of net monthly family income				0.078	0.454
(Very) hard to make ends meet with current income	25 (21.9%)	35 (12.9%)	190 (17.2%)		
Current income sufficient to make ends meet	53 (46.5%)	137 (50.4%)	539 (48.9%)		
Comfortable life led with current income	36 (31.6%)	100 (36.8%)	374 (33.9%)		
Marital status				0.359	0.121
Married/Legal cohabitation	77 (67.5%)	171 (62.9%)	681 (61.0%)		
Unmarried/Separated or divorced	34 (29.8%)	85 (31.3%)	352 (31.5%)		
Widowed	3 (2.6%)	16 (5.9%)	83 (7.4%)		

Information on family caregiving status was missing for *n* = 26 cases (1.7%).

Missing values family caregivers of people with serious illness: Educational attainment *N* = 1 (0.9%) and job situation *N* = 4 (3.5%).

Missing values family caregiver of people with other conditions: Job situation *N* = 3 (1.1%).

Missing values of people not providing family care: Job situation *N* = 3 (0.3%), perception of net monthly family income *N* = 14 (1.3%), marital status *N* = 1 (0.1%).

<sup>a</sup>Pearson Chi-square test testing for differences in socio-demographic characteristics between family caregivers of people with serious illness and family caregivers of people with other conditions or disabilities.

<sup>b</sup>Pearson Chi-square test testing for differences in socio-demographic characteristics between family caregivers of people with serious illness and people not providing family care.

region, Belgium provided family care for someone with a serious illness. Almost half of these family caregivers are a child of the ill person and work full-time, and a third provide 10 h or more of family care each week. Compared with family caregivers of people with other conditions, family caregivers of people with serious illness seemed to incur similar experiences in terms of work-life balance and the meaning derived from care but experienced a higher burden. In terms of caregiving tasks, family caregivers of people with serious illness more often take on medical and nursing care than family caregivers of people with other conditions.

### Strengths and limitations

A particular strength of this study is that it uses a representative sample of the adult population in Flanders, Belgium. The sample size of 2,581 participants, randomly sampled from a full population database, allows generalizability of the findings about family caregiving in serious illness to the entire adult population and, hence, provides a clear profile of family caregiving. Response rate to the survey is satisfactory and several measures have been implemented to enhance data quality, including the use of

**Table 3.** Family caregiving characteristics of family caregivers of people with serious illness compared to family caregivers of people with other conditions

Characteristics	People with serious illness (n = 114) n (%)	Other conditions (n = 272) n (%)	P-value <sup>a</sup>
The care recipient is the family caregiver's ...			0.192
Parent (in-law)	55 (47.8%)	128 (47.1%)	
Partner	17 (14.8%)	19 (7.0%)	
Other family member	16 (13.9%)	46 (16.9%)	
Not family member	13 (11.3%)	46 (16.9%)	
Sister/brother (in-law)	8 (7.0%)	19 (7.0%)	
Child (in-law)	6 (5.2%)	14 (5.1%)	
Sex of the care recipient			0.001
Man	53 (46.5%)	80 (29.5%)	
Woman	61 (53.5%)	191 (70.5%)	
Age of the care recipient			<0.001
Younger than 18	2 (1.7%)	12 (4.4%)	
18–34	4 (3.5%)	15 (5.5%)	
35–54	15 (13.0%)	18 (6.6%)	
55–74	42 (36.5%)	52 (19.2%)	
75 or older	52 (45.2%)	174 (64.2%)	
Living situation of the care recipient <sup>b</sup>			<0.001
Lives with relatives (partner, parent, or child)	55 (48.2%)	78 (28.7%)	
Lives with participating family caregiver	29 (25.4%)	108 (39.7%)	
Lives alone	27 (23.7%)	51 (18.8%)	
Institution (e.g., nursing home)	3 (2.6%)	33 (12.1%)	
Other	0 (0.0%)	2 (0.7%)	
Proximity of the care recipient (i.e., travelling time)			0.484
0 min (part of household)	27 (23.7%)	51 (19.1%)	
1–15 min	57 (50.0%)	150 (56.2%)	
16–30 min	17 (14.9%)	39 (14.6%)	
31–60 min	8 (7.0%)	22 (8.2%)	
>60 min	5 (4.4%)	5 (1.9%)	
Frequency of family caregiving			0.556
Daily	37 (32.5%)	79 (29.0%)	
Once or more/week	51 (44.7%)	132 (48.5)	
Once or more/month	23 (20.2%)	47 (17.3%)	
Once or more/year	3 (2.6%)	14 (5.1%)	
Intensity of family caregiving			0.821
10 h/week or less	77 (68.1%)	187 (71.1%)	
>10 h to <20 h/week	17 (15.0%)	34 (12.9%)	
>20 h/week or more	19 (16.8%)	42 (16.0%)	
Duration of family caregiving			0.477
<3 months	5 (4.4%)	25 (9.2%)	
3–6 months	11 (9.6%)	21 (7.7%)	
7–12 months	13 (11.4%)	23 (8.4%)	
13–24 months	13 (11.4%)	32 (11.7%)	

(Continued)

**Table 3.** (Continued.)

Characteristics	People with serious illness (n = 114) n (%)	Other conditions (n = 272) n (%)	P-value <sup>a</sup>
>2 years	72 (63.2%)	172 (63.0%)	
Family caregiving tasks <sup>b</sup>			
Emotional support	105 (92.1%)	235 (86.7%)	0.133
Household chores	79 (69.3%)	180 (66.4%)	0.583
Transport and guidance	73 (64.0%)	166 (61.3%)	0.608
Supervision	64 (56.1%)	125 (46.0%)	0.068
Administration	53 (46.5%)	133 (48.9%)	0.666
Personal care	28 (24.3%)	64 (23.5%)	0.863
Medical and nursing care	38 (33.3%)	61 (22.5%)	0.027

Information on family caregiving status was missing for  $n = 16$  cases (4.1%).

Missing values family caregivers of people with serious illness: Intensity of family caregiving  $N = 1$  (0.9%).

Missing values family caregiver of people with other conditions: Sex of the care recipient  $N = 1$  (0.4%), proximity of the care recipient  $N = 5$  (1.83%), intensity of family caregiving  $N = 9$  (3.3%).

<sup>a</sup>Pearson  $\chi^2$  test for differences in family caregiving characteristics between family caregivers of people with serious illness and family caregivers of people with other conditions.

<sup>b</sup>Percentages do not add to 100% because multiple answers were possible.

computer-assisted personal interviewing (CAPI) by trained interviewers, regular quality checks of interviews, and control for interviewer-variance (Carton et al., 2015).

A main drawback of this study is that the analysis was performed on data gathered in 2014, which was the latest available data on these topics gathered in the SCC. Nevertheless, considering the current increase in serious illness as well as an expected increase in the coming decades (Gaudette et al., 2015; Bell

et al., 2019), we believe that our estimation of the population-size of family caregivers for people with serious illness might be an underestimation, making our findings and the implications still relevant and applicable to the population. Furthermore, after the data-collection and -analysis, the global COVID-19 pandemic has had an impact on how family care has been operationalized as well as family caregiver experiences. Both patients with serious illness and family caregivers of people with serious illness

**Table 4.** Family caregivers' experiences of being a family caregiver

	Serious illness (N = 114)			Other conditions (N = 272)			P-value <sup>a</sup>
	(Completely) agree, %	Neutral, %	(Completely) disagree, %	(Completely) agree, %	Neutral, %	(Completely) disagree, %	
The care I provide is physically demanding	22.8	9.6	67.5	16.9	9.9	73.2	0.119
The care I provide is psychologically demanding	45.6	11.4	43.0	28.7	13.2	58.1	0.001
I experience family care as meaningful	97.4	1.8	0.9	93.7	2.6	3.7	0.019
I get satisfaction from the care tasks I take on	87.8	7.8	4.3	83.8	11.4	4.8	0.633
I have insufficient time for myself due to the care I provide	13.9	16.5	69.6	15.8	9.2	75.0	0.180
I have insufficient time for my family due to the care I provide	9.0	11.7	79.3	11.6	8.6	79.8	0.449
	High, %	Neutral, %	Low, %	High, %	Neutral, %	Low, %	
How burdensome is providing family care to you?	17.5	37.7	44.7	15.4	29.8	54.8	0.169
How appreciated by society do you feel for providing family care?	55.7	35.7	8.7	56.9	35.3	7.8	0.974
	Never to sometimes, %	Often to always, %	Never to sometimes, %	Often to always, %			
Job demands hinder(ed) my family caregiving tasks	87.1	12.9	81.0	19.0			0.893
Family caregiving tasks hinder(ed) my job demands	94.2	5.8	90.2	9.8			0.913

Missing values for family caregivers of people with serious illness: I have insufficient time for my family due to the care I provide  $N = 3$  (2.6%), job demands hinder(ed) my family caregiving tasks  $N = 44$  (38.6%), Family caregiving tasks hinder(ed) my job demands  $N = 55$  (39.5%).

Missing values family caregivers of people with other conditions: I have insufficient time for my family due to the care I provide  $N = 5$  (1.8%), How appreciated by society do you feel for providing family care  $N = 3$  (1.1%), job demands hinder(ed) my family caregiving tasks  $N = 119$  (43.8%), Family caregiving tasks hinder(ed) my job demands  $N = 119$  (43.8%).

<sup>a</sup>Mann-Whitney  $U$  test for family caregiver's experiences between family caregivers of people with serious illness and family caregivers of people with other conditions.

**Table 5.** Association between family caregiver type and experienced burden, experienced meaningfulness of family caregiving, and work-life conflict

Items	Family caregivers of people with serious illness ( <i>n</i> = 114) Mean (SD)	Family caregivers of people with other conditions ( <i>n</i> = 272) Mean (SD)	Mean difference	<i>F</i> -value	<i>p</i> -value <sup>a</sup>
Experienced burden	0.187 (−0.972)	−0.039 (1.007)	−0.226	4.333	0.038
Experienced meaningfulness of family caregiving	0.126 (0.859)	−0.033 (1.034)	−0.159	2.207	0.138
Work-life conflict	−0.040 (0.921)	0.033 (1.043)	0.074	0.449	0.503

Missing values *N* = 12 (3.1%).

<sup>a</sup>Univariate analysis of variance test.

**Table 6.** Association between family caregiver type and experienced burden controlled for family caregiving characteristics

Items	Burden experienced by family caregivers of people with serious illness ( <i>n</i> = 114) Mean (95% CI)	Burden experienced by family caregivers of people with other conditions ( <i>n</i> = 272) Mean (95% CI)	<i>p</i> -value <sup>a</sup>
Parameter <sup>b</sup>			
Sex of the care recipient			0.867
Man	0.219 (−0.224, 0.661)	0.067 (−0.306, 0.439)	
Woman	0.159 (−0.258, 0.575)	0.044 (−0.295, 0.382)	
Age of the care recipient			0.455
Younger than 18	0.334 (−0.794, 1.466)	−0.041 (−0.641, 0.559)	
18–34	−0.597 (−1.555, 0.361)	0.064 (−0.500, 0.629)	
35–54	0.542 (−0.016, 1.099)	0.277 (−0.241, 0.794)	
55–74	0.330 (−0.072, 0.731)	0.042 (−0.339, 0.423)	
75 or older	0.334 (0.020, 0.648)	−0.066 (−0.374, 0.241)	
Living situation of the care recipient			0.494
Lives alone	0.450 (0.034, 0.866)	0.550 (0.299, 0.802)	
Lives with participating family caregiver	0.143 (−0.321, 0.606)	0.070 (−0.221, 0.361)	
Lives with relatives (partner, parent, or child)	−0.155 (−0.526, 0.217)	0.162 (−0.113, 0.437)	
Institution (e.g., nursing home)	0.316 (−0.699, 1.331)	0.410 (0.023, 0.798)	
Other	<sup>c</sup>	−0.917 (−2.243, 0.409)	
Family caregiving task provided: Medical and Nursing care			0.026
Yes	0.261 (−0.211, 0.733)	0.400 (0.008, 0.793)	
No	0.116 (−0.283, 0.516)	−0.290 (−0.620, 0.039)	

Missing values *N* = 12 (3.1%).

<sup>a</sup>Two-way Analysis of Variance with interaction effect between type of family caregiver and parameters.

<sup>b</sup>Interaction effects reported between type of family caregiver and another parameter.

<sup>c</sup>This level of combination of factors is not observed.

experienced negative consequences such as increased strain, uncertainty, loneliness, and intensified distress due to the pandemic and related necessary mitigating measures (Kent et al., 2020). More research about the impact of the COVID-19 pandemic on the proportion and the experiences of family caregivers is therefore needed. Limitations include: only participants from private households are included, which means that participants in e.g., nursing homes are not included which could have impacted the findings about characteristics of caregivers and/or the caregiving situation. Additionally, selection bias due to non-response cannot be ruled out. However, non-response has been analyzed taking into account socio-demographic variables such as living area, age, and gender. There is also a possible social-

desirability bias in the responses due to the expectations that you should look after your partner or parent. Finally, because family caregiving was not the primary focus of the SCV survey, ascertainment bias for the caregiving outcomes may be limited.

### Interpretation and implications of the findings

According to our study, 7.6% of the adult population in Flanders and Brussels provides family care for someone with serious illness every year, which corresponds to about 494,000 people of the 6,500,000 adult inhabitants. While our operationalization of caregiving in serious illness was not limited to the imminently dying, we could broadly describe it as informal palliative care. This is in



line with e.g., the World Health Organization's definition of palliative care (2019) where palliative care is not limited to terminal or end-of-life care, but is considered an approach which improves the quality of life of patients with serious, life-limiting illness and their families, irrespective of disease prognosis. Research shows that, depending on the estimation methods, 38% to 74% of decedents had a need for palliative care prior to their death (Morin *et al.*, 2017). For Flanders, this means that annually approximately 22,800 to 44,400 of the 60,000 dying people require palliative care. However, palliative care also intends to provide support to family caregivers (World Health Organization, 2019). Our study, therefore, indicates that a substantially larger population than just the estimated number of patients can benefit from some kind of palliative care support and that family caregivers may well be one of the most overlooked groups in medical care in general. Family caregivers are both care providers and care receivers and could benefit from comprehensive assessment as a base for a proactive support plan. Furthermore, education of family caregivers such as skill training aimed at increasing medical skills and mental resilience, which reduces hopelessness and increases self-efficacy and social recognition, could empower them (Barbabella *et al.*, 2016; Berry *et al.*, 2017). Our findings highlight the need for policy makers to increase allocation of funds toward support for family caregivers, especially taking into consideration that people with serious illness spend most of their time outside professional healthcare settings, within their communities and with their family caregivers (Kellehear, 2013).

Our findings show that providing palliative family care results in a higher experienced burden, and particularly a higher psychological burden, than providing family care for patients with other conditions. This is in line with other research showing that family caregivers are likely to experience a higher perceived burden due to the duration of, and tasks related to providing, palliative care (Lee *et al.*, 2015; Choi and Seo, 2019). The burden they experience can be partly explained by the presence of physical symptoms and complaints such as sleep deprivation and pain (Harding *et al.*, 2003; Ishii *et al.*, 2012). Family caregivers might develop a passive attitude toward self-care because caring for the patient is their main focus, and may choose to minimize or ignore their own symptoms and complaints (Adelman *et al.*, 2014). Our study shows that providing palliative family care is psychologically demanding. Additionally, research indicates that up to 40% of family caregivers experience depressive symptoms (Costa-Requena *et al.*, 2015). Psychological burden might be related to a decrease in leisure time even though family caregivers did not report having too little time for themselves in one particular study (Yoo *et al.*, 2008). Nevertheless, we have to take into consideration that family caregivers might underreport on the actual time available for themselves or their families and the psychological burden that a lack of personal time might cause (Adelman *et al.*, 2014). On the other hand, we found that family caregivers also generally find providing family caregiving to be meaningful. Family caregivers can enhance the relationship with the care recipient, effectively creating meaning in the palliative care situation (Traa *et al.*, 2015).

Family care will become increasingly important due to continuous strain on the accessibility and workability of formal care because of current demographic and socio-economic developments. The proportion of the world's population aged 65 and older is expected to increase from 5% in 2015 to 16% in 2050 which implies an increase in people with chronic illness or comorbidities including heart disease, stroke, and cancer

(Leeson, 2018; Li *et al.*, 2019). The need for, and numbers of, family caregivers is therefore likely to grow. Yet our findings indicate that more than half of family caregivers of people with serious illness combine family caregiving with a full- or part-time job, putting them under increasing strain. Future research could study the constructs put in place to support family caregivers of people with serious illness or family caregivers in general and how often these constructs are used, whether or not they are sufficient and if they decrease experienced burden or strain.

Some of the aspects the current study was not able to look at and which may be specifically relevant in the "palliative family caregiving" group relate to how much family caregivers feel competent, confident, and supported in performing the caregiver tasks. Research indicates that communication between the healthcare team and the family caregiver is not only the basis of but essential to increasing feelings of competence and confidence in the family caregiver. Therefore, a participatory approach where the family caregiver is recognized as a part of the team is recommended (Vermorgen *et al.*, 2021).

In conclusion, we found that family caregivers who provide palliative family care spend a lot of time providing this care and can experience burden yet find family care to be meaningful. Our findings suggest the importance of tools and programs not only aimed at supporting patient well-being but also family caregiver wellbeing and self-efficacy in the context of serious illness. Additionally, supporting family caregivers in general and family caregivers of people with serious illness specifically should receive a higher priority in public health policies and allocation of health budget.

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