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How are family caregivers of people with a serious illness supported by healthcare professionals in their caregiving tasks?

A cross-sectional survey of bereaved family caregivers

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Abstract

Background: Due to medical advances and an increasingly ageing population, the number of people living with a serious illness is rising. This has major implications for the burden on family members of assisting with care. Support of family caregivers by healthcare professionals is needed to ensure they can provide quality care for people with serious illness.

Aim: To investigate how family caregivers of people with serious illness are supported by healthcare professionals in their caregiving tasks.

Design/Participants: Population-based cross-sectional survey of bereaved family caregivers of people with serious illness (N=3000) who cared for a person who had died two to six months before the sample was drawn (November 2019), as identified through three sickness funds in Flanders, Belgium. The survey explored support from healthcare professionals for family caregivers three months prior to bereavement.

Results: Response rate was 55.0%. Most family caregivers received support from one or more healthcare professionals for family caregiving tasks, ranging from 71% for promoting social interaction to 95% for managing symptoms. The type of support mostly involved providing information. Use of palliative care services was the strongest predictor of such support across physical, psychosocial, and practical tasks.

Conclusion: Most family caregivers of those with serious illness get some form of support from healthcare professionals for their tasks. However, an empowering support strategy e.g. one aimed at increasing self-efficacy of the family caregiver, is rare, and end-of-life communication between healthcare professionals and family caregivers needs improvement.

Keywords: family caregivers, serious illness, healthcare professionals, cross-sectional survey

Key statements

What is already known about this topic:

- As family caregivers of people with serious illness undertake a wide range of caregiving tasks, they are an essential part of the healthcare team.
- To ensure that family caregivers can perform their caregiving tasks successfully, they need sufficient support from healthcare professionals and the transfer of knowledge and skills.

What this paper adds:

- This is one of the first population-based surveys to examine the support given to family caregivers by healthcare professionals in end-of-life care.
- This support mostly involves informing rather than involving family caregivers.
- The strongest predictor of support of family caregivers by healthcare professionals across physical, psychosocial, and practical tasks is their use of palliative care services.

Implications for practice, theory or policy:

- Strategies aimed at empowering and increasing self-efficacy of family caregivers of people with serious illness need to be considered by the healthcare professionals involved.
- The unmet support needs which particularly need to be considered and investigated further are talking about end-of-life preferences and talking about emotions.

Background

People with serious illness are often faced with complex symptoms in the last phase of life¹ which involve needs which cannot be met by healthcare professionals alone. Consequently, family caregivers fulfill a wide range of caregiving tasks e.g. bathing, managing finances and communicating with healthcare professionals, which means they are an essential part of the healthcare team²⁻⁶.

Due to the increasingly ageing population and advances in healthcare, the numbers of people with serious illness are rising and at the same time, resources for professional healthcare are being limited⁷ so the need for family caregiver support continues to grow^{8,9}. In Europe, the proportion of family caregivers is estimated at 10%-25% of the population, depending on the country and the definition used¹⁰. However, family caregivers often report feeling unprepared for their role^{11,12}. For example they indicate a lack of support from nurses for physical tasks such as going to the bathroom but also report receiving good emotional support from healthcare professionals¹³.

The time family caregivers spend on providing end-of-life care is often more than that spent by healthcare professionals¹⁴ and periods without professional contacts show greater needs for both patients and family caregivers. Family caregivers experience health and emotional problems too¹⁵⁻¹⁷, which are particularly challenging at the end-of-life stage^{16,18,19}. Supporting them as partners in care, but also supporting them as care clients themselves, facilitating their relationship with the person who is dying, and considering them as experts in care, is recommended²⁰, in line with the interpretation of palliative care as supporting family caregivers as well as the patient²¹.

Previous studies have shown that good collaboration between family caregivers and healthcare professionals in end-of-life care leads to improved patient health outcomes²² and higher satisfaction with the care received²³. An interview study found that family caregivers want to be considered as a member of the care team, but rarely feel recognised as such²⁴. As the focus is typically on the patient, the support needs of family caregivers are often under-addressed^{25,26}.

Hitherto research has paid little attention to family caregivers as members of the care team and to the support they receive from healthcare professionals at the end of life. Additionally, most studies recruit family caregivers through professional care services meaning that they are people who have already found their way to professional support, thus resulting in a selection bias; studies are needed using samples that represent the wider population of family caregivers

This population-based study explored how family caregivers are supported by healthcare professionals in their caregiving tasks for people with a serious illness in the last three months before bereavement.

Five research questions were explored:

- 1) *What are the caregiving tasks performed by family caregivers of people with a serious illness and which of those tasks would they prefer to have performed by someone else?*
- 2) *Which healthcare professionals support family caregivers in their caregiving tasks?*
- 3) *How do family caregivers receive support from healthcare professionals?*
- 4) *To what extent is support from healthcare professionals considered sufficient?*
- 5) *What factors are associated with whether or not family caregivers receive support from healthcare professionals?*

Methods

Study design and setting

We conducted a population-based cross-sectional survey among bereaved family caregivers in Flanders, Belgium. In Belgium, people with long term extensive care needs can apply for a monthly care budget that helps cover non-medical care. We used registers of the three largest health insurers (accounting for 79% of the population) in Flanders to identify participants, as they keep records of people who apply for this care budget and of the names of their family caregivers. We applied the Strengthening of the Reporting of Observational studies in Epidemiology (STROBE)²⁷ statement to describe all relevant aspects of the study.

Participants

We randomly sampled 3,000 deaths of people with a serious illness who had applied for a care budget from one of the participating health insurers and selected the person registered in the database as the family caregiver. The sample was proportionately distributed between the health insurers according to the number of family caregivers meeting the inclusion criteria. Based on recommendations in other studies^{28–30}, we included people who had provided care to someone who had died between two and six months before inclusion to allow sufficient time for grieving while limiting recall bias. Additional criteria were that their postal address was complete in the database, and that both they and the deceased were at least 18 years old. To answer the research questions accurately, family caregivers were included for analysis if 1) they had contact with the deceased during the last three months of life (question 2 in questionnaire), and if 2) the deceased had had at least one of the listed serious illnesses (question 3 in questionnaire).

Data collection

An independent researcher sent out the questionnaires by post between November 2019 and January 2020. The Dillman's Total Design Method was applied, with the aim of obtaining a higher response to the survey³¹. At the start of data collection (day 1), each person received a questionnaire and information letter which described details of the study, the voluntary nature of their participation, and the option to complete an online version of the questionnaire. In cases of non-response, a reminder letter was sent after two and four weeks (days 15 and 29). After another two weeks (day 45), a non-response questionnaire was sent. The purpose of the non-response questionnaire was to evaluate reasons for non-response and possible response bias.

Measures

No pre-existing validated instruments were identified as appropriate to address our research questions, so we developed items based on the modification of existing instruments and previous qualitative interviews²⁴. We tested the questionnaire through two rounds of cognitive interviews with five family caregivers each, recruited through convenience sampling. The cognitive testing resulted in adding questions e.g. question 2 and 4 (Appendix A1), changing the sentence structure of certain items and clarifying certain concepts.

The questionnaire (Appendix A1) consisted of six sections of which we used three. The first contained categorical items about the care situation pre-bereavement, including their relationship to the patient and the illness of the patient. A second section evaluated ten caregiving tasks they had possibly performed during the three months pre-bereavement. For each task, four questions were asked: (1) did you perform this task at least once during the last three months of the patient's life? (yes/no), (2) which healthcare professionals have supported you in this task? (multiple choice), (3) how were you supported in this task by healthcare professionals? (multiple choice) and (4) to what extent was the support of healthcare professionals sufficient in supporting you to perform this task? (4-point scale).

The caregiving tasks were based on van den Berg & Spauwen³², additional literature^{33,34} and a preceding interview study²⁴. A third section concluded with sociodemographic items.

Statistical analysis

We used descriptive statistics to summarise sociodemographic characteristics, caregiving tasks, healthcare professionals, types of support and evaluation of support.

With the purpose of data reduction for a more condensed presentation of the findings, we performed exploratory factor analysis using Principal Component Analysis (oblique rotation) to explore types (dimensions) of support from healthcare professionals. The selection of components was based on our own theoretical assumptions about the grouping of caregiving tasks and on statistical criteria (scree plot, variance explained by the component, eigenvalues, and Cronbach's alpha). Final components were saved as variables with factor scores (i.e. mean=0 and standard deviation=1). We then performed one-way ANOVA tests to find associations between the caregiving task components and patient and family caregivers characteristics. Additionally, in order to correct these associations for confounding we performed multivariable analysis of variance (only of the main effects) with the caregiving task components as dependent variables and the variables for which the one-way ANOVA analysis indicated statistical significance as independent variables. Missing data were removed listwise and an alternative analysis with simple mean imputation functioned as a sensitivity analysis. Data were analysed using SPSS Statistics 27.

Ethical considerations

The Ethics Commission of Vrije Universiteit Brussel approved the study procedure and materials (approval number B.U.N. 143201940562 on 17/06/2019). This study is performed following the Declaration of Helsinki. Participants were informed that they gave their informed consent implicitly by completing and returning the questionnaire. Participants did not receive any financial compensation for participating in the study. Personal data were processed in line with the General Data Protection Regulation.

Results

Of the 3,000 people sampled, 2,889 received the questionnaire (Figure 1) and 1,539 completed it. The non-response survey was completed by 524 respondents (reasons for non-participation in Table A2 in Appendix) and eliminated the response of another 89 persons. As such the response rate was 55.0%. We included 1,334 respondents for analysis, who were family caregivers of someone with at least one serious illness and had had contact with them during the last three months of life.

The majority of these family caregivers were women (68.2%) (Table 1), their average age was 65.5 years; 13.2% had a professional healthcare degree and a majority were either the child (51.7%) or the partner (34.4%) of the seriously ill person with about one third (36.7%) living with them in the last three months of life.

The deceased persons had an average age of 78.3 and death was most often with cancer (31.8%) or dementia (30.7%); 36.7% received support from specialised palliative care services and half lived at home for most of the time during their final three months (51.6%).

Caregiving tasks pre-bereavement

Family caregivers commonly facilitated safe mobility inside or outside the house (85%), talked about emotions (73%), promoted social interaction (73%), assisted with administration (71%), provided physical comfort (72%) and managed symptoms (65%) (Table 2). Less than half (47%) talked about end-of-life preferences or made home adjustments for safety and comfort (39%). The majority of respondents (72-93%) had wanted to perform the caregiving tasks themselves; around 28% of those who provided personal care in the last three months and 23% who took on the task of managing symptoms reported they would have preferred to leave this task to someone else.

Healthcare professionals supporting family caregivers in different caregiving tasks

Most family caregivers received support from one or more healthcare professionals so they could perform the task themselves, ranging from 71% for promoting social interaction to 95% for managing symptoms (Table 3). The majority of family caregivers received support for making home adjustments (73%) and assistance with administration (72%). Of the family caregivers who didn't receive support for talking about emotions and end-of-life preferences, one out of five reported that they had needed support.

Home care nurses and GPs most frequently supported family caregivers in their caregiving tasks in the last three months of life. Palliative care nurses or doctors most frequently provided support for talking about end-of-life preferences (37%).

Types of support by healthcare professionals

Healthcare professionals mostly explained how family caregivers could perform the task (Table 4). This was the case for assessing and managing symptoms (72%), administering medication (70%), making home adjustments (64%), assistance with administration (57%), providing physical comfort (39%) and providing personal care (35%). Demonstrating how they could perform the task themselves was highest for providing physical comfort (38%), facilitating safe mobility (37%), providing personal care (30%), administering medication (26%) and managing symptoms (24%). For talking about emotions (41%) and end-of-life preferences (54%), healthcare professionals mainly exercised the task with the family caregiver. For making home adjustments, healthcare professionals mainly supported family caregivers by referring them to other services (31%). For promoting social interaction, healthcare professionals stressed the importance of a social life (33%), organised social activities (32%) and encouraged family caregivers to undertake social activities themselves (31%). (Table A3 in Appendix).

Evaluation of support received

The majority of family caregivers indicated they had received sufficient support from healthcare professionals for all caregiving tasks, ranging from 78% for promoting social interaction to 89% for facilitating safe mobility (Table A4 in Appendix). The number of family caregivers who reported not getting enough support was highest for managing symptoms (7%), making home adjustments (7%) and talking about emotions (7%). The number who reported that they got more support than they needed was highest for promoting social interaction (9%), providing personal care (9%) and facilitating safe mobility (7%).

Factors associated with family caregivers receiving support from healthcare professionals

A factor analysis identified three dimensions of support for caregiving tasks, i.e. support for physical, psychosocial and practical tasks (Table A5 in Appendix). One-way ANOVA tests (Table A6 in Appendix) showed that the use of specialised palliative care services is associated with receiving more support across physical ($p=0.001$), psychosocial ($p<0.001$) and practical ($p<0.001$) tasks. To account for confounding, we performed multivariable General Linear Model analyses with the three factors as dependent variables. Family caregivers of people who received specialised palliative care in the last three months received more support from healthcare professionals for physical, psychosocial and practical tasks than those of people who did not receive palliative care ($p<0.001$, coefficients of 0.388, 0.528 and 0.573, respectively) (Table 5). Family caregivers with a master's degree received less support for psychosocial tasks than those with a secondary degree ($B=-0.367$, $p=0.036$). Those between 18 and 55 years received less support for practical caregiving tasks than those between 56 and 65 years ($B=-0.385$, $p=0.004$). Family caregivers who were a parent of the patient received less support for practical tasks than those who were the child of the patient ($B=-0.728$, $p=0.008$) (Table 5). A sensitivity analysis with mean imputation confirmed these results (i.e. same significant associations, Appendix A7)."

Discussion

Main findings

This study aimed to investigate how family caregivers of people with serious illness are supported by healthcare professionals in their caregiving tasks. Most take on many different caregiving tasks in the final three months before bereavement and the majority had desired to take them on. Professional support in performing these tasks is mostly provided by GPs and home care nurses, mainly by explaining how they can perform the tasks themselves. The majority of family caregivers evaluated this support as being sufficient. The use of specialised palliative care services was the strongest predictor for receiving more support from healthcare professionals across all caregiving tasks.

Strengths and limitations

Our study has several strengths. Firstly, it is innovative in its focus on support for the family caregiver as a member of the care team, where previous studies have mainly focused on their roles as a provider of care for the patient or as people themselves in need of care. Secondly, our study used a unique sampling frame by combining registers of health insurers thus representing the targeted population more accurately. Our method has distinct advantages in avoiding selection bias compared with most other studies as they recruit family caregivers already using professional services like palliative care. Thirdly, our survey was available both on paper and online to minimise technical barriers, which resulted in a higher response rate (55.0%) compared with other studies with a similar population^{35–37}.

Our study also has limitations. Firstly, our sample was based on registered family caregivers, so we did not include people who provided family care without being registered by one of the health insurers. This could have introduced some selection bias, excluding those who did not consider themselves a family caregiver. Our selection probably corresponds well with the population recognised by healthcare professionals as family caregivers in serious illness, which limits the inclusion of relatively sudden deaths with little opportunity for family caregiving support. A second limitation is one inherent in the use of self-administered surveys i.e. missing data for certain questions are high, possibly due to the length of the questionnaire. As missings seem random, this is not likely to have had an impact on our findings. Thirdly, the retrospective approach can introduce recall bias, possibly altering the assessment of the support received. However, the time between the activity and the questionnaire completion was a maximum of nine months. Additionally, the death of a loved one is an example of a highly emotional, infrequent life event, which is more easily recalled than a neutral recurring event³⁸.

Interpretation

Previous studies have demonstrated that family caregivers experience a great impact on their emotional and physical health³⁹ while taking on a wide range of caregiving tasks⁵. Healthcare professionals can equip them with knowledge and skills and empower them in their role⁴⁰. The results of this study are reassuring as most family caregivers feel sufficiently supported by healthcare professionals. This is in contrast with a part of the literature where bereaved family caregivers report high levels of distress^{15–17} and a lack of support¹³. Post-hoc rationalisation could be a possible explanation, i.e. the tendency to retrospectively approve of what happened. Additionally, there are indications that care clients tend to perceive healthcare professionals as someone to only appeal to for tackling acute care needs⁴¹.

Most of the support by healthcare professionals was to inform family caregivers on how they could perform the tasks. An empowering collaborative approach, e.g. the items in the questionnaire referring to healthcare professionals letting family caregivers practise caregiving tasks or doing caregiving tasks together with them, was less frequently reported. Information is an important part of support⁴², yet other research has shown that family caregivers prefer a guided learning process⁴³.

Most family caregivers received support from healthcare professionals, yet only 36.7% received specialised palliative care services. As the involvement of specialised palliative care was associated with more professional support, these findings confirm that palliative care is also intended to support family caregivers²¹. This seems to suggest that integrating palliative care into standard care can lead to a more collaborative and empowering approach towards family caregivers. Research shows that when healthcare professionals involve family caregivers in adequate care planning and acknowledge their burden, the quality of care improves^{44,45}. Educational programs aimed at improving the self-efficacy of family caregivers such as the FOCUS program^{46,47} are examples of how this can be achieved.

Conclusion

This population-based survey of bereaved family caregivers of people with serious illness provides evidence that they do receive professional support in their caregiving tasks. However, this support mostly concerns provision of information whereas a more empowering approach, i.e. aimed at increasing self-efficacy, is rare. The finding that involvement of specialised palliative care is associated with more professional support for family caregivers for their various tasks indicates a need to diffuse the patient-and-family caregiver approaches of palliative care more widely.

Declarations

Authorship

J.C., A.D.V., L.D., P.H. and C.V. designed the study. O.M., S.D., A.D.V., J.C., L.L., L.D. and P.H. contributed to the interpretation of the results. O.M. wrote the manuscript and all authors critically revised the manuscript and approved the final version.

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Conflicts of interest

The authors declare that there is no conflict of interest.

Data sharing

The datasets are not publicly available to safeguard the privacy of the participants but are available from the corresponding author on reasonable request.

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Figures and tables

Figure 1: Participants flowchart

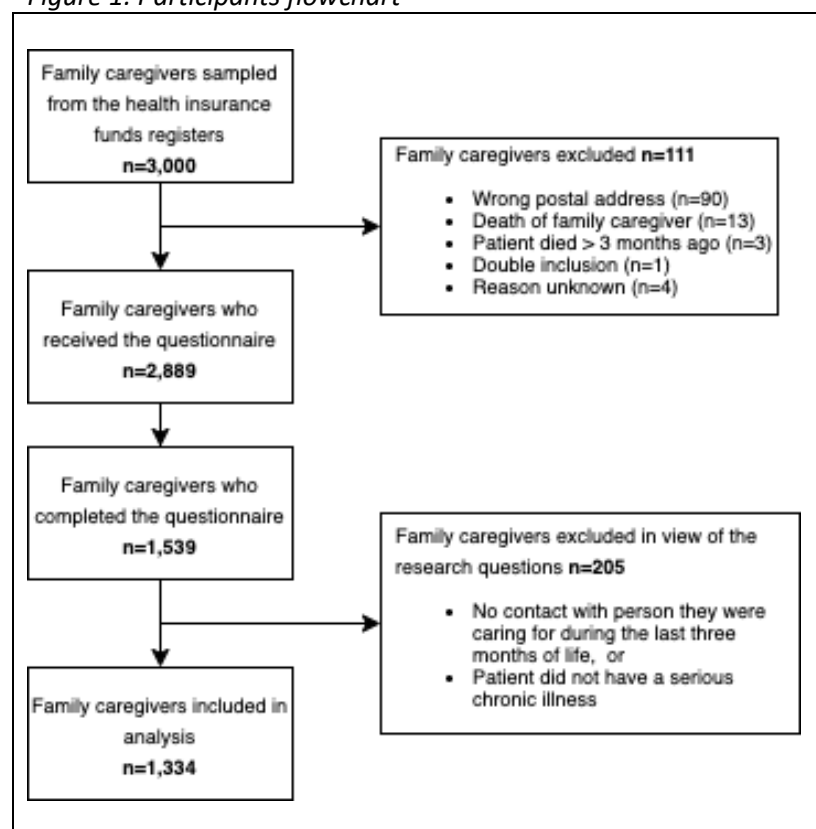


Table 1: Characteristics of the obtained sample (n = 1,334)

Characteristics of bereaved family caregivers	N (%)
<i>Age in years</i>	
18-55	238 (18.2)
56-65	488 (37.3)
66-75	305 (23.3)
76-85	202 (15.4)
>85	76 (5.8)
Mean (SD)	65.5 (11.96)
<i>Sex</i>	
Female	892 (68.2)
Male	416 (31.8)
<i>Educational attainment</i>	
Primary education	212 (16.2)
Secondary education	603 (46.1)
Bachelor's degree or equivalent	364 (27.9)
Master's degree (University)	90 (6.9)
None of the above	38 (2.9)
<i>Relationship with the deceased, family caregiver is ...</i>	
Daughter or son (in law)	687 (51.7)
Partner	457 (34.4)
Parent	67 (5.0)
Sibling	34 (2.6)
Other family member	55 (4.1)
Not family	29 (2.2)
<i>Lived together with deceased loved one in the last three months</i>	478 (36.7)
<i>Has a professional healthcare degree</i>	167 (13.2)
<i>Employment status</i>	
Retired	612 (46.9)
Full-time employed	271 (20.8)
Part-time employed	232 (17.8)
Homemaker	103 (7.9)
Other	58 (4.4)
Unemployed	30 (2.3)
Characteristics of deceased patient	
<i>Age in years</i>	
18-55	89 (6.7)
56-65	181 (13.9)
66-75	204 (15.7)
76-85	318 (24.4)
>85	510 (39.2)
Mean (SD)	78.34 (13.79)
<i>Serious condition*</i>	
Cancer	424 (31.8)
Dementia	410 (30.7)
Other	315 (23.6)
Heart failure	262 (19.6)
Respiratory illness	227 (17.0)
Diabetes	195 (14.6)

Renal or liver illness (not cancer)	171 (12.8)
Stroke (or the consequences thereof)	146 (10.9)
Illness of the nervous system other than dementia	95 (7.1)
<i>Decisional capacity of patient throughout the last three months</i>	
Yes	529 (40.2)
No	430 (32.7)
Sometimes / partly	357 (27.1)
<i>Specialised palliative care received[†]</i>	
No	762 (60.3)
Yes	464 (36.7)
I don't know	38 (3.0)
<i>Living at home in the last 3 months</i>	
Most of the time	663 (51.6)
Sometimes	124 (9.6)
Not at all	499 (38.8)

*Percentages do not add up to 100% as multiple answers were possible

[†]Palliative homecare team, palliative unit in the hospital, palliative support team in the hospital, reference person (palliative care nurse in a retirement home or a palliative daycare center)

Missing values bereaved family caregivers: Age in years: n=25 (1.9%); Sex: n=26 (1.9%); Education: n=27 (2.0%); Relationship with the deceased: n=5 (0.4%); Region: n=25 (1.9%); Living together with deceased loved one in the last three months: n=30 (2.2%); Diploma of doctor, nurse or healthcare professional: n=65 (4.9%); Employment status: n=28 (2.1%)

Missing values deceased patient: Age in years: n=32 (2.4%); Capable of making decisions about his/her care in the last 3 months: n= 18 (1.3%); Specialised palliative care received: n=70 (5.2%); Living at home in the last 3 months: n=48 (3.6%)

Table 2: Caregiving tasks taken on by family caregiver during the last 3 months before the patient's death (n=1,334)

Caregiving task	Total yes, %	Yes, but I would have preferred to leave this activity to someone else, %*	Yes, and I wanted to take on this activity myself, %*
Providing personal care	54.3	28.2	71.8
Assessing and managing symptoms	65.1	22.8	77.2
Administering medication	56.2	14.0	86.0
Facilitating safe mobility (inside or outside)	84.7	14.3	85.7
Providing physical comfort	71.5	16.6	83.4
Assistance with administration	73.1	12.5	87.5
Making home adjustments for safety and comfort	39.4	7.5	92.5
Talking about emotions	73.3	14.3	85.7
Talking about end-of-life preferences	46.9	14.5	85.5
Promoting social interaction	73.3	6.9	93.1

Percentages are row percentages. Missing values: Providing personal care: n=133 (10%); Assessing and managing symptoms: n=187 (14.0%); Administering medication: n=110 (8.2); Facilitating safe mobility: n=105 (7.9%); Providing physical comfort: n=127 (9.5%); Assistance with administration: n=127 (9.5%); Making home adjustments: n=147 (11.0%); Talking about emotions: n=118 (8.8%); Talking about end-of-life preferences: n=132 (9.9%); Promoting social interaction: n=123 (9.2%)

* n=family caregivers who performed the caregiving task

Table 3: Healthcare professionals who provided support to the family caregivers in different family caregiving tasks

	Caregiving tasks*									
	Providing personal care (n=652)	Assessing and managing symptoms (n=747)	Administering medication (n=688)	Facilitating safe mobility (n=1041)	Providing physical comfort (n=863)	Assistance with administration (n=882)	Making home adjustments (n=468)	Talking about emotions (n=891)	Talking about end-of-life preferences (n=564)	Promoting social interaction (n=888)
	%	%	%	%	%	%	%	%	%	%
No support received	10.1	4.7	11.7	21.3	14.0	27.6	27.3	17.9	21.9	28.6
Needed it	15.4	5.7	3.8	6.6	9.4	10.7	7.5	20.0	21.7	8.3
Did not needed it	84.6	94.3	96.2	93.4	90.6	89.3	92.5	80.0	78.3	91.7
Support received	89.9	95.3	88.3	78.7	86.0	72.4	72.7	82.1	78.1	71.4
<i>Support received from different healthcare professionals</i>										
Home care nurse	74.5	58.1	56.5	46.8	56.5	32.1	62.5	39.1	33.2	31.4
Nurse or care worker in hospital or residential care centre	35.0	41.9	28.7	49.6	45.9	n.a.†	n.a.†	42.5	32.0	50.4
GP	42.5	61.1	65.8	19.5	21.6	48.5	29.7	54.6	66.6	28.7
Specialist	11.6	20.7	20.1	4.6	5.9	9.1	2.8	10.9	16.5	4.3
Palliative nurse or doctor	14.2	15.1	15.1	7.6	10.5	10.3	9.4	23.8	36.6	9.7
Pharmacist	n.a.†	n.a.†	23.3	n.a.†	n.a.†	n.a.†	n.a.†	n.a.†	n.a.†	n.a.†
Physiotherapist	n.a.†	n.a.†	n.a.†	21.3	13.7	n.a.†	n.a.†	n.a.†	n.a.†	n.a.†
Social worker	n.a.†	n.a.†	n.a.†	n.a.†	n.a.†	52.0	23.8	13.4	n.a.†	11.7
Psychologist	n.a.†	n.a.†	n.a.†	n.a.†	n.a.†	n.a.†	n.a.†	7.3	n.a.†	n.a.†
Someone close with experience in healthcare	10.4	9.1	7.1	9.7	9.8	9.1	13.8	8.7	10.7	8.7
Other†	10.7	10.4	12.6	15.0	11.0	15.2	23.1	10.9	0.3	25.9
<i>Number of healthcare professionals of whom support was received from</i>										
1	41.6	31.5	33.3	53.4	53.8	51.9	56.6	36.8	38.3	55.9
2	31.2	35.8	34.0	27.8	27.6	28.1	26.9	33.5	36.3	25.2
3	17.3	21.7	21.1	12.0	11.9	13.7	13.4	18.4	18.9	13.7
4 or more	9.9	10.9	11.6	6.8	6.7	6.4	3.1	11.3	6.5	5.2

Percentages are column percentages.

*The n varies for every caregiving task (the number of family caregivers who performed the respective caregiving task in the last three months before the death of the relative varies)

†Not applicable as the respective healthcare professional wasn't an answer option for the task

‡This included for example a pastor (talking about emotions), a notary (Talking about end-of-life preferences), home care story staff (facilitating safe mobility), health insurance funds staff (all tasks).
Missing values: Providing personal care: n=10 (1.5%); Assessing and managing symptoms: n=8 (1.1%); Administering medication: n=22 (3.2); Facilitating safe mobility: n=44 (4.2%); Providing physical comfort: n=29 (3.4%); Assistance with administration: n=35 (4.0%); Making home adjustments: n=28 (6.0%); Talking about emotions: n=27 (3.0%); Talking about end-of-life preferences: n=35 (6.2%); Promoting social interaction: n=48 (5.4%)

Table 4: Types of support delivered to family caregivers

Caregiving tasks*	Explain (%)	Demonstrate (%)	Exercise (%)	Refer to services or information (%)	Other types of support (%)
Providing personal care (n=577)	35.4	30.3	6.6 [‡]	n.a. [†]	39.9
Assessing and managing symptoms (n=704)	71.9	23.7	4.5 [‡]	n.a. [†]	15.6
Administering medication (n=588)	70.4	26.0	6.3 [‡]	n.a. [†]	9.5
Facilitating safe mobility (n=781)	34.3	37.0	7.8 [‡]	n.a. [†]	24.8
Providing physical comfort (n=717)	39.1	37.5	7.8 [‡]	n.a. [†]	18.8
Assistance with administration (n=613)	56.6	21.4	29.0 [§]	n.a. [†]	8.5
Making home adjustments (n=320)	64.1	n.a. [†]	n.a. [†]	31.3	11.3
Talking about emotions (n=709)	32.9	n.a. [†]	41.2 [§]	10.7	28.5
Talking about end-of-life preferences (n=413)	17.9	n.a. [†]	53.8 [§]	9.4	16.5

Percentages are row percentages. Percentages don't add up to 100% as multiple answers were possible. Missing values: Providing personal care: n=48 (8.3%); Assessing and managing symptoms: n=35 (5.0%); Administering medication: n=33 (5.6%); Facilitating safe mobility: n=75 (9.6%); Providing physical comfort: n=77 (10.7%); Assistance with administration: n=32 (5.2%); Making home adjustments: n=18 (5.6%); Talking about emotions: n=50 (7.1%); Talking about end-of-life preferences: n=21 (5.1%).

*The n for every caregiving tasks is determined by the number of family caregivers who performed the caring activity in the last three months of life of the deceased relative and who received support from at least one healthcare professional

[†]Not applicable as the respective answer category wasn't an answer option for the task

[‡]The healthcare professional practice this task with the family caregiver.

[§]The healthcare professional did this task together with the family caregiver.

Table 5: Multivariable analysis for factors associated with family caregivers receiving support for physical tasks, psychosocial tasks and practical tasks (n=1,334)

Parameter	Support for physical tasks		Support for psychosocial tasks		Support for practical tasks	
	Estimate (B)	p	Estimate (B)	p	Estimate (B)	p
Intercept	-,209	,039	-,223	,152	-,204	,086
Decisional capacity of patient throughout the last three months						
Yes	-,131	,277	-,096	,524	/	/
Partly/sometimes	,212	,096	,292	,075	/	/
No	Ref. cat.	.	Ref. cat.	.	/	/
Specialised palliative care received						
Not sure	,206	,473	,678	,018	,388	,307
Yes	,388	,000	,528	,000	,573	,000
No	ref. cat.	.	ref. cat.	.	ref. cat.	.
Educational level of caregiver						
Elementary	/*	/	,019	,898	,320	,060
Secondary	/	/	ref. cat.	.	ref. cat.	.
Bachelor or equivalent	/	/	-,224	,051	-,115	,342
Master/university	/	/	-,367	,036	,110	,607
None of the above	/	/	-,173	,630	,538	,077
Age of the caregiver						
18-55	/	/	/	/	-,398	,004
56-65	/	/	/	/	ref. cat.	.
66-75	/	/	/	/	-,019	,896
76-85	/	/	/	/	,063	,748
86 or over	/	/	/	/	-,050	,855
Relationship of caregiver with patient						
Daughter or son (in law)	/	/	/	/	ref. cat.	.
Partner	/	/	/	/	-,057	,672
Parent	/	/	/	/	-,728	,008
Sibling	/	/	/	/	-,004	,991
Other family member	/	/	/	/	,433	,218
No family	/	/	/	/	-,239	,501

Support for physical, psychosocial and practical tasks are variables based on principal component analysis with the factor scores saved. Estimates represent Standardised mean differences with the reference category (ref. cat).

* Not applicable as the parameter was not included in the multivariate model of the respective task as it was not statistically significant ($p > 0.05$) in one-way ANOVA tests

Appendix

A1: Original Dutch questionnaire

A2: Reasons for non-participation based in the non-response survey (n=524)

Reasons for non-participation (multiple answers were possible)	n (%)
<i>No reason given</i>	<i>193 (36.8)</i>
<i>Too confronting</i>	<i>166 (31.7)</i>
<i>Questionnaire too long</i>	<i>88 (16.9)</i>
<i>No time</i>	<i>74 (14.2)</i>
<i>Respondent was not a family caregiver*</i>	<i>56 (10.7)</i>
<i>Instructions weren't clear</i>	<i>20 (3.8)</i>
<i>Wrong contact or address information</i>	<i>17 (3.3)</i>
<i>Patient has not died*</i>	<i>16 (3.1)</i>
<i>Unclear caring situation</i>	<i>9 (1.7)</i>
<i>Never received the questionnaire</i>	<i>5 (1)</i>

**Respondents with these reasons for non-response were not included in the calculation for the response rate as the reasons rendered them ineligible*

Table A3: Types of support for promoting social interaction

Caregiving tasks (%)	Encourage	Point out importance of social life	Organise social activity	Other types of support
Promoting social interaction (n=599)	30.7	33.2	31.7	26.2

Missing values: Promoting social interaction: n=56 (9.3%)

Table A4: Family caregivers' evaluation of the support received from healthcare professionals for various caregiving tasks they performed

%	Evaluation of support*		
	I didn't get enough support	I got enough support	I got more support than I needed
Providing personal care (n=377)	3.7	79.3	8.5
Assessing and managing symptoms (n=541)	7.2	81.5	6.3
Administering medication (n=476)	5.5	85.1	6.7
Facilitating safe mobility (n=467)	2.8	88.8	7.3
Providing physical comfort (n=473)	5.3	87.4	3.6
Assistance with administration (n=500)	5.4	84.8	6.2
Making home adjustments (n=253)	7.1	83.8	5.1
Talking about emotions (n=523)	7.1	82.0	6.1
Talking about end-of-life preferences (n=300)	5.0	87.4	5.0
Promoting social interaction (n=456)	4.2	77.5	9.2

*Percentages are row percentages

*The n for every caring activity is determined by the number of family caregivers who performed the caring activity in the last three months of life of the deceased relative, who received support from at least one healthcare professional and who was supported in any of the ways described in Table 4

Missing values: Providing personal care: n=32 (8.5%); Assessing and managing symptoms: n=27 (5.0%); Administering medication: n=13 (2.7%); Facilitating safe mobility: n=5 (1.1%); Providing physical comfort: n=18 (3.8%); Assistance with administration: n=18 (3.6%); Making home adjustments: n=10 (4.0%); Talking about emotions: n=25 (4.8%); Talking about end-of-life preferences: n=8 (2.7%); Promoting social interaction: n=42 (9.2%)

Table A5: Factor analysis rotated component matrix*

Items (received support for ...)	Component 1: support for physical tasks	Component 2: support for psychosocial tasks	Component 3: support for practical tasks
Providing personal care	,694	/	/
Assessing and managing symptoms	,747	/	/
Administering medication	,687	/	/
Facilitating safe mobility	/	/	,741
Providing physical comfort	,638	/	/
Assistance with administration	/	/	,757
Making home adjustments	/	/	,812
Talking about emotions	/	,837	/
Talking about end-of-life preferences	/	,788	/
Promoting social interaction	/	,779	/
Total variance explained (%)	47.979	64.270	59.372
Cronbach's alpha	0.745	0.718	0.655

*The Kaiser-Meyer-Olkin measure verified the sampling adequacy for the analysis, KMO = 0.829. Bartlett's Test of Sphericity (45) = 635.555, p=0.000, indicating that correlation structure is adequate for factor analyses. A three-factor solution seemed the best fit for the data, accounting for 66.33% of the variance. Factor 1 comprised of 4 caregiving tasks (providing personal care, assessing and managing symptoms, administering medication, providing physical comfort) that explained 47.979% of the variance with factor loadings from 0.638 to 0.747. Factor 2 comprised of 3 caregiving tasks (talking about emotions, talking about end-of-life preferences and promoting social interaction) that explained 64.270% of the variance with factor loadings from 0.779 to 0.837. Factor 3 comprised of 3 caregiving tasks (facilitating safe mobility, assistance with administration and making home adjustments) that explained 59.372% of the variance with factor loadings from 0.741 to 0.812. The three factors are respectively physical tasks, psychosocial tasks and practical tasks.

Table A6: Associations between patient and family caregiver characteristics and the support received for physical, psychosocial and practical caregiving tasks, one-way ANOVA (N=1,334)

Items	Component 1: Physical support	Component 2: Psychosocial support	Component 3: Practical support
Family caregiver characteristics			
<i>Age family caregiver</i>			
18-55	0,02	-0,17	-0,35
56-65*	0,08	0,05	0,01
66-75	-0,22	-0,02	0,11
76-85	0,14	0,06	0,31
>85	-0,08	0,42	0,07
	p=0.074	p=0.241	p=0.002
<i>Sex</i>			
Male	0,13	0,01	-0,10
Female*	-0,06	-0,01	0,04
	p=0.062	p=0.801	p=0.215
<i>Educational attainment</i>			
Primary education	0,14	0,19	0,38
Secondary education	-0,07	0,10	-0,02
Bachelor's degree or equivalent	0,02	-0,21	-0,22
Master's degree (University)	-0,08	-0,26	0,00
None of the above	0,13	0,05	0,46
	p=0.539	p=0.019	p=0.005
<i>Relationship with loved one</i>			
Partner	-0,10	0,06	0,15
Daughter/son	0,09	0,02	-0,09
Sibling	0,39	-0,27	-0,06
Parent	0,11	-0,39	-0,68
Other family member	-0,03	-0,37	0,14
No family	-0,22	0,08	-0,18
	p=0.403	p=0.267	p=0.031
<i>Lived together with deceased loved one in the last three months</i>			
No	0,05	-0,04	-0,09
Yes	-0,05	0,03	0,07
	p=0.318	p=0.505	p=0.118

<i>Has a physician, nursing or healthcare professional degree</i>			
No	0,04	-0,03	-0,02
Yes	-0,18	0,08	0,07
	p=0.067	p=0.406	p=0.553
<i>Employment status</i>			
Full-time employed	0,10	-0,15	-0,23
Part-time employed	0,12	0,05	0,01
Unemployed	0,04	-0,10	-0,41
Retired	-0,06	0,04	0,11
Homemaker	-0,12	0,08	0,16
Other	-0,11	-0,12	0,06
	p=0.593	p=0.715	p=0.109
<i>Characteristics of deceased person</i>			
<i>Age</i>			
18-55	0,06	-0,12	-0,40
56-65	0,10	0,14	0,03
66-75	-0,21	-0,05	0,10
76-85	0,02	-0,08	0,00
>85*	0,04	0,02	0,01
	p=0.265	p=0.590	p=0.165
<i>Capable of making own decisions</i>			
No	-0,04	0,01	0,15
Partly	0,18	0,22	0,04
Yes	-0,12	-0,12	-0,10
	p=0.020	p=0.010	p=0.155
<i>Palliative care services used</i>			
No	-0,18	-0,28	-0,28
Yes	0,18	0,23	0,25
Don't know	0,01	0,49	0,27
	p=0.001	p=0.000	p=0.000
<i>Serious illness</i>			
Cancer	0,07	0,07	0,00
Dementia	0,06	0,11	0,09
Organ failure	-0,16	-0,20	-0,15
Stroke	-0,16	-0,03	0,34
Other	0,15	0,23	0,47

	p=0.263	p=0.099	p=0.072
<i>Living at home in last 3 months</i>			
Most of the time	-0,03	-0,05	0,02
Sometimes	0,13	-0,04	-0,13
Not at all	0,03	0,06	0,04
	p=0,540	p=0,639	p=0,602

Values represent mean scores for the three factors (see appendix A5) where for each factor the mean=0 and standard deviation =1.

Table A7: Multivariable analysis for factors associated with family caregivers receiving support for physical tasks, psychosocial tasks and practical tasks with missing imputation (sensitivity analysis)

Parameter	Support for physical tasks		Support for psychosocial tasks		Support for practical tasks	
	Estimate (B)	p	Estimate (B)	p	Estimate (B)	p
Intercept	-,254	,004	,028	,826	-,138	,272
Decisional capacity of patient throughout the last three months						
Yes	-,120	,061	-,060	,456	/	/
Partly/sometimes	,120	,094	,065	,401	/	/
No	Ref. cat.	.	Ref. cat.	.	/	/
Specialised palliative care received						
Not sure	,248	,136	,343	,034	,243	,151
Yes	,216	<,001	,311	<,001	,331	<,001
No	ref. cat.	.	ref. cat.	.	ref. cat.	.
Educational level of caregiver						
Elementary	/*	/	,046	,565	,244	,080
Secondary	/	/	ref. cat.	.	ref. cat.	.
Bachelor or equivalent	/	/	-,186	,064	-,093	,176
Master/university	/	/	-,242	,025	,051	,647
None of the above	/	/	-,084	,599	,166	,343
Age of the caregiver						
18-55	/	/	/	/	-,102	,027
56-65	/	/	/	/	ref. cat.	.
66-75	/	/	/	/	,119	,209
76-85	/	/	/	/	,232	,555
86 or over	/	/	/	/	,087	,580
Relationship of caregiver with patient						
Daughter or son (in law)	/	/	/	/	ref. cat.	.
Partner	/	/	/	/	-,082	,403
Parent	/	/	/	/	-,217	,042
Sibling	/	/	/	/	-,209	,261
Other family member	/	/	/	/	-,036	,812
No family	/	/	/	/	-,394	,070

Support for physical, psychosocial and practical tasks are variables based on principal component analysis with the factor scores saved. Estimates represent Standardised mean differences with the reference category (ref. cat).

* Not applicable as the parameter was not included in the multivariate model of the respective task as it was not statistically significant ($p > 0.05$) in one-way ANOVA tests