

Original Article

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Support given by health professionals before and after a patient's death to relatives involved in general palliative care at home in Sweden: Findings from the Swedish Register of Palliative Care

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Abstract

Objectives. General palliative care (PC) is provided more at home, leading to increased involvement of relatives. Although support for relatives is a fundamental component of PC, there are deficiencies in the support provided to relatives when general PC is provided at home. This study aimed to describe the support provided by health professionals before and after a patient's death to relatives involved in general PC at home.

Methods. A cross-sectional register study was implemented, with data from the Swedish Register of Palliative care. The sample consisted of 160 completed surveys from relatives who had been involved in general PC at home, with 160 related surveys answered by health professionals. Only the questions about support to relatives were used from the surveys.

Results. The findings showed that although many relatives appear to receive support in general PC at home, not all relatives receive optimal support before or after a patient's death. The findings also indicated differences in whether relatives received some support before and after a patient's death depending on the type of relative. There were also differences in responses between health professionals and relatives regarding if relatives received counseling from a doctor about whether the patient was dying.

Significance of results. There is potential for improvements regarding support for relatives, especially after a patient's death, which has been confirmed in previous studies. The differences in whether relatives received support before and after a patient's death depending on the type of relative highlight the need for future research on how to support different types of relatives before and after a patient's death when general PC is provided at home.

Introduction

Relatives (family and other people, such as friends) play a crucial role in providing palliative care (PC) at home (Burns et al. 2013; Gomes and Higginson 2006; Hudson and Payne 2011; Zavagli et al. 2022). Increased life expectancy and technological advances in treatment and symptom control are enabling more people to be cared for and die at home (Wilson et al. 2018), and home care has become increasingly advanced, placing greater demands on the knowledge of relatives (National Board of Health and Welfare 2021). As the proportion of people receiving care and dying at home is expected to increase, the responsibility of relatives to provide end-of-life care at home for their loved ones may become more extensive in the future (Hellström et al. 2017; Wilson et al. 2018). As a result, adequate support for relatives is important in PC. Despite this, relatives have unmet support needs and would benefit from additional support (Ahn et al. 2020; Becqué et al. 2021; Bee et al. 2009; Funk et al. 2010).

Support for relatives is a fundamental component of PC (Hellström et al. 2017; National Board of Health and Welfare 2021), and relatives should be supported before and after a patient's death (National Board of Health and Welfare 2013; Regional Cancer Centres in collaboration 2021; World Health Organization 2002). The support for relatives should be person-centered (Diffin et al. 2018). Despite this, relatives do not receive the support they need either before or after a patient's death (Aoun et al. 2017; Becqué et al. 2021; Hoffstädt et al. 2022; Morris et al. 2015; O'Sullivan et al. 2021), and support for relatives needs improvement (Hudson 2013). Support can be provided in many ways and involves, for example, informative, emotional, and practical support (Hellström et al. 2017; National Board of Health and Welfare 2013, 2016). Information and counseling calls are examples of important support actions. Relatives should

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also be informed about the possibility of using the available cash benefit for the care of closely related persons (National Board of Health and Welfare 2021; Regional Cancer Centres in collaboration 2021). This is financial compensation for a relative who gives up paid work to be with a dying loved one (Regional Cancer Centres in collaboration 2021).

Many people would like to receive PC and end their lives at home (Ando *et al.* 2015; Cai *et al.* 2020; Gomes *et al.* 2013; Higginson *et al.* 2014), and a large part of PC is provided at home (Cai *et al.* 2020; National Board of Health and Welfare 2016). In high-income countries, 69%–82% of those who die are in need of PC (Murtagh *et al.* 2014). In Sweden, more than 90,000 people die each year, and about 80% of them are considered to need PC. About half of the people in need of PC in Sweden spend the last period of their lives in some form of home care (National Board of Health and Welfare 2016; The Swedish Register of Palliative Care 2019). Many people who die in hospitals or nursing homes have also often received a longer period of PC at home beforehand, so the place of death does not necessarily reflect the efforts made by relatives at home (Hellström *et al.* 2017). PC includes general and specialized PC. In home care, many people receive general PC rather than specialized PC, which health professionals with basic knowledge of PC usually provide (Regional Cancer Centres in collaboration 2021). The conditions for supporting relatives involved in general PC at home can be limited and challenging (Regional Cancer Centres in collaboration 2021), and there are deficiencies in the support provided to relatives when PC is provided at home (Mohammed *et al.* 2018; Morris *et al.* 2015).

Since previous research has identified that relatives involved in PC have unmet support needs and there is sparse research regarding support for relatives after a patient's death, this study aimed to describe the support provided by health professionals before and after a patient's death to relatives involved in general PC at home.

Methods

Study design and participants

This study was a register study with a cross-sectional design. Data were collected from the Swedish Register of Palliative Care (SRPC). The study population consisted of adult relatives who had been involved in general PC at home. Relatives who responded to the survey were divided into 3 groups based on the type of relative (see Table 1). There was no information about the gender distribution of the relatives, although the gender of the deceased patients was evenly distributed (50.6% women, 49.4% men).

Data collection and the surveys

The data were obtained from the SRPC, a national quality register in Sweden that was established in 2005. The SRPC aims to improve end-of-life care for patients and their relatives for all deaths regardless of diagnosis, gender, age, or place of death. The SRPC has 2 surveys – one for health professionals and the other for relatives – to assess how general or specialized PC has been provided in different health-care settings. The surveys aim to improve end-of-life care for patients and their relatives and serve as a research basis. In addition to support for relatives, the surveys also cover topics on disease that caused the death, information to the patient, the patient's care needs, and symptoms and symptom relief. Health professionals invite relatives to answer the survey a period of time

Table 1. Overview of the respondent's characteristics ($n = 160$)

	Total, $n = 160$	%
Type of relative		
Partner (spouse/partner)	$n = 87$	54.4
Child (adult)	$n = 64$	40
Other relative (siblings, friends, or other relatives)	$n = 9$	5.6
Geographic		
Northern Sweden	$n = 42$	26.25
Middle Sweden	$n = 2$	1.25
Southern Sweden	$n = 116$	72.5

after a patient's death, at the latest within 3 months from the date of death.

The data were requested and delivered de-identified. The data were collected between March 2016, when the survey for relatives was introduced, and March 2022. In total, 160 completed surveys from relatives who had been involved in general PC at home during this period, and 160 related surveys answered by health professionals were received. There is no information about how many surveys were sent to relatives throughout this period, but statistics from SRPC, however, show that between January 2021 and March 2022, a total of 2115 surveys were sent to relatives in different health-care settings, of which 818 surveys (38.7%) were answered. Of these 2115 surveys, 97 surveys were sent to relatives involved in general PC at home, of which 40 surveys were answered (41.2%). The surveys from SRPC were adjusted during 2020, in the start of the pandemic COVID-19. The adjustments of the survey for relatives concerned questions about symptom and symptom relief, and some of the questions related to support were adjusted in terms of formulation and developed response alternatives (see Table 2). Both the 2016 and 2020 versions were included in this study. The survey from 2016 consisted of 23 questions, and the survey from 2020 consisted of 21 questions. However, only the questions about support to relatives were requested from the SRPC – 8 questions from the 2016 survey and 7 questions from the 2020 survey. The data from 3 questions from the survey answered by health professionals were also requested for comparison with the data from the survey answered by relatives. Of the health professionals who had responded to the survey, 99% were nurses and 1% were doctors or other health professionals. See Figure 1 for an overview of how many questions were used from the surveys.

Data analysis

The data were processed in IBM SPSS version 28.0.1.1. Data were analyzed using descriptive statistics, and percentages were determined. A comparison of the answers between groups of relatives and between relatives and health professionals was done. To compare the questions and answers from the 2016 and 2020 surveys, some question and response alternatives were merged. The questions with 5-point scale response alternatives were merged into 3-point scale response alternatives – “very satisfied” and “satisfied” were merged into “satisfied” and “a bit unsatisfied” and “very unsatisfied” were merged into “unsatisfied.” Both the questions and the response alternatives to questions 2 and 3 from the 2016 and 2020 surveys were merged to compare the answers. Table 2 shows

Table 2. Description of the questions used from the surveys

Questions from the survey for relatives	Questions merged to	Response alternatives	Responses merged to
Survey from 2016 and 2020: Q1: Was anyone present at the moment of death? (n = 160)		Yes, relative/ yes, health professional/yes, relative and health professional/ No/don't know	
Survey from 2016: Q2: Did you or another relative receive a “breaking point” consultation, i.e. an individually tailored consultation informing you that your loved one was dying and that the care was focused on quality of life and symptom relief? (n = 117)	Q2: Did you or another relative receive counseling from a doctor who informed you or helped you understand that your loved one was dying? (n = 160)	Yes/no/don't know	
Survey from 2020: Q2: Did you receive counseling from a doctor who told you or helped you understand that your loved one was dying? (n = 43)		Yes, it was a good conversation/yes, but it was not a good conversation/ No/no, but by other health professionals/ Don't know	Yes/ No/ Don't know
Survey from 2016: Q3: Were you or another relative offered a conversation with health professionals 1–2 months after the death? (n = 117)	Q3: Were you or another relative offered counseling with health professionals a period of time after the death? (n = 160)	Yes/no/don't know	
Survey from 2020: Q3: Were you offered counseling with health professionals a period of time after the death? (n = 43)		Yes/ yes, but I declined/ No/don't know	Yes/ No/ don't know
Survey from 2016 and 2020: Q4: Did you know where to turn to receive emergency assistance (including night/weekend/holiday) for your loved one during the last week of life? (n = 160)		Yes/no	
Survey from 2016 and 2020: Q5: Did you receive information from health professionals about the possibility of using the cash benefit for care of closely related persons? (n = 160)		Yes/no/don't know/not relevant	
Survey from 2020: Q6: Did you receive the support you needed from health care before the death of your loved one at the ward/care team where your loved one died? (n = 43)		Yes fully/ yes, partly/ no, not fully/ no, not at all/ not relevant/ don't know	
Survey from 2016: Q7: Are you satisfied with the support that you as a relative received from health care before the patient's death? (n = 117)		Very satisfied/ satisfied/ Neither/ a bit unsatisfied/ very unsatisfied	Satisfied/ Neither/ unsatisfied
Survey from 2016: Q8: Are you satisfied with the support that you as a relative received from health care after the patient's death? (n = 117)		Very satisfied/ satisfied/ Neither/ a bit unsatisfied/ very unsatisfied	Satisfied/ Neither/ unsatisfied
Survey from 2016 and 2020: Q9: Filled in by (n = 160)		Spouse, partner/ Child/siblings/other relative/friend/parent	Partner/ Child/other relative
Questions from the survey for health professionals		Response alternatives	
Survey from 2016 and 2020: Q1: Was anyone present at the moment of death?		Yes, relative/ yes, health professional/ yes, relative and health professional/ no/don't know	
Survey from 2016 and 2020: Q2: Did the person's relatives receive counseling from a doctor who informed them that the person was dying?		Yes/no/don't know	
Survey from 2016 and 2020: Q3: Were the person's relatives offered counseling a period of time after the death??		Yes/no/don't know	

Q = question.

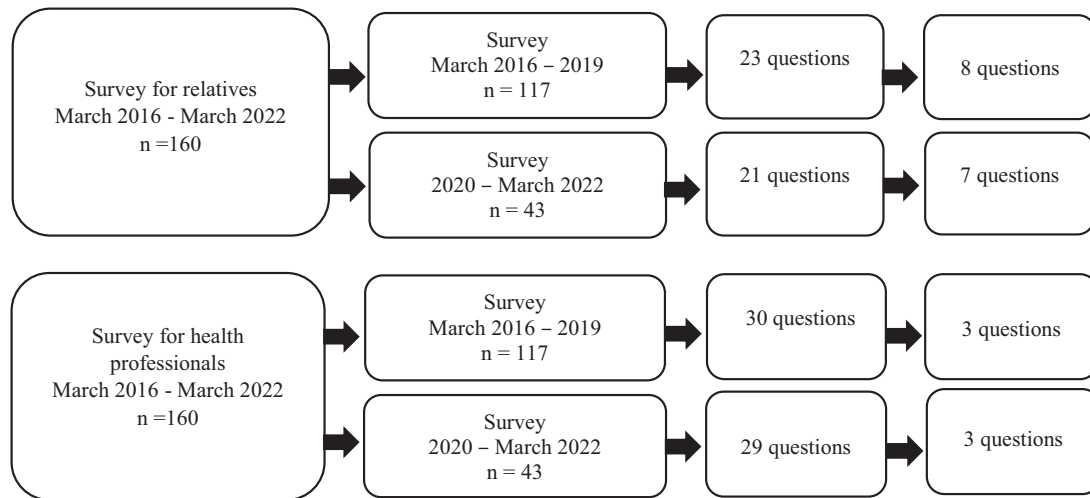


Figure 1. Overview of how many questions were used from the surveys.

the questions used from the surveys and how the questions and responses were merged to compare the 2016 and 2020 surveys.

Ethical considerations

The study was conducted according to the research ethics principles and ethical guidelines of the Declaration of Helsinki (World Medical Association 2013). Before the study, an application for ethical clearance was obtained from the Ethical Review Authority in Lund in Sweden (diary number: 2022-01668-01). As the data from the SRPC were delivered de-identified and there was no information about the respondents other than their relationship to a deceased patient, the respondents could not be identified. Data were stored in secure servers inaccessible to unauthorized people.

Results

Of the 160 relatives who responded to the survey, 54.4% were partners, 40% were children, and 5.6% were other relatives. The survey was answered by relatives from all over Sweden, although the majority were answered by relatives in southern Sweden (see Table 1). Of the 160 relatives who answered the survey, 69.4% had received information from health professionals about the possibility of using the cash benefit for the care of closely related persons. On the question of whether relatives knew where to turn for emergency assistance during the last week of the patient's life, 97.5% answered that they did. Furthermore, 96.3% of the relatives answered that relatives and/or health professionals were present at the moment of death. On the question of whether relatives had received counseling from a doctor about whether the patient was dying, 78.1% confirmed that they had. Finally, 92.5% of the relatives answered that they had been offered counseling with health professionals a period of time after the patient's death.

Health-care support before a patient's death

The question of whether relatives received the support they needed from health care before the patient died was answered by 43 relatives. This question was only included in the 2020 survey. Of the relatives who answered this question, 70% answered "yes, fully" or

"yes, partly," 23% answered "no, not fully" or "no, not at all," and 7% answered that the question was "not relevant."

Satisfaction with health-care support before and after a patient's death

The questions about whether relatives were satisfied with the support they received before and after the patient's death were answered by 117 relatives. These questions were only included in the 2016 survey. Of the relatives who answered these questions, 95.7% were satisfied with the support they received before the patient's death, and 81.2% were satisfied with the support they received after the patient's death. Table 3 shows how relatives responded to these questions.

Comparison of responses based on type of relative

Regarding the question of whether relatives had received counseling from a doctor about whether the patient was dying, 86.2% of the partners confirmed that they had compared to only 70.3% of the children and 55.6% of the other relatives. On the question of whether relatives had received information from health professionals about the possibility of using the cash benefit for the care of closely related persons, 72.4% of the partners and 68.8% of the children answered in the affirmative, while only 44.5% of the other relatives confirmed that they had. On the question of whether relatives had been offered counseling with health professionals a period of time after the patient's death, 96.9% of the children and 100% of the other relatives answered that they had been offered it, while 88.5% of the partners confirmed that they had. Table 4 shows how relatives responded to these questions based on the type of relative.

Comparison of responses between relatives and health professionals

On the question of whether anyone was present at the moment of death, 96.3% of the relatives and 98.1% of the health professionals answered that someone – relatives and/or health professionals – was present. On the question of whether relatives had been offered counseling with health professionals a period

Table 3. Relative's satisfaction with the support from health care before and after the patient's death

Q7: Satisfied with the support received from health care before the patient's death Total, <i>n</i> = 117 <i>n</i> (%)			Q8: Satisfied with the support received from health care after the patient's death Total, <i>n</i> = 117 <i>n</i> (%)		
Satisfied	Neither	Unsatisfied	Satisfied	Neither	Unsatisfied
112 (95.7)	2 (1.7)	3 (2.6)	95 (81.2)	14 (12)	8 (6.8)

Table 4. Overview of responses based on the type of relative

Variables		Partner <i>n</i> = 87 <i>n</i> (%)	Child <i>n</i> = 64 <i>n</i> (%)	Other relative <i>n</i> = 9 <i>n</i> (%)
Total, <i>n</i> = 160				
Q2: Received counseling from a doctor about whether the patient was dying	Yes	75 (86.2)	45 (70.3)	5 (55.6)
	No	8 (9.2)	16 (25)	3 (33.3)
	Don't know	4 (4.6)	3 (4.7)	1 (11.1)
Q3: Were offered counseling with health professionals a period of time after the patient's death	Yes	77 (88.5)	62 (96.9)	9 (100)
	No	3 (3.4)	2 (3.1)	
	Don't know	7 (8.1)		
Q4: Knew where to turn for emergency assistance during the last week of life	Yes	85 (97.7)	62 (96.9)	9 (100)
	No	2 (2.3)	2 (3.1)	
Q5: Received information from health professionals about cash benefit for care of closely related persons	Yes	63 (72.4)	44 (68.8)	4 (44.5)
	No	15 (17.3)	17 (26.5)	3 (33.3)
	Not relevant	6 (6.9)	2 (3.1)	
	Don't know	3 (3.4)	1 (1.6)	2 (22.2)
Total, <i>n</i> = 117		Partner <i>n</i> = 62 <i>n</i> (%)	Child <i>n</i> = 46 <i>n</i> (%)	Other relative <i>n</i> = 9 <i>n</i> (%)
Q7: Satisfied with the support received from health care before the patient's death	Satisfied	60 (96.8)	43 (93.5)	9 (100)
	Neither	1 (1.6)	1 (2.2)	
	Unsatisfied	1 (1.6)	2 (4.3)	
Q8: Satisfied with the support received from health care after the patient's death	Satisfied	51 (82.3)	37 (80.4)	7 (77.8)
	Neither	7 (11.3)	5 (10.9)	2 (22.2)
	Unsatisfied	4 (6.4)	4 (8.7)	

of time after the patient's death, 92.5% of the relatives and 91.9% of the health professionals answered that they had. Regarding the question of whether relatives had received counseling from a doctor about whether the patient was dying, the answers differed, with 92.5% of the health professionals answering that relatives had received it and only 78.1% of the relatives confirming this. [Table 5](#) shows how relatives responded to these questions compared to how health professionals responded.

Discussion

This study aimed to describe the support given by health professionals before and after a patient's death to relatives involved in general PC at home. Comparisons were made to see if there were differences in the support relatives received based on the type of relative and whether the responses from relatives and health professionals differed. The main findings are that, although many relatives seemed to receive support, not all relatives did so, and there is potential for improvement. Relatives were less satisfied with the support they received after a patient's death than with the support they received before, and there were differences between types of

relative in whether some support was provided. There were also some differences in the responses from health professionals and relatives.

The results that show that support for relatives after a patient's death is not optimal may have been influenced by when relatives were invited to respond to the survey, as some may not yet have been offered this support. It is also worth considering that relatives are in a difficult situation after a patient's death, which could influence how they assess the support they receive. Previous studies have also shown that support for relatives after a patient's death is inadequate. For example, in the study of O'Sullivan et al. (2021), relatives in different health-care settings expressed disappointment at not receiving support after a patient's death. Another study of Vermorgen et al. (2020), about specialized PC at home and in hospitals, shows that although 9 of 10 relatives felt supported just after the moment of a patient's death, almost half of them had not received any information about the possibility of receiving support after a death. Moreover, the study of Hoffstädt et al. (2022) shows that about one-third of health professionals in different health-care settings did not provide support to relatives after a death. This suggests that support for relatives after a patient's

Table 5. Overview of comparison of responses from health professionals and relatives

Variables		Health professionals <i>n</i> = 160 <i>n</i> (%)	Relatives <i>n</i> = 160 <i>n</i> (%)
Total, <i>n</i> = 160			
Q1: From the survey for relatives and health professionals: Was anyone presence at the moment of death?	No one	3 (1.9)	4 (2.5)
	Health professionals	8 (5)	13 (8.1)
	Health professionals and relative	49 (30.6)	43 (26.9)
	Relative	100 (62.5)	98 (61.3)
	Don't know		2 (1.2)
Q2: From the survey for relatives and health professionals: Did the relatives receive counseling from a doctor who informed them that the person was dying?	Yes	148 (92.5)	125 (78.1)
	No	1 (0.6)	27 (16.9)
	Don't know	8 (5)	8 (5)
	Missing	3 ^a (1.9)	
Q3: From the survey for relatives and health professionals: Were the relatives offered counseling a period of time after the death?	Yes	147 (91.9)	148 (92.5)
	No	2 (1.2)	5 (3.1)
	Don't know	11 (6.9)	7 (4.4)

^aNot answered when the patient's death was unexpected.

death could be improved, regardless of the health-care setting. The responsibility of health professionals does not end when a patient dies. Support for relatives is a fundamental component of PC, and all relatives should be offered support before and after a patient's death. Support after death includes offering counseling to relatives a period of time after a patient's death (National Board of Health and Welfare 2016).

This study's results, in line with those of previous studies (Ando *et al.* 2015; Aoun *et al.* 2015), indicate that it is usually a partner or the children who take care of a patient when PC is provided at home. Adams *et al.* (2009) point out in their literature review (focusing on the relatives of people with cancer) that it is important to note that most studies focus on partners rather than on other relatives. Although partners and children may be more common, it is important to consider other relatives with different relationships to a dying person, and the need for support may differ depending on that relationship. According to Burns *et al.* (2013), other relatives are an important component of PC and must also receive adequate support from health professionals, and this need for support may differ. The present study's results show differences in whether relatives received some support before and after a patient's death depending on the type of relative. This may be because more partners than children and other relatives answered the survey, and there was an uneven percentage distribution between the groups. Further research on support for different types of relatives is needed to confirm whether there are differences depending on the type of relative if some support is provided or not.

When comparing the responses of health professionals and relatives, the results show some differences regarding counseling from a doctor about whether the patient was dying. More relatives confirmed that they had not received counseling, while health professionals reported that they had. The health professionals reported that 92.5% of relatives involved in general PC at home had received counseling from a doctor about whether the patient was dying, while only 78.1% of the relatives reported that they had. This difference may be because the relatives may not have been aware that they had received counseling or may have received it from

other health professionals. Further research comparing relatives' and health professionals' perceptions of the support provided to relatives could provide important information on the reasons for different perceptions.

Although this study's results show that many relatives appeared to receive support before and after a patient's death in general PC at home, they also highlight that the support received was not optimal and was not offered to all relatives. This result, which is confirmed in previous studies in different health-care settings (Aoun *et al.* 2017; Becqué *et al.* 2021; Hoffstädt *et al.* 2022; Morris *et al.* 2015; O'Sullivan *et al.* 2021), indicates that support should be offered to more relatives, both before and after a patient's death, as everyone is entitled to it. A starting point for more optimal support is that it must be individualized from a person-centered perspective and based on a relative's situation and needs, regardless of the type of relative.

Limitations of the study

Although it is considered a strength that this study's data were collected from a national quality register, the study has several limitations that should be considered before any definitive conclusions can be drawn. The surveys, and thus the study, contained a limited number of questions regarding support. The study's results were influenced by the uneven percentage distribution in the groups of relatives and the small sample size, which affects the ability to draw firm conclusions from the results. Statistical analysis in form of Pearson Chi-square tests was carried out to see if there were statistical significant differences between groups of relatives and between health professionals and relatives, but they were not reliable since more than 50% of the cells had expected count less than 5. Furthermore, there is no information about the relatives who responded to the survey, except the type of relative or how many surveys were sent to relatives involved in general PC at home during the whole period between March 2016 and March 2022. This makes it difficult to estimate the selection bias and challenges the

study's validity and representativeness. The 160 surveys answered during this period indicate a low response rate. Statistics from the SRPC from January 2022 to January 2023 show that 47,521 deaths were registered during this period, only 2,472 surveys were sent to relatives in different health-care settings, and 934 surveys (37.8%) were answered (The Swedish Register of Palliative Care 2023). This suggests that health professionals need to become better at inviting relatives to respond to the survey. The fact that some questions and response alternatives were merged to compare the questions and answers from the 2016 and 2020 surveys, may also be a limitation as both questions and responses may have received attention in different ways. The survey for relatives in SRPC is partly developed from the survey for health professionals. Two validation studies have been carried out on the survey for health professionals and show that several questions have high validity (Martinsson et al. 2017). Although there is no validation of the survey for relatives, and there is a need for caution in generalizing the findings, the study provides important knowledge about the support given by health professionals before and after a patient's death to relatives involved in general PC at home. The results of this study can serve as a basis for further research on this important topic.

Conclusion

The findings of this study show that, although many relatives appear to receive support in general PC at home, not all relatives receive optimal support before or after a patient's death. The findings illustrate that there is potential for improvements, especially regarding support for relatives after a patient's death, which has been confirmed in previous studies. The findings also indicate differences depending on the type of relative in whether some support is provided or not, which highlights the need for future research on how to support different types of relatives before and after a patient's death when general PC is provided at home. Further research on this topic is needed to confirm these findings. Research could also, from the perspective of relatives, explore what improvements can be made to the support offered to them at home and investigate barriers and facilitators specific to the home care setting. Such research should also consider the gender perspective since the need for support may differ according to gender.

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