Nursing Manuscript

Practice of Supporting Family Caregivers of Patients with Life-Threatening Diseases: A Two-phase Study Among Healthcare Professionals

American Journal of Hospice
& Palliative Medicine®
2022, Vol. 0(0) 1–11

DOI: 10.1177/10499091221123006
journals.sagepub.com/home/ajh
SAGE

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Abstract

Background: Although support for family caregivers is an essential component of palliative care, routine provision of such support is often lacking. To improve support for family caregivers, we assessed current practice and influencing factors as perceived by healthcare professionals. **Methods:** A two-phase study was conducted including a survey exploring healthcare professionals' practice of supporting family caregivers in Western urbanized Netherlands in 2017, and focus groups exploring facilitators and barriers to supporting family caregivers in 2018. Focus group data were thematically analyzed with deductive coding based on the COM-B system. **Results:** Of the 379 survey respondents (response 11%), 374 were eligible (physicians, 28%; nurses, 64%; nurse assistants, 9%). The respondents practiced in academic hospitals (52%), general hospitals (31%), nursing homes (11%) and hospices (5%). They reported to always (38%), most of the time (37%), sometimes (21%) or never (5%) provide support to family caregivers during the illness trajectory. Respondents reported to always (28%), sometimes (39%), or never (33%) provide support after death. Four focus group discussions with 22 healthcare professionals elicited motivational facilitators and barriers to supporting family caregivers (e.g., relationship with family caregivers, deriving satisfaction from supporting them), and factors related to capability (e.g., (lacking) conversational skills, knowledge) and opportunity (e.g., (un) availability of protocols and time). **Conclusions:** Support for family caregivers, especially after the patient's death, is not systematically integrated in working procedures of healthcare professionals. The barriers and facilitators identified in this study can inform the development of an intervention aiming to enhance support for family caregivers.

Keywords

(6-8): family caregivers, informal caregivers, palliative care, bereavement care, supportive care, COM-B, barriers and facilitators, healthcare professionals

Introduction

Having a critically ill loved one can induce symptoms of depression and anxiety, and decrease quality of life.[1,2] Therefore, support for family caregivers is an essential component of palliative care and should start at the time of diagnosis and continue after the patient's death.[3] According to the Clinical Practice Guidelines for Quality Palliative Care, such support entails anticipating, preventing, and managing physical, psychological, social, and spiritual suffering to optimize quality of life. The guidelines recommend assessing and addressing emotional and spiritual support needs, providing education on what to expect around death, involving family caregivers in discussions regarding care for the patient, and providing access to bereavement support.[4]

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Interventions aiming to support family caregivers can reduce burden and improve quality of life.[5-7] However, previous research also shows that support for family caregivers is under-resourced in many healthcare settings, and that there is often no system in place to offer support to all family caregivers.[8-12] More detailed information on what support is provided by individual healthcare professionals is needed to understand current practice. An understanding of what hinders and what facilitates supporting family caregivers is needed to improve it. Facilitators and barriers have been identified in cancer settings,[13] end-of-life home care,[11] and hospital-based bereavement care.[14] An overarching mapping of facilitators and barriers across settings and illness trajectories is needed to improve support for family caregivers across a wider range of circumstances.

The Behavior Change Wheel (BCW) is a tool that can be used to design an intervention to enhance behavior, including supporting family caregivers. Central to the BCW is the Capability-Opportunity-Motivation-Behavior (COM-B) system, which suggests people need capability (C; physical and psychological), opportunity (O; physical and social) and motivation (M; automatic and reflective) to perform a behavior (B).[15] Mapping facilitators and barriers to the COM-B system allows for linking these to several intervention functions (i.e., education, training, modelling), which can help to develop an intervention to improve the practice of supporting family caregivers.[15]

The aims of the present study are 1) to assess current practice of support for family caregivers of patients with life-threatening diseases in hospitals, nursing homes, and hospices, and 2) to identify facilitators and barriers to the provision of support for family caregivers as perceived by healthcare professionals.

Methods

Study Design

A two-phase study was conducted with a survey and focus groups among healthcare professionals. The Medical Research Ethics Committee of LUMC declared the study exempt from the Medical Research Involving Human Subjects Act (WMO; no. N21.072). To the extent possible, the consolidated criteria for reporting qualitative studies (COREQ) were applied.[16]

Survey

Current practice of supporting family caregivers was assessed using a self-developed survey (Appendix A) in 2017. The survey was administered electronically and anonymously in 2017 through Google Forms in healthcare institutions located in urbanized Western Netherlands within the area of the regional palliative care consortium. We targeted physicians, nurses, and nurse assistants through the means of convenience sampling. The survey comprised demographics and 23 (8 closed-ended, 15 open-ended) items on supporting family caregivers before and after the patient's death. The open-ended questions offered respondents the opportunity to explain or elaborate on their answers to the preceding closed-ended questions. Responding to the survey took approximately 5 minutes. The data were analyzed using descriptive analyses in SPSS (Version 25).

Focus Groups

Subsequently, a topic list (Appendix B) to guide focus groups was developed in 2018 to identify facilitators and barriers to providing support for family caregivers, as perceived by healthcare professionals. We targeted nursing staff and physicians working in nursing homes and hospitals through convenience sampling by giving survey respondents the possibility to disclose their name to sign up for focus groups. The research team phoned or e-mailed them and sent a study leaflet. Two focus groups were conducted with nurses and nurse assistants working in nursing homes, one with nurses working in hospitals, and one with physicians working in hospitals. The focus groups lasted 2 hours and were moderated by MCT (female, MSc) or JTS (female, PhD) who both had experience with conducting focus groups. The moderators did not have a prior relationship with the participants. At each focus group, one of the other researchers (JAB, MCT, YML) was present to note observations. The focus groups took place at the LUMC-campus in Leiden or The Hague. All participants provided written informed consent to participate in the focus groups.

Qualitative Data Analyses

The focus groups were audio recorded and transcribed verbatim. Member checks were performed with summaries of the focus groups. The data were analyzed by HEH using ATLAS.ti software (Version 9), supervised by JTS and IDH, both experienced qualitative researchers. The analysis was mainly deductive, using a codebook approach to thematic analysis[17,18] with the COM-B system[15] as a framework that provided the initial codes. Open coding was used to identify specific barriers and facilitators as sub-codes. In the final stage, JAB and HEH discussed the results and reached consensus on final codes.

Results

Current Practice

The survey was sent to 3387 healthcare professionals in 26 nursing homes, 8 hospitals, and 40 hospices, of whom 379 responded (from at least 9 hospices, 9 nursing homes, and 7 hospitals; response rate: 11.2% (379/3387)). We excluded 5 respondents that did not belong to our target population (volunteers, spiritual counsellors, physiotherapist). Of 374 eligible respondents, almost three-quarters (73%) was nursing staff and most worked in hospitals (84%; Table 1).

Most respondents reported to 'always' (38%) or 'most of the time' (37%) inquire after the wishes and needs of family caregivers. The others reported to do so 'sometimes' (21%) or 'never' (5%). Respondents working in nursing homes reported to 'always' inquire after wishes and needs the most (62%). Some respondents explained that whether they inquired after wishes and needs depended on the relationship they had with the family caregivers and available time. A third of the respondents reported to never provide support after death (Table 2). Whether support after death was provided depended mostly on the needs of family caregivers as perceived by healthcare professionals (67%; Table 3). Support after death by individual healthcare professionals consisted mostly of follow-up conversations (57%) and sending sympathy cards or letters (35%; Table 4). Of the hospital staff, 32% was unaware of any support after death organized by the hospital, and 30% reported that their hospital did not organize any support after death (Table 4).

The GP was most frequently referred to by healthcare professionals (63%), followed by internal support services such as spiritual counselling (55%), social work (54%), and the palliative consultation team (42%; Table 5). Several respondents working in hospitals mentioned absence of internal support services that family caregivers can be referred to. Of the respondents, 32% reported to never refer to external support services with lack of knowledge on referral possibilities being the most frequently reported reason (24%). Some respondents commented that they do not refer family caregivers as this is not within their range of duties.

Table 1. Characteristics of Healthcare Professionals in The Survey Sample; n = 374.

Profession, n (%)	
Physician	103 (28)
Nurse	239 (64)
Nurse assistant	32 (9)
Setting, n (%)	
Academic hospital	197 (53)
General hospital	116 (31)
Nursing home	42 (11)
Hospice	19 (5)
Age, mean number of years (SD)	41 (13)
Working experience, mean number of years (SD)[a]	12 (11)

Abbreviation: SD, standard deviation.

[a] 3 respondents did not report working experience.

Facilitators and Barriers

Four focus groups were held with 22 healthcare professionals (21 females). Four participants were physicians and eighteen were nursing staff (nurses and nurse assistants). Thirteen participants worked in nursing homes and 9 in hospitals. Some participants also worked in hospices, besides their work in a hospital or nursing home. All healthcare professionals who were approached by the research team agreed to participate. Six participants responded to the member checks which led to 2 additions to the summaries. An overview of the results can be found in Table 6, including a description of the COM-B components.

Motivation: Automatic. Participants were motivated to support family caregivers as they derived satisfaction from it and perceived it as rewarding. They appreciated witnessing the resilience of family caregivers. Supporting family caregivers after the patient's death also helped to achieve a sense of

Table 2. Reported Frequency of Support for Family Caregivers; n = 374.

Before death ("In contact with patients and family caregivers who are dealing with life-threatening diseases, do you inquire after the needs and wishes of the family caregivers?")

	Never, n (%)	Sometimes, n (%)	Most of the Time, n (%)	Always, n (%)
All settings	**18 (5)**	**77 (21)**	**138 (37)**	**141 (38)**
Academic hospital	11 (6)	50 (25)	76 (39)	60 (31)
General hospital	5 (4)	22 (19)	42 (36)	47 (41)
Nursing home	1 (2)	4 (10)	11 (26)	26 (62)
Hospice	1 (5)	1 (5)	9 (47)	8 (42)

After death ("Do you provide support to family caregivers after the death of a loved one?")

	Never, n (%)	Sometimes, n (%)	Always, n (%)
All settings	**123 (33)**	**146 (39)**	**105 (28)**
Academic hospital	72 (37)	74 (38)	51 (26)
General hospital	35 (30)	49 (42)	32 (28)
Nursing home	8 (19)	19 (45)	15 (36)
Hospice	8 (42)	4 (21)	7 (37)

closure for themselves. A barrier reported for themselves and witnessed with colleagues was discomfort with supporting family caregivers. A strong or longstanding relationship with the family caregiver increased motivation.

Table 3. Determinants of the Provision of Support After Death; n = 146.[a]

	n (%)[b]
Needs of family caregiver as perceived by healthcare professional	98 (67)
Relationship with family caregiver	
Personal connection	52 (36)
Duration of relationship	46 (32)
Personal need of healthcare professional	10 (7)
Other[c]	35 (24)

[a] Selection of the respondents (146/374) who responded with 'sometimes' to the question whether they provide support after death (presented in Table 2).
[b] Total percentages may exceed 100 as multiple answers were possible.
[c] Including: presence during dying phase, acceptance of family caregivers of invitation for follow-up conversation.

Motivation: Reflective. Many participants were motivated to support family caregivers as they considered this an important aspect of high-quality care and therefore their responsibility. However, some had noticed among colleagues that their priority remained strongly with the patient. Some participants mentioned that empathizing with family caregivers helps them to realize the importance of supporting them.

Another motive to support family caregivers was the beneficial effect on the patients. Family caregivers can provide additional information that improves tailored care, and patients feel reassured when their loved ones are cared for too. Some mentioned to be motivated to conduct a follow-up conversation after death, as family caregivers' reflections can help improve future care for patients and family caregivers.

Capability: Psychological. According to the participants, mastering conversational skills facilitates providing support. Some reported to struggle themselves, or had noticed colleagues struggling with conducting conversations on death and dying and dealing with the emotions of family caregivers.

Table 4. Type of Support Provided After Death.

	Academic Hospital, n (%)[a]	General Hospital, n (%)	Nursing Home, n (%)	Hospice, n (%)	Total, n (%)
By individual healthcare professional; n = 251[b]					
Post-death follow-up conversation	90 (72)	38 (47)	11 (32)	4 (36)	143 (57)
Sending a sympathy card or letter	41 (33)	32 (40)	12 (35)	3 (27)	88 (35)
Telephone contact: Once	30 (24)	18 (22)	14 (41)	4 (36)	66 (26)
Asking a question such as; 'what do you need, what can the people around you do for you?'	22 (18)	23 (28)	6 (18)	3 (27)	54 (22)
Providing information: Brochures	10 (8)	20 (25)	2 (6)	3 (27)	35 (14)
Attending memorial or funeral service	2 (2)	3 (4)	17 (50)	7 (64)	29 (12)
Consult with GP on setting up a counselling program	17 (14)	3 (4)	1 (3)	0 (0)	21 (8)
Telephone contact: Multiple times	11 (9)	3 (4)	1 (3)	2 (18)	17 (7)
Active participation at funeral service	0 (0)	1 (1)	5 (15)	2 (18)	8 (3)
Providing information: Websites	3 (2)	3 (4)	1 (3)	0 (0)	7 (3)
Referral to bereavement counsellor	3 (2)	2 (3)	0 (0)	2 (18)	7 (3)
Other[c]	4 (3)	7 (9)	5 (15)	2 (18)	18 (7)
By healthcare organization; n = 374					
Sending a sympathy card or letter	54 (27)	40 (35)	20 (48)	10 (53)	124 (33)
Organizing a memorial service	0 (0)	6 (5)	20 (48)	16 (84)	42 (11)
Flowers to go with the coffin or for the grave	0 (0)	0 (0)	8 (19)	0 (0)	8 (2)
Opening a book of condolence	0 (0)	0 (0)	2 (5)	0 (0)	2 (1)
Other[d]	32 (16)	17 (15)	14 (33)	6 (32)	69 (18)
Organization does not provide support after death	54 (27)	39 (34)	4 (1)	1 (5)	98 (26)
Not known whether organization provides support after death	71 (36)	30 (26)	4 (1)	1 (5)	106 (28)

[a] Total percentages may exceed 100 as multiple answers were possible.
[b] Respondents (251/374) who responded with 'always' or 'sometimes' to the question if they provide support after death (presented in Table 2).
[c] Including: organizing a send-off ritual after death at the institution, contact with family caregivers at the institution directly after death, organizing a memorial service.
[d] Including: follow-up conversation, telephone contact, attending funeral service, providing information, organizing a send-off ritual, contact with palliative consultation team.

Table 5. Services that Family Caregivers with Needs for Additional Support Were Referred to and Reasons Not to Refer; n = 374.

	n (%)[a]
Internal support services	
Spiritual counsellor	206 (55)
Social worker	200 (54)
Palliative consultation team	157 (42)
Psychologist	84 (23)
Other internal support services[b]	52 (14)
"I do not refer to internal support services"	44 (12)
External support services	
General practitioner	234 (63)
Walk-in consultation services	53 (14)
Psychologist	37 (10)
District nurse	25 (7)
Family caregiver support service	23 (6)
Other external support services	43 (12)
"I do not refer to external support services"	119 (32)
Reasons not to refer externally	
Lack of knowledge on referral possibilities	91 (24)
Preference to support family caregivers themselves	26 (9)
Not considering a referral as necessary	22 (6)
Lack of time	1 (0)
Other reasons[d]	7 (2)

[a] Total percentages may exceed 100 as multiple answers were possible.
[b] Including: Physician, nurse, psychiatrist, hospice coordinator, art-therapy.
[c] Including: general practice assistant for mental healthcare, mindfulness/meditation training, bereavement counsellor, volunteer organizations.
[d] Including: considering referring family caregivers as the responsibility of other disciplines, short stay of patients.

Private life and work experience were reported to help in conducting such conversations.

The participants also mentioned the need to really understand the unique and difficult situation that family caregivers are in and what their corresponding needs are, and approach them with a non-judgmental attitude. For example, forgiving family caregivers for acting unfriendly due to their distress, or realizing that understanding medical information may be difficult for them. Furthermore, they mentioned the necessity to be sensitive to the unique needs, wishes, and capabilities of each individual family caregiver. For example, whereas some family caregivers may desire more attention, others may prefer to be mostly left alone. In addition, family caregivers in need for support do not always express this clearly, which requires some senstivity to subtle expressions of needs. Some participants mentioned that healthcare professionals may need to set aside their own opinions, wishes, and needs to make room for those of the family caregiver.

Knowledge regarding a variety of subjects (complicated grief (identification), referral options, cultural beliefs and rituals) was mentioned as a prerequisite to providing support. Additionally, knowledge was desired of the different approaches that may be required under different circumstances. For instance, an unexpected death versus an expected death, or the death of an older person versus the death of a young parent may require different approaches. Lastly, it was mentioned that strong initiative from individual healthcare professionals can be necessary to improve practice of supporting family caregivers within a healthcare team or on an individual level, rather than waiting for existing procedures to change.

Opportunity: Physical. The participants reported that supporting family caregivers would mean working (unpaid) overtime. The unavailability of reimbursement of support for family caregivers formed a barrier.

The availability of brochures to give to family caregivers was mentioned to facilitate providing support. Such brochures should provide information about the organization, the palliative phase and what to expect of the dying phase and after death, and possibilities for additional support. Facilities offered by the organization were also mentioned to be helpful, such as a separate 'family room' where informal conversations can be held with family caregivers, or the possibility for family caregivers to stay overnight. A checklist for conducting follow-up conversations after death was mentioned as a helpful tool. Some participants stipulated that such a checklist should be presented and used as a helpful guide rather than a scripted format as they prefer to conduct such conversations without strict guidelines.

Furthermore, administrative tools were reported to be helpful, such as the possibility to extensively report on the network around the patient in the electronic medical file and this information being accessible to every involved healthcare professional, including external disciplines. One participant also mentioned giving family caregivers access to the medical file, as it gives them control over when to retrieve information, decreasing dependence upon healthcare professionals. Administrative support from a secretary to send reminders and plan follow-up conversations after death was also mentioned.

The participants stipulated the necessity of family caregivers being in the picture while the patient is undergoing treatment, as well as the family caregivers being ready to receive support, which both were not always the case. Some participants also mentioned that they are often not notified of the death of a patient, which complicates providing support after death.

Lastly, support for family caregivers was suggested to be included in healthcare training and continued education. Courses on conversational skills were mentioned, but also on cultural rituals, and one that stimulated healthcare professionals to reflect on their own last phase of life to make them more aware of the family caregivers' situation.

Opportunity: Social. Standard routines embedded in healthcare organizations were reported to substantially affect the extent to which, and how family caregivers were supported. For instance, some organizations structurally invited family caregivers for a follow-up conversation, other organizations did not. The same goes for attending funerals, reporting on family

Table 6. Perceived Barriers and Facilitators by Healthcare Professionals to Providing Support for Family Caregivers Before and After Death.

COM-B Component	Identified Barriers and Facilitators	Barrier	Facilitator	Representative Quotes
Automatic motivation: Automatic processes involving emotional reactions, desires, impulses, inhibitions, drive states, and reflex responses	1. Satisfaction derived from supporting family caregivers		X	1: "*It makes you feel good when you can do something for someone. Through the years you learn so much from all different types of family caregivers. Everyone who deals, or copes with it in his or her own way or with their own family. Yes, it will always be unique and enlightening.*" (nursing staff, nursing home)
	2. Wish for closure as a healthcare professional		X	2: "*It gives you some sense of closure. We as healthcare professionals also have a relationship with some residents, so it [providing support after death] can also be a way for us to deal with the loss.*" (nursing staff, nursing home)
	3. Discomfort with supporting family caregivers	X		
	4. The relationship between the healthcare professional and the family caregiver	X	X	4: "*You wouldn't call the family caregivers of every patient [who dies], because you don't have contact with all families. Then it would be a phone call like "Why are you calling me when we don't know each other well at all?" So there has to some kind of relationship.*" (nursing staff, hospital)
Reflective motivation: Reflective processes involving plans and evaluations	1. (Not) considering supporting family caregivers as a responsibility	X	X	1: "*I think care is mostly targeted at the patient, and not on the people surrounding the patient. The patient remains the priority, while really you should be looking at it as a system.*" (nursing staff, hospital)
	2. Empathizing with family caregivers		X	2: "*Try to envision what you would want at such a time. I would really want to be involved in everything if I were the partner.*" (nursing staff, hospital)
	3. Considering supporting family caregivers as benefiting the patient		X	3: "*If you support the family caregivers, often the patient also becomes calmer. If he sees that family caregivers are looked after as well.*" (nursing staff, nursing home)
	4. Wish to learn from experiences of family caregivers in order to improve care		X	
Physical capability: Physical strength, skills, or stamina required to perform a behavior	*No identified barriers and facilitators*			
Psychological capability: The knowledge and skills to engage in the necessary thought processes	1. Conversational skills of healthcare providers	X	X	1: "*I think conversation techniques would help as well. Because how do you conduct a conversation when someone is very emotional, for example? It really helps to name those emotions, but not everyone knows this, so I think we need some training for that as well.*" (nursing staff, nursing home)
	2. Private life and work experience		X	
	3. Understanding the difficult situation family caregivers are in		X	3: "*I think it is important to explore what makes a family difficult. Most of the time there is so much pain underneath, not being able to bear watching your loved I change so much. Due to dementia, for example, or something else.*" (nursing staff, nursing home)
	4. Sensitivity to the needs of family caregivers		X	4: "*Some people don't want you to pop in constantly to see how they are doing or if they need anything. That is something you need to explore: 'how is someone wired?'*" (nursing staff, nursing home)
	5. (lack of) knowledge required to support family caregivers	X	X	
	6. Ability to take initiative		X	6: "*I was specialized in palliative care and I have proclaimed repeatedly "It is outrageous that we don't provide any bereavement care!" And eventually a pilot was set up and now bereavement care is embedded, so I think some of the responsibility also lies with us.*" (nursing staff, hospital)

(continued)

Table 6. (continued)

COM-B Component	Identified Barriers and Facilitators	Barrier	Facilitator	Representative Quotes
Physical opportunity: Opportunities as provided by the environment	1. Lack of time	X		
	2. Lack of reimbursement	X		
	3. Availability of brochures		X	3: "*Yes, maybe a bereavement folder, so that people can look up information such as: What happens when someone dies, or what if you feel really overwhelmed after that person dies?*" (nursing staff, nursing home)
	4. Facilities and tools provided by the organization		X	4: "*We have a family room just for family, so not for the patients. And if someone is there, I'll grab a cup of coffee and sit with them.*" (nursing staff, nursing home)
	5. Administrative tools and support		X	5: "*A transmural transfer system would be fantastic of course. One that goes wherever the patient goes and contains an extensive description of the family caregiver.*" (nursing staff, hospital)
	6. The family caregivers not being in the picture or ready to receive support	X		6: "*But there are also people that just don't want it, they really want to do it all themselves. It's only 5 percent or so, but they are there.*" (nursing staff, hospital)
	7. Available educational resources		X	
Social opportunity: Opportunities as provided by interpersonal influences, such as social cues and cultural norms	1. Practices and routines as determined by the organization	X	X	1: "*Personally, I think the right thing to do would be if we called people, just to see how they are doing. But that is not something we do.*" (nursing staff, hospital)
	2. Clarity on responsibility of individual healthcare providers	X	X	2: "*The only reason that we conduct follow-up conversations is as a friendly gesture, but we don't have a doctor-patient relationship with those people, so it is not in our domain.*" (physician, hospital)
	3. The relationship between the healthcare provider and the family caregiver		X	
	4. Complicated family relationships between family caregivers or their relationship with the patient	X		3: "*It is very complicated when a family is in conflict. When 1 daughter or son is not allowed to visit and the other 1 is, and then they call for information (…). It is heartbreaking not being allowed to answer their questions.*" (nursing staff, nursing home)
	5. Collaboration with other healthcare providers and disciplines	X	X	5: "*I often ask the spiritual counsellor to get involved. (…) They learn many conversation techniques that we don't know (…). And often they can make real progress (…). So you don't have to do it alone. You just have to involve the available internal disciplines to make sure that support before and after death is as smooth as possible.*" (nursing staff, nursing home)
	6. Support for the healthcare professional		X	6: "*I can only do this job because I have a great team around me that I am comfortable asking for support, because if I didn't have that… I wouldn't be able to do this job with so much passion and dedication.*" (nursing staff, hospital)

caregivers in the medical file, or sending a sympathy card. However, the participants felt that designing a one-fits-all protocol would not meet the diverse needs and wishes of family caregivers. Some protocols can also interfere with supporting family caregivers, such as a protocol that dictates family to remove all personal belongings from the room within a few days after the patient's death.

Responsibilities of individual healthcare professionals with regard to supporting family caregivers were unclear. Some participants questioned whether supporting family caregivers fit their function description at all, and others wondered when they should refer to external services or leave it to the initiative of the family caregivers.

A strong and longstanding relationship between the family caregiver and the healthcare professional was reported to help understand the family caregiver's needs and to start conversations about sensitive topics. Complicated relationships between family caregivers or between patient and caregiver(s) formed a barrier as it can cause tensed social situations.

Another facilitating factor was easily accessible collaboration with other healthcare professionals, for example between nurses and physicians, but also between healthcare teams and other disciplines, such as palliative consultations teams, transfer agencies, spiritual counselling, psychologists and the GP. Multidisciplinary meetings were reported to facilitate such close collaboration.

Lastly, to deliver high-quality support for family caregivers, the healthcare professionals felt they also needed support themselves. They needed to be aware of their personal boundaries and be sure not to cross those. Personal connections with team members and a safe environment in which difficulties can be discussed helped participants to feel supported. Close contact with colleagues also offers opportunity to learn from each other.

Discussion

This study showed that most, but not all healthcare professionals working in institutional settings in the urbanized western part of the Netherlands occasionally or more frequently inquire after the wishes and needs of family caregivers of patients with life-threatening diseases, but one-third does not provide support after death. These findings are in line with previous literature demonstrating that support for family caregivers is provided ad hoc and depends on circumstances, preferences, and intuition of individual healthcare professionals.[8-12] The identified barriers in this study, such as the experienced discomfort of healthcare professionals when dealing with family caregivers or not feeling responsible for their wellbeing, limited knowledge and conversational skills, and shortage of resources, help to understand why support for family caregivers is not part of routine practices. These results correspond with previous literature in more specific target populations.[11,13,14]

Interventions aiming to improve family caregivers' outcomes have proven effective.[5-7,19,20] However, the barriers experienced by healthcare professionals may have to be overcome first, or parallel to implementing such an intervention, which requires a certain extent of organizational change. Organizational support is necessary to provide the necessary time, money, tools, and facilities, and to train and educate healthcare professionals. Furthermore, the organization holds a responsibility to care for their employees.[21,22] When these preconditions are met, healthcare organizations can work towards a more systematic approach to providing support for family caregivers. Support after death appears to be in most need of improvement, but also during the illness-trajectory healthcare professionals should feel sufficiently comfortable, knowledgeable and motivated to support family caregivers. Structured use of needs assessment tools may help to achieve this.[6,23,24]

To facilitate implementation of enhanced support for family caregivers, Parmar et al[25] recommend, among others, composing a multidisciplinary implementation team, ensuring support from senior management, and the availability of a toolkit that contains intervention strategies. The mapping of barriers and facilitators to the COM-B system enabled us to use the Behavior Change Wheel[15] to formulate possible intervention strategies. These suggestions are shown in Table 7 and include setting up peer-to-peer coaching to decrease experienced discomfort, and investing time in facilitating closer collaborations with other disciplines within or outside the organization. These intervention strategies should be carefully considered for suitability in the specific context of a healthcare organization[25,26] and should meet the APEASE criteria[26] within this context (Acceptability, Practicability, Effectiveness, Affordability, Side-effects, Equity).

Strengths and Limitations

Our study has several strengths. The survey was multi-professional and covered multiple settings, and its sample size was relatively large. Further, the use of the Behavior Change Wheel framework allowed for practical, actionable suggestions to improve support for family caregivers within healthcare organizations based on the identified barriers and facilitators. The study also has limitations. First, as the survey was self-developed and not pre-tested, we cannot report on its validity and reliability. Further, due to the retrospective nature of this study and use of self-reported questions, it is possible that participants were unable to fully recall the support delivered to caregivers. Third, only a few survey respondents worked in hospices. Fourth, the response rate to the survey was low. Therefore, we might overestimate the proportion of healthcare professionals that structurally support family caregivers. Last, the urban setting of the study differs from rural settings in a relevant manner, as the frequency or normalcy of informal care and community support, and thus the (expected) role of the family caregiver, can differ.[27,28]

Table 7. Examples of Possible Interventions Based on the Identified Barriers and Facilitators and the Behavior Change Wheel.

COM-B Component Identified in the Data Linked with Intervention Functions according to Behavior Change Wheel	Possible Interventions APEASE Criteria: Affordable, Practical, Effective, Acceptable, Safe and Equitable
MOTIVATION – reflective responses Required intervention functions: Education[a] Persuasion[b] Incentivization[c] Coercion[d]	1. Organizing lessons on the importance of supporting family caregivers 2. Using visual material (eg videos of bereaved family caregivers describing their experiences and needs) to persuade healthcare providers of the importance of providing support for family caregivers 3. Management addressing the topic of supporting family caregivers on a regular basis and giving verbal rewards when such support has been provided. Management may also identify cases of insufficient attending to the needs of family caregivers
MOTIVATION – automatic responses Required intervention functions: Persuasion Incentivization Coercion Environmental restructuring[e] Modelling[f] Enablement[g]	1. Providing prompts for professionals to provide grief support, for example posters or email reminders that remind healthcare providers of the importance of supporting family caregivers 2. Peer-to-peer coaching or a buddy system, matching healthcare providers that are comfortable with supporting family caregivers to healthcare providers that are less comfortable or deem supporting family caregivers to be unnecessary 3. Supervisors role modelling the behavior aimed for 4. To prompt team-based goals regarding providing support for family caregivers and give (verbal) rewards when goals are achieved. (eg inviting every bereaved family caregiver for a follow-up conversation after a patients' death)
CAPABILITY – psychological Required intervention functions: Education Training[h] Enablement	1. Providing training options (eg conversational skills) to healthcare providers to increase their competencies to provide support for family caregivers 2. Organizing lessons on the many ways healthcare providers can support family caregivers and the factors that need to be taken into account while doing so, such as cultural background, referral options, and identification of complicated grief 3. To facilitate feedback on performance, such as frequent team meetings in which experiences with supporting family caregivers are discussed so that healthcare providers can learn from each other
OPPORTUNITY- social Required intervention functions: Restriction[i] Environmental restructuring Enablement	1. Creating a supportive environment in which healthcare providers feel comfortable sharing their insecurities and difficult experiences, for example through the means of regular supervision session among peers 2. Management presenting guidelines and/or protocols with regard to supporting family caregivers (eg inviting bereaved family caregivers for a follow-up conversation 6 weeks after a patients' death) 3. Management enabling different disciplines and healthcare providers with different functions to work in close collaboration (eg for sources of information and for referrals) so that together they provide high-quality support for family caregivers
OPPORTUNITY – physical Required intervention functions: Restriction Environmental restructuring Enablement	1. Creating smart solutions to create the necessary extra time to devote to family caregivers 2. To create opportunities for healthcare providers to have the practice of supporting family caregivers reimbursed 3. The provision of tools and facilities that can help healthcare providers to support family caregivers (eg brochures with information for family caregivers, tools for healthcare providers that help with conducting a follow-up conversation, a family-room within the organization where difficult conversations can be held)

[a] Education: increasing knowledge or understanding.
[b] Persuasion: using communication to induce positive or negative feelings or stimulate action.
[c] Incentivization: creating expectation of reward.
[d] Coercion: creating expectation of punishment or cost.
[e] Environmental restructuring: changing the physical or social context.
[f] Modelling: providing an example for people to aspire or imitate.
[g] Enablement: increasing means/reducing barriers to increase capability or opportunity.
[h] Training: imparting skills.
[i] Restriction: using rules to reduce the opportunity to engage in competing behaviors.

Future Research

Based on the current findings, an intervention can be developed, implemented and evaluated in a variety of healthcare settings to reach more structurally embedded support for family caregivers in palliative care. Suggestions made based on the Behavior Change Wheel (Table 7) can inspire interventions.[15] Further research could also investigate barriers and facilitators specific to the home care setting. Our study did not include professionals practicing in home care settings, yet supporting family caregivers in this setting may come with specific challenges such as disconnection with family caregivers during hospitalization of the patient, and extra vulnerability as the dying phase approaches.[29]

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Netherlands Organization for Health Research and Development (ZonMw) under grant numbers 844001312 and 844001706.

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Supplemental Material

Supplemental material for this article is available online.

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