

# Resilience for family carers of advanced cancer patients – how can health care providers contribute? – A qualitative interview study with carers

Ingebrigt Røen<sup>1,2</sup>, Hans Stifoss-Hanssen<sup>3</sup>, Gunn Grande<sup>4</sup>, Anne-Tove Brenne<sup>1,5</sup>, Stein Kaasa<sup>1,6</sup>, Kari Sand<sup>1</sup>, Anne Kari Knudsen<sup>1,6</sup>

## Abstract

**Background:** Caring for advanced cancer patients affects carers' psychological and physical health. Resilience has been defined as "the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of threat".

**Aim:** The aim of this study was to explore factors promoting carer resilience, based on carers' experiences with and preferences for health care provider support.

**Design:** Qualitative, semi-structured, individual interviews with family carers of advanced cancer patients were performed until data saturation. The interviews were recorded, transcribed, and analyzed using systematic text condensation.

**Setting/participants:** Carers (n=14) of advanced cancer patients, not receiving curative treatment, admitted to an integrated curative and palliative care cancer outpatient clinic or to a university hospital cancer clinic, were included.

**Results:** Fourteen carers of advanced cancer patients were included; seven men, seven women, mean age 59; three were bereaved; 12 were partners; five had young and teenage children. Four main resilience factors were identified: 1) being seen and known by health care providers – a personal relation; 2) availability of palliative care; 3) information and communication about illness, prognosis and death; and 4) facilitating a good carer-patient relation.

**Conclusions:** Health care providers may enhance carers' resilience by a series of simple interventions. Education should address carers' support needs and resilience. Systematic assessment of carers' support needs is recommended. Further investigation is needed into how health care providers can help carers and patients communicate about death.

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<sup>1</sup> European Palliative Care Research Centre (PRC), Department of Cancer Research and Molecular Medicine, NTNU, Trondheim, Norway

<sup>2</sup> Chaplaincy, St. Olavs Hospital HF, Trondheim University Hospital, Norway

<sup>3</sup> VID Specialized University, Center of diakonia and professional practice, Oslo, Norway

<sup>4</sup> Division of Nursing, Midwifery and Social Work, The University of Manchester, England

<sup>5</sup> Cancer Clinic, St. Olav's Hospital, Trondheim University Hospital, Trondheim, Norway

<sup>6</sup> Department of Oncology, Oslo University Hospital, Oslo, Norway

## Corresponding author:

Ingebrigt Røen, European Palliative Care Research Centre (PRC), Department of Cancer Research and Molecular Medicine, Norwegian University of Science and Technology (NTNU), Trondheim, Norway  
Chaplaincy, St. Olavs Hospital HF, Trondheim University Hospital, Norway

E-mail: ingebrigt.roen@stolav.no

## **Key words**

Resilience, cancer, palliative care, family caregivers, support, preferences, needs assessment, interview

### **What is already known about the topic?**

- Caring for advanced cancer patients (ACPs) negatively affect carers' health, relations, and bereavement outcomes, and the carers need more support
- Research has tended to focus on carers' problems, and interventions to solve the problems
- Research on how HCPs' behaviour and attitudes could promote carer resilience is scarce

### **What this paper adds?**

- This paper focuses on how health care providers (HCPs) can contribute to enhancing carers' resilience
- Carers reported important support from health care providers: Being seen and known – a personal relation to HCPs; availability of palliative care; information and communication about illness, prognosis and death; and support to maintain good relations to patient and family
- Carers and patients may have conflicting support preferences and need communication assistance from health care providers

### **Implications for practice, theory or policy**

- HCPs should create a trustful relationship to carers, and HCPs who carers trust should be available 24/7
- HCPs should receive practical education in how to communicate with carers about illness, prognosis and death, and how to facilitate carer-patient communication about the same
- There should be pro-active, systematic assessment of carers in order to explore what is best support for the individual carer

## Introduction

In cancer palliative care, carers are exposed to the psychological and physical suffering, inevitable decline, and death of a close person. “Family caregiver” and “informal carer” have been used interchangeably with “carer” in the literature; “carer” will be used in the following. To be a carer of an advanced cancer patient throughout an often complex disease trajectory with several symptoms and treatment interventions, as well as the fear of losing a close person, is associated with considerable burden, and has been reported to negatively affect carers’ psychological and physical health, relations, and bereavement outcomes (1-3).

Carers play an important role in supporting patients (4). Studies have reported that carers of advanced cancer patients receive too little support (5, 6). Recommendations from the European Association for Palliative Care (EAPC) Task Force on Family Carers state that improvement of carer support is needed e.g. as information, psychological support such as counseling, education, out-of-hours support, crisis prevention, respite care, and assessment of support needs (6, 7). A review reported that carers often are not seen by health care providers (HCPs), or recognized for their burden, and that HCPs should give more support to carers to improve their health and well-being. It was also reported that educational or counseling interventions aiming at improving the carer-patient relation, and handling conflicts and losses may have a positive effect on coping and quality of life (5).

Resilience protects against carer burden (8), and has been found to be associated with better carer outcomes (9). The American Psychological Association (APA) defined resilience as “the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of threat”, and stated that the primary resilience factor is supportive and caring relations (10). In this study resilience is used as a multidimensional concept in the sense that factors influencing resilience could be personal, relational, and environmental (11). It has thus been suggested to promote carers’ resilience by enhancing their physical, mental, social, and spiritual/existential resilience (12), in accordance with the World Health Organization’s (WHO) definition of palliative care (13). However, there is a lack of research concerning how HCPs can contribute to resilience in carers of advanced cancer patients.

On this background, and as part of an ongoing evaluation of a newly established totally integrated outpatient clinic for oncology and palliative care, the “Orkdal Model” (14, 15), the aim of this study was to elucidate the contribution of health care providers to resilience in carers of advanced cancer patients. Improved carer support could improve patient outcomes (4, 16). Based on carers’ experiences with and preferences for HCP support, the following research questions were addressed:

1. What are carers of advanced cancer patients’ experiences with and preferences for support from health care providers?
2. How does support from health care providers contribute to resilience in carers?

## Methods

### *Design*

This study used a qualitative exploratory design with individual, semi-structured interviews with carers of advanced cancer patients.

### *Participants and setting*

A total of 15-20 carers of patients with advanced cancer, not receiving curative treatment, were planned to be included, or until saturation. The carers were identified as primary carers by the patients. Purposeful sampling guided the inclusion of carers, seeking to obtain a maximum variation in sex, age, relation to the patient, area of residence, employed, retired, having children at home or not, and stages of the patient's disease. Experience from diverse locations of care was sought for. Inclusion criteria were: Age 18 years or above, carer of advanced cancer patients, and providing written, informed consent.

The carers were recruited from two sites of the oncology department of St. Olavs Hospital, Trondheim University Hospital: 1. the integrated curative and palliative care cancer outpatient clinic at the local hospital Orkdal (hereafter: Orkdal), and 2. the cancer clinic at Trondheim University Hospital (hereafter: Trondheim). In Orkdal, carers being included in a local ongoing prospective controlled non-randomized study, were approached (17). In Trondheim, carers were recruited from the integrated oncology and palliative care department. Patient consent was obtained before approaching carers for participation. A dedicated study nurse, one at each site, identified carers who met the inclusion criteria. The study nurses or IR approached the carers for participation face-to-face or by telephone.

Seventeen carers were approached for participation, 11 in Orkdal, and six in Trondheim. The carers' experiences stemmed from home care and nursing homes in nine municipalities; and from cancer outpatient clinics and palliative wards at two hospitals.

### *Data collection: semi-structured interviews*

Qualitative semi-structured interviews were conducted with carers by IR, and were performed with the carer alone, in rooms where confidentiality and no interruption were secured. Each carer was interviewed once. The interviews were based on an interview guide (Table 1). Predefined questions and sub-questions were used when needed to encourage carers to share experiences and to ensure that all themes were covered. A natural flow in the carers' reporting was sought to explore both rewarding and burdensome experiences with support from HCPs.

**Table 1.** Main Interview Topics

1. How is the patient doing?
2. Can you tell me how it has been for you to be the carer of a cancer patient?
3. How have you experienced the meeting with the health care system?
4. Can you tell me about your experiences with health care providers (HCPs)?
5. How can HCPs best support you?
6. Do you remember times that were particularly difficult for you as a carer and for your family?
7. What support needs have others in the family and others close ones had?
8. How can HCPs best support children and young people?
9. What may promote or hamper HCPs' support to you and your family?
10. What gives/has given you motivation and strength to be a carer?

### **Data analysis**

The audio-recorded files were transcribed verbatim, and analyzed according to the principles of systematic text condensation as presented by Malterud (18-20). Systematic text condensation consists of four steps: identifying themes based on a total impression of the interviews, identifying, coding and grouping meaning units, condensing the content of the meaning units across the interviews, and finally summarizing the findings. Two authors (IR, and AKK or HSH) read and analyzed all interviews independently. The findings were compared and discussed by all three at each stage of the analysis.

### **Ethics**

The Helsinki declaration was followed. The study was approved by the Regional Committee for Medical Research Ethics Central (2014/212).

### **Results**

Fourteen carers of advanced cancer patients, living in nine municipalities, agreed to participate, 11 in Orkdal, three in Trondheim; seven males and seven females, mean age 59 years, 12 were partners of the patients, two were daughters (Table 2). The patients had advanced cancer and were enrolled in a palliative care programme (Table 3). In Trondheim, three carers refused to participate; one gave difficult relations as a reason; two gave no reason. Interviews were performed between 25.11.2015 and 23.6.2016, were on average 60 minutes long, and occurred in doctor's office (n=11), in chaplaincy's meeting room (n=1), in carer's workplace office, (n=1), and in carer's home (n=1). Eleven were still caring, three were bereaved.

**Table 2.** Carer characteristics (n=14)

		<b>N</b>	<b>Mean</b>	<b>Range</b>
Gender	Women	7		
	Men	7		
Age			59	36-83
Relation to patient	Partner	12		
	Daughter	2		
Have children <18 at home	Yes	5		
	No	9		
Age of children		3		0-6
		1		7-12
		5		13-17
Same household	Yes	12		
	No	2		
Employment status	Active	6		
	Sick leave	2		
	Retired	6		

Highest education completed		
Prim.school	2	
High school	9	
University	3	

**Table 3.** Patient characteristics (n=14)

	N	Mean	Range
Gender			
Women	8		
Men	6		
Age		64	34-84
Deceased before interview	3		
Weeks before interview		26	16-32
Deceased after interview	9		
Weeks after interview		23	9-58
Metastatic cancer	13		
Locally advanced cancer, receiving pall. treatment	1		
Cancer site:			
Breast	4		
Colon	3		
Gallbladder	1		
Kidney	1		
Lymph	1		
Pancreas	1		
Prostate	2		
Skin	1		
ECOG/WHO performance status	11		
0	1	1,2	
0-1	2		
1	4		
1-2	1		
2	2		
3	1		
4	0		

### HCP related carer resilience factors

In the following, superscript numerals refer to quotes

When the participants talked about their experiences of support from HCP, they referred to various professions at the hospital and in the community: oncologists, nurses, general practitioners, secretaries, physiotherapist, occupational therapists, chaplains, and social workers. Overall, the carers reported satisfaction with the support received from HCPs<sup>1</sup>.

*<sup>1</sup>I: Is there any support you have needed as a carer, but not received? P: No, I can't think of anything" (9,140-141). "From then on (cancer diagnosis) it has been fantastic" (1,579).*

Four main categories of support from HCPs were identified as resilience factors (Table 3).

**Table 4.** Resilience factors identified by carers of advanced cancer patients

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| <ol style="list-style-type: none"><li>1. Being seen and known – a personal relation to health care providers</li><li>2. Available palliative care</li><li>3. Information and communication about illness, prognosis, and death</li><li>4. Facilitating a good carer-patient relation</li></ol> |
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***Being seen and known – a personal relation to HCPs***

Seeing the carer, and not only the patient, was reported to be the most important support HCPs could give<sup>2</sup>.

*<sup>2</sup>I: What is the most important from HCPs to your mind? P: I think – that they see me too", (1,308-309).*

Seeing carers meant being interested in them, actively taking contact with them, talking to them, asking them how they were doing, being updated on the patient's illness, symptoms and treatment, and knowing how this affected the carer. The carers felt that HCPs knew them, and this made them feel safe, and also made it easier for them to ask questions<sup>3</sup>.

*<sup>3</sup>"It feels so safe. They know who we are" (3,49-51). "... it's easier to ask somebody you know" (5,485-486).*

It was reported that HCPs should ask carers individually about their preferences for support<sup>4</sup>.

*<sup>4</sup>"HCPs should just ask what we need, I think. Because it's so individual, in my head, because what I need, you perhaps don't need. And it's a bit like that. I actually think they just have to jump into it and ask, even though it may be a bit awkward to ask – often. But, they are, well, most have worked for many years, so they manage to a large extent to read people. They do. So, praise to them!" (13,393-396).*

Outside the outpatient clinic, some carers had felt overlooked by HCPs in some situations<sup>5</sup>.

*<sup>5</sup>"... I feel a little excluded, you might say. Because they don't ask me about much there, carers are kind of ... people who are there, but who could as well not have been there ... . It's*

*weird to say that (laughs). (...) they address only him [the patient] "I can't say they've asked me how I'm doing" (4,293-299).*

Being overlooked could hurt and bring them to tears<sup>6</sup>.

*<sup>6</sup>"... if they'd cared only about NN (name of the patient) leaving me in a corner the whole day long, I don't know..." (about to cry) (1,310-312).*

In most situations, the patient was in focus. HCPs coming to talk specifically with the carers made them feel cared for<sup>7</sup>.

*<sup>7</sup>"... like when we are in consultations with the doctor, you know, then he concentrates on NN [name of patient], but - I always follow him every single time - but it's the fact that she [name of nurse at the outpatient clinic] comes and talks with me that makes me feel taken care of" (7,135-138).*

### **Available palliative care**

Contact information for support from HCPs 24/7 was reported to be available, e.g. phone numbers "hanging on the fridge"<sup>8</sup>.

*<sup>8</sup>"...she's [the patient] got phone numbers she can use hanging on the fridge..." (3,291-292).*

The carers were confident that palliative care would be available when needed, both in specialist and community care; this made them feel safe<sup>9 10</sup>.

*<sup>9</sup>"It's extremely good to have the Home Care. That's a safe reference point, because that's every day the whole year, you know. (...) When you need it, they're there" (6,225-229).*

*<sup>10</sup>"And we've got a GP who is fantastic. I think we're the only ones who've received her personal phone number and we're welcome to call, whenever. (...) She knows everything, all three of us have her as our GP, so she knows the family in and out. So she's fantastic, actually" (13,195-200).*

When HCPs worked pro-actively to assess needs and to inform, this empowered the carers. Carers found it important that e.g. community cancer nurses visited patients and carers at home, assessed needs, informed about help available, and gave carers the opportunity to ask and communicate<sup>11 12</sup>.

*<sup>11</sup>"...everything has been very good. And we got the cancer nurse in NN [name of place] where I live at the door. They have come a couple of time to support us, and 'just call!' and come with brochures – we've got phone numbers and what help they can give us and we are welcome to call" (2,239-242).*

*<sup>12</sup>"The occupational therapist paid us a visit, and that really opened for possibilities we hadn't thought of" (4,390-391).*

HCPs called pro-actively on a regular basis<sup>13 14</sup>.

*<sup>13</sup>"...when the doctor calls about a result, I ask them about everything I want to know there and then" (3,221-222).*

<sup>14</sup>“...they [HCPs at the Cancer outpatient clinic] call her [the patient] at home (...) every two weeks I think” (3,64.70).

The positive contributions of community cancer nurses were often mentioned in the interviews. However, some carers reported that they had to actively contact HCPs in order to be consulted about decisions, or to obtain communication with HCPs<sup>15 16</sup>.

<sup>15</sup>“NN [the patient] has been hospitalized in other wards here, and – at least when I’m there – they never talk with her” (3,256-257).

<sup>16</sup>“ I don’t think I talked with anyone, except when I went to ask myself (...). Concerning in town, it would perhaps have been all right if they came to the patient room (...), perhaps greeted us, asked who we are (...) tried to show themselves kind of (...), then it would be much easier to know who to ask too” (5,235.526-534).

### **Information and communication about illness, prognosis and death**

It was important to receive prognostic information and to get help to communicate with the patient to prepare for the future, the death and the funeral. Carers wanted HCPs to listen to children, and answer their questions without hiding the reality<sup>17 18</sup>.

<sup>17</sup>I: How do you think HCPs can give best possible support to children and young people? C: I think the best is if you get to know things the way they are” (8,398-399).

<sup>18</sup>“I think it’s extremely important that they have time to answer their [children’s] questions” (3,421).

Most carers reported overall to have received direct and honest information about the seriousness of the patients’ illness<sup>19</sup>.

<sup>19</sup>“We were constantly told how things were” (5,220).

The carers underlined the importance of such information<sup>20</sup>.

<sup>20</sup>“...and they must be clear and honest and say how things are. I find that important” (3,506-507).

Two patients did not want information about short life expectancy, contrary to their carers’ preferences<sup>21</sup>.

<sup>21</sup>“So when I was together with her, nobody would break their deal with her (sighs), and personally, what I miss most now, is to have had a talk with NN [name of the deceased] about what she actually wanted when she died” (8,146-150).

HCPs and carers followed the wishes of the patients<sup>22 23</sup>.

<sup>22</sup>“Our model has been that she sits in the front seat. So she decides, and has decided how we should handle this. And I follow her decisions. But that means that I haven’t had that much contact with the health services” (12,75-78).

<sup>23</sup>*"It was never said in a way that made me understand how serious it was. I wasn't at all prepared for her to die" (8,140-142).*

Thus, two carers got less information than they reported to have wanted and needed, and reported that this negatively affected their preparedness for death and funeral, and their relation to the patient<sup>24 25</sup>.

<sup>24</sup>*"... that is what I've found it hardest to find peace with: did she want to be buried here or did she want to be buried in NN [name of place]?" (8,203-205).*

<sup>25</sup>*"We haven't talked about death, for example (...) And not having those kind of talks has affected our relationship (...)" (12,221-222.228-229).*

The two carers suggested two interventions: that HCPs offer carers to talk alone, and to provide counseling for couples<sup>26 27</sup>.

<sup>26</sup>*"But I kind of wish that somebody had grabbed hold of me and said: 'do you want to talk face to face', or something like that" (8,174-175).*

<sup>27</sup>*"Let us meet in three months to hear which road you have chosen. What have you chosen, which model do you seem to be choosing now? Let us talk a little about the advantages and disadvantages with it" (12,673-675).*

### **Facilitating a good carer-patient relation**

Some carers described their own and the patients' personal traits with potential relevance for their resilience as individuals and as a carer-patient unit<sup>28 29</sup>.

<sup>28</sup>*"I'm not the kind of person who worries about what will come" (4,189-203).*

<sup>29</sup>*"She's a pessimist and I'm an optimist" (10,73).*

A good carer-patient relation was very important for the carers' resilience. Being able to help in a way that the patient appreciated, was crucial, especially if the relation to the patient was strained<sup>30 31</sup>.

<sup>30</sup>*"I: What has given and gives you strength and motivation to be a carer? C: First of all that NN [name of patient] is so grateful that I'am here. And that we've had such a good relation. I'll do all I can to help him" (1,991-994).*

<sup>31</sup>*"What has given you and gives you motivation and strength to be a carer?" C: "It's that, I think, that it's useful for her, that she appreciates it (...) that it makes her life easier. That is the motivation. And through that (choked) easier for the kids too" (12,596-604).*

However, it seemed that the patient was a resilience factor up to a certain point. When patients were very ill, their behavior might change, i.e. criticizing the carer, which was difficult to handle for carers<sup>32 33</sup>,

<sup>32</sup>*"... he looked at me with horrible eyes (...) as if I were a troll" (7,271)*

<sup>33</sup>*“And it’s a strain if he’s discontent (...) so if he talks somewhat critically to me, it’s hard on me (...). Because then I feel that I’m unable to encourage him, since I’m a little down myself” (4,112-116).*

or talking excessively about the illness, making the carer want HCPs to come and talk illness with the patient regularly<sup>34</sup>.

<sup>34</sup>*“...he’s got an enormous need to talk with many people and ask about the same, so if they could come a little often, perhaps, and talk to him, then they support a lot” (4,406-410).*

To work was for some carers rewarding and important to maintain a good relation to the patient; for others a barrier to staying in a meaningful relation to the patient, making them want financial support to stay with the patient<sup>35 36</sup>.

<sup>35</sup>*“My job is devilishly fun (...). Then I’m very far away from everything. If I dive into a funny professional issue, then I’m completely gone. That motivates me” (12,618-623).*

<sup>36</sup>*“... I was on sick-leave for a year after she got worse, and it was very hard to start working again, ‘cause I felt I had to leave her alone, ‘cause she was still pretty ill, but I had no choice! ‘Cause the state doesn’t pay those who sit there watching over [the patient]” (9,195-200).*

## **Discussion**

Semi-structured interviews with carers’ of advanced cancer patients were conducted to explore their preferences for support from health care providers (HCPs) and how the support could promote carer resilience, defined as “the process of adapting well in the face of adversity, trauma, tragedy, threats or even significant sources of threat” (10). Carers were overall satisfied with the support given. A personal relation to HCPs was identified as a particularly important resilience factor, while other identified resilience factors were available palliative care, information and communication about illness, prognosis and death, and a good carer-patient relation.

The most evident finding was the great positive importance the carers attributed to being seen by HCPs, i.e. being seen as an individual with particular strains and support needs. When HCPs regard the patient as their primary responsibility, the carer may feel overlooked (21). Carers reported a need for HCPs assessing their needs for support individually, and a wish to be treated “like guests” in the sense of being welcome, respected, and paid attention to.

In some studies, carers have reported that HCPs have contributed to augment their carer burden (22-24). HCPs may support or hurt by their attitude. Carers of advanced cancer patients are often in crises, are vulnerable, and dependent on the HCPs for information, treatment, and care. Thus, carers need to be seen, and HCPs are in a special position to do so. Due to HCPs’ knowledge about cancer and experiences with carers and patients in similar situations, HCPs might understand the carers’ burdens and needs better than friends and family. The present study points to the fundamental importance of the attitude and relational skills of HCPs to promote carer resilience. HCPs should devote energy and time to establish a good relation to carers, e.g. simply by greeting them and asking about their well-being.

Resilience was found to be promoted by available support from HCPs whenever needed. The reported availability of palliative care services in or close to home spared patients and carers from exhausting trips to hospital, and probably led to a reduced number of hospitalizations, as intended in governmental policy documents (25). Trust in the availability of support from HCPs made carers feel safe, as reported elsewhere (26, 27). Regular contact on the phone and contact information was essential. The importance of telephone services in rural areas (28), and contact information to help 24/7, concur with other studies (29, 30).

The community cancer nurses seemed to be key persons for creating safety in carers. They were described as persons pro-actively contacting and assessing patient's and carer's needs, informing carers about available support, and coordinating services. The importance of the cancer outpatient clinic in Orkdal was evident; oncologists and cancer nurses knew the carers well and was a safe reference point throughout the disease trajectory. HCPs may tend to wait for the carers to present their needs and ask for support. However, carers may not know what to ask about, and may think that HCPs do not regard carers' needs as their responsibility. Pro-active, systematic work with carers empowers carers to know what support is available and choose the support they prefer.

Information about illness, prognosis, and death as well as support regarding how to communicate with the patient about these themes, enhanced carers' resilience by facilitating preparedness for death and by improving the relation to the patient. Carers wanted to talk with the patient about illness and death to prepare for death and funeral, which is supported by other studies (29, 31). The present study revealed conflicting interests between patients and carers concerning information and communication about prognosis. In most countries, including Norway, information about prognosis can only be given to carers if the patient consents (32, 33). Guidelines endorsed by key national and international organizations recommend HCPs to assess carers' preparedness for death, and assist carers in such preparations (34). Carers in the present study suggested two interventions for such situations: to talk with a HCP alone, and counselling for couples. However, according to the guidelines, patients have the right to refuse. Furthermore, despite the fact that studies have shown that carers and patients need help to communicate about prognosis and death (35), and that being prepared for death positively affects bereavement outcomes (36, 37), the guidelines recommend none of these.

It is an ethical dilemma for HCPs that information important to the carer cannot be given due to confidentiality towards the patient. Carers - and patients - lose the possibility to talk about how to live as well as possible with the diagnosis, and to prepare for death, which might also have strengthened their relationship. Thus, giving priority to the patients' wishes may result in carers' suffering. It might be argued to strengthen carers' rights and offer them more intensive support in cases where carers' needs conflict with patients'. Palliative care is team work (13). Family therapists, chaplains, and professional social workers are team members who have special qualifications for implementing the two suggested interventions.

The findings support the importance of the palliative care approach to include both patient and family to optimize services (13). A non-professional carer has been shown to be an important prerequisite for home death (16, 38). Palliative care services increase carers' health related quality of life and satisfaction with care (39-41). However, to systematically include carers as part of daily clinical practice in a busy outpatient clinic may be challenging, but should be aimed for.

The relation to the patient was for most carers an important source of resilience and gave value and meaning to the carers' life. The hardships of caring gave meaning if the patient appreciated their presence and support. Carers were vulnerable and easily hurt if the patient criticized their efforts (42, 43). To promote carer resilience HCPs should acknowledge the importance of the patient as the carer's potentially most important support and source of resilience. A husband-wife relationship risks to be transformed to only a carer-patient relation. However, HCPs can enable carers and patients to be partners by e.g. relieving carers from some carer tasks. HCPs should facilitate a supportive carer-patient relation.

### ***Strengths and limitations***

A strength of this study was the broad variation in carers' experiences, covering home care and nursing homes in nine municipalities; and two hospitals' cancer outpatient clinics and palliative wards. A varied sample in terms of sex, age and employment status was also obtained. The selection assured a variation in the patients' symptom burden at the time of the interview. Another further strength was that all interviews were performed by an experienced interviewer. A limitation was that all, except two carers, were partners of the patient. Another limitation was that the carers interviewed were overall very satisfied with the care provided, thus limiting the perspectives from unsatisfactory care situations. Furthermore, the number of patients with heavy symptom burden was limited. However, inclusion of bereaved carers (n=3) gave insight in experiences from the time close to and around death.

### **Conclusions and implications**

Based on the current study and in light of previous literature, it could be recommended that HCPs make an effort to establish a good and trustful relation to the carers, i.e. by greeting them, and showing interest for their life as a whole and as an individual with separate needs, and thus enhance their resilience. Systematic assessment of carers' support needs is recommended. HCPs should have separate talks with carers as a routine to assess their needs. Education of HCPs should address carers' support needs, and communication between carer and patient about prognosis and death.

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