



# Gender-specific problems and needs of family caregivers during specialist inpatient palliative care: a qualitative study on experiences of family caregivers and healthcare professionals

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**Background:** Previous studies have demonstrated gender-specific impacts on symptoms and problems of patients receiving palliative care; however, there is limited knowledge about the impact of gender on the problems and needs of their family caregivers (FCs).

**Methods:** Using a qualitative design, semi-structured interviews with FCs and healthcare professionals (HCPs) of a specialist palliative care inpatient ward were conducted. Themes and categories were identified using qualitative content analysis, with data coded using MAXQDA.

**Results:** Ten FCs (6 female, 4 male) and 16 HCPs (8 female, 8 male) were interviewed. Analysis revealed seven main categories of gendered problems and needs: role as FC, physical and emotional burden, self-care and coping strategies, adaptation to new life circumstances, interaction with the palliative care team, use of psychosocial or care-related support, as well as advance care planning and caregiving after inpatient palliative care. Stronger identification with the caregiver role, less consideration of own needs, and more active utilization of professional and informal support were ascribed to female FCs. With regard to male FCs, respondents had the impression of better self-caring strategies, less expressiveness of emotions, less involvement in care and more target-oriented interactions with the palliative care team.

**Conclusions:** Gender has a relevant impact on roles, coping, communication and support as well as psychosocial needs of FCs of patients receiving palliative care. These gender-related aspects have to be taken into account during palliative care including care for FCs.

**Keywords:** Gender; gender bias; end-of-life; palliative care; family caregiver (FC); qualitative study

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## Introduction

Due to role expectations people attribute male or female characteristics to themselves, resulting into a role picture which is called gender, the social or psychological sex (1). As

it is an all-encompassing phenomenon, it is not surprising that studies on patients receiving palliative care suggest gender as a highly relevant variable (2-7). Understanding the impact of gender on problems and needs of family

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caregivers (FCs) may lead healthcare professionals (HCPs) to provide better caregiver support during palliative care of patients. However, most of the evidence on gender associations is related to palliative patients' symptomatology and quality of life. Although it is a main principle of palliative care to consider patients and their FCs as a unit of care (8), evidence on the impact of gender on needs of FCs is rare and needs to be improved urgently (9).

Prior studies reporting results of gender analyses found that female FCs caring for palliative patients at home experience significantly higher levels of caregiving strain (10), feelings of anger, impaired emotional capacities (11), hostility (12,13) or despair (13), feeling abandoned (11,14), various unmet needs (15-17), higher burden, distress, and suffering (11,15-20) and lower quality of life (21) compared to their male counterparts. In addition, studies showed higher levels of depression and anxiety in female FCs (13,16,22) as well as lower self-esteem (23). Further, female FCs receive less social support from others (10). Higher role-specific expectations and stereotypical gender norms might be causal for these disparities (24,25).

Research has shown that emotion-oriented coping strategies and being employed are predictive for higher distress in women, but not in men caring for a terminally ill patient (19). The caring experience at end-of-life seems especially burdensome for female FCs providing continuous long-term daily care (26); however, negative caregiving experiences of female FCs are less frequent than generally expected (24). Beyond problems associated with caregiving, FCs also describe positive aspects such as personal growth, with women reporting higher gains (27).

There is evidence that the type of support FCs provide is also associated with gender: while males are mainly involved in mobility-related tasks, females more often provide hygiene-related tasks (10). For female FCs, quality of care more frequently depends on medical-technical skills, identity-oriented and socio-cultural approaches than that of their male counterparts (28). Further, female FCs of cancer patients expect more information and emotional support from the treatment team, while emotional support is more often considered inappropriate by male FCs (29). However, male FCs regularly require more help concerning symptom- and pain-management (10). In the specific situation of dying patients showing death rattle, male family members show a stronger need for care (20). Further aspects of suspected gender-related impact can be found in FCs' assessment of patients' symptoms (30) and in FCs' role in end-of-life decision-making (31).

Overall, these findings indicate various gender-related effects on the problems and needs of FCs of patients undergoing palliative care. However, the existing evidence is fragmented and the number of studies focusing on the gender-issues of FCs during palliative care is scarce. Systematic information is required to recommend gender-sensitive palliative care to equal quality of end-of-life care (32). Thus, we aimed to identify the gender-specific problems and needs of FCs in the context of specialist inpatient palliative care from the perspectives of HCPs and FCs. We conducted a qualitative study in order to inductively establish a data-driven framework of gender issues in palliative care with special attention to the informal caregivers of patients.

We present the following article in accordance with the MDAR reporting checklist (available at <https://dx.doi.org/10.21037/apm-20-2553>).

## Methods

### *Study design, setting and participants*

Using a qualitative study design, semi-structured interviews with FCs and HCPs of the specialist palliative care inpatient ward of a university medical center in Northern-Germany were performed between March and July 2016. We used the insights of both FCs and HCPs in order to validate the range of gender-related problems and needs from different perspectives.

Among FCs, primary FCs of patients with advanced, incurable diseases treated at the study ward were eligible for study participation. FCs aged <18 years and those not able to participate in an interview due to insufficient language skills or cognitive incapacities were excluded. Among HCPs, members of the palliative care team with a minimum of 12 months professional palliative care experience were eligible. FCs were invited for participation personally by the research team, HCPs were invited via email.

We initially employed a purposive sampling strategy, but in the course of research attempted theoretical sampling in order to reach a saturated sample (33). All interviews were conducted one-on-one in a face-to-face setting at the premises of the palliative care ward, and were audiotaped and transcribed verbatim. To minimize bias, a study member (SE), who had no clinical or personal relationship to the participants, undertook the interviews supervised by a senior researcher experienced in qualitative research (AU).

The study was conducted in accordance with the

**Box 1** Interview guide

## Introduction

We are interested in how professional caregivers who assist seriously ill and dying patients and their families experience the role of a family caregiver's gender in palliative care (healthcare professionals)/We are interested in how family caregivers of seriously ill and dying patients experience the role of their gender in palliative care (family caregivers).

First, we would like to clarify: What is your personal understanding of "gender"?

## Opening question

Initial narrative question: Please tell me how you experience the role of a family caregiver's gender in palliative care. How does gender impact family caregivers' problems and needs? Please elaborate on all details that seem important to you.

Keyword prompts (word-cards to further structure and expand the narration):

We will now present some word-cards reflecting problems and needs that are common in family caregivers of patients receiving palliative care. Please tell me: Do you experience gender-role differences in any of these problems and needs? If yes, please elaborate on all details that seem important to you.

Physical strain

Emotional strain

Communication

Professional support

Social aspects

Decision-making

## Additional questions (to deepen the issue)

What is typically problematic to you when thinking about a family caregiver's gender and their ability to provide care to a seriously ill or dying patient?

What kind of experiences did you have throughout your career where gender played a significant role? (healthcare professionals)/What kind of experiences did you have throughout caregiving where gender played a significant role? (family caregivers). Please elaborate on any specific situations that stick in your mind.

## Closing the interview

Is there anything you want to tell me? Maybe there is something else relevant to you, and we did not have talked about?

How did you feel about this interview and how did it make you feel?

Declaration of Helsinki (as revised in 2013). The study was approved by regional ethics committee of the General Medical Council of Hamburg, Germany (reference number 5116) and informed consent was taken from all individual participants.

**Data collection**

A semi-structured interview guide was used, which is displayed in Box 1. After clarifying their personal concept of gender, participants were first asked to freely narrate their experiences of gender regarding the problems and needs of FCs during palliative care. However, the narrative technique depends on the level of detail in a respondents reply and their ability to provide information relevant to the

research question. Since this is often not the case, we used keyword prompts ("word-cards") covering generally known problems and needs of FCs in palliative care as stimuli (34). The prompts were visually presented (all at the same time) after the participants' initial response, in order to support the interviewees to answer in a more structured way. These visual stimuli involve certain risks. Such as, participants misinterpreting the meanings behind given keywords (35). Nevertheless we took the opportunity to improve the quality, relevance and trustworthiness of the answers and, therefore, the interview data. Two pre-tests were conducted to examine the resonance of questions and usability of the prompts. Given no need for adjustment, the pre-test interviews were included in the sample.

Additionally, basic sociodemographic variables of the

respondents were obtained by written questionnaires. To characterize the sample's masculine or feminine gender role orientation, participants answered the positive masculinity (M+) and femininity (F+) scales of the "German Extended Personal Attributes Questionnaire" (GEPAQ) (36). Each scale consists of 8 item pairs concerning positive attributes traditionally associated with males or females. Two independent sum scores are calculated (possible range, 8–40) with higher values representing higher self-ascribed masculine (M+) or feminine (F+) attributes.

### Statistical analysis

Interviews were iteratively analyzed on basis of the qualitative content analysis according to Mayring (37), supported by the software program MAXQDA. Analysis was conducted using inductive coding techniques. Categories and subcategories were developed by two female researchers representing medical (SE) and psychosocial (AU) disciplines, and were discussed by the research team on a regular basis. To develop the coding scheme, SE coded a subset of four transcripts line by line. Through a series of meetings, a final coding framework was decided and interpersonal memos describing each category and subcategory were attached. To ensure the reliability of the coding process, both researchers analyzed the interview material independently using the final coding framework. Differences were resolved by verbal discussions within the research team.

We used the Consolidated Criteria for Reporting Qualitative Studies (COREQ) framework (38) to report on the design, conduct, analysis, and findings of our study.

## Results

### Characteristics of the respondents

Overall, 26 semi-structured interviews were conducted. HCPs interviews averaged 45 minutes in length (range, 22–84), while FCs averaged 29 minutes (range, 12–53). Of 10 FCs, 6 were female and 7 were non-spousal caregivers. Of 16 HCPs, eight were female and 10 reported a professional experience in specialist palliative care of 5 years or more. The average sum score for each scale of the GEPAQ questionnaire gave a balanced gender-role identity in FCs, while average sum scores of HCPs indicated higher self-ascribed feminine attributes in a balanced sample of male and female HCPs. More detailed characteristics of the

respondents are reported in *Table 1*.

### Gender-specific problems and needs of FCs

Overall, seven main categories of gendered problems and needs emerged (*Figure 1*).

#### The role as FC

The first category, which is comprised of four subcategories, is linked to the influence of gender on the role as FC (*Table 2*). HCPs and FCs described a stronger identification with the caregiver role in females. Possible over-identification was mostly ascribed to female FCs, and related burdens for the FC (e.g., heightened emotionality), the relative patient (e.g., loss of autonomy) and other family members (e.g., standing back) were identified. Respondents shared the impression that female FCs were more skillful in assessing the patient's needs and responding to them with greater creativity, care competence, and self-confidence. In addition, female FCs were reported to be more intensively involved in basic care. As one male FC stated:

*"I come and say "hello", probably provide her [the patient] something to drink, but when it comes to hygiene, body care or intimacies, that part is left to the woman."*

Respondents also felt that female FCs spend more time on the palliative care ward, including overnight stays.

#### Physical and emotional burden

The second category is linked to gender-differences regarding the manifold burdens that FCs carry during palliative care, which is comprised of three subcategories (*Table 3*). Respondents identified various physical impairments (e.g., sleeping problems, physical exhaustion, and loss of appetite) and emotional burden (e.g., anxiety, sadness, and helplessness) of FCs, but few primarily expressed gender-related differences. However, they identified differences in how female and male FCs cope with such burdens. Many respondents felt that male FCs more often suppress or hide their emotions and are less likely to disclose their current physical and emotional well-being to the patient or the palliative care team. The example below demonstrates gender-differences in dealing with emotions as perceived by a HCP:

*"Well, men fall silent more often and pull back into their shell. Probably also become angry sometimes."*

#### Self-care and coping strategies

The third category is linked to gender-differences in self-

**Table 1** Characteristics of the family caregivers and healthcare professionals

Characteristic	n
Family caregivers (n=10)	
Sex	
Male	4
Female	6
Age (years)	
≤40	3
41–50	2
51–60	2
>60	3
Relationship to the patient. Patient is...	
Mother/father	4
Spouse	3
Other <sup>a</sup>	3
Place of care prior to the patient's admission to the palliative care ward	
At home	5
Hospital ward	5
Gender-role identity, M (SD) <sup>b</sup>	
Masculinity (M+, 8–40)	29.6 (2.1)
Femininity (F+, 8–40)	30.3 (3.1)
Healthcare professionals (n=16)	
Sex	
Male	8
Female	8
Age (years)	
≤40	5
41–50	7
>50	4
Profession	
Physician	5
Nurse	6
Psychosocial therapist	3
Pastoral worker	2

**Table 1** (continued)**Table 1** (continued)

Characteristic	n
Professional experience in specialist palliative care	
<5 years	6
≥5 years	10
Gender-role identity, M (SD) <sup>b</sup>	
Masculinity (M+, 8–40)	27.6 (3.3)
Femininity (F+, 8–40)	33.4 (2.5)

<sup>a</sup>, brother, close friend and granddaughter in respectively one case; <sup>b</sup>, the gender-role identity average for masculinity and femininity were obtained of the GEPAQ questionnaire. Higher values reflect higher expression of masculinity and femininity. M, mean; SD, standard deviation; GEPAQ, German Extended Personal Attributes Questionnaire; F+, positive femininity scale of the GEPAQ; M+, positive masculinity scale of the GEPAQ.

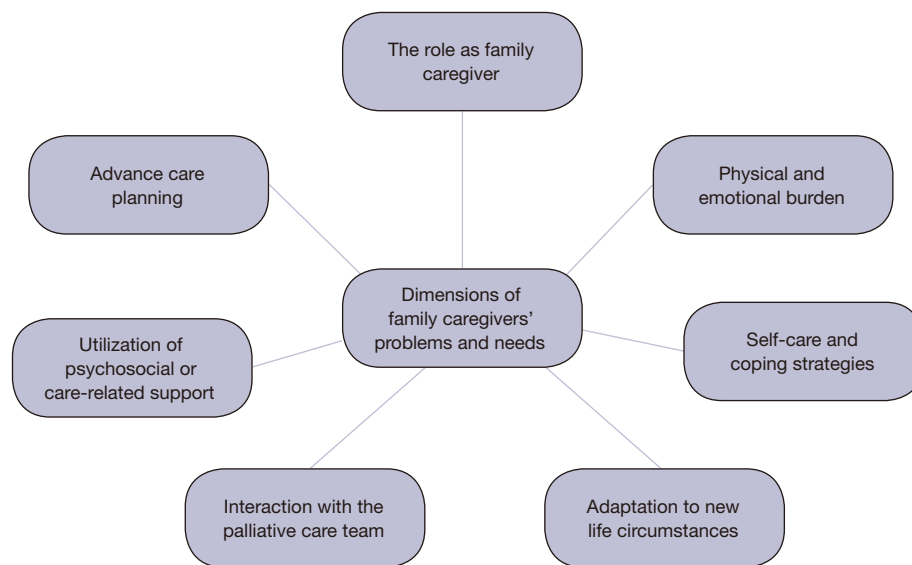
care capacities and coping strategies of FCs, composed of five subcategories (*Table 4*). Respondents attributed male FCs with a more balanced sense in responding to their own needs and in valuing perceived boundaries. They described gendered motives of self-care with females regularly relying on external reassurance regarding self-care activities. A HCP stated in reference to such differences:

*“In terms of self-care, men look after themselves better. Men more easily say: “I will not do this and that, because I have to protect myself.” And women, in their sacrificing, caring role, say: “I do this, too”, although excessively overburdening themselves by doing so.”*

Regarding maintaining activities, respondents felt that female FCs are more likely to withdraw their job, and leisure and family activities. Some expressed concerns about the inequality that male FCs more frequently seem to receive practical assistance in patient care or household tasks by other informal caregivers, whilst female FCs both receive and ask for it less. With regard to coping, respondents ascribed female FCs with emotional coping approaches and male FCs with a problem-focused coping and a wider range of coping strategies overall. In contrast, personal growth associated with caregiving was not perceived differently between the genders.

### Adaptation to new life circumstances

The fourth category is linked to gender-differences



**Figure 1** Dimensions of family caregivers' problems and needs affected by gender.

**Table 2** Category 1: gender-differences with respect to the role as family caregiver

Category	Subcategory	Example quotations
1. The role as family caregiver	1.a: Identification with the caregiver role	"I notice that women are faster in assuming responsibility. With a risk of taking too much responsibility. Some become quite motherly towards their husband." (HCP06, 28)
	1.b: Taking action as a caregiver	"They [men] are good at practical tasks. But as soon as psychology or spiritual care is required...such competencies rather pre-exist in women [...] since women tend to bring up the children and busy themselves with the human mind more than men in their course of life." (FC04, 3)
	1.c: Involvement in physical nursing	"[...] I come and say "hello", probably provide her [the patient] something to drink, but when it comes to hygiene, body care or intimacies, that part is left to the woman." (FC08, 12)
	1.d: Presence at the palliative inpatient ward	"When you can't go on any longer, you just can't go on any longer and it's no use to be exhausted and tired and the patient himself has a bad conscience. I think in this context a male relative reaches his limits rather than a female and says: "I won't go [to the palliative ward] today"." (FC08, 23)

FC, family caregiver; HCP, healthcare professional.

**Table 3** Category 2: gender-differences with respect to the physical and emotional burden of family caregivers

Category	Subcategory	Example quotations
2. Physical and emotional burden	2.a: Prevalence of physical and emotional problems	"Psychological burden exists on both sides, I couldn't draw distinctions here, because relatives' feelings, such as grief, emotional pain et cetera, are the same for everyone." (HCP06, 29)
	2.b: Dealing with physical symptoms	"Physical symptoms are rather suppressed by men, whilst women tend to express them, for example exhaustion." (HCP13, 33)
	2.c: Dealing with emotions	"Well, men fall silent more often and pull back into their shell. Probably also become angry sometimes." (HCP03, 32)

HCP, healthcare professional.

**Table 4** Category 3: gender-differences with respect to self-care and coping strategies of family caregivers

Category	Subcategory	Example quotations
3. Self-care and coping strategies	3.a: Motives of (lacking) self-care	“In terms of self-care, men look after themselves better. Men more easily say: “I will not do this and that, because I have to protect myself.” And women, in their sacrificing, caring role, say: “I do this, too”, thereby excessively overburdening themselves by doing so.” (HCP13, 27)
	3.b: Maintenance of activities	“Women more often say: “I quit my job now, because I need to care for my spouse, parents or whatever”—certainly that is a societal difference compared to a man addressing his employer like: “I need to stay home and care for my family”.” (HCP14, 33)
	3.c: Receiving help in patient care	“Women, who care for someone also receive less support than men... I mean, support by other family members or so. Women expect from themselves “you have to do it somehow”. They won’t hint at it so early.” (FC05, 59)
	3.d: Coping strategies	“Yes, I think men have a hard time showing weakness, accept their own emotions and tend to appear rather rational...like a manager: “I have to make it!”.” (FC05, 15)
	3.e: Personal growth	“You are forced to deal with it automatically, which isn’t bad at all, but you have to get used to so many things and clearly you grow, too. Well, people who have never done this, will shy away and say “oh god, will I even make it through?” But doing it as time goes by, you will grow. And this fact is similar for men and women.” (FC04, 13)

FC, family caregiver; HCP, healthcare professional.

**Table 5** Category 4: gender-differences with respect to the adaptation to new life circumstances that family caregivers face

Category	Subcategory	Example quotations
4. Adaptation to new life circumstances	4.a: Activities of daily living	“For men, the problem will rather be how to do the laundry once their wife passes away. Especially female patients express their concerns regarding how a relative, the husband, will get along. Particularly in the elderly...” (HCP09, 27)
	4.b: Finances and insurance	“Who will file the tax return? Who will negotiate with the insurance? This, in fact, is still gender-specific, and it’s rather men, who had done those things. Now the female relatives end up in the position of organizing things, which is difficult for them at first.” (HCP04, 18)
	4.c: Imminent loss of a beloved person	“I often notice this for married men, when children have left home already and the husband faces living in the house alone... that they can hardly imagine being alone and are struggling way more than a married woman does in the same situation.” (HCP05, 28)

HCP, healthcare professional.

regarding FCs’ ability to adapt to new life circumstances. This category is comprised of three subcategories (Table 5). Respondents perceived gender-differences in activities of daily living and financial insecurity, often associated with FCs’ older age (e.g., household for men, financials for women). Thinking of families with younger children, respondents expressed concerns about the high responsibility of male and female FCs alike, but perceived greater financial concerns in female FCs. Moreover, respondents reflected on FCs’ perspectives without the beloved person attributing more anxiety of future loneliness

and loss of intimacy to male FCs. A HCP who reflected on the FCs’ life after loss stated:

*“I often notice this for married men, when children have left home already and the husband faces living in the house alone... that they can hardly imagine being alone and are struggling way more than a married woman does in the same situation.”*

#### **Interaction with the palliative care team**

The fifth category is linked to gender-issues regarding communication and cooperation with the palliative care team. It is composed of four subcategories (Table 6).

**Table 6** Category 5: gender-differences with respect to the interaction between the family caregiver and the palliative care team

Category	Subcategory	Example quotations
5. Interaction with the palliative care team	5.a: Need for communication and contact	“I think women remain more talkative. Men need some time to express themselves. Sometimes they need a little help to voice their concerns. I’m witnessing that myself: What I rid myself of, I get rid of - and I get rid of here on the palliative ward, too. Whilst my father rather returns home and tells me about it, so I say “did you ask about it?” and he replies “No, I don’t intend to burden anyone.” (FC05, 29)
	5.b: Information seeking	“And that male more often than female relatives seek factual information with regard to the disease. Women’s queries more often relate to emotional aspects or related to feelings.” (HCP07, 9)
	5.c: Cooperation with the team and trust	“Women trust and cooperate more [with the palliative care team] than men. Men are rather on their own behalf, open up less...tend to avoid building trust or relationships.” (HCP11, 49)
	5.d: Significance of health professionals’ gender	“And I would also make a distinction between a conversation with a female doctor or with a male doctor. That is because I still think, that two women have a different basis for discussion than man and woman do, thus I think it matters. Say, that there are different connotations in terms of wording.” (FC01, 41)

FC, family caregiver; HCP, healthcare professional.

Respondents felt that female FCs show a greater desire for communicating with HCPs, in order to seek relieve, get distracted and find social contact or to talk about the patient’s well-being. Also, they believed that contacts by male FCs are often initiated to receive specific information about the patient’s symptoms and treatment or to address ad hoc needs. Respondents were ambivalent about gender-specific aspects of FCs’ cooperation with and trust in HCP: female FCs were described to be more trustful; then again, it was argued that males just need more time and are more specific in choosing confidants compared to their female counterparts. Respondents also reflected on the significance of the HCP’s gender which shapes the interaction between FCs and HCPs, e.g., in terms of frequency and content. As one FC stated:

*“And I would also make a distinction between a conversation with a female doctor or with a male doctor. That is because I still think, that two women have a different basis for discussion than man and woman do, thus I think it matters. Say, that there are different connotations in terms of wording.”*

#### Utilization of psychosocial or professional care-related support

The sixth category is linked to the gendered use of supportive measures and is comprised of three subcategories (Table 7). Respondents thought that female FCs use professional support and specialist psychosocial interventions to a larger extent than their male counterparts.

Also, respondents believed that female FCs have larger social networks from which they actively seek emotional support. One FC stated:

*“To avoid any additional strain, I don’t want to talk about my fears and concerns with my husband. I rather seek help from my friends. This step seems easier for me than for my husband or other men, I mean, men as relatives.”*

Additionally, respondents felt that male FCs require and utilize more professional care-related or practical support in cases of home-based caregiving.

#### Advance care planning and caregiving after inpatient palliative care

The seventh category is linked to gender-differences in further end-of-life care and is comprised of three subcategories (Table 8). Respondents were ambivalent about the existence of gender-specific differences in the place of patient care (home-based versus hospice care) depending on the FC’s gender. One HCP who felt ambivalent stated:

*“There are men alike, who say, “I want my wife to stay here in my house with me, so I’m not on my own, I couldn’t get along with that”. Like women, who say “when he moves to a hospice, I can maintain the relationship rather than having to manage and organize the whole situation... keeps me from sitting by his side.”*

However, respondents felt that decision-making regarding advance care planning is gendered: they thought that decision-making is often shaped by role expectations in female FCs, internal or external (e.g., patient, family,



**Table 7** Category 6: gender-differences with respect to the use of support among family caregivers

Category	Subcategory	Example quotations
6. Utilization of psychosocial or professional care-related support	6.a: Actively asking for psychosocial support	“To avoid any additional strain, I don’t want to talk about my fears and concerns with my husband. I rather seek help from my friends. This step seems easier for me than for my husband or other men, I mean, men as relatives.” (FC01, 13)
	6.b: Extent of professional psychosocial support	“I notice, that female relatives more readily avail themselves of conversations with psychologists or even enquire about a talk. Men, I would say, more often tackle things on their own—or actually I’m not sure whether they do it on their own or by discussing things with other people—but they are more restrained in terms of the actual utilization of such offers.” (HCP05, 5)
	6.c: Kind of support	“That’s my experience, that [for women] practical support starts too late, because the decreasing energy too late states: “I can’t handle it anymore, I need help”. That’s the nub of the matter. And on the face of it: “You got this”. I do believe, that expectations are higher of female caregivers or women in general.” (FC05, 65)

FC, family caregiver; HCP, healthcare professional.

**Table 8** Category 7: gender-differences with respect to the further care of a palliative patient

Category	Subcategory	Example quotations
7. Advance care planning and caregiving after inpatient care	7.a: Place of patient care	“There are men alike, who say, “I want my wife to stay here in my house with me, so I’m not on my own, I couldn’t get along with that”. Like women, who say “when he moves to a hospice, I can maintain the relationship rather than having to manage and organize the whole situation all day long, that keeps me from sitting by his side.” (HCP06, 33)
	7.b: Motives in decision making	“What’s happening very frequently: that a patient wants to go home, but it isn’t feasible. Women having a harder time to say, “that doesn’t work, a hospice is the only option”, they tend to feel guilty. Men rather try to convince their wife argumentatively. Or female patients are more, say, realistic. The situation of a husband doubting to go home, whilst the female patient insists on going...that constellation is less frequent than the other way around.” (HCP05, 34)
	7.c: Involving others in decision making	“We try to figure out, that he gets placed in a hospice. And time and again I am a little concerned, since at home I see... that’s his armchair, his blankie, that’s his home. Today he sadly asked me: “Will you terminate the lease?” I said “I don’t terminate anything without your consent. “Women rather adjust decisions, share decisions with family and friends.” (FC02, 55)

FC, family caregiver; HCP, healthcare professional.

friends), and by rational motives in their male counterparts (e.g., capacities). Furthermore, respondents reported that female FCs more commonly involve the patient and other family members in decision-making processes.

### References of respondents to role expectations

Across all interviews, respondents emphasized the influence of gender socialization and gendered societal expectations. All respondents noted that society expects women to be the caring person in the family, and that such role expectations are especially not questioned when families face the imminent loss of a beloved one. Further, they thought

that women more often see caregiving as part of their self-definition, which could trigger over-identification with the caregiving role and neglect within their own needs. Regarding professional support, women were ascribed to be habituated to provide support due to biographical experiences (e.g., childcare) and are therefore less likely to seek professional care-related support.

### Discussion

This qualitative study explored gendered problems and needs of FCs of patients receiving specialist inpatient

palliative care from the perspectives of FCs and HCPs. Seven main categories of gender-related problems and needs were identified, showing that gender deeply affects end-of-life care. Gender-specificity in the role as FC was omnipresent with women spending more time providing care. Caregiving in palliative care continues to be a female domain, and studies show that approximately two thirds of FCs are female (61–84%) (14,29,39). The relationships between female socialization, gender norms, societal role expectations and caregiving are well recognized, in both general care (40,41) and palliative care (24,25). Our findings on female FCs being more likely to provide basic care, being less assisted by other informal caregivers in their care work, and being more skillful in assessing the patient's needs are in line with previous studies on gender-differences in caregiving at the end of life (10,14). These findings suggest the need of gender-sensitive interventions to support FCs caring for a palliative patient: while men might benefit from knowledge and hands-on training in basic care, women might need counseling on mindfulness of their own needs and coping with role expectations.

Our findings indicate that men and women have different approaches to deal with care work as well as with the threatening, life-changing situation that they and the patient face. Female FCs of palliative patients might need more psychosocial support, since emotional coping strategies are associated with higher distress (19). Problem-focused coping might allow male FCs to have a stronger sense of control and the opportunity to choose how to act. Previous palliative care research merits special attention to interventions that activate coping strategies and to promote self-esteem and self-efficacy of FCs (13,14,22).

Our study expands the understanding of gender-differences in FCs' adaptation to new life circumstances after the patient's death by pointing to male FCs who might be more anxious about feelings of loneliness and loss of intimacy compared to their female counterparts. Apart from these findings, psychological burden like anxiety and depression were not identified to be gender-specific, which contradicts results from prior studies (13,16,22). However, men were generally perceived as less expressive in their emotionality, more target-oriented in their interactions with the palliative care team, and less likely to seek emotional/psychosocial support compared to women, although they would benefit from such support, as it has been observed before (29).

Further, FCs and HCPs reported that men predominantly wanted to be informed about palliative care,

while women were more likely to prefer information on psychosocial issues and support. A study on information needs of FCs of terminally ill cancer patients confirm that gender impacts on how FCs view the importance of different types of information (31).

This study has several strengths and limitations. We investigated the phenomenon of gender issues among FCs in specialist palliative care from the perspectives of those experiencing them personally and professionally. We undertook efforts to validate the findings, including analysis by a multidisciplinary research team. However, our findings should be viewed with a degree of caution in light of the possible bias caused by shared experiences of HCPs due to the monocentric design. Further, the sample size of FCs did not equal the number of interviews conducted with HCPs, and the average duration of interviews was shorter. In this vulnerable group of patients treated on an acute palliative care ward, interview timings and lengths had to be adjusted to the FCs' individual circumstances. However, we reached data saturation, suggesting a sufficient overall sample size. A further limitation is the exclusion of non-German speaking FCs, which might bring biases in terms of cultural context. Further, data collection and analysis on this gender-focused study was done by female researchers. Being interviewed by a female might have encouraged female respondents to be more open as they may assume shared assumptions and experiences. However, reflexive reflections were enhanced by discussions within the research team during the study. Analysis did not focus on differences between male and female respondents; thus, we cannot interpret results in relation to the respondent's gender.

## Conclusions

In conclusion, FCs and HCPs perceived many gendered problems and needs of FCs caring for a patient receiving specialist inpatient palliative care. Respondents were aware of existing role expectations and highlighted their relevance. They viewed female FCs as more experienced and involved in caregiving and to seek for more support and interaction with the palliative care team. Male FCs were considered to be more self-caring, adopt more problem-focused coping strategies, and are more anxious regarding loneliness. We think that our study provides empirical support for future quantitative studies that systematically analyze the influence of gender on problems and needs of FCs in palliative care. Due to the manifold problems and needs of FCs that are affected by gender, HCPs should be trained on how they

can address FCs in a gender-sensitive way. Trainings should also strengthen HCPs' knowledge and critical reflections about gender concepts, socially ascribed gender roles, and the gendered assumptions that shape their interactions with patients and their FC. However, like in other areas of healthcare, the implementation of gender-sensitivity in palliative care can only be successful, if actions will also be taken on the organizational and the policy level (42).

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*Ethical Statement:* The authors are countable for all aspects of the work ensuring the questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). The study was approved by regional ethics committee of the General Medical Council of Hamburg (reference number 5116) and informed consent was taken from all individual participants.

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