

Title

Supportive relationships between patients and family caregivers in specialist palliative care:
A qualitative study of barriers and facilitators

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Table 1. Summary of participants

Table 2. Mode of interview for data collection

Abstract

Objectives: Patients with advanced illness and their family caregivers can be mutually supportive. However, what facilitates and/or restricts supportive relationships between patients and family caregivers in palliative care remains unclear. We aimed to identify key barriers to and facilitators of supportive relationships between people with advanced illness and family caregivers in specialist palliative care.

Methods: A qualitative study using grounded theory methodology was conducted. Semi-structured interviews were undertaken with 15 patients with advanced illness and 21 family caregivers purposively and theoretically sampled from a large regional specialist palliative care service. Verbatim transcripts were analysed in line with grounded theory coding procedures.

Results: Mutual support was underpinned by mutual concern and understanding. Facilitators of supportive relationships included patients and family caregivers already having a close relationship, caregivers assuming caregiving duties by choice, caregivers feeling competent in a caregiving role, patients valuing caregiver efforts, availability of respite for the caregiver, and direct support from healthcare professionals to help both patients and caregivers adjust to advanced illness. Barriers to supportive relationships included absence of support from the wider family, prior mutual conflict between the patient and caregiver, caregivers feeling constrained in their caregiving role, and patient and caregiver distress induced by mutual loss.

Conclusions: Multiple factors at both a micro (e.g., relationship based) and meso-level (e.g., assistance from services) impact patient and family caregiver ability to support one another

in specialist palliative care. Supportive relationships between patients and family caregivers are mediated by feelings pertaining to both control and loss.

Key words: Specialist Palliative Care, Caregivers, Patients, Supportive Care, Family Relations, Qualitative Research

What is already known on this topic

- Patients with advanced illness and their family caregivers in palliative care can be mutually supportive through open disclosure and by jointly adapting to changing roles.

What this study adds

- Support from both healthcare professionals and the wider family facilitates supportive relationships between patients and family caregivers in specialist palliative care.
- Assuming caregiving duties by choice and being valued by their ill family member makes family caregivers in specialist palliative care feel competent in a caring role and fosters support between them and the patient.
- Pre-existing conflict and distress induced by mutual loss can make it challenging for patients and family caregivers in specialist palliative care to feel effective as a source of support to one another.

How this study might affect research, practice and/or policy

- Healthcare professionals in specialist palliative care have capacity to increase supportive relationships between patients and family caregivers through patient-family caregiver dyadic interventions focused on enabling control and adapting to mutual loss.

INTRODUCTION

Research has focused on the role and benefit of the family caregiver in providing care and support to people with advanced illness in palliative care, including specialist palliative care.[1,2] Provision of support by family caregivers to patients in palliative care takes multiple forms, ranging between direct physical and emotional care, to advocating for patient services and coordinating care for the patient.[3] The impact of caring on the family caregiver, including both potential burdens and beneficial outcomes for family caregivers in specialist palliative care is documented.[4,5]

In most existing studies in palliative care to date, people with advanced illness tend not to be defined from the outset as key providers of support to their family caregivers.[6]

However, examination of the patient and family caregiver relationship in advanced illness has identified that patients and family caregivers have capacity to reciprocate in the provision of support to one another.[7,8] A systematic review of the limited evidence on mutual support between patients with advanced illness and family caregivers in palliative care[9] identified that patients and family caregivers can support one another through mutual and open disclosure, mutual recognition of the challenges they face, and by jointly adapting to change in roles in the context of advanced illness. The absence of mutual

disclosure in relation to distress was highlighted as a source of conflict between patients and family caregivers.[9]

Evidence points to the positive effects of dyadic psycho-social and psycho-educational interventions for patients and family caregivers in advanced stages of illness[10-12] including in a specialist palliative care setting.[12] Such interventions have included strategies for communication, joint problem solving, and maintaining relationships.[10-12] They have also included strategies to help patients and family caregivers understand their choices in relation to each other and within the constraints and possibilities of their situation.[12] These interventions have shown positive effects on caregiver burden,[11] patient and caregiver quality of life[11], patient and caregiver anxiety, and distress,[10-12] patient and caregiver competence and relatedness,[10] and patient and caregiver self-efficacy.[11] However, what facilitates and/or restricts supportive relationships between patients with advanced illness and family caregivers in palliative care remains unclear.[9] In this study, we therefore aimed to identify key barriers to and facilitators of supportive relationships between people with advanced illness and family caregivers in specialist palliative care.

METHODS

We conducted a qualitative study using a grounded theory approach[13] to investigate key dimensions of mutual support between patients and family caregivers in specialist palliative care including facilitators of and barriers to supportive relationships between them. The grounded theory method comprises both inductive and abductive analytical strategies to generate substantive data and explanatory frameworks that can explain psychosocial

processes[13,14] (in this case, supportive relationships between patients with advanced illness and family caregivers). We used a grounded theory approach[13] because we sought to explain at a substantive level, key actions, behaviours and contexts which can explain the phenomenon of interest (factors that enable and/or restrict supportive relationships between patients and family caregivers in specialist palliative care). The epistemological underpinnings of the approach taken are rooted in symbolic interactionism, a broad sociological theory which emphasises that the way in which people construct meaning is influenced by their interaction with others. We referred to the Standards for Reporting Qualitative Research[15] to report this study.

Setting and recruitment

Participants were recruited from two hospice sites in the Republic of Ireland which together constitute a large regional specialist palliative care service covering a catchment of approximately 700,000 people (circa 14% of the national population). The palliative care service provides a mix of inpatient, outpatient, day hospice and community-based care. Inclusion criteria for patient participants were: a formal diagnosis of a life-limiting condition(s), ≥ 18 years of age, able to provide informed consent, and in receipt of specialist palliative care. Inclusion criteria for family caregivers were: ≥ 18 years of age, able to provide informed consent, and identified by a patient in receipt of specialist palliative care as their primary caregiver. The term 'life-limiting condition' was understood by the research team as an incurable condition that would shorten a person's life. Our definition of family caregiver for this study was not restricted to familial-based relationships but rather extended to any category of significant other who was identified as a primary caregiver. Gatekeepers at both hospice sites assisted with recruitment by informing potential

participants about the study. Interested participants were then provided with detailed participant information leaflets by the investigators. Each participant gave informed consent to participate in the study.

Whilst we primarily sought to recruit patient-family caregiver dyads, we were conscious at the outset of the study that fully restricting participation only to dyads might push the sample towards the more consensual dyad (e.g., the possibility of a patient and family caregiver not wanting to participate together if they were undergoing major conflict or disagreement). Sampling and analytical procedures[13] allowed for the possibility to incorporate variation as required. Recruitment took place between July 2021 and May 2022.

Sampling

Participants were initially purposively sampled for variation (e.g., age, life stage, gender, and variation in patient and family caregiver relationship), and then in later stages of the study theoretically sampled based on key findings in the data.[13] We ceased sampling when key findings that emerged from the data were saturated for meaning and incorporated variation to explain the data (in grounded theory terms, when no new data were extending our theoretical and integrative understanding of the data).[14]

Data collection

Semi-structured interview schedules containing open-ended questions were formulated and informed by a systematic review of the evidence on mutual support between patients and family caregivers in palliative care already conducted by the authors[9] and by wider literature pertaining to supportive relationships between patients and family caregivers in advanced illness, including sources identified by the last author on how patients and

caregivers in palliative care can reciprocate in support of one another.[6] Questions were also informed by public, patient, and carer involvement (PPI) at the design stage of the study. The PPI review of the study reported was undertaken by a member (former caregiver) of an established Irish-based palliative care PPI group. The semi-structured interview guides were devised to capture contexts and processes.[13] The interview guides allowed for consistency in data collection and the open-ended questions served as a platform for subsequent probing, prompting, and clarifying questions to further interrogate data as the study proceeded.[16] Interview schedules are available in online supplementary Appendix 1.

Our initial protocol was for interviews to be in-person. However, we had to adjust procedures to facilitate remote interviewing as restrictions imposed by COVID-19 reduced the possibility in most cases for in-person interviews. RMCC transcribed all interviews verbatim prior to analysis. A copy of each transcript was then returned for the purpose of member checking to respective participants except for four participants who did not wish to receive their transcript. No participant requested alteration to their data. RMCC also recorded field notes after each interview to help contextualise the interview data.

Data analysis

The data were analysed using the constant comparison technique.[17] First, the data were open coded[13] which means broken down into codes and concepts (aggregation of similar codes) that captured key incidents, events, and patterns that tentatively pointed to mutual support including barriers and/or facilitators to supportive relationships between patients and family caregivers. Data were then coded to achieve conceptual saturation[13] which involved building categories from identifying relationships between concepts and

accounting for actions/interactions and/or behaviours in similar and different contexts. For example, in the early to mid-stage of data collection, few patients and family caregivers reported dissatisfaction with each other. At this point, 'obligation' had emerged as a category which constituted feeling a need to support one another but *also* in some cases, family caregivers feeling constrained by having no choice but to support their ill family member. We then (theoretically) sampled some participants where there was known tension in their relationship to better account for how obligation functioned between patients and family caregivers.

The final stage of analysis involved a theoretical integration[13] of the data to fully link key barriers and facilitators. Analysis of data at this point focused on mapping out fully saturated categories and their relationships (which had derived from across the dataset) to decipher key behaviours and contexts that comprised and explained the nature of supportive relationships between patients and family caregivers. This final stage of analysis enabled us to ascertain how and why supportive relationships between patients and family caregivers could be hindered and/or facilitated. The sampling and analytical procedures used[13] allowed for constant comparison of data *across* the dataset (not limited only to comparison within, between or across dyads). Both descriptive and theoretical memos were formulated by RMCC at key stages of the analysis which together with coding, comprised an audit trail of the analysis. Rigour was enhanced through peer debriefing and cross-checking of data between RMCC and GF. The final narrative was reviewed and refined by the whole team. The NVivo qualitative data analysis software (version 12) was used as a tool to code and manage the data.

Ethical approval

Ethical approval to undertake the study was granted by the Research Ethics Committee of St. Francis Hospice Dublin, and by the Faculty of Health Sciences Research Ethics Committee, Trinity College Dublin (ref 191002).

RESULTS

Participant characteristics

The participants were 15 patients (n=14 cancer, n=1 neurodegenerative disease) and 21 family caregivers. The sample comprised 14 patient-family caregiver dyads, seven family caregivers who participated as non-dyad participants, and one patient who also participated without their respective other. Family caregivers participated on their own when the patient's health status deteriorated between investigators' initial approach and the scheduling of interviews to the point that the patient felt too unwell to participate. For the one patient who participated without their family caregiver, the family caregiver had declined to participate because of her own distress.

The sample was primarily suburban based. The majority of patient participants were men (11 out of 15) and the majority of family caregiver participants were women (17 out of 21). Most of the patient participants and the non-participating patients of participating family caregivers had advanced cancer. The average age of patient participants was 64.9 years, and the average age of family caregiver participants was 52.5 years. No patient participant or non-participating patient of a participating family caregiver were deemed by their medical team to have a prognosis of >18 months at time of the patient and/or caregiver

participation. The majority of the 15 patient participants (n=9) had already ceased full, active treatment (e.g., radiation therapy, chemotherapy). All family caregivers were actively providing care to their respective other to assist the patient in everyday activities. The majority of the 36 participants were recruited via the community (i.e., home-based) specialist palliative care service as other locations at point of recruitment (e.g., outpatient and day hospice services) were affected by periods of COVID-19 restrictions. Table 1 provides a detailed summary of participants.

Description of the dataset

The 15 patients and 21 family caregivers participated in 30 qualitative interviews (Table 2). Interviews were conducted with eight of 14 patient-family caregiver dyads separately (i.e., each member of the dyad interviewed on their own), and six dyads requested that they be interviewed together (i.e., both patient and family caregiver in one interview). The seven family caregivers and the patient who participated without their respective other were each interviewed alone. Twenty-seven of the 30 interviews were conducted remotely: 25 by phone and the remaining two by the video-conferencing platform Zoom.[18] All participants were offered the option of a video-based online interview[19] but only a small minority of participants chose this. The average duration of interviews was 43 minutes, and each interview was digitally recorded.

Table 1. Summary of participants

Participant	Relationship to FCG/P	Dyad / non-dyad participants	Participant age	Diagnosis of patient participant / patient cared for by FCG	Recruitment source - Care setting *	Urban/suburban /non-urban
P1 FCG1	Wife Husband	Dyad	40 43	Stage IV breast cancer	SCPC	Suburban Suburban
P2 FCG2	Husband Wife	Dyad	46 45	Progressive multiple sclerosis	Inpatient hospice	Suburban Suburban
P3 FCG3	Partner (M) Partner (W)	Dyad	64 64	Stage IV lung cancer	SCPC	Suburban Suburban
P4 FCG4	Mother Daughter	Dyad	77 48	Stage IV Hodgkin's lymphoma	SCPC	Suburban Suburban
P5 FCG5	Husband Wife	Dyad	62 60	Stage IV pancreatic cancer	SCPC	Suburban Suburban
P6 FCG6	Mother Daughter	Dyad	57 26	Stage IV lung cancer	SCPC	Suburban Suburban
P7 FCG7	Father Daughter	Dyad	54 22	Stage IV liver cancer	SCPC	Suburban Suburban
P8 FCG8	Husband Wife	Dyad	70 67	Stage IV lung cancer	SCPC	Suburban Suburban
P9 FCG9	Father Daughter	Dyad	90 52	Stage IV stomach cancer	SCPC	Urban Urban
P10 FCG10	Husband Wife	Dyad	83 80	Stage III prostate cancer	SCPC	Suburban Suburban
P11 FCG11	Wife Husband	Dyad	58 62	Stage IV breast cancer	Inpatient hospice	Urban Suburban
P12 FCG12	Husband Wife	Dyad	61 60	Stage IV lung cancer	SCPC	Suburban Suburban
P13 FCG13	Husband Wife	Dyad	72 68	Stage IV colorectal cancer	SCPC	Suburban Suburban
P14 FCG14	Father Daughter	Dyad	72 42	Stage III Colorectal cancer	SCPC	Suburban Non-urban
P15	Husband	Participating without other	68	Stage IV lung cancer	SCPC	Suburban
FCG15	Daughter	Participating without other	61	Stage III ovarian cancer	SCPC	Suburban
FCG16	Daughter	Participating without other	43	Stage III lung cancer	SCPC	Suburban
FCG17	Husband	Participating without other	70	Stage IV lung cancer	SCPC	Urban
FCG18	Daughter	Participating without other	52	Cardiac failure	SCPC	Suburban
FCG19	Daughter	Participating without other	44	Stage III lung cancer	Outpatient hospice	Suburban
FCG20	Daughter	Participating without other	41	Stage III colorectal cancer	SCPC	Suburban
FCG21	Son	Participating without other	54	Advanced bone cancer	SCPC	Suburban

* SCPC = specialist community palliative care, M = Man, W= Woman

Table 2. Mode of interview for data collection

P/FCG	Interviewed together / alone	Mode of interview
P1	Together	Zoom audio & video
FCG1	Together	Zoom audio & video
P2	Together	Phone
FCG2	Together	Phone
P3	Alone	Phone
FCG3	Alone	Phone
P4	Alone	Phone
FCG4	Alone	Phone
P5	Alone	Phone
FCG5	Alone	Phone
P6	Together	Phone
FCG6	Together	Phone
P7	Alone	Phone
FCG7	Alone	Phone
P8	Alone	In person
FCG8	Alone	In person
P9	Together	In person
FCG9	Together	In person
P10	Together	Phone
FCG10	Together	Phone
P11	Alone	Phone
FCG11	Alone	Zoom audio & video
P12	Together	Phone
FCG12	Together	Phone
P13	Alone	Phone
FCG13	Alone	Phone
P14	Alone	Phone
FCG14	Alone	Phone
P15	Alone	Phone
FCG15	Alone	Phone
FCG16	Alone	Phone
FCG17	Alone	Phone
FCG18	Alone	Phone
FCG19	Alone	Phone
FCG20	Alone	Phone
FCG21	Alone	Phone
Total = 30 interviews		

Here, we report key dimensions of mutual support between patients and family caregivers followed by facilitators of supportive relationships between patients and caregivers and barriers to these relationships. Data extracts are tagged with the unique participant ID code, with ‘FCG’ indicating family caregiver and ‘P’ indicating patient; shared numeric identifiers indicate a patient-caregiver dyad except for P15 and FCG15 who were non-dyad participants.

Key dimensions of mutual support between patients and family caregivers

We ascertained primarily two forms of mutual support between patients and family caregivers. First, patients and caregivers reciprocated in emotional support of one another because they were aware of the other person's psychological distress living with the challenges of advanced patient illness. A caregiver and patient stated respectively:

A lot of my issues would be how [patient] is doing emotionally ... I am coming to terms with situation for him ... I just find that when [patient] is in a good place, it takes an awful lot of [his] anxiety away. (FCG2)

My sense of trying to support [family caregiver], if I can show her that I am fighting this and that I'm well and happy, that seems to be one of the things she needs from me, and also to check in with her that she has somebody that she can speak with.

(P2)

Second, mutual support involved reciprocation through different modes of support. In many cases, patients were unable to reciprocate in physical care or to sufficiently engage in instrumental activities of daily living for their caregiver. Instead, patients provided emotional support (e.g., listening, reassuring) in lieu of other supports they no longer felt able to provide. A patient and caregiver conversed:

I get a bit lethargic. I get tired ... [But] there are certain things that I can still do to help the situation with [family caregiver]. (P10)

[To patient:] I think the best support you give me is you listen to me. (FCG10)

In some cases, patients felt that the support they provided might not necessarily be proportionate to the support they received from their family caregiver given their

worsening health status. However, in these cases, caregivers still valued support from their respective other:

I can see that he knows I'm doing a lot for him ... and he does always say to me "I always appreciate what you are doing for me" ... and he does always try to reassure me and that's nice to hear as well. (FCG16)

To attend to the needs of one another, understanding one another's perspective was important for both patients and family caregivers. Indeed, mutual understanding was often key to patients and caregivers feeling able to support their respective other:

We are an emotional support for each other because we understand each other ... We are singing from the same hymn sheet ... understanding of one another and the way each other handles things and copes with things. (P3)

Overall, mutual support between patients and family caregivers was underpinned by patient and caregiver concern and regard for one another:

She [patient] is the most important person ... But she's also worried about me ... I'm the person she wants to see and she's the person I want to see. (FCG11)

Facilitators of supportive relationships

A strong pre-morbid relationship between the patient and family caregiver was generally perceived by participants to foster supportive relationships when confronted with the challenges of life-limiting illness. Pre-existing closeness and understandings of one another's habitual behaviours helped both patients and family caregivers cope with advanced illness:

We have had that close relationship, like through our entire lives so it wasn't difficult on the way in that sense. But like decisions and talking about things, and obviously I think we've gotten even closer since the diagnosis. (FCG6)

We have always been so close and a unit ... I can't hide anything from [family caregiver]. She knows my moods and can tell if there's something wrong with me ... she could tell right away. (P7)

The importance of strong pre-morbid relationships was observed particularly among patients and family caregivers who were spouses and who had already navigated life together and raised children. The experience of having already raised a family together provided a sound foundation for ongoing partnership in times of adversity. It also provided reassurance that they would face issues together and work as a team to deal with problems.

For example, a caregiver shared:

The effort of the two of us [raising family] means we are far greater [stronger] and it helps ... that realisation ... It's a great relief to know that, oh my, that's okay, we will manage this together. (FCG10)

Supportive relationships between patients and family caregivers were also strengthened when non-spousal family caregivers nominated themselves to act as caregiver. Assuming caregiving responsibilities by choice, often in return for receiving support in the past, motivated caregivers to provide support to their ill family member. Caregiver FCG6 communicated:

I want to help my mom because she's done so much for us [family] as a single parent, like she was always there, so I think that would be nice to return the favour ... me and my sister help out and be a carer. That wouldn't be an issue.

Family caregivers were sustained in their ability to provide care by feeling competent and satisfied in their caregiving role. Feeling competent in a caregiving role was necessary for caregivers to manage their distress and help ease tension in their relationship with the patient. Of note, gratitude from the person they cared for was important for caregivers:

She does say to me ... "I don't know what I'd do without you" ... She does say "I'm a burden on you" ... but she does appreciate that we try our best for her and she knows that we do try our best. (FCG18)

Respite for family caregivers mainly in the form of time to engage in non-caregiving activities was also important for both patients and family caregivers to feel effective in a supportive role. Patients were for the most part acutely aware of the burden they felt they imposed on their caregivers and encouraged caregivers to avail of respite that could alleviate caregiver burden:

I want to make sure she [family caregiver] is okay and get them all [other family] to look after her if she needs help or anything. (P13)

However, support from the wider family (other family members who were not the primary family caregiver) was necessary to allow caregivers and patients spend time apart and re-energise caregivers in their supportive role:

I have always gone to the gym more so for my mental health than my physical health, so I still do that whilst [family member] is with her [patient]. We need that

[family assistance] and I feel if I have done that [taken respite], I can look after her.

(FCG20)

Lastly, direct support from healthcare professionals was important in facilitating patients and family caregivers to be of support to one another. Both patients and caregivers valued support from specialist palliative care services, particularly in situations when they both needed assistance to cope:

We are doing extremely well ... like we have had a lot of positive feedback, a lot of helpful input that's given us information, that has given us the ability to deal with a lot of things together day to day. (FCG1)

I came home [from hospital] and they [specialist community palliative care] were quick on the scene ... [family caregiver] was not sure how to be taking it and they took her aside ... gave her an idea of what's going on ... That was helpful. (P5)

Barriers to supportive relationships

A lack of assistance from other family members was a key barrier to supportive relationships between patients and family caregivers. Absence of support from other family members resulted in some caregivers feeling acutely distressed and then less able to provide the level of support and care they felt was needed by the patient. For example, one caregiver who was responsible for her ill-family member's care without additional informal care from other family members reported:

I find I am under a good bit of pressure now with her [patient] ... because obviously I want to do everything I can for her and everything she wants ... She was saying I want my hair done and my nails done, and I want my eyebrows done and I want new

clothes and I just feel she's wanting loads from me at the moment ... So, it can be quite hard. (FCG4)

In some cases, family caregiver distress in the absence of other family support limited open communication between patients and caregivers. For instance, patient P5 expressed concern about the burden of care being primarily with his spousal family caregiver as opposed to other family members. In this context, he did not wish to increase carer burden by communicating his distress to his wife:

It's dealing with that, that side of the family [lack of support] ... I sometimes need now to talk to somebody without [family caregiver].

Pre-existing conflict between patients and family caregivers was also a barrier to supportive relationships. Distress experienced by both patients and caregivers was exacerbated further when patients and caregivers had a history of mutual conflict. Pre-existing conflict was often associated with caregivers feeling forced into a caregiving role. Moreover, pre-existing conflict was an antecedent to caregivers not feeling supported by the person they cared for. Caregiver FCG21 explained:

She [patient] always has been quite a difficult person to live with over the years ... I think she is a selfish person ... a self-oriented person ... She doesn't do praise, she does complaining and I'm going to be told I am doing it [caring] wrong.

In general, tension between patients and family caregivers impeded their ability to engage in challenging conversations surrounding impending death:

I'm [expletive] off with the cancer and she [family caregiver] takes the brunt of it ... She will talk to me [about other things] but talking about death and what's going to happen ... I don't think she wants to be listening to that now. (P15)

We found that deterioration in the patient's health, particularly when it resulted in the need for continuous care from the family caregiver out of concern for patient safety, also impacted adversely on supportive relationships between patients and caregivers. Change in patient health status exacerbated family caregiver distress but also (from the perspective of the family caregiver), limited them to caregiving duties without choice. Caregiver FCG17 recounted:

Because of her head the way it is, the problem is she smokes and does oxygen [home oxygen therapy]. She would pick up the cigarettes ... She would just light up and so there has to be somebody with her all the time. I can't move ... I can't move outside the house or anything.

Deterioration in patients' health was also frustrating for patients themselves, not only heightening their own awareness of their impending death, but also making some patients feel less able to be of support to their family caregiver. Reflecting on his deterioration, patient P15 said:

When I look at myself in the mirror and I was thirteen and a half stone, and I am down to eight and a half stone. I just want to run away from myself and them.

Both patient and family caregiver difficulty in coping with loss of prior roles and routines functioned as a barrier to supportive relationships. Some patients struggled with being a recipient of support if they had previously provided significant levels of support (e.g., financial, organisational) to their caregiver, and some caregivers resented the constraints

now upon them that severely impacted on their own lives. For example, patient P8 (who had been a primary bread winner prior to his illness) and caregiver FCG4 (who cared for her mother in addition to her own family) shared:

She [family caregiver] is over the top ... making sure everything is right which I don't like ... She wants to do everything. She is overprotective ... I keep telling her there is no need for it. (P8)

I miss my own family sometimes, I miss being at [my] home ... But when I do go home, I find myself worrying about my Mam ... It is hard because she can be quiet demanding on me. (FCG4)

Overall, distress associated with bereavement was high for patients and family caregivers. Feelings of loss since the onset of the patient's illness combined with the prospect of having to cope with future loss could make it challenging to decipher how best to support one another:

I think we are grieving already for each other and have been doing for a while. I am sitting there talking to her and [patient] saying "I don't want to be in a box, I don't want to die, I don't want to leave." So, the most difficult contemplating the fact that she's going to die. By a mile that is the most difficult ... us knowing what best to do [for each other]. (FCG11)

DISCUSSION

This study is one of few studies which aimed from the outset to investigate how mutual support manifests and functions between patients and family caregivers in palliative care.[9]

Findings are further evidence that patients with advanced illness and family caregivers in palliative care have capacity to be mutually supportive. Patients and family caregivers reciprocate in emotional support, but mutual support between patients and family caregivers also involves patients providing emotional support to compensate for other forms of support they feel less able to provide in the context of advanced illness.

Our findings pertaining to what enables and/or restricts supportive relationships between patients and family caregivers in specialist palliative care are new to the field. Research has reported on the importance of support from the wider family to assist family caregivers in their caregiving role.[20] However, we have identified that support from the wider family to the primary caregiver not only benefits the primary caregiver: it also helps foster support *between* the patient and primary caregiver because patients also encourage the primary caregiver to avail of respite to lessen carer burden.[21] Our findings expand the evidence on the significance of control for family caregivers in a caregiving role for patients with advanced illness. Research has reported on family caregivers' need to feel in control of the challenges they face in a caregiving role.[22] In our study, feeling in control was strongly associated with assuming caregiving responsibilities by choice. Importantly, assuming caregiving duties by choice made family caregivers feel more effective in a supportive role.

Already having had a close relationship prior to the patient illness was a key facilitator of mutual support. However, as reported, some patients and family caregivers had conflict in their relationship with their respective other. Previous studies in palliative care have documented conflict between patients and family caregivers arising from a lack of awareness of and communication about each other's preferences for care[23] but also in the context of family caregivers' need to have some autonomy.[24] We found that *pre-*

existing conflict also impacted on the quality of the relationship between patients and family caregivers and was associated with family caregivers feeling restricted in a caregiving role. Indeed, pre-existing conflict was commonly identified in situations when family caregivers felt caregiving was more out of obligation than choice.

Our study adds weight to the evidence that family caregivers who feel competent caring for a patient with specialist palliative care needs have capacity to reassure the person they care for.[25] For caregivers in this study, feeling competent was itself bolstered by patients' overt expression of gratitude and support. For family caregivers to feel effective in a caregiving role, they needed support reciprocated by the patient. Conversely, absence of mutual affection between patients and family caregivers made caregiving more difficult for family caregivers.

We observed across the data incidents and patterns of patient and family caregiver distress. Patients and family caregivers in specialist palliative care have reported high levels of distress.[26,27] In our study, distress was exacerbated by deterioration in the patient's health and lessened by assistance from healthcare professionals. However, we found that overall, it was awareness of mutual loss which explained why patients and family caregivers felt so distressed. Moreover, anticipation of future loss (i.e., anticipatory grief) made some participants question their capacity to adequately attend to the needs of their respective other.

In terms of methods and procedures, our study has strengths and limitations. We successfully managed to recruit patients with advanced illness in receipt of specialist palliative care for a qualitative study during the COVID-19 pandemic, a period in which palliative care research necessitating this type of patient participation was universally

challenging to undertake.[28] Data were member checked[29] and then examined between two investigators to ensure rigour. We have described the setting and participants in detail to enable transferability[30] of the findings to similar and different contexts. Many of the participants who agreed to participate in the study had not routinely used General Data Protection (GDPR) compliant platforms (e.g., Zoom, Teams, and Webex) and were not readily able to engage with these platforms as a mode for interview. Phone interviews in qualitative research can be as productive as face-to-face interviews.[31,32] More traditional in-person or video-based online interviews would have allowed for observation of participants in interviews to help further capture and/or contextualise depth of emotion conveyed by them.[19] Our study protocol did not include formal neuropsychological testing of patient participants which if done could have resulted in further contextualisation and explanation of the data. Of note, we did not manage to capture variation in patient diagnoses (beyond variation in cancer diagnoses) ordinarily seen in specialist palliative care and so the findings are contextualised primarily to specialist palliative care in cancer.

Relevance of findings for policy or practice

Our findings have relevance for practice. From the perspective of patients and family caregivers in specialist palliative care, multiple factors both micro (e.g., relationships based) and meso-level (e.g., assistance from healthcare professionals) impact on their ability to support one another. However, key was family caregivers needing to have some choice in a caregiving role which was restricted in many cases, by being a *primary* caregiver to their ill family member. Primary family caregivers in palliative care, by definition, assume most day-to-day caregiving duties.[33] The findings point to the benefit of strategies to help the primary caregiver feel more in control of their situation and have more choice with respect

to how they assume a caregiving role. Healthcare professionals need to be cognisant of the need to optimise caregiver autonomy to counterbalance initial caregiver loss in assuming a caregiving role, including helping caregivers process and deal with loss of choice when taking on a caregiver role. Healthcare professionals also have capacity to step in and increase the level of formal support when needed by the caregiver.

Feelings of loss predominated for both patients and family caregivers regardless of the quality of the relationship they reported. The findings warrant addressing the consequences of mutual loss for patients and family caregivers as part of formal care. This could, for example, take the form of patient-family caregiver dyadic interventions focused on relationship change and adaptation to their own and each other's loss. In addition, educating all members of the healthcare team about patient and family caregiver mutual loss including instruction on how to source additional support from the wider family and community to help the patient and family caregiver adapt to their loss, would be beneficial.

Implications for future research

As stated, our findings are limited primarily to the experience of patients and family caregivers in advanced cancer. In addition, while our definition of a family caregiver at the outset of this study extended beyond familial-based relationships, recruitment was limited to either spousal/partner or first-degree relatives. Substantial informal caregiving in palliative care is provided by people beyond spouses, formal partners, or blood relatives.[34] Further studies in specialist palliative care focused on mutual support between the patient and family caregiver in contexts beyond cancer and which capture heterogeneity in category of family caregiver are needed to both expand on and/or substantiate our findings. Importantly, any future intervention focused on supportive relationships intended

to accommodate multiple diagnostic groupings and their family caregivers would need to account for such variation.

CONCLUSION

We have identified and reported key barriers to and facilitators of supportive relationships between patients and family caregivers in specialist palliative care. Some family caregivers did feel constrained in a caregiving role, and mutual loss at times undermined both patient and family caregiver capacity to feel effective in a supportive role. However, external support from both the wider family and healthcare professionals helped both patients and family caregivers cope with advanced illness and could enable supportive relationships between them. The findings are particularly useful for healthcare professionals in specialist palliative care who work closely with both patients and their family caregivers, and where possible members of the wider family, to navigate key challenges associated with loss, including loss of control.

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interpretation of the data. The final narrative was refined by all authors. KR and RMcQ facilitated recruitment and advised on recruitment strategies. GF wrote the manuscript assisted by RMcC. KR, RMcQ, and LES made critical contributions to the manuscript. All authors reviewed, commented on, and approved the final version. GF is the guarantor of this study.

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Patient consent Obtained

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