A Qualitative Study of Mutual Support between Patients and Family Caregivers in Palliative Care

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Introduction

- Informal caregiving in palliative care has traditionally been considered as unidirectional (i.e., family caregivers viewed as 'providers' of care and patients viewed as 'recipients' of care).[1]
- Patients in palliative care have capacity to reciprocate in supportive relationships with their family caregiver(s).[2,3]
- A systematic review of limited evidence 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.[4]
- A paucity of studies exist focused on processes of mutual support between patients and family caregivers in palliative care.

Aims

To identify:

1) Key actions and behaviours which comprise mutual support between patients and family caregivers in palliative care.

2) Factors that enable or restrict mutual support between patients and family caregivers in palliative care.

Methods and Materials

- Grounded theory study.[5]
- Setting – large regional specialist palliative care service in Republic of Ireland (ca. 700,000 population).
- Fifteen patients with advanced illness (cancer n=14, neurodegenerative n=1) and 21 family caregivers purposively and theoretically sampled.
- Thirty semi-structured interviews conducted with participants.
- Data collected and analysed in line with grounded theory method.[5]
- Memos and field notes compiled.
- Data member checked with participants.

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Participants' characteristics

P/FCG number	Gender	Relationship to P/FCG	Other member participating	Condition of patient participant/patient cared for	Care setting at recruitment
P1	F	Wife	Yes	Metastatic breast cancer	SCPC
FCG1	M	Husband	Yes		SCPC
P2	M	Husband	Yes	Multiple sclerosis	Inpatient hospice
FCG2	F	Wife	Yes		Inpatient hospice
P3	M	Partner	Yes	Metastatic lung cancer	SCPC
FCG3	F	Partner	Yes		SCPC
P4	F	Mother	Yes	Hodgkin's lymphoma	SCPC
FCG4	F	Daughter	Yes		SCPC
P5	M	Husband	Yes	Metastatic pancreatic cancer	SCPC
FCG5	F	Wife	Yes		SCPC
P6	F	Mother	Yes	Metastatic lung cancer	SCPC
FCG6	F	Daughter	Yes		SCPC
P7	M	Father	Yes	Metastatic liver cancer	SCPC
FCG7	F	Daughter	Yes		SCPC
P8	M	Husband	Yes	Metastatic lung cancer	SCPC
FCG8	F	Wife	Yes		SCPC
P9	M	Father	Yes	Metastatic gastric cancer	SCPC
FCG9	F	Daughter	Yes		SCPC
P10	M	Husband	Yes	Prostate cancer	SCPC
FCG10	F	Wife	Yes		SCPC
P11	F	Wife	Yes	Metastatic breast cancer	Inpatient hospice
FCG11	M	Husband	Yes		Inpatient hospice
P12	M	Husband	Yes	Metastatic lung cancer	SCPC
FCG12	F	Wife	Yes		SCPC
P13	M	Husband	Yes	Metastatic colorectal cancer	SCPC
FCG13	F	Wife	Yes		SCPC
P14	M	Father	Yes	Colorectal cancer	SCPC
FCG14	F	Daughter	Yes		SCPC
P15	M	Husband	No	Metastatic lung cancer	SCPC
FCG15	F	Daughter	No	Ovarian cancer	SCPC
FCG16	F	Daughter	No	Lung cancer	SCPC
FCG17	M	Husband	No	Metastatic lung cancer	SCPC
FCG18	F	Daughter	No	Cardiac failure	SCPC
FCG19	F	Daughter	No	Lung cancer	Outpatient hospice
FCG20	F	Daughter	No	Colorectal cancer	SCPC
FCG21	M	Son	No	Bone cancer	SCPC

SCPC = specialist community palliative care

Mode for qualitative interviews

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	

Findings

'Mutual support' between patients and family caregivers took the following forms:

- Remaining positive for one another. *(FCG10)*
- Being open about their care preferences and mutual distress.
- Counselling one another. *(P7)*
- Making decisions together about care.
- Collectively preparing for financial implications of the patient's impending death.
- **Patients provided emotional support** (through overt expressions of concern, encouragement, and affection) in lieu of physical care / physical support they received and felt unable to provide to family caregiver. *(FCG16)*

Examples of participant quotes

Remaining positive – "*We have been very positive. It's a great relief to know we'll manage this together … The ability to laugh to me is a very big thing … and talking. I have to admire [patient] … he's good humoured."* (FCG10)

Counselling one another - *"I just let [emotions] out and know that [caregiver] is there for me … Obviously we have bad days and just talk ... I try to just put her mind at ease too."* (P7)

Patient emotional support – "*I can see that he knows I'm doing a lot for him … he always says to me 'I always appreciate what you are doing for me' and he always tries to reassure me and that's nice to hear as well."* (FCG16)

Barriers	Facilitators
• Pre-existing conflict within relationship • Mutual distress • Mutual concealment of distress • Discordance in perspective • Family caregiver burden • Family caregiver feeling constrained in caregiving role • Lack of support from wider family *(FCG14)*	• Strong pre-morbid relationship • Open disclosure • Family caregiver feeling competent in caregiving role *(FCG4)* • Family caregiver competent in self-care • Family caregiver having choice in caregiving role • Support from wider family • Direct support from healthcare professionals

Examples of participant quotes

Barrier to support - *Lack of support from wider family*
"*I would prefer more support … My brother wouldn't give him the time he'd need. [But] I would get more stressed asking for help and not getting it than I would just doing it."* (FCG14)

Facilitator of support – *Family caregiver feeling competent*
"When she [patient] grabs your hand and says 'I love you' and 'I know I'm putting you under stress, I'm sorry'… [it] makes me feel that she's happy with me and I'm doing good for her." (FCG4)

Discussion

- Multiple micro-level factors (e.g., relationship based) impact on patient and family caregiver ability to support one another in palliative care.
- Patients can reciprocate in the provision of support with emotional support to compensate for other forms of support they feel unable to provide.
- Open communication between patients and family caregivers in palliative care underpins mutual support between them.
- Participants recruited through specialist palliative care services and primarily in advanced cancer. Findings might not be as transferrable to non-specialist palliative care and non-cancer.

Conclusions

- Patients with advanced illness in palliative care can still reciprocate in a caring role[6] and remain sensitive to needs of their family caregiver.[7]
- The findings directly inform the development of psychosocial interventions in palliative care focused on supportive relationships between patients and family caregivers.

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