

# Relationship between patients and family caregivers

## ***BMJ Supportive and Palliative Care***

*Pre-publication version*

*Accepted for publication 11.01.2018*

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**Key words:** patient, family caregiver, supportive relationship, caregiving

Family caregiving in palliative care is defined broadly as the process in which family members or loved ones provide unpaid care for a terminally-ill family member in need of assistance. The care recipient may be a member of the caregiver's family of origin, or his or her family of choice, such as a friend or life partner.<sup>1</sup> Fiscal constraints in formal care provision means that patients in palliative care are now increasingly dependent on family members for care.<sup>2</sup> Indeed, a growing expectation that family members be involved directly in end-of-life care,<sup>3,4</sup> are likely to increase demands placed on family caregivers in palliative care.

Family caregivers in palliative care assume multiple caregiving roles. They may provide day-to-day physical care to their terminally-ill family member.<sup>5</sup> Although the psychosocial and existential situation of family caregivers in palliative care are not routinely evaluated,<sup>6</sup> family caregivers in palliative care also provide emotional, psychological and existential support to their family member.<sup>7</sup> In palliative care, the patient and family are viewed as the unit of care. Family caregivers can be directly involved in the delivery of complex interventions to patients, effectively operating as an extension to formal services. Family caregivers also participate regularly in the decision-making process for palliative care interventions (e.g. symptom management, advance care planning, counselling) and can function as key advocates and care co-ordinators for the patient. Not surprisingly, perhaps, burden of care for family caregivers in end-of-life care has shown to be severe and can increase with greater intensity of caregiving.<sup>8</sup>

Notwithstanding the pivotal roles of the family caregiver in caring for their terminally-ill family member, there has been less focus in palliative care on the dimensions of support rendered by the dying patient to their family caregiver. Commentary on conceptual challenges in the study of caregiver-care recipient relationships has highlighted that informal care-giving can involve caregivers who themselves are care recipients.<sup>9</sup> Bodily decline for terminally-ill patients can render it

impossible for them to provide support to their family in the form of physical care. However, studies in palliative care have reported on caring roles enacted by dying patients towards family caregivers in non-physical domains. For example, patients have been shown to conceal their own needs from their family caregiver and have encouraged family caregivers to engage in activities that would give them respite from their caregiving role.<sup>10</sup> Moreover, patients have steered the direction of their own care to alleviate family caregiver distress and have advised family caregivers on matters that relate to their (family caregivers') wellbeing.<sup>11</sup> Indeed, in a study of patients' experiences of end-of-life care,<sup>12,13</sup> dying patients' preference for hospice end-of-life care was explained by their desire to alleviate family caregiver burden and reduce distress for family members.

The reciprocal nature or interdependence of the psychosocial and existential dimensions of caregiving among dying patients and their family caregivers has been reported. Terminally-ill patients have expressed concerns about the burden they impose on family caregivers whilst family caregivers have expressed concerns about patients' distress.<sup>14</sup> The burden that dying patients feel that they impose on their family caregivers and the obligation that family caregivers feel toward the terminally-ill family member can make them prioritise each other's needs over their own.<sup>15</sup>

Sociological-based examination of the dying patient and family caregiver relationship have captured how remaining positive for one another can help both accommodate to advanced illness<sup>16</sup> and how mutual obligation to remain stoical in the face of adversity is a dimension of caring.<sup>17</sup> Studies in psychology fields have shown that reciprocity (in the form of mutual empathy) between patients with heart failure and their family caregivers was associated with patient confidence in self-care<sup>18</sup> and that positive dyadic coping strategies (e.g. supportive listening, sharing feelings) among patients and family caregivers in metastatic cancer resulted in greater dyadic adjustment.<sup>19</sup> Positive dyadic coping among cancer patients and their partners may also improve relationship functioning.<sup>20</sup> However, there remains a dearth of palliative care research which has asked questions directly of

the bidirectional nature of caregiving between dying patients and their family caregivers. We still know far too little about the dimensions of support exchange between patients and their family caregivers in palliative care.

One possible explanation for our limited understanding of support exchange between patients and family caregivers in palliative care is that we have conceptualised dying patients predominantly as *recipients* of support from family caregivers rather than as *providers* of support to family caregivers. Have questions pertaining to informal caregiving in palliative care been shaped fundamentally by the assumption that the provision of support between the dying patient and their family caregiver is predominantly unidirectional i.e. from family caregiver to patient? What of the supportive roles of dying patients in the patient-family caregiver relationship? We know that people with terminal illness can maintain caring roles. Understanding the bidirectional nature of support provision between the patient and family caregiver in palliative care necessitates investigation of the under-researched supportive roles that patients enact in their relationship with family caregivers and the substantive domains in which dying patients and their family caregivers support *one another*.

Understanding the mechanisms (i.e. the 'what', 'how' and 'why') of support exchange between patients and their family caregivers in palliative care requires identification of the conditions, consequences and processes of that support exchange. In other words, what micro- (e.g. personal, family structure) and macro-level (e.g. service provision) conditions or factors drive terminally-ill patients and their family caregivers to support one another and through what actions or interactions do they render that support? For example, how might severity of patient illness or the intensity of palliative care intervention shape how patients and family caregivers support one another? Do patterns of support exchange differ between terminally-ill patients and their family caregivers across diagnostic groupings (e.g. advanced cancer, advanced neurological disease) in palliative care? What

of the influence of the wider family (i.e. family members who may not have direct caregiving duties) on reciprocity between terminally-ill patients and their family caregivers? How do terminally-ill patients' and their family caregivers' experiences of formal services impact on how they support one another? Importantly, how do patients and family caregivers in palliative care demonstrate their care and support for one another?

In practice, understanding the nuances of support exchange between terminally-ill patients and their family caregivers is needed to help guide health and social care professionals on how they can best enable supportive relationships between dying patients and their family caregivers. Identification of key domains in which terminally-ill patients and their family caregivers support one another could facilitate the development of interventions focused specifically on support exchange between patients and family caregivers in palliative care. Moreover, key parameters of support exchange between terminally-ill patients and family caregivers could be translated into instruments that measure that support exchange and then tested among larger populations and/or different diagnostic groups in palliative care. Support exchange between terminally-ill patients and family caregivers could be judged as an outcome in palliative care and correlated with other variables or outcomes in palliative care. Ultimately, a fuller understanding and measurement of support exchange between dying patients and family caregivers would inform the direction of future research on the dynamics of informal caregiving in palliative care.

**Funding:** No funding was received for this work.

**Competing interests:** None declared.

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