Qualitative study - other

Professionals need to discuss more effectively the holistic needs of their patients regarding palliative care

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Commentary on: Collins A, McLachlan, SA, Philip, J. Communication about palliative care: A phenomenological study exploring patient views and responses to its discussion. *Palliative Medicine* 32:133–42.

Implications for practice and research

- Professionals could be more assertive in leading discussion around palliative care and be clearer about what this means in terms of disease trajectory and well-being for their patients.
- Professionals need to discuss more effectively the holistic needs of their patients. Where it is appropriate to have open conversations about death and dying, this can be worthwhile for patients to encourage uptake of palliative care services and end-of-life care planning.
- There is scope to explore further the communication practices and needs of professionals and patients with a range of life-limiting or life-threatening conditions in different care settings.
- Due to the sensitive and complex nature of palliative care communication, therapeutic interventions are needed to be developed.

Context

A key element of good end-of-life care is effective communication.[1] However, there is a hesitance among professionals to use the term 'palliative care' and to discuss related issues, not least because it is assumed that patients will become distressed and lose hope. There are also studies that confirm that discussions about death and dying are avoided by both professionals and patients.[2] As a result, the language used by professionals and patients alike may not reflect the reality of the situation. Few studies have explored the experiences of patients when palliative care has been discussed.[3]

Methods

The study[4] aims to explore patients' views and experiences of their communication with professionals about palliative care. An exploratory qualitative design was used, interviewing 30 patients with cancer, recruited from inpatient and outpatient services of oncology, haematology and palliative care. Each participant was guided to provide a narrative of their cancer story. An interpretative phenomenological approach was undertaken,[5] analysing transcripts case by case prior to providing a collective thematic overview.

Findings

The total sample of participants included 17 females and 13 males. Each had a cancer condition; lung (n=10), breast (n=10), prostate (n=5) and relapsed non-Hodgkin's lymphoma (n=5). Participants were on average 62 years of age, 10 months post diagnosis, eligible to receive palliative care, with 14 already engaged with services. Three major themes were derived from the phenomenological analysis, including 'death as unspeakable', 'palliative care as a euphemism for death' and 'palliative care as unspeakable'. The findings suggest that discussions around palliative care are highly complex, with direct talk using the terms death and dying being somewhat taboo. Language used in consultation is often unclear, ambiguous or technical. Patients fear discussions around palliative care itself because they assimilate such with meaning their own death.

Commentary

This study has explored in depth the communication experiences patients with cancer have with professionals about palliative care. Building on existing research,[1] the study uniquely obtains the patients' perspective, highlighting how patients are hesitant to discuss issues of death and dying with medical doctors and how they do not always fully understand the remit of palliative care and what it may mean for them and their illness.

There is a common misperception that doctors' interests are solely focused on the disease, active treatment and cure. When professionals do not use a shared language about palliative care, offer toned-down language or avoid direct discussion about death and dying, they are not supporting their patients. Instead, they are encouraging misunderstanding and false hope which can be a major barrier to patient well-being and the uptake of supportive services. Successful communication in this context involves baring witness, supporting patients in their distress and discussing ways to optimise the life that they have yet to live.

Although we already have checklists, guides and communication training,[6] more engaged therapeutic approaches are needed, mindful of the very delicate space these communicative needs occupy. There is also a broader issue highlighted here, a total focus on disease negates the patients' experience of the illness. Having knowledge of how that illness experience is being lived is helpful for professionals to provide compassionate and patient-centred care.

Competing interests None declared.

Patient consent Not required.

Provenance and peer review Commissioned; internally peer reviewed.

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