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Considering the role of social work in palliative care: some reflections from the literature

Social workers have a very varied and challenging role in palliative care – and one that potentially overlaps with that of psychologists working in the field. **Jacqueline H Watts** has looked at the literature on social work in palliative care and shares her reflections

Social work is integral to the professional practice of the multidisciplinary palliative care team, both in hospice and hospital settings. Alongside nursing, medicine and a range of other clinical and complementary therapies, social work provides practical and psychosocial support to those coming to the end of their lives. Death and dying involves loss and transformation, and for many can be experienced as overwhelming such that they require help to manage their feelings and come to terms with this significant transition.¹ Loss is always both personal and social, so the focus of social work practice in this area includes family and social network responses to the end of life.²

While the literature has devoted much space to discussing the nature of the work of clinical and pastoral practitioners within the multidisciplinary palliative care team (see, for example, Payne *et al*³ or Nolan⁴), less has been written about the role played by social work. Drawing on both professional and academic literatures, this article sets out to explore in more detail the complex and diverse nature of palliative care social work. In outlining the psychosocial and practical tasks undertaken by social workers, consideration is also given to the allied work of psychologists and the potential for disciplinary role overlap in the provision of both psychological and psychosocial support.

Insights from the professional literature

Much palliative care social work is centred on helping people to deal with core existential

questions associated with facing one's mortality, coping with serious illness and managing the dying process. Because within most cultures and societies, talking about death continues to be taboo and is generally avoided,⁵ this is often difficult and emotionally challenging work that has both personal and community elements. It also may involve complex ethical dilemmas related to end-of-life care decision-making, as social workers often act as a liaison between patient/family and healthcare providers.⁶

The professional literature characterises palliative care social work as very diverse to include:⁷

- Facilitating advance care planning
- Advocacy on behalf of the patient and family
- Leading community education workshops
- Facilitating psycho-educational support groups

Key points

- Palliative care social work is centred on helping people to deal with core existential questions associated with facing one's mortality, coping with serious illness and managing the dying process.
- Usually, palliative care social workers work in a medical specialty and often have to justify the value of social work interventions.
- All social work is relationship work and the establishment of positive relationships between social workers and palliative care clients is particularly crucial.
- There is a debate to be had about how social work and psychology can work effectively together across professional boundaries.

- Mediating conflicts within families, between clients and the interdisciplinary team and between service organisations
- Counselling and psychotherapy for individuals, couples and families
- Intervening in crises.

This is not an exhaustive list of functions, but serves to illustrate the myriad ways in which social workers contribute to the support of dying people and their families.

Information from the National Association of Social Workers⁷ emphasises that, usually, palliative care social workers find themselves working in a medical specialty and often have to justify the value of social work interventions. As medical care becomes more 'high tech' and the dying process may be more prolonged, the importance of establishing good relationships between social workers and the medical team is a heightened concern.⁸ Parker notes that the role of social workers may be wider than that of other palliative care professionals and that it has a 'socio-educative' component directed towards the reintegration of death and dying into our vision of society.⁹ As we see an increase in the

Good relationships between social workers and the medical team are a heightened concern

individualising nature of much health- and social care practice and the neglect of social forces, particularly economic ones that give rise to structural inequalities,¹⁰ it could be argued that social work, more than any other profession operating in palliative care, practices in the fullest context.

Skills and practical problem-solving

Focusing on specific social work skills, Sheldon and Firth argue that, with their understanding of social issues that can lead to distress in individuals and families, social workers have significant expertise to offer psychosocial palliative care.¹¹ Negotiating the sensitive social terrain of family splits, social isolation and social inequality is part of mainstream social work and is also required in the context of death and dying. Writing about the role of the social worker in palliative care, Monroe develops this point, arguing that social workers' training 'helps them to locate the patient and family within a social and cultural context and thus to exploit resources which may help the family to resolve the difficulties they face'.¹² Related to this, Parker cites, for example, how common it is for

palliative care social workers to receive requests for assistance completing benefit forms or for advice about charitable awards.⁹ These and other problem-solving functions contribute to the development of a relationship between the social worker and the client/family, and this is highly valued by clients.¹³ All social work is relationship work and the establishment of positive relationships between social workers and palliative care clients is particularly crucial, as life and time are limited and the future uncertain. Mallon calls attention to the importance of professionals working in this area 'building a relationship which offers safety, emotional warmth, consistency, commitment and genuine care'.¹

The very practical contribution of social work within palliative care is drawn out further by Connor who, writing in the US context, paints a vivid picture of the different types of help provided by social workers.¹⁴ He explains: 'If Meals on Wheels or help from a food bank is needed, they arrange for it. If insurance coverage is confusing, they straighten it out. If the phone is disconnected, they are the patient's advocate to see that it gets turned back on. If respite is needed, a volunteer or short inpatient stay is arranged. When it's time to leave the hospital, the social worker helps to do the discharge planning'.¹⁴ The emphasis here is very much on problem-solving action to resolve difficulties as they crop up.

Within the palliative care model, care also extends to patients' family and friends, and Connor comments that families can be severely disrupted by the impending death of one of their members and that sometimes the role of the social worker is to act as the listener of difficult and anguished emotions.¹⁴ The social worker is an outsider who can share the burden. A further social work role is that of helping the dying person to undertake a life review, which may include important family milestones, instructions to survivors and the documenting of values and beliefs that have given meaning to their life. Connor argues that life review can be very positive, noting that: 'Helping patients to discover a coherent narrative for their life and to be able to put their illness and impending death in a context that fits that narrative can be a powerful psychological and spiritual intervention'.¹⁴ Leming and Dickinson comment that family members may find it difficult to communicate

with each other, such is the level of their distress, and the social worker is the primary provider of emotional support in helping families come to terms with the death of their relative.¹⁵ Connor notes that the social worker 'functions as both counselor and practical guide to the dying process'.¹⁴

Social work and psychology in palliative care – role overlap?

In 2009, the European Association of Palliative Care formed a Task Force on Education for Psychologists in Palliative Care, specifically to gather information on the situation and role of psychologists working in palliative care in different European countries.

Findings show that psychologists undertake bereavement support, advocacy and counselling, and contribute to policy development and research, though their role in palliative care is not yet well delineated, with limited systematic data concerning the detail of their function and responsibilities.¹⁶ The lack of clarity about the role of psychologists in this area may arise because psychological and psychosocial support in palliative care is not assigned exclusively to psychologists.¹⁶ This, as discussed above, is also the province of social work, which now has an established place in this sphere of professional healthcare practice.

Looking at the numbers and location of psychologists working in palliative care in Europe, one is tempted to ask if the presence or otherwise of psychologists as members of the multidisciplinary palliative care team is a cultural issue. Figures presented by Jünger *et al* indicate a higher number of psychologists practising in palliative care in Belgium, Italy, the Netherlands and Spain.¹⁶ One question is whether, in these countries, the contribution of clinical specialties are more highly developed and acknowledged than non-clinical specialties. Whether this is the case or not, there is clearly a debate to be had: how can the disciplines of social work and psychology work effectively together, across professional boundaries for the benefit of dying people and their families?

Conclusion

The challenges of palliative care social work are many, particularly those arising from the

increasing social inequalities present in many countries in the West. Offering appropriate 'respectful' care to those from diverse cultural backgrounds is a further challenge. Cskai and Chaitin argue that this challenge depends on professionals thinking through how race, culture and gender impact on an individual's value system and life circumstances.¹⁷ Because social workers practise in varied and divergent settings across the lifespan and are committed to promoting culturally competent care for the most vulnerable and oppressed members of society, they have an important contribution to make in helping to improve the quality of

end-of-life care for all sections of society. Since the essence of all social work practice entails matters of loss and adjustment to changes in a person's assumptive world,

I would argue that social workers are the professional group particularly well placed to provide skilled psychosocial support of all kinds to those struggling to come to terms with terminal illness.

Declaration of interest

The author declares that there is no conflict of interest.

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