

# KNOW YOUR COLLEAGUES: ROLE OF SOCIAL WORK IN END-OF-LIFE CARE

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Effective care at the end of life requires input from all members of the multidisciplinary team. Nurses working in all settings need to be aware of the different roles and expertise of other professionals so that they can refer patients accordingly. This article will describe to nurses the role of social workers. Social work differs from medicine and nursing in that it is not a health care profession. Instead its practice aims to integrate social justice and social problem-solving with personal help in order to empower people and enhance their wellbeing. Social work should not be equated with counselling, taking children into care or merely sorting out social security or discharge problems. Within this article a detailed case study will illustrate how these different aspects of social work are integrated within end-of-life care. *Declaration of interests: none*

## KEY WORDS

Empowerment  
End-of-life care  
Family relationships  
Social change  
Social work  
Problem-solving

Social work has played a role in health care since the end of the 19th century. It has always been central to the concept of palliative care because palliative care deals with the whole person and requires the care team to work closely with the patient and the family and community that surround them. Family and community may both support and hinder the patient in achieving personal goals at the end of life, and a bad end-of-life

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experience may mean that the family struggles in the future. Social work focuses on the patient as part of a wider social network, complementing the emphasis in health care on the patient.

### What social work is not

Social work is not a health care profession. Most social workers are employed in child protection, family work and child development in education departments of local councils. They also work in education welfare, youth justice and care services. Part of their work involves helping people deal with difficulties when using various services in society, including health care. They also have an important legal role in mental health services, since they are responsible for compulsory admissions to mental hospitals.

Only a minority of social workers operate in health care. The majority of social workers are located in local government education and adult social services departments and voluntary organisations. However, certain health care specialisms, including end-of-life care, are attractive to social workers because the work is interesting and complex (Monroe, 2004).

Social work is not counselling or psychology, although social workers

have some training in psychology and often use counselling skills. Counsellors and clinical psychologists mainly focus on changing the thinking patterns or feelings and attitudes of the people with whom they work. Social work aims to help improve people's relationships with the people, social networks and organisations around them. So, while they may try to change attitudes and thinking, their role is to work on both sides of the interaction between individuals and society, and not just help people function or feel better. Integral to the social work role is trying to make services and policies work more effectively for the people they serve.

Social work is not about taking children into care and mentally ill people into mental hospitals. An important role of social work is safeguarding vulnerable people, such as children, frail or disabled people or people with learning disabilities or mental health problems. As a small part of this, they have responsibility for assessing possible abuse of, or danger for, people living at risk in the community and then doing something about it. Much of the social work role is helping to sort out the problems leading to that risk, rather than forcing people to do what they do not want to do.

Integral to the social work role is helping people maintain independence while also promoting social justice and freedom. That is why social workers are often concerned about fairness to people who have had a raw deal in life: promoting equal opportunities and reducing inequality is part of the definition of what they do.

Some professionals mainly encounter social workers sorting out social security benefits or debts, or organising care services so that people can be discharged from hospitals and hospices. However, that is only an incidental part of social work. They do this in order to reduce unfairness and, by 'negotiating' between people and society, to ensure that people get what is their right. Social workers also aim to improve how families function, in order

to promote successful interpersonal and family relationships and a better society with better services.

**So what is social work?**

The definition of social work agreed by the international organisations for social workers and social work schools is given in *Table 1*. There are four elements to this definition:

- ▶▶ Social work's aims, e.g. empowerment, problem-solving and social change
- ▶▶ Social work's knowledge base
- ▶▶ The focus of its work
- ▶▶ Its values.

The three aims of social work can be seen as a triangle of territory in which social workers operate (Payne, 2006) (*Figure 1*). The example in the case scenario (see box) helps to

**Table 1**

**The definition of social work**

'The social work profession promotes social change, problem-solving in human relationships, and the empowerment and liberation of people to enhance wellbeing. Utilising theories of human behaviour and social systems, social work intervenes at the points where people interact with their environments. Principles of human rights and social justice are fundamental to social work.'

*Source: International Federation of Social Workers, International Association of Schools of Social Work (2000); International Association of Schools and Social Work (2001)*

**Case scenario**

Mrs Onukwe was in her 40s and had been diagnosed with cervical cancer and lung metastases. She was in the terminal stages of her condition but was managing to stay at home. She had three children: a young woman in her twenties, and a son and daughter who were in their late and early teens respectively. She was separated from her husband, who was thinking of returning to the Caribbean. She also cared for her elderly widowed mother, who lived alone nearby. The elder daughter had learning disabilities and lived with a group of other people with learning disabilities, supported by carers from social services.

Mrs Onukwe had serious rent arrears with the local council as well as other debts. She was worried about her teenage son who had to help her with toileting and personal care; she thought that this was inappropriate for a young man of his age, although he wanted to help her. She was contacted by the education social worker because her daughter was missing school as a result of her anxieties about her mother's impending death; she wanted to spend more time with her mother.

The nurses and doctors involved with Mrs Onukwe's care were concerned with her health and enabling her to maintain a good quality of life for as long as possible. This was crucial as Mrs Onukwe needed the time and capacity to deal with the many affairs that had to be sorted out. The social worker's role, however, was to work alongside Mrs Onukwe to remove as many of her problems as possible. For a social worker involved in end-of-life care, this would be partly for Mrs Onukwe's benefit, so that she died feeling at ease, but mainly for the benefit of family members and their security and future development. If Mrs Onukwe died leaving such a complicated and disorganised family situation, it would be more difficult to maintain the family in the future and its fragmentation might lead to social and bereavement difficulties at a later stage.

illustrate the social work role within the context of end-of-life care.

**Discussion of the case scenario**

Social workers in any service often have to deal with complicated family problems. The approach is usually to assess the situation in order to be clear about the many factors involved, and then to divide them up into small, manageable tasks. Dealing effectively with a clear practical problem first often gives families the confidence to go further with more complex problems. In Mrs Onukwe's case, the social worker dealt with five family issues which are discussed below.

**First:** The social worker targeted the rent arrears. She called in a welfare benefits adviser, who found that the rent rebate that Mrs Onukwe was entitled to had been wrongly calculated; this wiped out thousands of pounds of debt. Doing this eased family anxieties. Social workers are problem-solvers, but they also empower families. As mentioned above, if the family has confidence in the social worker, they may believe that even apparently impossible problems can be sorted out.

**Second:** The social worker then talked to the carers from social services about the elder daughter. Like many people

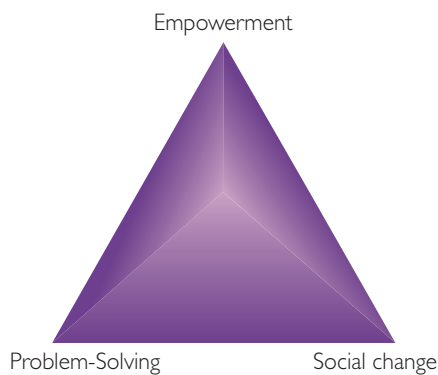


Figure 1. The three aims of social work. Source: Payne (2006).

who are inexperienced with regard to the process of dying, they had thought that the best thing was not to tell the daughter about her mother's impending death to avoid upsetting her. They had also decided to reduce the daughter's contact with her mother. This is a common reaction. The aim is to protect children from distress. However, it is an inappropriate reaction, as it does not help children to prepare for the death. The social worker helped the carers to realise the problems that this would cause in the future. The social worker helped Mrs Onukwe to plan the discussion with her daughter; rehearse what to say and think how to reply to difficult questions. This gave Mrs Onukwe confidence to manage a difficult process.

As a result, Mrs Onukwe and her daughter worked together to prepare a memory box that would help the daughter to remember her mother. A memory box is a collection of personal items that will remind a bereaved person of important shared experiences with the person they have lost. This task was about fulfilment and empowerment for the daughter and Mrs Onukwe; it also related to social change, as it helped to educate the carers from social services and their department about appropriate responses in the future.

**Third:** The social worker also talked with social service staff about the future care of the patient's elderly mother, so that a suitable package

of care services could be organised. This included regular checks on her condition, assistance in managing her household, referral to a day centre and regular delivery of hot meals. This was mainly a problem-solving role.

**Fourth:** The next issue was to help Mrs Onukwe talk with her younger daughter about staying away from school. Mrs Onukwe was encouraged to organise herself so that she could find some special time for her daughter. However, while facilitating this process, the social worker uncovered a concern about whether after Mrs Onukwe's death the separated father, who would take on parental responsibilities, would want to return with the daughter to the Caribbean. The daughter wanted to stay in England, perhaps with her elder brother, who was willing to help. Mrs Onukwe's relationship with her former husband was not good enough for her to negotiate with him and so the social worker started that negotiation by approaching the husband, arranging a date and neutral place for a meeting and helping Mrs Onukwe prepare what she wanted to say. The meeting was difficult. However, after two subsequent meetings and a discussion with his daughter (whom the social worker also helped to prepare what she wanted to say), he agreed to rethink his plans. This again was a problem-solving role, with a strong element of empowerment for the people involved. The social worker enabled all parties to talk and plan child care for the future.

**Fifth:** Another role was to talk with the son about his caring responsibilities, helping him to feel valued for the contribution he was making, before identifying people outside the family who would give him support. This was also a problem-solving role. It empowered the son to learn the importance of planning personal support for difficult life-tasks and events. Eventually, more home care had to be provided, but the son continued to make a valuable contribution that he felt was a personal achievement.

As can be seen from this case scenario, although health care services

were aiming to help Mrs Onukwe maintain her quality of life and health for as long as possible, the aim of the social worker was to assist her to make use of that life and health, to achieve what she wanted with her remaining time. The object of the social work was to benefit Mrs Onukwe's family and the other people around her. In this way, social work contributes to the stability of society, by assisting people to contribute what they can to their relationships with others.

This is particularly relevant within families. When someone has very little time left, they often need help in deciding their priorities, working out what to do and how to get through a lot of different tasks. Many people can do this on their own or with the help of their families. However, for people like Mrs Onukwe, who find themselves in difficult situations, social work provides extra personal support, experience and knowledge of how things work.

#### Where does social work come from?

All societies have systems of social welfare for dealing with problems that arise in the relationships between people and groups, such as their families, and people at their workplace and in their communities. Social work is a modern form of welfare, and is based on professional practice. It grew up in the late 1800s at the time of urbanisation and industrialisation in European countries and the USA, when local help received from churches declined. This was part of a general social trend for the state to take responsibility for dealing with social problems (Offer, 2006).

The main focus of British and American social work is to help people sort out their family problems so that more supportive social structures develop. An alternative form of social work, 'social pedagogy', as practised in Europe (Lorenz, 1994), emphasises education through groupwork as a form of self-help, rather than the Anglo-American problem-solving approach, which is a bit like medicine: 'diagnose' the 'problem', then 'cure' it. In the UK,

some of the work of community and family support centres for families who need help in bringing up their children is similar to social pedagogy.

The method of social work developed through two important influences: charity organisation and reform. It therefore always contains elements of social help and social change, which are sometimes in tension. The 'charity movement' of the late 1800s tried to organise rich people's donations to the poor, and to encourage the poor to provide for themselves rather than relying on charity. One aspect of charity organisation was to give alms only after an assessment of character. This encouraged friendly visiting to help families in their own homes and efficient recording of information about people applying for assistance; that is one origin of social work. In addition, a welfare role in hospitals grew up, where 'almoners' were employed to check people's eligibility for the free health care provided from charity hospitals. This led eventually to medical social work (Payne, 2005).

Social work was also part of social movements in the early 1900s designed to change society and improve the lives of poor people. This led to the development of group and community work methods (getting groups of local people together to identify their problems and organise means to solve them), and self-help (setting up new services or campaigning to develop or change social policy) (Payne, 2005).

A third element of social work is the provision of social care. From medieval times until the 1900s, many social problems were dealt with by setting up institutions, e.g. almshouses, asylums, hospitals, prisons and workhouses, to take difficulties out of ordinary society and provide specialised help. When the British welfare state emerged in the 1940s, some of these institutions became the backbone of the NHS and of residential care provision. Since then, much of this care has come to be provided outside institutions, through the policy of 'community care', which

was first introduced for mentally ill people and people with learning disabilities in the 1960s (Payne, 2005).

In recent years, this 'social care' service, e.g. residential care homes and the provision of personal care in people's own homes, has been distinguished from nursing and health care by government policy (Twigg, 2003). Social work aims to help people and families achieve personal and social fulfilment, and strives for social change. In contrast, the emphasis of social care is on organising social services efficiently and making them more responsive to people's needs and wishes which, in the UK, is now called 'care management'.

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#### **What is 'care management'?**

Many staff in adult social services are called 'care managers'; some, but not all, are social workers. Care management was introduced into community care by the British government in the 1990s, after experiments with an American form of social work called 'case management' in the 1980s (Payne, 1995). Care management focuses on caring services rather than therapeutic social work. It uses the traditional assessment role of social work to try to identify the care needs of adults. It then puts together, from the family/social network of the person concerned and formal social care agencies, a 'package' of services that is 'tailored' to meet the person's needs. Part of the skill is tailoring without seams: the package from different agencies and people should fit together, so that the service user cannot see the joins.

This development is controversial. The American approach and the original policy were a creative way

of using discretion and professional judgment in order to put together new ways of providing care that fitted people's needs (Payne, 1995). However, the British system was introduced as part of restraining the expanding costs of community care (Lewis and Glennerster, 1996). To achieve this end, care management has sometimes become a tick-box exercise, i.e. fitting people into administrative categories rather than looking for imaginative responses to their needs. Some social services departments have used administrative workers rather than social workers, with the result that professional discretion and flexibility in creating care arrangements have declined. Hence, many people see care management as being inflexible, bureaucratic and cost-cutting (Gorman and Postle, 2003). However, at its best, it should be the exact opposite.

#### **How is social work different from health care professions?**

Health care professions and social work share many values, i.e. to help people in difficulties and to treat people with respect and dignity and in confidence. As stated earlier, the primary aim of social work is to make society work more effectively. Social workers also try to improve society's services and way of dealing with people who present with social problems. Trying to improve services, e.g. by using decisions in individual cases to effect change in policy or practice that benefits society in general, is an important part of social work values. As a result, social workers are often regarded as trouble-makers. Rather than accepting decisions, it is part of the role to apply the principles established in one case to other cases, arguing for people against unfair procedures or consequences of inflexible service provision.

The focus on improving social relationships is one of the most important differences between social work and health care. The primary emphasis of health care is to improve the health of individuals and the health of society in general. Social work supports that aim, and health-related

social workers try to help people deal with the social and relationship problems that arise when someone is ill or dying. This helps health care colleagues achieve their objectives, but has the eventual aim of improving how society works and developing the strength of social structures, such as families and communities, to cope with adversity.

In end-of-life care, as in Mrs Onukwe's case, social workers help the families of people who are dying to sort out their relationships, support each other, arrange finances and plan future child-care arrangements. They hope to strengthen the family's ability to manage adversity in the future, and give people confidence that they can cope with the death of another loved one. This can strengthen social relationships in general.

The most obvious difference is that social workers are trained in the social sciences rather than biomedical knowledge. However, they will usually have some basic training in biomedical aspects of the main long-term disabilities and in mental health. Social work generally focuses on the personal and social changes that result from the illness for the patient, the family and social network, and the community. It does not focus on the illness and its treatment. However, people in specialist posts will usually have extra training in the biomedical information they need.

Another practice difference is that the emphasis on social change in the values of social work, and a training based on social policy studies, leads social workers to be more interested in the organisation and policy of services than many health care workers, who tend to focus on individual health needs. Also, social workers often come across aspects of services that are not working well. As a result, the social work view of advocacy is not only sticking up for patients' needs in the system, which health care workers do as well, but also arguing for changes in policy and services that will benefit people in a similar position.

## Conclusion

This article, in describing the role and tasks of social workers, has aimed to show nurses how the social objectives of social work are connected with, but different from, the objectives of health care. The social science basis of social workers' training and knowledge base gives their work a different emphasis, but is an important contributor to the mix of skills and knowledge available in end-of-life care.

Health care professionals often see family and community as contexts in which care is provided and which can hinder or support good care at the end of life. Social workers, on the other hand, see health care and end-of-life care as settings in which they can pursue their overall objective of improving social cohesion by strengthening the capacity of people and the family and community groups around them to manage important life events. This helps nurses and health care professionals by removing some of the hindrances in the patient's life to their making the best use of the care that they are offered.

Nursing and health care professionals often call upon social workers to make the application for a package of care, or sort out discharge arrangements. In so doing, however, the social worker will often help a patient and family think through how they will manage the change in life when a seriously ill patient, approaching the end of life, returns home and needs more care. The social worker will also help people to think through changes, such as the need to move to a nursing home because their spouse can no longer manage to care for them and the subsequent feelings of loss and grief that may be engendered. Social work is characterised by a mix of managing the practicalities and feelings, while being alongside people as they go through the changes that the process of dying brings. **EOLC**

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## Key Points

- ▶▶ Social work is not a health care profession, although social workers and health professionals share many values.
- ▶▶ The aim of social workers is to promote social change, encourage problem-solving within families and to empower people within society to enhance wellbeing.
- ▶▶ At the end of life it is important to help people use what time they have left to achieve what they can, both for themselves and their families. By working with families through this difficult time, social workers can help bring stability within the family unit.