

Service users' views of specialist palliative care social work

This UK-wide study by Peter Beresford, Lesley Adshead and Suzy Croft focused on service users' experience of specialist palliative care social work. Two groups use this service: people living with life-limiting illnesses and conditions and those facing bereavement. The participatory project explored service users' views of specialist palliative care social work practice as a basis for improving it by their involvement in its organisation, training, evaluation and review. The study found:

- Service users held overwhelmingly negative views of social work and social workers prior to meeting the specialist palliative care social worker. These were based on both media accounts and direct experience. They associated social work with the removal of children into care and loss of independence.
- In contrast, service users overwhelmingly valued their experience of specialist palliative care social workers, highlighting the quality of the relationship between service user and social worker, the personal qualities of the social worker and the nature and process of the work with them. The service users saw them as having a particular contribution to make to improve their lives. However, negative expectations of social work generally suggest that some may turn down this highly-valued form of social work.
- Service users appreciated the wide range of support social workers offered, including counselling and advice, practical help, advocacy, individual and group work, tailored to match their individual needs and preferences. They valued the informal, participative approach to practice adopted by social workers.
- Access to and the organisation of specialist palliative care social work support is currently undermined by limited availability, limited status, poor self-image and the dominance of medical approaches in palliative care.
- A very high level of consistency emerged across all groups in terms of their satisfaction with specialist palliative care social work service. Service users from black and minority ethnic backgrounds seemed to highlight issues of poverty and inadequate housing as being important to them. Specialist palliative care social workers seemed to be very responsive to these types of issues. The evidence, however, indicates that black and minority ethnic communities generally have inferior access to palliative care.



Background

The 'quality' of health and social care services has become an increasing focus of political, policy and public debates. This has resulted in the development of a range of measures to define and measure quality. Outcome measures have been key to this, focusing on what services achieve rather than on their provision and operation. However, such developments have been based mainly on professional and managerial definitions of quality and outcomes. The aim of this project was to explore what service users wanted from specialist palliative care social work. This field of social care has tended to be neglected and this project builds on and links with other work developing user-defined outcome measures, by the service user organisation Shaping Our Lives.

The project included the views of service users in a wide range of palliative care settings throughout the United Kingdom. This included both people facing life-limiting illnesses and conditions and people facing bereavement. It explored their views and experience through the 'palliative care journey'.

The negative view of social work

Service users held overwhelmingly negative views of social work and social workers prior to meeting the specialist palliative care social worker. They saw social workers as intrusive, bossy, controlling, ineffectual and 'for other people', and associated them with dependence and taking children into care. These negative views mainly came from the media; in a minority of cases they were based on previous direct experience of social work. The project only included people who had actually accessed specialist palliative care social work. Some said that their preconceptions of social work had almost deterred them from accepting support.

"I thought that's it, they want to come in and take the kids because they know I'm not going to be able to look after them ... I was frightened."

(Young, white bereaved woman)

In contrast, almost all service users valued specialist palliative care social work practice and expressed very positive views about it.

Referral and assessment

Service users valued the informal way in which most had been approached by the social worker. This seemed to make them feel safe and cared for. It was clear most social workers were not using formal referral and assessment agendas or checklists. This did not mean that practitioners were working on a hit-or-miss basis. Rather, they were avoiding the more mechanistic

approaches which seem to have developed more generally in social work, particularly in the field of care management. Less formal approaches worked well where people had negative views about social workers more generally, which might have led them to reject more formal approaches.

The support offered

"I was looking forward to her coming as a friend, I felt I could talk to her about anything, I wouldn't need to watch my tongue ... I had complete confidence in her, complete confidence."

(Older, white European bereaved woman)

Service users reported taking a wide range of issues to their social worker and social workers' willingness to respond to very varied concerns. Most people wanted help with emotional and practical or financial matters; the two emerged as closely interlinked and service users valued social workers' holistic approach. The support from the social worker was frequently extended to family and friends as well as to the patient or bereaved person. Much of the work involved liaison with external agencies, and the social workers had extensive knowledge of other resources and groups. Advocacy was a central part of the work. It was also clear that social workers were able to use varied approaches, with individual, group and family work all evident, helping service users to support each other.

There was strong agreement among service users about what they valued. This was true of different groups of service users and in all settings. They particularly valued:

The quality of the relationship between service user and social worker

Service users valued what they experienced as a genuine relationship with the specialist palliative care social worker. While appreciating that this was a professional relationship, 'friendship' was seen as an important part of it, with some service users highlighting reciprocity.

The personal qualities of the social worker

The importance of appropriate personal qualities was stressed repeatedly as being vital. These qualities included kindness, warmth, respect, compassion, caring, sensitivity, empathy, and thoughtfulness. Many service users saw these qualities as being inherent in the person rather than learned skills. They also identified a number of skills which they saw as key for user-centred social work.

The nature and process of the work

Service users emphasised the importance of being able to determine their own agenda and work in partnership with the specialist palliative care social worker, and being listened to by someone with a non-judgemental and respectful attitude. They also valued the social worker giving them time, being accessible and ensuring continuity of support; being reliable and delivering promised action; offering a wide range of social work approaches to suit different needs and having a good level of expertise and willingness to learn.

“She was just prepared to listen, she listened basically and where she felt that she needed to give some counselling, advice, whatever, she would offer it to me but she wouldn’t force it on me.”

(Young, black woman patient)

Positive outcomes of specialist palliative care social work

Service users reported that specialist palliative care social work had a significant positive impact on their lives. They identified a range of positive outcomes, including improvements in their own capacity to deal with the difficult situations they might be facing and support with material problems they might face. They highlighted that such social work:

- Enhanced their ability to cope and increased their feelings of control and safety;
- Increased their self-esteem, morale and helped reduce suicidal feelings;
- Reduced social isolation and exclusion and increased opportunities for mutual solidarity and support between service users;
- Increased support for family members and other loved ones, including children;
- Reduced people’s anxieties about practical matters and increased their access to services through liaison and advocacy;
- Improved service users’ quality of life through improving their financial security;
- Increased their ability to cope with medical aspects of illness, through providing support, counselling and information.

Working with difference

The project sought to explore differences in people’s experience of specialist palliative care social work. While some differences did seem to emerge between some groups, there were no discernible differences between groups in terms of their view of the quality of the social work. Most striking was the extremely high level of consistency across all groups in terms of their satisfaction. Service users from black and minority ethnic backgrounds seemed to highlight issues of poverty and inadequate housing as being important to them. Specialist palliative care social workers appeared to be very responsive to these types of issues.

Problems of referral

Significant problems relating to referral emerged, which denied people this valued source of social support. Few service users seemed to be referred to palliative care services specifically to access social work support despite the particular value they attributed to it. Many do not receive it at all and some service users in this study said they would have liked to receive it earlier. There was a low rate of self-referral to specialist palliative care social work (which is likely to be linked with service users’ negative perceptions of social work generally) and service users repeatedly mentioned late referral by other professionals. The problem seemed to be greater for patients than bereaved people. There also seemed to be problems of inconsistent referral, the dominance of medical approaches in referral and restrictions on, and unequal access to, specialist palliative care social work.

Negative views of practice

The very small number of cases where there were negative feelings about the social worker’s role were generally those where there was an element of a risky discharge from palliative care, for example to their home or a nursing home. Here, social workers might have been constrained by dominant medical professionals and agendas. In such instances, the specialist palliative care social worker’s role had restrictions placed on it, comparable to those operating on the role of mainstream social worker in statutory services. These constraints put at risk the valued contribution of the specialist social workers, to the detriment both of service users and the profession. This requires careful re-examination for the future.

Broader problems

Service users see specialist palliative care social work as an essential part of palliative care provision, identifying its distinctive role and valuing the particular contribution it can offer them. Yet specialist palliative care social work seems to be beset by internal uncertainty and external misunderstanding. Social work is not prioritised and is

not universally available to palliative care service users. There is widespread lack of knowledge about what social workers actually do among other professions, which in turn limits referrals.

Furthermore, the characteristics which service users seem to see as the strengths of specialist palliative care social work – its flexibility, informality and ‘ordinariness’ – generally do not attract professional value or recognition. Other factors – such as the limited representation of social workers on the bodies which govern and develop palliative care, and the lack of influence that social care managers have – work together to diminish its profile. This low profile is not exclusive to palliative care. Social work in general is often seen as a marginal activity.

User involvement

Little evidence emerged of routine and regular formal evaluation of the work of specialist palliative care social workers, or of seeking the views of service users. It was clear, though, that social workers themselves carried out informal evaluation and review as part of their practice.

The project confirmed that many service users were interested in being involved in research and evaluation, both as participants and in its process, and that with sufficient support and employing imaginative approaches, this would be possible. However, it was difficult to involve some groups of service users, and in some cases this seemed to reflect their unequal access to palliative care and specialist palliative care social work. The project highlighted five areas where users were interested in getting involved: in service evaluation and feedback, sharing service user knowledge of social work, offering peer support, working as volunteers and user involvement in training.

Implications

The project examined the qualities and issues that service users saw as making for good practice, raising the question of whether these may also apply to other palliative care professional disciplines and highlighting the need to follow this up from service users’ perspectives. It considered the significance of the psycho-social support role of social work in an area where issues of the right to death and the right to a good quality of life are likely to become increasingly significant.

“I don’t think I would be here, I tell you now; well, I know I wouldn’t be here ... I would have done something, I couldn’t live like I was, I couldn’t live with this, how I was doing; I felt of no value at all. I don’t think I would be here without [the social worker] ... So I cannot put a price on what she does.”

(White, middle-aged male patient)

About the project

A total of 111 service users were interviewed in the project individually and in group discussions; nine per cent were identified as black or members of minority ethnic groups. The scheme was carried out in a participatory way, involving service users in its design and management. This included three steering groups made up of palliative care service users who met during the project. The project raised complex ethical issues involving service users, specifically relating to recruitment, information needs, confidentiality and consent, interviewing, meeting people’s support needs, feedback and further involvement.

For more information

Palliative care, social work and service users: making life possible, by Peter Beresford, Lesley Adshead and Suzy Croft, with a Foreword by Dorothy Rowe, is published by Jessica Kingsley Publishers (ISBN 978 1 843104 65 0, price £22.99).

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Published by the Joseph Rowntree Foundation, The Homestead, 40 Water End, York YO30 6WP. This project is part of the JRF’s research and development programme. These findings, however, are those of the authors and not necessarily those of the Foundation. ISSN 0958-3084

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