

Why Service Users Say They Value Specialist Palliative Care Social Work:

and how the medicalisation of palliative
care gets in the way

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Palliative Care

Palliative Care is defined by the World Health Organisation as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual
(Cited in Davies and Higginson 2004, p14)

Specialist Palliative Care Social Work

- The Association of Hospice Social Workers (now the Association of Palliative Care Social Workers) was founded in the UK in 1986
- The Association currently has around 260 members, but there is no reliable data available for the overall numbers of social workers now working in palliative care
- Specialist palliative care social work is provided in a range of settings, including independent hospices, day hospices, NHS specialist palliative care units, oncology wards and in home care teams
- Specialist palliative care social workers offer a wide range of support to service users and their families from practical help and advice around income maintenance, debt counselling, help with housing and accessing other services through to advocacy, individual counselling and group support. This will include bereavement work with adults and children.

What the Association Says About Palliative Care Social Work

Social work is an integral part of the multi-disciplinary team within palliative care, offering an holistic service to patients and families. Unlike many fields of social work it is potentially a universal service and we are used to working with a diverse range of people in terms of age, diagnosis, class, ethnicity, sexual orientation, religion and culture. Palliative care social work involves working with two groups of people – direct service users with experience of terminal or life threatening conditions and those who have been bereaved. Social workers are skilled at balancing the different and sometimes competing needs of the two groups...Key to specialist palliative care social work is the desire and ability to see people as whole people and not as a set of problems, to understand the connections of their lives and to seek to act on, rather than ignore, the constraints and discriminations they experience in society.

User views of Specialist Palliative Care Social Work: Implications for palliative care

- Specialist palliative care social work has tended to be a marginalised field of both palliative care and social work practice
- The first national study, on which this paper draws shows that specialist palliative care social work is highly valued by service users and perceived as having a distinct contribution to make

(Beresford, Adshead and Croft, 2007)

- While the focus of the project was people's experience of individual social work practice, their comments also raise wider issues about the organisation, provision and philosophy of palliative care more generally.

The Project

- Three year UK wide research project, supported by the Joseph Rowntree Foundation, which set out to explore what service users wanted from specialist palliative care social work.
- The project included a range of settings: Independent hospices, NHS hospice units, hospital oncology units and palliative care day centres.
- It distinguished between two groups of service users: those who were living with a life threatening illness and those who had been bereaved. All of those interviewed had used the services of the specialist palliative care social worker
- People were interviewed either as individuals or through group discussions, using a semi-structured schedule.

Who we interviewed

- A total of 111 people were interviewed in the project: 61 were bereaved people, 52 people with life limiting illnesses and conditions (two people were both bereaved and patients)
- 39 men and 72 women were interviewed
- 9% of participants identified themselves as black and/or members of minority ethnic groups
- Service users came from 26 different specialist palliative care settings, located in urban, suburban, rural, small town and coastal settings in England, Scotland, Wales and Northern Ireland

Social Work Findings

Service users overwhelmingly valued their experience of specialist palliative care social workers. They highlighted:

- The quality of the relationship between service user and social worker
- The personal qualities of the social worker
- The nature and process of the work with them
- They valued the wide range of support social workers offered to them and their families/partners/children/loved ones, 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
- However negative views/expectation of social work more generally suggest some may turn down this highly valued form of social work

Social Work Findings

- Service users saw social work as having particular contribution to make in meeting both their personal and practical needs
- A very high level of consistency emerged across all groups in terms of satisfaction with specialist palliative care social work
- Service users from black and minority ethnic groups seemed to highlight help with issues around poverty and poor housing as particularly important to them and specialist palliative care social workers were very responsive to these issues
- The evidence indicates that black and minority ethnic groups have inferior access to palliative care

What service users said

...the quality of life that I think my children have is very, very significantly different to what it might have been had we not had all the help that we've had. It has made a fairly crucial difference

(White UK bereaved man, age group 46-55)

Just talking to me. Talking to my husband, she very quickly realised she had to do something, or we were going to disintegrate as a family

(White UK bereaved woman, age group 46-55)

The doctor operated on my body and removed all the disease and all that but he didn't take the disease out of my head and you know (the social worker) done that, you know

(White UK male patient, age group 46-55)

I don't think I would be here, I tell you now; well 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 UK male patient, age group 46-55)

She doesn't take a particular course of action or whatever, without first talking about it, and then she asks me if that is what I want to do...(I am) consulted and there is communication

(White UK Asian male patient, age group 19-25)

...one of the things I found so difficult, why I couldn't cope with it, and it was the social worker constantly saying to me, this is quite normal to feel like this, because you sometimes feel as though you aren't normal and she was reassuring me, you know, you are normal, this is a normal thing, you will feel like this...and as she was saying it, I felt, that's me so I must be alright, I must be a normal person somewhere, because it can be quite frightening because you are not in control

(White UK woman patient, age 46-55)

Broader Findings

- Most service users who participated commented that the research was the first time they had ever been asked to give their views about palliative care. They added that that was one reason why they had agreed to take part
- This is important because service users have unique and valuable insights to offer on policy and practice and the failure to elicit this is likely to result in the loss of an important source of evidence and knowledge
- In their comments they highlighted a number of interrelated issues with broader implications for palliative care

Broader Findings

- Referrals to specialist palliative care social work
- The underpinning philosophy of palliative care
- Equality of access to palliative care

Social Work Referral

- Service users seemed particularly to value the psycho-social contribution of specialist palliative care social work
- As the project got underway, it became clear that the quality of the social work practice service users experienced was inseparable from how it was organised and managed
- While social work practice itself was essentially valued as positive, problems with its organisation and management began to emerge
- There seemed to little consistency throughout hospice and specialist palliative care services as to when or even whether service users and their families would get referred to the social worker
- Very few people referred themselves to the social worker
- But it was clear that many people had been desperate for support before they met the palliative care social worker.

As one service user said

I just remember coming out of a black hole and that's how I described it seeing her face, and that was the first contact. And I don't know why, you know, I just don't know why, I just felt I had to talk to this person

Social Work Referral

- In our study few people were referred to hospice or palliative care settings for social work support despite the importance those who accessed it attached to it
- Frequently referrals came through other professionals, but there was individual evidence that those professionals were not always helpful and could act negatively as gatekeepers. One patient told us:

They actually said to me, 'well we've got a social worker here but we don't think that you'll like her and get on with her very well'

Social Work Referral

- Given that many service users said they wanted early referral to the specialist palliative care social worker, why were so few patients referred to specialist palliative care specifically for this kind of support?
- Almost all service users stated their referral to specialist palliative care had been for a medical reason
- Our findings are corroborated by a study looking at reasons for referral to specialist palliative care by General Practitioners (Shipman et al 2002)
- Eagle and De Vries (2005, p588) found that admissions to hospices for purely psycho-social reasons (even in crisis) were reluctantly agreed even when there were beds available
- Gott, Ahmedzi and Wood (2001) found that doctors and nurses in an acute hospital setting had very different views on which patients needed palliative care. Nurses were more likely than doctors to pick up on psycho-social issues and on the needs of non-cancer patients.

Implications for palliative care's underpinning philosophy

- One of the basic definitions of palliative care is that it 'integrates the psychological and spiritual aspects of patient care (WHO 2002)
- Yet it was evident from many of the service users' accounts that psychological need had not led to social work referral
- Still less evident was that social problems, for example housing or financial difficulties had played any part in bringing about a referral
- Other research has also shown that the gaps service users identify in both oncology and generalist palliative care services relate to social and psychological support (McIllmurray and others 2001, Hill and others, 2003)
- Thus palliative care, despite its holistic ideal, may be revealing and increasing over-reliance on a more narrowly medicalised approach to service users

Equality of Access

- This may also play a part in perpetuating palliative care's continuing difficulties in ensuring quality of access to its services regardless of diagnosis or demographics.
- Specialist palliative care services are still largely restricted to people with cancer and some groups (for example older people and members of black and minority ethnic communities) appear to have inferior access.
- Yet there are growing policy, public and patient concerns that palliative care should be a more truly inclusive and universalist service

Conclusion

- Our study focused on service users' views of specialist palliative care social work.
- It highlighted the shortcomings in the access service users had to this valued service because it is still not regarded as core to the provision of palliative care and because other professionals, particularly medical professionals, do not necessarily understand the importance of the psycho-social needs it serves or the nature of the social work role itself.
- A useful next step is likely to be to extend the remit of the present study and explore service users' perceptions of other professions, their interrelations, their understandings of each other and of the range of personal, medical and social needs that come to their attention.

References

- Beresford, P. Adshead, L. and Croft, S. (2007), *Palliative Care, Social Work And Service Users: Making life possible*, London, Jessica Kingsley.
- Eagle, LM., De Vries K. (2005) Exploration of the decision making process for inpatient hospice admissions, *Journal of Advanced Nursing* 52 (6) 584-591
- Gott, M., Ahmedzai, S.H., Wood, C. (2001) How many inpatients at an acute hospital have palliative care need? Comparing the perspectives of medical and nursing staff, *Palliative Medicine*, 15 (6): 451-460
- Hill, K.M. Amir, Z. Muers, M.F. Connolly, C.K. Round, C.E. (2003), Do Newly Diagnosed Lung Cancer Patients Feel Their Concerns Are Being Met?, *European Journal of Cancer Care*, 12 (1), pp35-45.
- McIlmurray, M.B. Thomas, C. Francis, B. Morris, S. Soothill, K. Al-Hamad, A. (2001), The Psychosocial Needs of Cancer Patients: Findings from an observational study, *European Journal of Cancer Care*, 10, (4), pp261-269.
- NICE – The National Institute for Clinical Excellence (2004) Supportive and Palliative Care Cancer Service Guidance: www.nice.org.uk
- Shipman, C., Addington-Hall, J., Barclay, B., Briggs, J., Cox, I., Daniels, L., Millar, D., (2002) How and why do GPs use specialist palliative care services? *Palliative Medicine* 2002: 16: 241-246
- WHO (2002) Definition of Palliative Care Source: www.who.int