

'Swampy Territory'

The role of the palliative care social worker in safeguarding children of adults who are receiving specialist palliative care

This qualitative study explores the role of the palliative care social worker in safeguarding and promoting the welfare of children of adults who are receiving specialist palliative care. It examines what palliative care social workers understand by the term 'safeguarding children' and how they and other members of the palliative care multidisciplinary team identify situations where there are concerns about the present and future care of a child. These concerns could have existed prior to, arisen because of, been exacerbated by, or become evident because of the parent's illness. The purpose of the study was to both draw and analyse the picture of the 'real-life' work of the palliative care social workers with children and their families. This included the palliative care social workers' perception of the quality of their relationship with the local authority children's services as well as a consideration of the support and training they receive to help them in their task of safeguarding children.

Key points

- Palliative care social workers considered safeguarding and promoting the welfare of children to be part of their role, but generally it was a very small element of their total workload.
- Engagement with a family could be very short-term in nature due to the timing of referrals and a rapid progression of the illness, and covered a wealth of practical and emotional issues.
- Whilst there was evidence of direct work being undertaken by palliative care social workers with children, support was mainly given to children via their parents. The choice of support given to children seemed to depend on the workers' own interpretation of their role, as well as that made by their agency and colleagues, plus any previous experience, training and confidence in this aspect of work.
- There was a general feeling of palliative care social workers working without support; to a lesser extent in relation to their own agency and to a greater extent in relation to local authority children's services. Part of their role in safeguarding children was knowing whether and when to make contact with these children's services. This appeared to centre on how thresholds regarding formal intervention were interpreted by both parties as well as the relationships between them.
- The examination of the involvement of palliative care social workers illustrated the dedication of the workers involved and the dynamic nature of their task, as well as the benefits and difficulties in carrying it out and the 'swampy' territory in which it is situated.

Background

Whilst there is a stress on the importance of the family in palliative care, reference in the literature generally refers to partners, adult relatives and carers. There is minimal research into families where a person who is receiving specialist palliative care has dependent children. The studies that have been undertaken show that the life-threatening illness of a parent has a major impact on family life both emotionally and physically, and particularly for children who rely on their parents for their physical and emotional support. There is also a lack of information about the work that palliative care social workers undertake with such families.

The wellbeing of every child is now the focus of the governments of England, Scotland and Wales. All people who have contact with children and families in their everyday work, including those who do not have a specific role in relation to child protection, have a duty to safeguard and promote the welfare of children. There have been studies exploring the role of workers in adult services, for example mental health and substance misuse in relation to child protection, which highlight the many difficulties and challenges. There is, however, a gap in the literature regarding the role of social workers in palliative care in their work with children where a parent is terminally ill.

This study gathered the views of palliative care social workers mainly working in England, but also in Scotland and Wales. Information was gathered in three ways during the period June 2007 to November 2008: 22 workers contributed in focus groups and 57 completed a questionnaire, of whom 17 were interviewed individually. The majority of participants were from combined in-patient and day hospices with others based in community services, hospitals and in-patient hospices.

What 'safeguarding children' means to palliative care social workers

The overwhelming response from the palliative care social workers was that safeguarding children carried a much broader remit than child protection alone: *'Ensuring children are safe in the widest possible way and not just at risk from a particular person.'*

However, whilst the findings suggest that palliative care social workers were aware of the requirement for them to safeguard and promote the welfare of children, the extent to which this was carried out varied considerably. Most embraced it enthusiastically and considered themselves to be competent, while others felt less skilled or knowledgeable. It was a child's emotional needs during the parent's terminal stage of illness that caused the workers most concern. Whilst physical, emotional and sexual abuse was seen to be an important part of safeguarding, such abuse was reported to be a rare occurrence. However, there were workers who considered that some children experienced 'unwitting' emotional neglect or harm due to their parents being caught up with their own emotions and difficulties.

Safeguarding children was considered to be an agency-wide responsibility with all staff being required to attend child protection training. Generally, the agencies were considered by the palliative care social workers to be 'child friendly' and 'child-centred', although there were some exceptions where the response of a few medical and nursing staff was thought to be poor. Nearly all reported that there was a child protection policy in place in their agency. There were occasions when decisions about referring a family to the children's services were delayed due to medical and nursing staff considering that such action would be too upsetting for the parent. Also mentioned was the unavailability of senior agency staff or a lack of staff in post who could give appropriate guidance, particularly in situations where decisions needed to be made quickly. This lack of guidance could cause lone palliative care social workers particular problems. There was also a fear that by making a referral, the dying parent might withdraw from the palliative care service as a whole or the palliative care social worker in particular. This was reported to have happened in some instances.

The issue of parental capacity challenged many of the palliative care social workers: what is reasonable in the circumstances where a parent is dying? There was an acknowledgement that illness might prevent parents from parenting in the way they had previously which, in some instances, may cause a child to be at risk. The dilemma for workers appeared to be whose needs should take priority: those of the dying parent or the child? There was a tension of accepting less than adequate care for the child, knowing that it was likely to be short-term, against taking action and alienating the parent. It was the accepted view that short-term measures needed to be found to assist the parents in the care of their children. Generally, the workers saw the family as their priority with a focus on children, being alert to their needs especially emotional ones. This meant offering support to parents to help them understand their children's needs, particularly keeping them informed of what was happening.

Palliative care social workers believed that they would be more effective if their social work role was clarified and their role with children affirmed within the workplace. Also, their practice would be enhanced if they had more time to get to know the families and to provide follow-up; had more experience of working with children; and received more training to keep up-to-date in child welfare matters. More multidisciplinary and 'joined-up' working with the local authority children's services were also considered to be ways of helping them be more effective in their safeguarding role.

Referrals

In general, palliative care social workers did not have a clear profile of the pattern of referrals regarding families with children. Compared to the overall number of patients seen by palliative care social workers, the number of those with children under 18 years was reported to be relatively small, although growing. One worker reported being involved with 15 families a year whilst another was unable to give examples of any recent involvement. Almost all referrals were reported to come from members of the multidisciplinary team, mainly from the nursing staff. There was a low rate of self-

referral that may be linked to negative perceptions of social work generally. Being part of a multidisciplinary team meant that palliative care social workers were in a position to exert some influence on the 'child awareness' of their professional colleagues, thereby ensuring that children's needs were not lost in the particular concerns about the patient-parent. There was evidence that this did happen, particularly at multidisciplinary team meetings. There were reports of how the team members' attitudes to children had changed over the years which was considered to be due to this prompting by the palliative care social workers.

Whilst there was general praise for the community nursing staff regarding their ability to recognise the needs of children and to raise concerns, there were a few reported instances where this was not the case. A small minority, it was believed, concentrated solely on the needs of adults and showed a noticeable lack of knowledge about child development. There was also a view that some nursing staff acted as gate-keepers and filtered families away from the palliative care social worker. A small number of palliative care social workers believed their social work role was not generally understood by the team, with some lone workers feeling particularly vulnerable.

Reasons for referrals fell into four main categories:

- advice and support to parents about informing children about a parent's illness and imminent death
- the daily care of children during the period of illness and beyond
- planning for the future care of children following a parent's death
- advice and support to parents regarding children's behaviour.

Once a palliative care social worker engaged with a family, further areas of concern had often become apparent due to the progression of the illness, ongoing assessment, the ability of the family to share concerns, as well as the development of trust in the worker.

There was evidence that referrals to a palliative care social worker were not always made 'in good time'. Reasons for delay included a late referral to the palliative care service itself, or nursing staff not making a referral until a crisis point was reached. Palliative care social workers recognised that some families may refuse help offered by a social worker; this resistance was reported to be particularly noticeable in vulnerable families who may be concerned that their children might be removed from their care. Often palliative care social workers were dependent on nursing staff introducing them positively to the family: *'our social workers are different'*. Because of negative first reactions there were palliative care social workers who had changed their title to 'family support worker'. Others considered that to do this would be denying their social work profession.

The findings revealed a complex process, frequently affected by professional roles and team functioning, which had not been previously addressed in the literature. The process was influenced by the value that the palliative care social workers placed on the significance of safeguarding the needs of children and their confidence in working with and for these children.

Children's experiences

Previous studies had drawn attention to the many difficulties and issues that may face children and families when a parent is dying from a terminal illness. In this study, palliative care social workers described situations where there were concerns about the present and future care of children in such families. All age groups were represented in the sample and there were more mothers than fathers who were dying, approximately a third of whom were lone carers. Three main themes emerged. The first theme was concerned with the effects of the parent's illness on the child and included such issues as the child's awareness of the illness; how children were informed about it; its impact on the child; the parents' coping abilities; and care arrangements for children following the parent's death. Children of lone parents who were dying could be placed in an uncertain situation. Not only did they have to cope with the terminal illness of their parent and the subsequent loss, but also their future may not have been known or secured. The second theme referred to the relationship context surrounding the illness and highlighted changes in family functioning including role changes and the impact of relationships on the child's care. The changing nature of the illness may worsen an already difficult relationship between a parent and child. Examples highlighted aspects that are either not featured or minimally so in research studies: children living in neglected or abusive situations and families where there was existing conflict between parents, including situations of domestic violence.

The third theme addressed an aspect that was missing from most of the existing studies which were 'psycho-social' in approach and appeared to pay little attention to the social context. The issues here related to poverty, gender roles and immigration status. Concern about finances was seen as an extra burden carried by parents which in turn impacted on their children. Severe financial difficulties were often due to a parent being unable to continue working either because of illness or because of taking on caring responsibilities. Poor quality housing was also identified as an issue for many families. For those children where a parent's immigration status was in question there were additional stresses on the family including coping with the legal procedures, uncertainty and possible financial hardship. There were reports of the Home Office allowing families to remain in the country only until the ill parent died. Leaving the country would mean that a child would not only be losing a parent but also friends and a familiar way of life.

From all the examples provided it would be reasonable to believe that, to varying degrees, the children might be feeling bewildered, frightened, unhappy, threatened, lost, guilty, depressed, scared, unsupported and maybe unloved. In these circumstances it would be reasonable to suppose that such children would require consistency and continuity, to be informed, supported, listened to, protected, taken account of, respected and to be prepared for what was and might be happening to them and the people around them.

Working with children and their families

Palliative care social workers claimed ownership of a child-centred approach to their work. However, whilst the study established that their work was wide-ranging, engagement with parents was the main vehicle for promoting children's welfare. Where concerns were raised about the care of particular children, it appeared that they were not always seen by the palliative care social workers. They did not always deem this to be necessary, as work was undertaken through the parents or nursing staff. Not all agencies were reported to be supportive of direct work being undertaken with children, the emphasis rather being on work with parents. As many palliative care social workers were not working on a regular basis with such families there was consequently a lack of opportunity for them to build up knowledge, understanding and expertise, not only about child-care practice but also about the underlying legislation, policies and guidance. Indeed, there were those who considered that they did not have the skills and/or experience to offer a suitable service to children directly.

Five key features underlying the work with children and their parents could be identified:

- children need to know what is happening
- planning for the future needs of children is essential
- practical support is crucial
- a family does not exist in a vacuum
- joint work with others can be beneficial.

A family systems approach was evident in many of the practice examples given. Workers appeared to have a sound knowledge base about child development, attachment and the impact of bereavement on children. There was acknowledgement that child-related personal and previous work experiences gave palliative care social workers confidence in their work with children. Restrictions of time available due to the impact of the illness meant that the building of relationships and trust and carrying out in-depth assessments were often limited. There were a small number of examples given where children were invited to live in the hospice so that they could spend more time with their dying parent. In each case this was considered to be a positive experience for both the family and staff.

There were reports of agencies that either did not encourage or allow palliative care social workers to provide direct support to children after the death of a parent. The policy rather was to provide support to them via the surviving parent. This would seem to suppose that the relationship between the parent and child was a positive one. This, however, may not always be the case and also denied a child-centred approach. There were examples given where children had built up a positive relationship with the palliative care social worker prior to the parent's death and were seeking continued support from the worker, but this was not encouraged by the agency. This could mean another loss for the child and a lack of trust in adults.

Relationships with local authority children's services

The study considered the quality of relationships between palliative care social workers and social workers in children's services from the perspective of the palliative care social workers. The findings confirm those in other studies which have examined relationships between adult care service workers and those in children's services. In the main, inter-agency co-operation was not a regular feature in everyday practice and there was frustration and disappointment that this should be so. Whilst there were pockets of co-operation and productive joint working, these were in the minority.

There appeared to be a range of impediments to productive co-operation with poor communication being a key issue. For some palliative care social workers there was a fear of alienating the family by involving children's services. Occasionally difficulties occurred due to a lack of information about each other's tasks and responsibilities. There did not appear to be any sustained attempts by managers in either setting to alter the situation. Individual palliative care social workers had tried to improve communication but these attempts tended to fall by the wayside due to lack of time and effort. A commonly held view by palliative care social workers was that children's service social workers did not have enough understanding of death and dying and its impact on families, particularly in relation to children, and hence shied away from involvement.

Reasons for contact with social workers in children's services fell into two broad categories: seeking advice and guidance regarding an individual family, and making referrals. Contact could be complex as some palliative care social workers could be involved with as many as six local authorities due to their agency's catchment area. There were reported difficulties in having the opportunity to talk directly to a social worker due to the intake procedures in place within local authorities.

The issue of 'thresholds' was a recurring one. Many children deemed to be 'in need' by the palliative care social workers were not considered to be a priority by the local authority and services were not made available to them. This lack of response from local authority workers left palliative care social workers with the feeling of letting down the child and family as well as feeling powerless and concerned about the consequences for the children. Some palliative care social workers were reluctant to make future referrals as a consequence of this previous lack of response to requests.

Support and training

A variety of models of supervision were in place and all palliative care social workers in the study received supervision in some form, usually from their line manager. Not all had access to supervision from another social work professional. Unless the internal supervisor had a child-care background, finding someone who could provide advice and guidance on child-care matters was not always straightforward. There were particular difficulties for those workers who were lone social workers in their agency as they had very limited opportunities to share concerns with social work colleagues.

All palliative care social workers participated in basic agency training about child protection and some had attended further inter-agency training about safeguarding children. However, there were those who had difficulty in knowing about and/or accessing relevant training in order to keep up-to-date with changes in legislation, guidance and policy. The emphasis was rather on adult protection. Indeed, there was evidence that in a small number of agencies palliative care social workers were not encouraged to attend safeguarding training. However, there were agencies where the palliative care social worker was the child protection officer and had taken on the responsibility of training other staff members as well as drawing up the agency child protection guidelines and procedures.

Implications

This is a 'one-dimension' study in the sense that no children or parents were involved and there is a lack of information from other professionals both in the multidisciplinary team and in children's services. However, the study has been successful in extending the knowledge about the practice of palliative care social workers in a particular aspect of their work that is currently under-researched. It also contributes to the knowledge about how workers in adult-focused care and health services safeguard and promote the welfare of children with whom they have contact in their everyday work. It also continues the debate around the extent to which services for adults are child-centred.

Children should be recognised as social actors with their own views and concerns so that their welfare may be known and promoted. If all settings that provide palliative care services acknowledge the presence and involvement of children it would help to ensure that children in the family are acknowledged from the beginning and their circumstances and needs taken into account. Palliative care social workers should receive appropriate training and ongoing professional support to enable them to develop their knowledge and skills so that they can provide an appropriate service to children and their families. In addition, the quality of the relationship between palliative care social workers and local authority social workers requires to be examined in order to improve communication. This would help to establish ways in which the needs of this community of children can be fully understood and realised. In these ways the role of the palliative care social worker in safeguarding children of adults who are receiving specialist palliative care would be made more certain.

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