Swampy territory:

The role of the palliative care social worker in

safeguarding children of adults who are

receiving specialist palliative care

Carole Ruth Comben

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Abstract

There is minimal research into families where a person who is receiving palliative care has dependent children. In particular, there is a lack of information about the work that palliative care social workers undertake with such families. This study examines the role of the palliative care social worker in safeguarding and promoting the welfare of children of adults receiving specialist palliative care. This is a qualitative study involving the collection of information from a total of 57 palliative care social workers in three ways: focus groups, survey and semi-structured interviews. The analysis demonstrates that palliative care social workers understand the term 'safeguarding children' to mean more than child protection alone. The analysis also focuses on the process of referral, institutional barriers, supports for their work with children, and inter-agency collaboration. An equally important aspect of the analysis, and one generally neglected in psycho-social studies, relates to the socio-economic context of the palliative care social workers' work, including the effects of the immigration status of families on children.

In the main, concerns about the present and future care of children come to the attention of palliative care social workers via members of the multidisciplinary team in which they are based. The numbers are reported to be relatively small in contrast to the total number of referrals received. The extent to which support to children is provided varies considerably; some palliative care agencies do not encourage palliative care social workers to work directly with children prior to bereavement and others restrict direct work with children post-bereavement. The main emphasis for all workers, however, is on support to the parents to help them understand their children's needs during the terminal phase of the illness. The well-being of children at this time of emotional stress is included in the palliative care social workers' definition of 'safeguarding children'. In addition, the

wide-ranging examination of the palliative care social workers' involvement with the families illustrates the extent of the dedication involved in an under-resourced and little understood area of their work. Whilst palliative care social workers reported receiving basic training on child protection within their agency, with some themselves providing this training, further training on safeguarding children is not always available or known about. The amount and type of professional supervision and support is also varied, particularly in relation to child-care matters; not all have access to supervision from another social work professional.

There are a small number of examples given in the study where children are considered to be at risk in some way. Children cared for by lone parents are recognised as being especially vulnerable, particularly if future care plans are not in place before the death of the parent. Also identified as vulnerable are children of parents whose immigration status is in question as their future location may be in doubt, placing children and the surviving parent under additional stress. One of the major difficulties for palliative care social workers is securing support services from the local authority children's services. Whilst there are examples of collaboration and co-operation, the findings in this study echo those of others which examine the relationship between adult and children's services. In this study, palliative care social workers speak of frustration and disappointment in the responses they receive, and they are concerned that the needs of children of dying parents are not understood.

This study contributes to the debate about the focus of children in care services for adults and how staff may be supported in their task of safeguarding and promoting the welfare of children. The study also adds to the limited existing knowledge about palliative care social work practice.

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Chapter One

Introduction to the thesis

> Every professional who meets a child in their working life must
> take time to understand the stories that children tell them and
> gain a meaningful picture of what is happening in their lives.
> Collier 2004

Rationale and context of the study

This thesis weaves together two strands of enquiry: safeguarding children where a parent is dying and specialist palliative care social work. It is not an exploration of the role of the workers in bereavement counselling but rather of their perceived role where there are concerns about the present and future care of the children. These concerns could have existed prior to, arisen because of, been exacerbated by, or become evident because of the parent's illness.

Since the end of the Second World War there have been changes in the care of people dying with cancer (Clark 2007). Advances in medicine have led to better pain control and pain relief and this, together with a clearer understanding of the impact of death and dying on all concerned, has helped to provide a more holistic approach to the dying person (Reith and Payne 2009). This approach has been developing since 1957 when Dame Cicely Saunders, herself a social worker, nurse and doctor, initiated the modern hospice movement by publishing her first paper on hospice care (Clark 1999; Clark 1998a) and in 1967 by opening the St Christopher's Hospice in south London (Clark 1998b). Her approach took account of the person's 'total pain' which highlighted not only the physical aspects of the pain but also the psychological, emotional, social and spiritual dimensions of distress which could contribute to their suffering (Saunders 1993). Indeed, the National Institute for Health and Clinical Excellence (NICE 2004:20) reflects this approach in their definition of palliative care which is:

> …the active holistic care of patients with advanced, progressive illness.
> Management of pain and other symptoms and provision of psychological, social
> and spiritual support is paramount. The goal of palliative care is achievement of
> the best quality of life for patients and their families.

'Specialist palliative care' in the UK differentiates itself from the general palliative care provided in mainstream health settings. It is care delivered by a multi-professional team, where practitioners, the majority of whom are trained and acknowledged specialists in palliative care, are almost exclusively concerned with the needs and care of terminally ill patients (NCHSPCS[1] 1995; NHS Quality Improvement Scotland 2002). The core personnel are generally doctors, nurses, social workers, chaplains and, where funding allows, physiotherapists and occupational, art and complementary therapists (Firth 2003). One of the principles of the care provided is to help family members cope during the patient's illness and their own bereavement. Although most commonly associated with the hospice movement for people with cancer, specialist palliative care may be provided in a number of settings: at home, in independent (charitable) and NHS hospices and palliative care centres, in hospice day centres and in hospitals, and for people with other life-limiting illnesses. Not every patient who is terminally ill will require or receive specialist palliative care. This type of care is only usually needed when 'the problems of the patient are either so numerous, so severe, so difficult to relieve or so unusual that a team with expert and special skills be called in' (Doyle et al. 2004:2).

Social work is concerned with people across all age groups and with particular needs. Social workers have a dual role of care and control, particularly in work with offenders but also in other aspects of work, especially child care and child protection. They are mainly employed by local authorities, charitable and for-profit organisations. Since 1948, local authority social work has moved from the specialist (work with one group of

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[1] National Council for Hospice and Specialist Palliative Care Services

people) to the generic (work with a range of people across the age spectrum and with a range of needs) and back again to the specialist. Specialist palliative care social work itself has a relatively short history. It has been seen as having an important complementary role within the hospice movement (Dunlop and Hockley 1998) and has come to be considered a specialist area of social work (Sheldon 2000; Cadell et al. 2010). A small group of hospice social workers first met in 1982 at St Christopher's Hospice and in 1986, recognising the emerging specialisation of social work in both hospices and the developing community palliative care teams, formed the Association of Hospice Social Workers since renamed the Association of Palliative Care Social Workers (APCSW). Currently the Association has approximately 300 members. However, it is difficult to ascertain the total number of specialist palliative care social workers as there is a lack of information about the number of posts.

The Association defines specialist palliative care social work as follows:

> Social work is seen as an integral part of the multidisciplinary team within palliative care offering an holistic service to patients and families. Specialist palliative care social workers offer a wide range of support to patients and 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 both as individuals and in group settings. 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 discrimination they experience in society (APCSW 2006:6).

Specialist palliative care social work is therefore but one small area of social work and whilst there are palliative care social workers who work with children who have a life-threatening illness and their families, the majority are involved with adults who are receiving specialist palliative care. This area of social work could be considered both specialist and generic in nature because, whilst the focus is on the dying adult, workers

may be involved with a variety of people of all ages in differing circumstances and with diverse needs.

Small (2001:961), in a critical commentary on the interface between social work and palliative care, commented that there was a paucity of literature in this area and noted that the amount published in peer reviewed journals was 'very small', a view also shared by Sheldon (2000). It would appear that this position is slowly changing. There are now some specific texts on palliative care social work (for example, Parker 2005; Beresford et al. 2007; Reith and Payne 2009); chapters in books on palliative care which refer to aspects of palliative care social work; and, articles in a range of palliative medicine, palliative care and social work journals. Some articles present conceptual frameworks, many are discussions often containing descriptions of social work activities. In 2005, the *'Journal of Social Work in End-of-Life and Palliative Care'* was established in the United States; this continues to be the only journal concerned with this specialist area of social work. However, there are few empirical studies that investigate aspects of social work in palliative care (Brandsen 2005). Interestingly, mainstream social work literature contains little or no mention of specialist palliative care social work (Beresford et al. 2007:24). Indeed, a literature review undertaken to support the scrutiny of social work services and identify the key social work roles and tasks to meet the challenges of the 21st century (Blewett et al. 2007) contained no references to palliative care social work. Palliative care social work continues to be 'a service in the shadows' because of its low profile both within and outside the profession as a whole (Beresford et al. 2007:206).

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. Despite the expansion of interest in children in other areas, there have been limited references to children under the age of 18 whose parents are dying and receiving palliative care. There is, however, more emphasis on bereavement counselling and support for children after the

parent's death. A reason for this, Chowns (2006:2) suggests, is that 'the territory that is children anticipating bereavement is unpredictable, uncharted and swampy underfoot'. Bereavement counselling on the other hand is based on an event, the death of a parent, which has already occurred and therefore may seem to be more 'manageable'. However, there are studies that show that the life threatening illness of a parent has a major impact on family life both emotionally and physically (Visser et al. 2004; Kennedy 2009). All family members will be affected but particularly children who are dependent on their parents for their physical and emotional well-being (Christ 2000). The ability of the dying parent to continue to meet the needs of their child is likely to be compromised due to the decline in their condition (Saldinger et al. 2003). Indeed, where a parent is already struggling to provide appropriate care or to protect their child from harm from others, a terminal illness is likely to exacerbate an already difficult situation for the child. The parent's terminal stage of illness exposes children to significant levels of stress (Thastum et al. 2008) although some children appear to fare better when faced with adversity whilst others suffer poor outcomes (Zaider and Kissane 2007). For any child the death of a parent, according to Worden (1996), is one of the most significant losses a child will ever have to face.

The wellbeing of every child is now the focus of the governments in England, Wales and Scotland (Statham and Chase 2010). There is an expectation that in endeavouring to achieve the shared vision of improving the outcomes for all children, key people and agencies should work well both individually and together to safeguard and promote the welfare of children (Scottish Executive 2002; HM Government 2007). 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 (Department of Health 2003; Welsh Assembly

Government 2006; Scottish Executive 2008[2]). Safeguarding has been a concept that

has evolved in meaning (Walker and Thurston 2006). In 2007, in statutory guidance on

Section 11 of the Children Act 2004, the Government described safeguarding and

promoting the welfare of children as:

- protecting children from maltreatment

- preventing impairment of children's health or development

- ensuring that children are growing up in circumstances consistent with the
  provision of safe and effective care; and

- undertaking that role so as to enable those children to have optimum life
  chances and to enter adulthood successfully (HM Government 2007:11).

Illness and death will occur in families where relationships are not totally loving (Pardoe

1989; Hurdman 1995) and children may be vulnerable and at risk. Whilst there have

been studies exploring the role of workers in adult mental health, domestic violence and

substance misuse services in relation to child protection (Taylor and Kroll 2004;

Darlington et al. 2005; Humphreys and Stanley 2006; Stanley et al. 2010), there is a gap

in the literature concerning social workers in palliative care.

Aim of the study and development of research questions

The aim of this study is to explore what is the role of the palliative care social worker in

safeguarding and promoting the welfare of children of adults who are receiving

specialist palliative care.

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[2] The wording in Scotland is slightly different: promoting the well-being of individual children and keeping children safe.

In order to achieve this aim, I developed the following key research questions:

- What do palliative care social workers understand by the term 'safeguarding children'?

- How do palliative care social workers identify situations where there are concerns about the care of a child and where a child may be at risk? What is the involvement of the palliative care team in the identification?

- How do palliative care social workers go about their work with children and their families?

- What is the palliative care social workers' perception of the quality of their relationship with the local authority children's services?

- What support and training do palliative care social workers receive about safeguarding children and from whom?

- What insights do the views of palliative care social workers offer to improve how children may be safeguarded within the palliative care setting?

Structure of the thesis

In this chapter I have outlined the rationale and context of the study together with the aim and research questions developed. The literature relevant to the study is reviewed in chapters two to four providing a platform on which to understand, develop and support the research. Chapter two considers specialist palliative care social work with specific emphasis on the role with children and families. Chapter three focuses on the experiences of children where a parent is dying and chapter four explores the literature regarding safeguarding children, particularly in the context of workers in adult care services. In chapter five the journey of the research is described. I explain the rationale for the methods used, the theoretical perspective and how the analysis was conducted, together with a self-reflection.

Chapter six uses the material from the stories of the palliative care social workers to describe some of the experiences of children and their parents as they journey through the last stages of a parent's life. In chapter seven the respondents' perceptions of their role in safeguarding children is examined. Chapter eight considers how the palliative care social workers become involved with families where there are concerns about the children, and in chapter nine I explore how palliative care social workers engage with these children and their parents. The relationship between the palliative care social worker and the local authority children's services is the focus of chapter ten. Chapter eleven analyses what informs the palliative care social workers' practice with children and families. Finally, in chapter twelve I present the key findings of the study, its strengths and limitations, and implications for practice and further research.

I have chosen to present my findings together with a discussion of their relevance to existing theoretical knowledge and empirical studies as an integrated whole in each chapter (Holloway 2005).

Notes

1   The first year of this study was conducted when I was registered at the University of Dundee in the School of Education, Social Work and Community Education.

2   Throughout the thesis, the term 'children' should be read as shorthand for the more inclusive term 'children and young people' and 'palliative care social workers' as shorthand for 'specialist palliative care social workers'. These workers are referred to in the text in the female gender which reflects the composition of the current workforce and aims to protect the anonymity of the respondents.

Chapter Two

Palliative care social work: context and role

> Caring, the palliative way, is to focus on the medical, nursing, spiritual,
> emotional and social needs of patients and their families and to seek
> to meet them through a variety of means. It is thus a style of caring:
> an acknowledgement of the need to approach patients holistically.
> Robbins 1997

Introduction

In order to put palliative care social workers' involvement with children into perspective, I will explore in this chapter the literature that refers to the context and role of the palliative care social worker generally, their specific work with children and their families, their role in the multidisciplinary team, and their knowledge and skill base. As stated in chapter one, the role of the palliative care social worker has been poorly addressed in literature with few empirical studies, but over the past few years this position is slowly changing particularly with contributions from North America.

The context of palliative care social work

The modern hospice movement and palliative care in the United Kingdom that began in 1957 has continued to develop both alongside and inside the NHS (Mathew et al. 2003; Small 2003). The NHS was primarily concerned with widespread acute and chronic health problems during the first two decades of its existence and little attention had been given to the care of the terminally ill (Clark 1999). Voluntary hospices provided the majority of in-patient care and continue to do so. The following tables show the provision of in-patient and support services at January 2009 (Help the Hospices 2009: 164-165).

Table 2.1 Number of adult in-patient units and beds

Country	Total units	NHS units	NHS beds	Voluntary units	Vol. beds
England	173	40	490	133	2139
Scotland	24	10	96	14	355
Wales	15	9	65	6	78
Total	**212**	**59**	**651**	**153**	**2572**

Table 2.2 Number of community and hospital support services

Country	Home care	'Hospice at home'[3]	Day care	Hospital support teams
England	226	95	225	228
Scotland	47	1	25	39
Wales	26	7	22	23
Total	**299**	**103**	**272**	**290**

These figures, however, do not reveal the disparity of services across the country. The Palliative Care Survey 1999 (NCHSPCS 2000:2) shows that 96% of health authorities described their palliative care services 'as not yet adequate across the board' and 15% felt they were 'struggling in developing all the service components'.

There appears to be a reduced access to, or uptake of, palliative care services within socio-economically deprived areas and by people from minority ethnic groups (Department of Health 2000; Payne 2010). Bowling (2009:35) points out that, compared to other social groups, poorer people tend to mistrust modern medicine, know less about how to access services and are reluctant to do so. Firth (2001) refers to the black and minority ethnic population in 2001 in England being estimated to be around 10% but figures from the Hospice Information Service show that 3% of recorded adult patients who used palliative care and hospice services in 1999-2000 were from these groups. Various reasons given in the literature for this low uptake include a lower incidence of certain types of cancer and other chronic diseases plus the younger socio-demographic

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[3] 'Hospice at home': teams that provide extended specialist palliative nursing, medical, social and emotional support and care in the patient's home.

profile. Another potential explanation is the 'culturally insensitive' nature and 'ethnocentric outlook' of the services provided (Randhawa and Owens 2004; Larkin 2008). In addition, a lack of knowledge about palliative care services and 'gatekeeping' by GPs leads to a lower referral rate (Koffman and Higginson 2001). Also reported is an ethos of mistrust that affects the decision-making of black and minority ethnic groups (Cort 2004) and in Bonifant's (2000) view there is no clarity about the cultural acceptance of palliative care. Oliviere (1999:55) writes about the need to respect and nurture cultural difference and offers clear advice on how to provide 'culturally safe practice' in palliative care.

There is evidence in one recent study of just over 100 service users that attitudes of people in receipt of palliative care are generally positive (Beresford et al. 2007). Many reported that despite initial feelings of 'horror and dread' when a referral to a hospice was mentioned, these views changed once contact had been made. Many service users reported that 'their health and sense of well-being actually improved after they entered specialist palliative care' (p.51). Indeed, there is no dispute in the literature that the patient and his or her needs are at the centre of specialist palliative care. This emphasis on the individual has always been a major feature. Saunders herself was clear that patients should be able to give their views and make their own choices; giving 'a voice for the voiceless' (Oliviere 2000).

Although specialist palliative care social work is provided in a range of settings, its provision, like palliative care, is not uniform throughout the UK. In a study by Lloyd-Williams et al. (1999) into the provision of social work support in hospices, out of the 97 hospices who responded, 73 stated that they had full or part time social work support, 18 had 'social work support available if required' and six had no social work support at all. Palliative care social workers are mainly employed by hospices, others by the local authority and a few by the NHS. Despite the NCHSPCS's (2000) recommendation that

social workers should be included as core members of the palliative care team there has been a reduction in provision in some adult services (Beresford et al. 2007). Many palliative social workers are lone workers or in a very small team of social workers, thus restricting the service they are able to provide.

However, gaining an understanding of the provision of palliative care social work is hampered by the problems of definition. Leading specialist social work practitioners (Sheldon 1997; Oliviere et al. 1998) make little reference to 'social work' in their writing referring rather to 'psychosocial care' although their work strongly reflects the values and principles of social work practice (Currer 2001). 'Psychosocial care' has come to be widely recognised as an integral part of holistic palliative care (Dix and Glickman 1997) providing a 'jigsaw of support' for the patient (Hearn et al. 2008). The definition offered by the National Council for Palliative Care's Working Party on Psychosocial Care is that:

> Psychosocial care is concerned with the psychological and emotional well-being of the patient and family/carers, including issues of self-esteem, insight into adaptation to the illness and its consequences, communication, social functioning and relationships (Dix and Glickman 1997:6).

The Working Party recognised that staff of all disciplines in specialist palliative care services routinely provide psychosocial care in a 'broad sense'. Specialist psychosocial care, they concluded could be provided by 'appropriately trained and qualified staff' including clinical psychologists, social workers and counsellors.

Field (2000), however, is concerned that too much emphasis is being placed on the psychological aspects of psychosocial care and that 'social care' could become sidelined as 'practical help'. More focus, Field argues, should be placed on addressing and valuing the patient's family, cultural and social relationships, a view supported by Oliviere (2001). Hodgson (2005) suggests that social workers over-emphasise working with psychological issues rather than social needs because that fits in with the

'biomedical approach'. Sheldon (2008) also draws attention to 'social pain' which she sees as sitting alongside the physical, psychological and spiritual pain, supporting Field's view (2000) that it this the least understood aspect of 'total pain'. Oliviere (2001) describes the role held by palliative care social workers as an 'eccentric' one that is away from the centre of care on which the medical and nursing team focus. Social workers, he argues, advocate for a community and family perspective. The findings from a study of patients and carers (Clausen et al. 2005:283) support the view that both medical and nursing staff can often marginalise this 'social aspect'. The evidence, they argue, points to the need for a social model of illness. Napier (2003:151) also stresses the social dimensions and puts forward three basic aims for social workers:

- to address the social concerns and problems of seriously ill and dying people and their families
- to create and strengthen the social supportiveness of their environment and,
- to find ways of redressing the social inequalities that permeate the experience of illness and dying.

Psychosocial care then is generally considered a 'shared realm' with no one discipline having sole responsibility (Monroe 1998) and is 'poorly articulated' in the palliative care literature (Payne and Haines 2002). Palliative care social workers themselves add to the confusion. Some prefer to use the term 'family support worker' or 'counsellor' (Beresford et al. 2007). There does seem to be a reluctance on the part of some palliative care social workers to 'own' their profession (Currer 2001).

Social work itself has undergone a radical change in the wake of the NHS and Community Care Act 1990 with social workers adopting the role of care managers rather than working in the more traditional casework or therapeutic role. Although based in a specialist setting, palliative care social work is practised in a way which is consistent

with the traditional understanding of social work values, roles and responsibilities (Monroe 1998; Oliviere et al. 1998). It is also practised according to the current values of partnership, involvement, empowerment, respect and equality (Beresford et al. 2008:1405). In the view of Beresford and colleagues (2007:189) when a palliative care social worker has been available 'people's journey through their illness and palliative care system had been made more bearable'.

Role of the palliative care social worker

The role of the palliative care social worker is shaped by the attitudes and expectations of patients, their families, colleagues and society (Firth 2003). It has, Hodgson (2005) believes, been compromised by the dominance of the medical approaches to palliative care as well as a limited understanding and poor public image of social work (Oliviere 2001; Firth 2003; Raymer and Reese 2004; Beresford et al. 2007).

In each of the three editions of the *Oxford Textbook of Palliative Medicine,* Monroe has clearly and comprehensively described the role of social work in palliative care drawing on a wide literature base (Monroe 2004). She commences the introduction to each edition with the statement:

> Social work is a necessary and appropriate part of palliative care. Palliative care starts with specific physical symptoms but it can only be completed by consideration of the patients' feelings, family and friendship networks, and social circumstances (2004:1007).

Monroe then describes three 'forces' which shape the social work role: the identification of non-medical social goals set by the palliative care team, the teamwork required to meet those goals, and the expectations and attitudes not only of the patients and families but society and colleagues. Once the physical pain has been relieved, the patient's non-medical needs she believes are threefold: a need to express emotional

pain, a need to explore spiritual pain and a need for practical help. Monroe (2004:1008) describes the core social work task as 'the social and psychological health of the patient, family, friends, and carers, before and after death'. However, she also cautions that palliative care social workers may have to 'balance individual needs and wishes against a social control and protection function as in child protection' (p.1107).

According to Monroe (2004) the social work task involves both assessment and intervention. Assessment includes that of the individual, the family and physical and social resources. Intervention includes: the provision of information; facilitating communication between patients and their families; assisting the patient and family to make realistic goals and giving them the confidence to achieve them; and bereavement counselling. Methods to achieve these interventions include working on a one-to-one basis, meetings with families or couples and group work. Earlier, Sheldon (2001:243) had concluded that it is the counselling aspect of the role 'which is inseparable from good palliative care social work, which makes this area of care so stimulating and challenging'.

Sheldon (2000), recognising the lack of research into the 'essence' of social work in palliative care, conducted a small qualitative study into the role. She acknowledged that there were limitations to her study as the conceptual framework was developed from the exploration of seven cases of only one palliative care social worker and then validated and further refined by another four workers. The framework centred around 'knowing and working with families'. The core values were seen as encouraging self-determination, being non-judgemental and affirming the client. The key elements identified were: having a family focus, being a team member, influencing the environment and managing anxiety in the family, the professional team and oneself. Of these, the social worker perceived having 'a family focus' was a key area of work (p.493). Interestingly, Sheldon speculates how far this study differentiates between the

specialist role of the social worker in palliative care to that in a multi-professional setting such as mental health. She concludes that it is the starkness of working with people who are dying, and the anxiety that this can cause the worker and the team, that sets it apart from other settings.

Sheldon (2000) recognised that one element was missing from her study: the views of the service users. She considered that this was an essential element in capturing a clearer picture of the complexity of the social work task in palliative care. This element has been recently addressed in a UK-wide study using a grounded theory approach involving 111 service users of specialist palliative care social work who were interviewed individually and involved in group discussions (Beresford et al. 2007:37). Out of the total number of service users 61 were bereaved and 52 had life-limiting illnesses and conditions (two of whom were both bereaved and patients); 39 were men and 72 were women; 10 described themselves as black and/or members of minority ethnic groups; and 15 had children of school age. Service users were involved in the design and management of the research. This in-depth study found that prior to meeting the palliative care social worker, service users held very negative views about social workers in general, based mainly on reports in the media but in some cases on direct experience. One service user is quoted as saying:

> 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 (p.47).

However, once engaged with the social worker the study suggests that service users particularly valued the personal qualities of the social worker which included 'kindness, warmth, respect, compassion, caring, sensitivity, empathy and thoughtfulness' (p.92).

Service users also saw early contact with the palliative care social worker as 'very important' (Beresford et al. 2007:56). Generally referrals came to the palliative care social worker via other professionals, although some service users questioned how

much these professionals knew about the work of the palliative care social worker. Some palliative care social workers made an informal 'proactive approach' to all new patients and this personal approach was generally welcomed as it made people feel 'cared for and safe' (p.141). However, there seemed to be an inconsistency in the process and some families did not have any contact with a palliative care social worker until after the patient's death when they were contacted about bereavement services. There were few self referrals. In Zaider and Kissane's view (2007:73), because families may not be able to ask for or indeed recognise their need for psychosocial support, palliative care social workers and others in the multidisciplinary team need to be able to identify those families which 'carry the most vulnerability and distress'.

Evidence in the Beresford et al. study (2007) suggested that few people were referred to a hospice or a palliative care service specifically for social work support. A referral seemed to come about when the physical symptoms 'caught up with the emotional distress' rather than for any psychological need or indeed social problems (p.140). This, the authors argue, seems to go against the holistic approach to care and support.

The study further revealed that assessments were carried out informally and holistically. Service users valued this, feeling able to talk about the issues that were important to them. They were reported to like the use of 'everyday language' and saw the palliative care social worker 'as an ally' - someone who was 'on their side' (p.155). Service users also valued the time given to them by the palliative care social worker plus their accessibility, reliability and continuity of support. The reported interventions involved a range of issues including coping with change and loss; helping support the family; meeting children's present and future care needs; assisting with welfare benefits; and support needs. A key role identified by service users was the way palliative care social workers helped them to negotiate the health and welfare systems. The positive outcomes included an increase in self-esteem; increased support for family members

including children; a reduction of anxiety regarding practical matters; and, an increase in ability to cope with the medical aspects of the illness. Palliative care social workers were also involved in organising and facilitating bereavement groups both for adults and children.

In addition, Sheldon (1993), Egnew (2004) and Parker (2005) all stress the need for palliative care social workers to come to terms with their own fears of dying and death, including any previous losses, allowing them to feel more comfortable with the emotional aspects of death and dying.

Work with children and their families

When a person is dying, Saunders (2004:xix) describes the family as:

> finding themselves in a crisis situation with the joys and regrets of the past, the demands of the present and the fears of the future, all brought into stark focus. Help may be needed to deal with guilt, depression and family discord; may be the possibility of resolving old problems.

Indeed, the World Health Organisation (1990 and 2002) in its definitions of palliative care has identified the need to both support and address the needs of the patients' families. Placing the patients in the context of their families is seen an essential part of the task of the social worker (Egnew 2004; Beder 2006). This placing includes gathering information about how the family functions, its strengths and limitations as well as the existence of any vulnerable members such as children.

Palliative care social workers routinely assess symptoms of distress such as depression and anxiety in family members and, in addition, symptoms that indicate 'family system' distress (Walsh-Burke 2004). These symptoms might include anger, abuse or violence; substance abuse or dependence; and emotional cut-offs, including the isolation or scapegoating of a family member. Napier (2003) argues that in order that the family's

confidence be restored and strength be 'galvanized', the social worker may be most

helpful by being the informer, coach, advocate and a reliable, safe person 'to steer them

through' (p.160). She believes that thinking about families by focusing on their strengths

and resilience does not ignore or minimise problems but rather 'lends respect to the

idea of partnership' (p.160). Whilst each family member is at risk of distress due to the

strong emotions and changes in the family structure and functioning caused by the

impact of the illness, it is especially evident in the case of children facing a parent's

death (Walsh-Burke 2004). Studies have shown the damaging effect that a life-

threatening illness of a parent may have on various aspects of a child's life (Vachon

1993; Rutter 1996) and the importance of children being kept informed about what is

happening (Walter 1994).

There is literature that recognises how the needs of this community of children can

impact on the role of the palliative care social worker (Oliviere et al. 1998; Monroe

2004). Monroe (2004:1011) believes that palliative care professionals 'have a

responsibility to ensure that potential difficulties for children are minimized and social

workers possess specialist skills in this area'. She considers that help for children

should start with their parents. Describing these children as 'vulnerable', she reminds us

that they may be unable to voice their needs and emotions; however, these may be

displayed through their behaviour (Jewett 1997). Palliative care social workers, Zaider

and Kissaine (2007:80) argue, may need to help a child develop a 'resilient mind-set' so

that the child may better cope not only with the current circumstances of the dying

parent but also with the bereavement process.

Sheldon (1997) drew up a framework to guide practice in supporting children when their

parent is dying:

- find out what the child knows or believes about the situation
- help parents talk to their own children themselves

- use simple language, play and relevant books when engaging with children

- recognise the individual relationship of the child and the dying person

- help parents to consider what resources there might be within their family or community that could also be helpful to their children while they themselves have so much to cope with (pp.83-86).

Sheldon, therefore recognised the importance of communicating with children. Whilst Luckock et al. (2007) agree that all social workers should be able to communicate with children, they argue that evidence shows that there is no guarantee that on qualification social work students have been prepared to do so.

In her study of the role of social workers in palliative care, Sheldon (2000) found that it was apparent that palliative care social workers are often in the position of hearing about risk to vulnerable children and adults and therefore need to make judgements about how to 'manage risk'. She also raises the point that because social workers have a legal duty to protect vulnerable children 'there may be a preventive purpose alongside counselling which may therefore bring in advice and information giving' (Sheldon 2001:243). Sheldon (2001) and Monroe (2004) both consider that a core part of the role of the social worker is to assist patients and families to communicate. If family members are not open with each other then 'social adjustment' is unlikely to take place, since everyone is putting up a wall of secrecy' (Faulkner and Maguire 1994:76). Family meetings 'can be a powerful tool for change and resolution of problems' (Monroe 2004:1010) and for helping individual members to communicate more openly (Firth and Anderson 1994; Fineberg 2010).

There is one important aspect that Sheldon (1997) believes a palliative care social worker should keep in mind: the recognition of the individual relationship of the child to the dying person. Indeed, Monroe (2004) considers that learning about the family's

strengths and difficulties, finding out about the normal patterns of communication, identifying any areas of conflict and support prior to the illness will go some way to understand the family's current and future ability to cope. The illness can be the 'final burden that topples a delicately balanced system of nurture and support' (p.1008).

There is, however, a lack of literature analysing the palliative care social worker's role in relation to children. More specifically, whilst Beresford and colleagues (2007) did not interview children and young people in their study, there was evidence from parents that palliative care social workers were carrying out some 'intensive individual and/or group work' with them which parents and children were reported to value highly (p.107). However, it appeared that palliative care social workers were only working directly with a small proportion of the children of parents interviewed in the study; a small number of those parents where this did not happen reported they would have welcomed some direct support for their children.

A particularly sensitive area of practice identified in the literature is regarding the future care arrangements of children, particularly where they are being cared for by lone parents who are receiving specialist palliative care. Indeed, these parents may be frightened of agreeing to see the palliative care social worker because they fear the risk of their child being taken into care (Beresford et al. 2007). This can cause uncertainty and anxiety for both the parent and the children. Who has parental responsibility after death is not always a straightforward matter particularly now that family relationships are becoming more complex (Sheldon 2008). Willis et al. (2001) found in their retrospective review of ten oncology patients who were single parents that the making of care plans, either verbally or formally prior to the parent's death, was no guarantee that they would be put in place. In a substantial minority of these cases, a person who the dying parent had not wanted to care for the child ultimately did so. In one case, the plan made was felt to be unacceptable by the children and later resulted in a suicidal crisis for one of

them. Nadimi and Currow (2008:171), as a result of their own small study of three families, suggest that 'social workers' multifaceted involvement' should include a sensitive exploration of the available options. Assessment by social workers as soon as 'sole parenthood' is identified would, they believe, allow more time for the legal, emotional and social issues to be addressed.

In addition to the stresses of working with people who are dying, Firth and Anderson (1994) describe the pain and anxiety that is borne by workers where a patient has young dependent children. Firth (2003) also draws attention to the powerful emotions that can be released in staff members, for example anger, fear and anxiety. These emotions, they argue, may be projected on to other members of the team, the organisation, worker's own family and sometimes the patient and their family. A team of reliable professionals who are communicating well with each provides patients with a sense of security, consistency and comfort, which according to Jeffrey (2004:112) is essential to meet the needs of patients and their families.

The palliative care social worker within the team

Another important aspect of literature relates to the multi-professional team in specialist palliative care. The team model was very much part of Saunders' vision of palliative care; she saw the strengths in bringing together professionals who could respond to the patient's 'total pain'. However, she also saw the need for them to overcome professional rivalries, the temptation to compete and learn how to share and when to hand over (Saunders 1990). Both Ajemian (1993) and Firth (2003) identify the importance for staff to have a strong professional identity before joining a palliative care team because of the need to be secure enough within their professional role to allow other staff to sometimes share some aspect of it without being threatened.

Different palliative care services organise their teams in different ways in terms of size and personnel depending on local circumstances (Speck 2006). Whilst there is much debate in the literature about whether palliative care teams are multidisciplinary or interdisciplinary in nature (Meier and Beresford 2008) the consensus appears to be that they should be inter-disciplinary. Raymer and Reese (2004:150) argue that a distinguishing core value of hospice care is that care is provided by an interdisciplinary team as opposed to a multidisciplinary one. In the view of Farber et al. (2004) and Egnew (2004) interdisciplinary teams, where people are openly communicating with each other, share common goals and expectations of care can support the patient and family more effectively than working on an individual basis. Corless and Nicholas (2004) describe the focus of the interdisciplinary team being the knowledge and expertise possessed by each of the team members as well as personal talents. They consider the hallmark of the interdisciplinary team is the process of interaction based on respect, information sharing and shared decision-making. They describe 'role blending' as an indication of the degree to which professionals do what needs to be done with less attention to which discipline is responsible for what, a view supported by Hill (1998), Payne (2000), Sheldon (2000) and Molyneux (2001). Bronstein (2003) points out that unless social workers collaborate with other professionals it is virtually impossible for them to serve clients effectively.

The potential barriers to multidisciplinary working are numerous, however, and include language, communication, values, professional loyalty and role ambiguity (Hill 1998; Payne 2000). In Firth's view (2003:118), subtle differences in the value base of specialist palliative care professionals can be a problem and a patient's voice might be 'lost' if there is conflict in a team (p.110). Issues of confidentiality may also cause some difficulties in terms of what should be shared with whom within the team (Egnew 2004).

Dunlop and Hockley (1998) argue that having a social worker as a core member of the multidisciplinary team can lead to a more creative service for patients and their families, as well as providing for the individual and collective needs of the team. However, NICE guidelines (2004) distinguish between core members and others, and it appears that social workers are optional core members which Hodgson (2005:53) considers to reflect a 'hierarchy of care'. Social workers therefore are not always seen as an equal member of the team but supporting the medical and nursing staff as an 'internal consultant' or 'resource' (O'Connor et al. 2006). A social worker, Monroe (2004) believes, can remind the team to keep 'the whole person' in mind whilst interventions are planned. This view is supported by Raymer and Reese (2004) who argue that historically social work has differed from other disciplines in health care; social workers, they argue, 'advocate for the individual and family within the system' (p.155), ensuring that psychosocial care is a core activity (Cadell et al. 2010). However, Firth and Anderson (1994:158) believe that a singleton palliative care social worker in a team has an 'impossible task' that may lead to defensive adaptations in the individual worker and the team. Power issues may be present if people from different disciplines assert their perspective is superior (O'Connor et al. 2006). Payne (2006:149) argues that palliative care social workers should practise jointly with other professional colleagues, and Dunlop and Hockley (1998) and Monroe (2004) advocate engaging in teaching activities with other members of the team. In doing so palliative care social workers may demonstrate their worth, gain acceptance and help build a 'community of practice' (Wenger 1998).

However, Berzoff and Silverman (2004) put forward the view that social workers are generally not socialised to practise as part of a team. In their opinion social workers take on a subordinate role particularly in a medical setting, a view supported by Firth (2003). Reese and Sontag (2001) identify various potential barriers to the full use of social workers in a hospice team. These include:

- a lack of knowledge of social workers' expertise

- role blurring - an overlap of roles which may mean other professionals take on roles that are more appropriate for the social worker

- conflicts arising from differences between professions in values and theory base

- negative team norms

- lack of commitment to the team process

- power differentials in the team

- client stereotyping - clients may refuse to see a social worker due to misperceptions held by the client (pp.168-173).

In contrast, Blacker and Deveau (2010:243) argue that social workers bring a useful understanding of group dynamics and communication that is invaluable to the team's development.

Knowledge and skill base of palliative care social work

As suggested by the above studies, the breadth of theoretical information informing palliative care social work is therefore 'formidable' (Egnew 2004: xxi). The literature describes the various theories that specialist palliative care social workers should understand in order to be effective in their work (Sheldon 1993; Quinn 1998; Egnew 2004; Monroe 2004; Parker, 2005; Blacker and Deveau 2010). This knowledge base, it is considered, should build on that already gained from basic social work training. Areas identified include: theories of loss and grief; death, dying and bereavement; historical and sociological perspectives on death and bereavement; the psychosocial context of illness; attachment theory; ethical issues in palliative care; communication skills; bereavement counselling; advocacy and concepts of collaborative practice. How a family may be affected by legislation and what community services and welfare provision might be available is also considered to be important. There is, however, an

apparent lack of reference to knowledge about the immigration system and to child care legislation, policies and guidance.

Having knowledge and skills in various therapeutic techniques, for example cognitive-behavioural work, is seen to be an advantage (Reith and Payne 2009) and considered to be a valid model for end of life care (Moorey and Greer 2002). The importance of being knowledgeable about spirituality is also mentioned (Lloyd 1997; Everard 2005) although many social workers in Lloyd's study (1997) did not see their role as including any spiritual care element. In Thomson's (2005:41) view, having an awareness of people's different ways of life, beliefs and traditions is essential for a sensitive delivery of palliative care together with the concepts of 'cultural competence' and 'culturally safe practice' (p42).

In addition, highly developed communication skills are perceived to be crucial. Egnew (2004:xii) refers to the 'sensitive in-depth end of life discussions that accompany a respectful death' highlighting the importance of the social worker being an 'extremely skilled interviewer'. Reith and Payne (2009:65) advocate palliative care social workers using a 'narrative approach'. Since good interpersonal skills are essential to 'listen and hear the person, carer and family' (Cullen 2005: 93). The use of counselling skills in communication or counselling as an intervention have been well established in palliative care (Vachon 1993). Skills in communication and work with children in particular have received less attention in the literature in the past but there is now a growing recognition of their importance (Kennedy 2008; Fearnley 2010).

Conclusion

The recent investigation of palliative care social work from the perspective of service users (Beresford et al. 2007) provides a new dimension and important insight into how

palliative care social work is understood and valued by those receiving the service.

Whilst there is literature concerning preparation of children for the death of a parent,

there appears to be a gap in how palliative care social workers work specifically with

families where there are concerns about the present and future care of children. This is

even though Sheldon and Monroe, the two main British contributors to this body of

literature, believe that palliative care social workers are in a position to be alert and

respond to children who might be at risk. The next chapter moves on to explore this

aspect of their role further through the existing literature about children's experiences

during the terminal phase of a parent's illness.

Chapter Three
Children's experiences of living with a dying parent

> Coming to terms with death and loss is the most difficult
> challenge a family must confront in life.
> Walsh and McGoldrick 1998

Introduction

Since the 1990s there has been a gradual increase in interest in the experiences of
families with children where a parent is seriously ill or dying. Most of the research is
North American in origin with a limited amount from Britain and Australia. In addition,
there are a small number of studies from Northern Europe in the English language
literature. The majority of the research has been conducted by health care academics
for health care professionals, although the findings are very relevant to social workers in
general and to palliative care social workers in particular. A large proportion of the
research has been qualitative in nature or mixed method producing rich data from small
samples. Contradictions and non-uniformity in findings may be attributable to differing
reporting mechanisms, methodologies, sample sizes and illness-related characteristics.
There are also some practice-based papers that describe the reactions of children and
parents to the terminal illness and death of a parent.

The chapter will point to gaps in the literature as there are few studies that explore the
nature of the relationship between the dying parent and the child and the impact of that
relationship on the child's emotional and physical well-being during this time of
disruption and uncertainty. In contrast, the focus rather is on what happens after the
parent's death and the literature on child bereavement is extensive. There is also more
research on the period after diagnosis and during initial treatment which concentrates
mainly on mothers with cancer with a limited exploration of the experience of fathers.
Most of the studies are psychosocial in approach and pay less attention to the social
context. Further, a very large proportion of studies consider families where there are two

parents in the household and most studies do not include families where there is a history of emotional and behavioural problems concerning the child prior to the illness or where the child is vulnerable. Similarly, the relationship between parents and between parents and children before the onset of the illness is not usually explored. Whilst there are studies reporting on children of various ages, there is little reference to pre-school age children. Finally, the context is mainly white Caucasian, middle and upper class families and generally studies do not include families living in poverty or trans-national families.

In this part of the literature review I will first report on the incidence and prevalence of children living with a dying parent, before moving on to consider the nature of the literature on the impact of this experience on children's lives. Consideration will then be given to the literature on how children cope with the terminal phase of the parent's illness and finally on the impact of the illness on family functioning. The aim is to extrapolate lessons from this body of literature that may be applied to the practice of palliative care social workers in safeguarding children.

Incidence and prevalence

In the UK it is estimated that approximately 1 in 10 of all cancer cases occur in adults aged 25-49 (Cancer Research UK 2009) and in 2007, more females (4,015) died from cancer than males (2,929) in this age group. The most common cancers included breast, malignant melanoma, bowel and cervical cancer. It is likely that many of these people will have been caring for children under the age of 18. Based on data gathered from a large sample of adolescents in the north of England, it is estimated that the risk of experiencing parental death by 16 years is 6% (Harrison and Harrington 2001). In the United States, the National Cancer Institute estimates that 24% of patients receiving treatment for cancer have children under 18 (Rauch and Muriel 2004). It is to be

expected therefore that many children live much of their childhood with a sick parent and can often become young carers[4]. Information from the 2001 Census indicated that there were approximately 175,000 young carers in the UK (HM Government 2008:123). A UK survey conducted in 1993 found that 56% of young carers are living in lone parent families and that it was mothers who were cared for in 70% of lone parent families (Dearden and Becker 2004).

The nature of the literature on the impact of parental terminal illness on children's lives

Studies regarding the terminal phase of the illness tend to be retrospective in nature and based on the responses of the remaining parent and other bereaved family members. The remembering of past events and feelings will be influenced by the individual's emotional state and perspective both at the time and at recall (Addington-Hall and McPherson 2001; McPherson and Addington-Hall 2004). Whilst it is important to view incidents from a 'historical' time frame, it is also important to consider the contemporaneous experience of participants, particularly the children, whilst their journey is taking place. Whilst there has been an expansion of user involvement in research and in participatory approaches in research generally, there is still a reluctance to involve patients and their families, particularly children, during a time of such uncertainty and vulnerability. Issues of 'gatekeeping' by service providers and the 'protecting' of vulnerable service users by 'paternalistic cultures' are evident (Beresford et al. 2007) including bureaucratic barriers imposed by various ethics approval processes (Peck and Jones 2004; Balen et al. 2006; Part and Comben 2007; Kendal et al. 2009). However, feedback from participants, particularly children, in prospective studies has indicated that involvement in such research, although emotional at times,

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[4] Young carers: those under 18 who are carrying out 'significant caring tasks and assuming a level of responsibility for another (adult) person which would usually be taken by an adult' (Department of Health 1999a).

was positive and helpful (Chowns 2005; Sheehan 2007; Kennedy 2008).

Few studies therefore include direct information from the children. Chowns (2005:131) suggests that this area of research is both 'scary' and 'swampy' in nature. This is because the uncertainty of the situation might lead both the researcher and practitioner to question their abilities and skills; there may be an instinct to protect children from painful issues by not talking about them; and being involved might mean confronting adults' own memories of childhood distress and mortality (Monroe 1990). Given the larger numbers of research studies into the effects of bereavement, the journey would appear to be more difficult to manage than the destination, death and bereavement. However, where studies have gathered direct information from children it has been found that parents and children did not always perceive child functioning in the same way (Osborn 2007). There is often more agreement between the responses of parents and children concerning behavioural problems than emotional ones, maybe because these are easier for the parent to recognise (Visser et al. 2004). The child's ability to self-reflect will depend on their stage of development and confidence in describing how they feel (Lewis 2007).

The child's experience of the terminal phase of a parent's illness

The literature concerning the terminal phase of a parent's illness, has identified several factors that may influence the child's experience particularly the age and gender of the child and practices of communication and sharing information with the child. Whilst this study concentrates on the terminal phase of a parent's illness, it is important to acknowledge that the experiences of children and their parents at the diagnosis and early treatment phase of the illness are also likely to have implications for the family and

the professionals involved at the later stage[5]. However, Visser et al. (2004) argue that longitudinal studies are needed to test this hypothesis.

Age and gender

Children's understanding of the concept of death will shape their thoughts, feelings and reactions to a parent's terminal illness (Rauch and Muriel 2004; Dent 2005; Christ and Christ 2006; Diareme et al. 2007; Himebauch et al. 2008; Fisher 2009). Parents may not realise that a child's experience of the disease process and the losses that happen along the way are different from those of an adult. Christ (2000) undertook a landmark piece of qualitative and quantitative research over several years with 88 families and their 157 children (aged 3-17 years) who coped with the terminal illness and death of a parent. Christ divides her findings regarding the children into five age groupings.

In the first group (3-5 years) Christ found that children were distressed not by the illness, but by the changes in and the preoccupations of the care-giving parent as well as by the separations caused by the ill parent's hospital admissions. Any psychological symptoms or misbehaviour, which were few, were dependent on the adequacy of care arrangements, the number of separations and emotional climate generally. Some children's behaviour regressed and others became aggressive. Children in the second group (6-8 years) showed strong emotions of sadness, anger, fear and anxiety and were much troubled by what was happening around them, particularly any separations and restrictions on their activities. Most were found to be reluctant to talk about their fears.

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[5] A comprehensive discussion on the range of literature regarding the early stages of parental illness and its impact on children is given by Visser et al. (2004); Diareme et al. (2007); Grabiak et al. (2007); Osborn (2007); Semple and McCance (2010).

The children in the third group (9-11 years) showed a need for information during all the stages of the illness. Some exhibited few reactions whilst others became angry and most had problems concentrating at school. In the fourth group (12-14 years), although able to cognitively to understand what was happening, children could still have misunderstandings due to lack of experience and avoidance of facts. They were typically argumentative and demanding; their distress symptoms included sleep problems, anger and sadness. Girls seemed to experience more emotional distress than boys. Where there were pre-existing family conflicts and communication problems, the children's anxiety was often displaced, causing angry and provocative interactions that could become out of control. Children in the final group (15-17 years) were found to be more realistic and flexible in their thinking about their parent's illness. Unless they had pre-existing emotional problems, their behaviour appeared more constrained than younger adolescents although most showed irritability.

Whilst Christ's findings are important due to the nature of the study and sample size, there are limitations. The sample only included families who were white Caucasian, middle class, emotionally stable, economically productive, affluent and articulate: 'an idealised population' (Chowns 2006). Christ herself recognised that other contextual factors such as poverty, illness-induced separation and difficult family relationships may influence the outcomes.

Communication and sharing information

Communicating with and providing information to children have been found to be important ways of supporting children when their parent is ill (Christ 2000; Christ and Christ 2006; Thastum et al. 2008). Dunning (2006), writing on her practice in a hospice in North America, describes children whose acting out behaviour caused referrals to her service. When investigated she found that the basis of the behaviour was in misconceptions and fantasies about the parent's illness due to a lack of communication.

However, informing children that their ill parent is dying is a challenging and daunting task. A retrospective qualitative study of nine surviving parents highlights some of the issues and difficulties involved (Macpherson 2005). Parents' reluctance to tell children stemmed from their own feelings of powerlessness and vulnerability. Parents experienced confusion and paradoxical struggles: knowing that the death would happen but denying it. They were struggling to look after themselves, their partners and their children and felt torn between the conflicting needs, leaving them feeling isolated. All the well parents respected the wishes of the dying parent with regard to what information was given to the children. Siegel et al. (1996) in a larger study with 90 children aged 6-16 years found that even in families that have good communication practices, parents need guidance and encouragement to discuss the probable death of an ill parent. The study suggested that well mothers were more likely to be perceived by adolescents as 'open communicators' regarding illness and death than well fathers.

In a qualitative study involving interviews with parents and children, Kennedy (2008) explored the experiences of 12 families in order to identify the children's main underlying need/s. Children described wanting honest information and access to both emotional and practical support within and outside the family. This support was often described as lacking. Parents focused on difficulties in telling the children they were terminally ill and would have liked further information and support in this area especially in relation to younger children and those children with special needs. Communication was felt by both children and parents to be difficult due to each not wanting to upset the other. However, children who had open communication within the family were described as having better access to information and support both within and outside the family, leading to decreased concerns and increased coping.

Whilst for some children visiting a parent in a hospice may be a positive experience (Thastum et al. 2008), for others it has been found to be a forbidding and frightening

experience. They do not generally ask questions, possibly because they are intimidated by the environment and lack of opportunity (Thompson and Payne 2000). Giving children information by way of a workbook designed to facilitate communication between children, their parents and nursing staff was found in one small study to help children to become more involved in their visits to the hospice (Macpherson and Cooke 2003).

One small study of three mothers with cancer (Barnes et al. 1998) considered their communication strategies with their children who had learning disabilities and behavioural problems. The findings show that mothers chose to protect these children by withholding information; siblings, however, received more detailed and explicit information. The children with learning difficulties had particular difficulties coping with changes in routine, the observable changes in their mother and her unavailability. There were also reported behavioural changes in the children.

In researching the experiences of children facing the life-threatening illness of a parent, Chowns (2006) approached her study in a groundbreaking way. Aware that children's voices are not generally centre-stage, Chowns used a collaborative inquiry approach with nine children aged 7-15 years whose parents had cancer. The children, together with four adults, co-researched their experience through the making of a video for public use. The children came from five families, four with an ill mother and one an ill father. A major finding was that the children were clear that they preferred to be informed and involved, wishing to be told the truth as fully and as soon as possible. They saw delay and deception, whatever the motives, as a breach of trust; whilst they could understand why parents might not be open and honest with them, it did not, in their minds, justify their actions. Having to face the life threatening illness of a parent brought with it a sense of isolation. The uncertainties about their parent's future and their own were ever present. Children sought support and understanding rather than 'protection and

prevarication'. A key finding was that the children demonstrated sophisticated communication strategies, distinguishing between talking, telling and foretelling, and made careful choices as to when and with whom to 'not-talk'. Landry-Dattee and Delaigue-Cosset (2001) reporting on the benefits of support programmes for children noted similar findings.

These studies suggest therefore that children both want and need to be informed and involved. However, parents may not know how to prepare the children, particularly as they feel they need to come to terms with what is happening first.

Coping with the terminal phase of a parent's illness

Saldinger et al. (2003) found that the anticipation of death may provide one of the biggest strains of all for parents and their children. These findings are from a retrospective, qualitative study regarding 32 parental anticipated deaths involving 58 bereaved children, aged 6-16 at the time of initial contact, and their surviving parents. Saldinger and colleagues concluded that when a parent is terminally ill, the child's relationship with that parent is compromised by 'two mutually-reinforcing factors'. One factor is the parent's inability, both physically and emotionally, to reach out to the child, and the other is how able the child is to tolerate the parent's physical, mental and emotional deterioration. For those children who have a low threshold of tolerance, a guilty tension develops between the wanting and not wanting to connect with the dying parent. It is also easier for parents to overlook the plight of children who internalise their distress but children can also be protective of parents by not showing how they feel. The evidence from Sheehan's small study (2007) echoed these findings. However, none of the participants revealed any significant family dysfunction which may alter the process.

Christ (2000) also suggests that the terminal phase of a parent's illness may be a period of greater psychological stress for children than the period after the actual loss and that anxiety experienced during the course of the illness 'waxes and wanes' (p.24). This is supported by Siegel et al. (1996) who in a quantitative study showed that children reported significantly higher levels of depression and anxiety in the pre-death period but 7-12 months post death, their reports were similar to children in the community who had not experienced such a loss. Heiney et al. (1997) suggest that children, particularly aged 6-12 years, experience a higher level of anxiety themselves if their parents also display a high level of anxiety.

Siegel et al. (1992) compared 62 school-aged children with a terminally ill parent with a community sample using a variety of standardised rating scales. Children of a terminally ill parent self-reported higher levels of depression and anxiety and lower levels of self-esteem. Parents who were terminally ill reported higher levels of behaviour problems in their children than those in the community sample. Whilst able to describe behavioural problems, for example aggression (externalised behaviour), the parents were unable to describe anxiety and depression states (internalised behaviours). It has been suggested that the ill parents may not have recognised their children's emotional state and needs due to their own high anxiety levels or because behavioural problems are easier to recognise (Visser et al. 2004). Siegel and colleagues (1992) suggest that such distress among children may be seen as an important aspect of mourning. Such mourning might be temporary and helpful (anticipatory mourning) during the terminal phase, or something which might lead to pathological mourning and depression and anxiety in later life. In a later study Siegel et al. (2000) found that low levels of self-esteem in children correlated to being younger, having high levels of anxiety and also to the child's perceptions of the well parent's parenting. What was not explored was the quality of parenting as a variable in these studies.

Similarly, Beale et al. (2004) found that children with dying parents manifest significant distress as well as a greater understanding of their parent's illness than is usually suspected. They interviewed 28 children, who were aged 3-18 years, and had been referred to their Palliative Care and Symptom Service and their parents both together and alone. This was a group of children who had been referred to clinicians at the parents' request. They were seen in a playroom where they were free to choose a play activity. The results showed that all the children had some understanding of their parent's condition but were frightened about the outcome. Even small children demonstrated 'a remarkable awareness' of the illness and its implications. The children displayed high levels of aggressive behaviour and separation anxiety. The authors concluded that discussions between parents, children and other adult caretakers are important when the patient is first aware of the terminal condition. Timely intervention, particularly with children, they believe, should take place to encourage better communication and possible resolution of conflicts before death is imminent.

Other studies have found that children perceive very little opportunity for control over their parent's cancer and the more serious the cancer the more children try to avoid it (Compas et al. 1996). The children in Chowns' (2006) study found that a key strategy for coping was to focus on the positives in life. Another was a need to experience a safe place in order to both hold on to and let go of the strong emotions generated by the experience of living with a seriously ill parent. Siblings, it was found, could be both sources of support and stress, as were grandparents and friends. School was seen as another source of stress even though individual members of staff might be experienced as being highly supportive.

A small, retrospective, qualitative study of five young people who had experienced the chronic illness and death of a father showed that whilst a parent was ill they had felt powerless and isolated (Semmens and Peric 1995). These feelings of isolation and

alienation were echoed in another retrospective, qualitative study conducted by Dehlin and Martensson (2009), also with five adolescents who were aged 14-17 when their parent died. The adolescents described the illness and death as a great threat, and in spite of all the difficulties retained a hope that the parent would recover. They had developed different managing strategies to cope with the threat, including wanting and trying to make their lives function normally even though they were aware they were not. They saw their friends as a 'protected zone' where they did not have to think about the illness, and unlike responses within the Chowns' study above, saw school as a place where they could get away and be normal. Another strategy was to avoid talking about the illness. Again, the variability of parenting was not considered in these studies.

Children have consistent styles of coping with transitions and these will have an impact on their reaction to the parent's terminal illness (Rauch and Muriel 2004). Children living with a dying parent may be described as living in adversity, yet many will be able to cope and achieve positive outcomes (Spira and Kenemore 2000). This will be due to the existence of protective factors, 'resilience', that can help explain why one child may cope better with adverse life events than others (Alvord and Grados 2005; Daniel et al. 2010). Gilligan (1997) identified three bases that underpin the factors associated with resilience: a secure base, good self-esteem, and, a sense of self-efficacy. In a small, qualitative study of a Family Support Programme for children aged from 5 to 18 years, Bugge et al. (2008) found that children need help to understand themselves and to learn about how to deal with a range of difficult and confusing feelings, thoughts and reactions. They need to talk in private about the imminent death of a parent but dialogue with other family members is important too. Adolescents, for example, may have more people they can rely on than younger children to discuss matters with, for example, a teacher, school nurse, friends (Christ et al. 1994). From Dunning's (2006) experience, children require help to identify and label their feelings. This includes feelings about the current situation, losses already experienced and worries about their own future and

what will happen to them. If such help is offered this may act as a buffer against the effects of the adversity. Children however may be experiencing other adversities in life such as racism, marital violence, abuse and neglect (Daniel et al. 2010) prior to the additional adversity of the terminal illness of a parent to which palliative care social workers should be alert.

Particular difficulties have been identified in the literature regarding child carers. Aldridge and Becker (1999) and Dearden and Aldridge (2010) provide a detailed overview of research regarding children as carers. Disability and illness are often associated with poverty (Dearden and Becker 2000) and children are more likely to become young carers if their family lacks sufficient personal or family support (SCIE 2005). 'Children as carers' is explored specifically by Gates and Lackey (1998) in a small study of 11 children aged 10-19 years. Whilst the study mainly considers children's care of older relatives in the household, rather than parents who had cancer, it does highlight certain key points. Caring responsibilities frequently interfered with doing homework and spending time with friends. Feelings of stress, fear and fatigue were described by the children, and observations made during the study provided evidence of the effect of the stress and strain of the illness on the family. The children expressed anger about not being informed about the diagnosis, the current status of the illness and changes in treatment (Lackey and Gates 2001).

In one study, Aldridge and Becker (1993) found that young carers were often reluctant to identify themselves or make it known how much caring they do. They were frightened of professional intervention that might lead to separation and the disintegration of the family as well as a fear of bullying from other children. As such, young carers may often feel isolated (Underdown 2002). They may have fewer opportunities for social activities and caring duties which set them apart from the friends that they do have and inhibit them forming new friendships (Thomas et al. 2003). More than a fifth of all young carers

in a UK study experience educational problems and this is more marked in the 11 to 15 age group (Dearden and Becker 2004). Being a young carer may put additional pressures on a child or young person at a time in their life that is potentially already stressful and support may not always be available (Cree 2003). However, whilst there might be detrimental effects for children there are also positive aspects too, with children being provided the opportunity to develop and mature in terms of confidence levels and organisational abilities (Aldridge and Becker 2003).

Family functioning

Family functioning has been found to deteriorate when a parent has cancer (Visser et al. 2004). In a review of earlier research, Lewis (1990) came to the view that it was probable that a small number of families might be at high risk for functional breakdown but that studies to date had focused on identifying high risk patients rather than high risk families. Since then more research has been conducted, although there are more studies that consider family functioning during the initial phase of illness rather than the terminal phase (Huizinga et al. 2003; Zaider and Kissane 2009).

A parent with a terminal illness presents a challenge for the family and often requires changes in parenting roles, responsibilities and goals (Helseth and Ulfsaet, 2005). Parents describe themselves living in a state of emergency. The illness consumes their energy, physically and emotionally but they strive to be good parents. The prospect of the death of a parent may revive memories of past losses and hurts (Kissane and Bloch 2002) for children as well as adults, for example due to unfinished business through remarriage. This may cause tension and conflict in the family, therefore affecting its functioning. There is also evidence that maternal depression can impair family functioning, particularly in domains of problem solving and role functioning, and a sense of coherence in the family can improve it (Schmitt et al. 2008). The quality of marital

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adjustment can further be affected by the level of depression in women and the demands experienced by the illness (Lewis and Hammond 1992). The depression of the mother has been found to be more significant than that of the ill parent, which suggests that if a father is ill it is the mental health of the mother that remains the important factor in maintaining positive family functioning. However, there is little research on how much the terminal stage of the illness of one parent impacts on family functioning, on parenting generally, or about how men's experience of their own illness affects their role as fathers. In her study of six families facing the death of a parent, Kennedy (2008) describes the participating family members as being profoundly distressed. The physical and emotional manifestations of the illness were all-consuming for parents which led to their children's needs taking a 'back seat'. For the well parent there was a struggle to reconcile the competing claims being made upon them from the sick parent and their children.

Family functioning during palliative care is the focus of a research study by Kissane and Bloch (2002) into the effectiveness of family-focused grief therapy in preventing pathological grief during which they screened families of patients dying of cancer. Whilst the focus of this research is on a family-centred model of care, the screening process used validated measures to identify dysfunctional families who were then invited to participate in the trial. Although this study did not solely concentrate on families with children under the age of 18 (the mean age of the children was 29), it is helpful here as it considers descriptors of family behaviour that may indicate where there could be concerns about children in a family due to poor family functioning.

Kissane and Bloch (2002) describe three key dimensions of family functioning: cohesiveness, conflict and expressiveness, and allocated names for five classes of

families that formed their typology of family functioning[6]. Two showed characteristics of well-functioning: 'supportive' and 'conflict resolving'. 'Supportive' families are highly cohesive, have good expressiveness and are low in conflict. 'Conflict resolving' families have moderate conflict characteristics, high cohesiveness and above average expressiveness. They are able to tolerate a degree of difference of opinion with respect. In the authors' view, neither of these classes need specialised psychological help and in the clinical work it is estimated that a third of families are 'supportive' and a fifth are 'conflict resolving'. Two classes were clearly dysfunctional, however. 'Hostile' families (about 6% of the families) are described as tending to reject help and are distinguished by high conflict levels, poor expressiveness and poor cohesion. They are fractured and chaotic, structure and order are absent, and children, primarily adolescents, may become scapegoats for unresolved tensions elsewhere, including those in the parental relationship. 'Sullen' families (about 9% of the families) are described as having moderate levels in each area. They have the highest rates of depression and exercise the highest level of control over family life. The final class was 'intermediate' (a third of the families) because of their position between well-functioning and dysfunctional types and are characterised by moderate cohesiveness. Therapy by those trained in family focused grief therapy is offered to families thought to be at risk before bereavement and takes a systemic approach which includes children. This study is included here because it demonstrates that a proportion of families with children who are likely to come to the attention of palliative care social workers will be affected by poor family functioning. Whilst not advocating undertaking family therapy, Lichtenthal and Kissane (2008:45) are of the opinion that applying a family-centred approach to assessment and intervention increases the likelihood of successful resolution of family strain.

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[6] The authors stress that the names are not intended as clinical descriptors to be shared with the family but as a 'shorthand' in communicating about the model (Kissane and Bloch 2002:37).

Conclusion

Having a parent who is dying is a stressful life experience for a child. Much of the literature on the experiences of this community of children concentrates on the importance of open communication between them and their parents. Others examine the psychological effects on the children. The research provides evidence that children have higher levels of anxiety and distress than the norm population and parents may not recognise the symptoms. The quality of parenting was rarely a variable in the reported studies, however.

There are lessons from the literature that may be applied to palliative care social workers in safeguarding and promoting the welfare of children. These include: recognising the importance of the age and stage of development of the children; parents and children 'seeing' things differently; and parents needing assistance to recognise and understand their children's needs as children, including those with special needs, who want and need to be kept informed about what is happening. Young carers may be particularly vulnerable and children generally may feel isolated and look for support from people they can trust. Maternal depression is likely to have an influence on family functioning; children, particularly adolescents, whose behaviour is causing concern may be reacting to poor family functioning. There is a need to consider what protective factors may be put in place for children already affected by other adversities.

In the following chapter, I will explore the literature on safeguarding and promoting the welfare of children with particular reference to how it relates to palliative care social workers based in an adult-focused service.

Chapter Four

Safeguarding children:
implications for practitioners working with adults

Safeguarding children is everyone's responsibility.
HM Government 2007

Introduction

The literature on safeguarding children is fairly extensive and so I will draw on the most relevant for the study: the implications of safeguarding children for those practitioners working primarily with adults as their focus. In doing so I will consider the role of adult services and children's needs; interagency relationships; parenting, with reference to the potential impact of serious illness on its effectiveness; assessment of children in need; and last, but not least, the child's voice. The literature reviewed consists mainly of legal, policy and guidance documents, practice literature and statements of opinion. Reference is made to empirical research studies where available, the majority of which relate to practice in England. The first section briefly considers the background and context as well as the prevalence and incidence of abuse in the general population before moving on to explore the current practice regarding safeguarding children in England, Wales and Scotland.

Background and context

Since the establishment of Children's Departments by the Children Act 1948, there have, according to Corby (2006a), been three phases in the provision of services to children and their families[7]. The first phase was from 1948 to the early 1970s which was characterised by 'a family breakdown approach'. The second phase, from mid-1970s to

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[7] For a detailed description of the developments in England and Wales see Ball (1998); Holman (1998); Stevenson (1998); Hendrick (2003); Ferguson (2004); Corby (2006a, 2006b), and for those in Scotland see Murphy (1992); Hothersall (2006); Stafford and Vincent (2008).

the mid-1990s, was a 'period dominated by the goal of child protection'. The third current phase, from the mid-1990s, is one of 'support to families'. Child welfare practice in Scotland is underpinned by the Children (Scotland) Act 1995 and in England and Wales by the Children Acts 1989 and 2004. The need to improve the quality of life for all children has informed the governments' planning and guidance. Initiatives have been introduced in all three countries to target children and families in need of support as well as those defined as children in need and those at 'risk of harm' (Horwath 2010:30).

Whilst the philosophy of the Children Act 1989 was to provide support to families, workers were found to be much influenced by the public inquiries of the 1970s and 1980s (Aldgate and Tunstill 1996). The findings of 24 studies commissioned by the Government were published in *Child Protection: Messages from Research* (Department of Health 1995). The research found that professionals had not achieved a satisfactory balance between child protection, family support and child welfare. There was too much stress on child investigations rather than enquiries, and a failure to provide family support to meet the needs of children and their families. Only a small number of referrals actually led to child protection registrations. Further, the assessment tended to be one of risk rather than one of an assessment of need (Thoburn et al. 1997). There was also a concern that children were being routed inappropriately into the child protection system as a means of gaining access to services (Platt 2006a). Calls were made for a 'refocusing' of child protection work which 'prioritised' section 17 and Part 3 of the Act in order to help support families with children 'in need' (Parton 2007:19). In response, government guidance (Department of Health 1999b) expected that child care referrals would receive initial assessments, using a framework to assess needs unless the situation clearly called for a child protection core assessment. Policy had moved from concern about 'the family' to 'the welfare' of the children, their vulnerability and well-being, whilst at the same time upholding parental responsibility (Parton 2006).

Lord Laming's inquiry into the tragic death of 8 year old Victoria Climbié (Laming 2003) highlighted poor practice within and between the agencies. The resulting Green Paper *Every Child Matters* (DfES 2003) led to the introduction of the *Every Child Matters: Change for Children* programme (HM Government 2004). The Government's aim was for every child, whatever their background or their circumstances, to have the support they needed to be healthy; stay safe; enjoy and achieve; make a positive contribution; and, achieve economic well-being. The Children Act 2004 provides the underpinning for the programme. It requires local authorities to lead on integrated delivery through multi-agency children's trusts, to develop a children and young people's plan, and to set up a shared database of children, containing information relevant to their welfare. A raft of statutory and other guidance supporting the programme has been produced (HM Government 2005). Area Child Protection Committees have been replaced in England (HM Government 2010) and Wales (Welsh Assembly Government 2006) with Local Safeguarding Children's Boards (LSCB) with stronger statutory powers. Children and young people are now to have far more say about issues that affect them, individually and collectively (HM Government 2010).

Following devolution in 1999, the Scottish Parliament made children and young people a key priority in the shaping of its policies. The findings of a multidisciplinary audit and review into the child protection arrangements in Scotland *'It's Everyone's Job to Make Sure I'm Alright'* (Scottish Executive 2002) drew attention to the serious weaknesses in the system and, despite examples of good practice with children, identified a significant number of children left unprotected or with their needs not met (Daniel 2004:247). A three-year Child Protection Reform Programme '*Protecting Children and Young People'* was introduced with an action plan designed to provide early support to children and families, better direct help to children in need of protection and effective continuing support. A review assessing the progress of the Programme provided evidence that the programme, according to practitioners from different disciplines, had had a positive

impact and that there were improvements in child protection practice (Daniel et al. 2007).

In 2001, the Scottish Executive published *For Scotland's Children: Better Integrated Services* (Scottish Executive 2001) highlighting the problems caused by a lack of joint working across children's services and making recommendations for integrated children's services. The Local Government Act (2003) places a duty on local councils and their partners (particularly police and health services) to develop Community Plans that bring together the delivery of local services. The findings of a major review into the effectiveness of the children's hearings system (Scottish Executive 2004) led Scottish Ministers to look at children's services more widely and published proposals in '*Getting It Right For Every Child*' (Scottish Executive 2005a). The resulting Getting it Right For Every Child programme (GIRFEC) aims to 'place children at the centre of service provision in Scotland' (Scottish Executive 2006a:3) and to refocus children's services towards prevention, early intervention and family support. In particular, the agency of first contact must aim to offer help; the child should not automatically be passed to another agency. The aim is to ensure that every child is safe, healthy, active, nurtured, achieving, respected, responsible and included. It seeks to do this by providing a framework for all services and agencies working with children and families with a view of achieving a co-ordinated approach. It is a long-term programme which recognises that changes in systems, practices and professional cultures take time to develop. There are various projects in selected local authorities that have specific remits to test the implementation of the GIRFEC approach (The Scottish Government 2010). Child Protection Committees replaced Area Child Protection Committees with a clearer remit and duties (Scottish Executive 2005b).

Whilst Scotland has not moved so clearly from 'protecting children' to 'safeguarding children', the philosophy is similar and the resulting policy and guidance carry similar

implications for children, families, agencies and their staff as their counterparts in England and Wales.

Prevalence and incidence of abuse in the general population

A study of the prevalence of child maltreatment (Cawson et al. 2000) estimated that 7% of children under 18 years had experienced serious physical abuse at the hands of parents during childhood. Another 6% had frequent and severe emotional maltreatment. Serious absence of care[8] was experienced by 6% of children. Of those children under 16 years who had experienced sexual abuse, 1% was by a parent or carer, 14% by another relative or someone known to them and 4% by an adult stranger or someone they had just met. Bullying by other children was a feature of childhood experience of almost a third of the sample. Another study which examined abuse and neglect within the family (Cawson 2002) found that 16% of children (1 in 6) experienced serious maltreatment by parents with one third experiencing more than one type. Maltreatment was more common in families where there was social disadvantage, stress, health problems, domestic violence and family breakdown.

Incidence refers to the number of new cases identified as occurring in any one year. Statistics gathered by local authorities include those for the number of child protection referrals[9] made to the local authority in any one year as well as the number of children placed on the child protection register or in England are subject to a child protection plan (see Table 4.1). However, they can only be an indicator of the size of the problem, as abuse and neglect are both under-reported and under-registered. At 31 March 2007, the rate of registration per 10,000 children under 18 was 25 in England, 36 in Wales and

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[8] Serious absence of care at home covers aspects of physical neglect e.g. frequently going hungry; not being taken to doctor when ill; regularly having to take care of themselves when parent had problems with alcohol and/or drugs.
[9] A referral is the first stage of the child protection process in all areas of the UK.

28 in Scotland. Child neglect accounted for the largest number of registrations: 44% in England, 52% in Wales and 49% in Scotland (Vincent 2008).

Table 4.1   Number of child protection referrals and registrations 2006/07

	England	Wales	Scotland
Number of referrals in year ending 2006/07	545,000	49,561	11,960
Total number of registrations as at 31 March 2007	27,900	2,295	2,593

Whilst it is difficult to give an accurate figure for the prevalence of child maltreatment, the above figures would indicate that it is likely that palliative care social workers will be working with some families where child maltreatment has occurred or is occurring.

Current practice

The policy of 'safeguarding' has a much wider remit than 'protecting children from abuse and neglect' (Munro and Parton 2007:14). The governments' plans therefore are to mainstream services so that they can support all children, including those at risk, preferably in their home environment and to use family support as a primary mechanism to protect children from harm (Axford and Little 2004:168). This approach is no longer just the responsibility of social services but of all professionals who might come into contact with children (Axford and Little 2006).

However, a lack of resources both in terms of personnel (staff recruitment and retention) and money for a wide range of support services creates difficulties. Social workers are struggling to deliver both child protection services and family support services (Spratt 2001). Because of the inadequate services available, families with low-level problems are often turned away without receiving the help they seek (Munro 2007). From a child protection file study of 205 children in one local authority, Thorpe and Bilson (1998) suggest that once a referral was judged to be one that required investigation, any welfare or needs issues that were beyond this focus were frequently ignored, and where

child protection issues were not substantiated, the cases were closed and no services were provided.

Although a case might be classed as one of family support it does not in Spratt's view (2001) negate the social worker having to manage the tension between support and evaluating risk. Platt (2006a:278), in a qualitative study conducted in two local authorities between 1999 and 2001 on the impact of the refocusing initiative, found that initial assessments on 'borderline' cases enabled social workers to focus on both helping and protecting children. However, the focus on the event that triggered the referral was often the deciding factor on the choice between an investigation and initial assessment together with the worker's interpretation of its seriousness (Platt 2006b:13).

Parton et al. (1997) have argued that social workers mainly carry out their duties as defined by their employing organisation and both social workers and organisations are anxious not to be in a position where they are blamed if things go wrong. Recent child deaths, for example, Victoria Climbié, Baby Peter and Kyra Ishaq, can only heighten this anxiety and so issues of child protection take priority (Aldgate and Tunstill 1995).

A child 'in need' refers to a child's state of development and health, both of which are defined in s.93 of the Children (Scotland) Act 1995 and s.17 of the Children Act, 1989. However, no definitions are provided for the legal terms 'a reasonable standard of health and development' or 'significantly impaired'. Because it is only a duty for authorities to 'take reasonable steps' and 'as they consider appropriate' it depends on how each local authority (and social worker) defines and prioritises the concept of 'a child in need' (Colton et al. 1995). 'Vulnerable children' are defined more broadly than 'children in need' and are described as those who have acquired or encountered some difficulty that requires additional help from public agencies if their life chances are to be optimised (Preston-Shoot and Wigley 2005). Out of a total of 11 million children in

England, the government estimated in 2004 that 3.66 million were 'vulnerable children' and 388,200 were 'children in need' (DfES 2005).

Local authorities throughout England, Wales and Scotland are legally required to determine the nature and extent of children's needs in their areas in order to provide a needs-led service. Axford et al. (2009) conducted an analysis of reports on children's needs produced by two local authorities in England between 1997-2007. They drew particular attention to one local authority that investigated the need for a support service for young people aged 11-18 years who were struggling to come to terms with parental separation, divorce or other issues related to family change (p. 247), a definition which might include the death of a parent. It is not clear whether local authorities generally might consider that children who are risk of being, or are bereaved, might be 'children in need'.

In a study of eight local authorities in Wales and a comparable eight in England, social workers and managers considered that ideally there should be more emphasis on family support work but resources for doing this were scarce (Colton et al. 1995). Social workers were found to be interpreting the concept 'a child in need' in a wide variety of different ways with little agreement as to how it should be defined. In the absence of any substantial guidance social workers were relying on their own experience plus material that was primarily designed for child protection work. The Social Services Inspectorate (1997:1) in their report on the inspection of management and practice of eight local authorities noted the imbalance: 'Departments continue to respond to child protection and looked after children to the exclusion of other families of children in need'. However, Spratt (2000) in a small study found that Inspectors themselves were not able to agree about whether situations described in a number of vignettes were child protection investigations or child-care problems. This highlights the general problem that there is no agreement regarding definitions. Jack (1997) has argued for a more fundamental

change in attitudes towards social welfare provision for families involving a 'deconstruction of child protection discourse and the development of a new child welfare discourse' (p.670). If a lack of clarity exists within children and family services about 'children in need', then this is even more likely to be the case among workers in agencies for adults, such as palliative care social workers.

The role of adult services and children's needs

The current discourse that 'it is everyone's job' or 'it's everyone's responsibility' to support children has significant implications for those working primarily with adults who may also be parents. This is particularly pertinent in situations, like palliative care, where there is the potential for children's lives to be significantly affected in different ways, for example by changes to parenting capacity, family dynamics, and living conditions (Barnard 1999; Kroll and Taylor 2003).

As there were no studies found that relate specifically to palliative care, it is possible to draw analogies from those in other fields of adult services. For example, in their qualitative study of practitioners who encountered parental substance misuse in both adult-focused and child and family settings within the voluntary and statutory sector, Taylor and Kroll (2004) report that child and family workers expressed concerns about the division between services for children and those for adults. Not only was there a different agenda at times but a 'polarization' that significantly affected the assessment process. Taylor and Kroll consider that mental health professionals appeared to avoid asking their adult patients or clients crucial questions about their children. Specialist drug workers were similarly too exclusively focused on the needs of their adult clients, and concerns about sustaining trust and breaching confidentiality appeared at times to override the principle that the child's welfare was the paramount consideration. Reder and Duncan (1999:56) similarly write about professionals getting so caught up in

assessing parents' mental health that 'it interfered with thinking about the needs of the child'.

During the mid-1990s social work practitioners 'rapidly perceived themselves as being deskilled as generic social workers' (Pearce 2003:114). She describes the separation of adult care, mental health and child care services as leading to 'a distance of workers from each other, with a consequent lack of understanding about both the work that is carried out and the issues that inform practice' (p.115). Drug social workers in Taylor and Kroll's (2004) study felt uncertainty in assessing parenting and child development, whilst child care workers felt uncertainty about the impact of substance misuse. All the staff from non-child care agencies felt they lacked experience and training in child protection issues and the majority of child care workers felt vulnerable in relation to knowledge about drugs and alcohol. There were anxieties and insecurities therefore for both child care workers and adult based professionals about their levels of knowledge and the degree to which they felt equipped to assess behaviours outside their immediate realm of expertise. Further, all practice regarding children raised dilemmas about access, confidentiality and the distress caused by encountering children living in damaging environments. The same issues could apply both to palliative care social workers, who may feel unsure about assessing parenting capacity and child development, and to child care workers who may not understand the impact of terminal illness on parenting and on children in the family. Indeed, some workers may not feel able to admit their lack of understanding and others may not appear to value the knowledge that other workers may have about the family (Stevenson 2007).

D'Cruz and Stagnitti (2008:158) draw attention to the fact that parents and professionals may unintentionally become 'collusive'; if professionals identify so closely with the parents' experiences they may excuse or minimise problematic parenting. Where a parent is dying, the concerns of the child, according to Segal and Simkins (1996), can

very often take second place. In addition, there may be feelings of betrayal: a worker avoids raising concerns with parents and child protection agencies to protect their relationship with the parents. Professionals may also wish to avoid raising difficult issues with ill patients because doing so may cause distress and this may be particularly the case where medical advice is against doing so (Altschuler 1997). Interestingly, Fitzgerald and Kay (2008) take another view. They consider that safeguarding may best be achieved through services to adults in terms of parenting support, for example, drug and alcohol services, although palliative care services would also be relevant here. This is because many services to children have high thresholds for access and families may not otherwise receive support.

Children as carers can also present challenges to workers whose focus is the parent. I drew attention to the stress that children caring for an ill parent may experience in chapter three. Young carers have only recently been recognised as children who may need support and services in their own right (Dearden and Becker 2001). However, significant factors such as lone parenthood, low income or poverty, lack of adequate parental and family services and informal support may lead to a child to undertake 'the type of caring responsibilities that may be inappropriate to their age and level of maturity' (Aldridge 2008:254), in turn making them vulnerable. Often young carers are hidden from children's and adults' services or may be treated as a low priority until there is a crisis (The Princess Royal Trust for Carers 2006). In addition, many children and families are not aware of their right to an assessment either under s.17 Children Act 1989 and s.93 Children (Scotland) Act 1995 or the Carer's Recognition and Services Act 1995 (Underdown 2002). Subsequently, young carers are not often assessed as children in need. Dearden and Becker (2001) suggest four reasons for this:

- a lack of awareness among health and social services staff about young carers' needs and rights

- families' fear of professional interventions - that the children will be removed from home

- a lack of consensus regarding which department, community care or child and family services, should be responsible for assessing need with children falling through the net and their needs not being met by either service

- whether young carers should be assessed as children in need, at risk or as carers (p.227).

Young carers themselves have emphasised that for an effective assessment to take place, staff in children's and adults' services should communicate with each other (Underdown 2002). Using a whole family approach to assessment under the above specified legislation would ensure that the needs of all the family members are taken into account rather than a concentration on either the parent or child.

Inter-agency relationships

The concept of inter-agency working in safeguarding children and providing family support services is at the core of governments' policies in this area. Guidance was first issued in 1988 by the Department of Health and Social Security. The latest edition in England is *Working Together to Safeguard Children* (HM Government 2010) and in Wales is *Safeguarding Children: Working Together Under the Children Act 2004* (Welsh Assembly Government 2006). The current document in Scotland is *Protecting Children - a Shared Responsibility: Guidance on Inter-agency Co-operation* (The Scottish Office 1998) and is under review. However, interagency working is something that has proved to be very difficult thing to achieve and continues to be a constant theme in inquiries, inspections and serious case reviews as a contributing factor as to why children have not been protected (Laming 2003; Ofsted et al. 2008; Rose and Barnes 2008). Communication is crucial in bringing about change and it appears to be the most difficult

to get right (Walker and Thurston 2006). Reder and Duncan (2003:82) comment that 'problems of communication seem to haunt professional practice'. They put forward various factors that can have an effect on inter-agency relationships including status and power; stereotypes; value systems about children and families; disrespect for the other's expertise; resource pressures; and, mutual unfulfilled expectations. The literature describes how different professional groupings have their own knowledge and practice base that they will draw on which will influence the way they consider issues of safeguarding children and child protection (Hallett and Stevenson 1980) and may inhibit a development of positive inter-agency relationships. There have been some reported improvements (Joint Chief Inspectors 2005, 2008), however. In Scotland, findings from the evaluation of the Highland Pathfinder[10] (The Scottish Government 2009:135) have shown the 'emergence of an inter-professional culture to support multi-agency working across children's services'. This has been partly attributed to collaborative working according to a set of agreed principles and values. There was evidence of more inter-agency trust and a shared understanding of children's needs. Whilst the language of tariffs and thresholds was found to be still present, it was less apparent in inter-agency and inter-professional language than at the outset of the project. The engagement of frontline workers in adult services has been identified as a target for the next phase.

Whilst the literature on multidisciplinary working in child welfare is growing (Frost and Robinson 2007) the emphasis seems mainly to be on professionals from different disciplines working together. Such literature has notably explored how the construction of their identities, including their value base, influences their way of interpreting situations and seeking solutions. This aspect was explored in chapter two when considering the palliative care social worker as a member of a multidisciplinary team.

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[10] Pathfinder projects have been established 'to help shape, develop and test the practice tools and training materials and to inform the development of national guidance'. The Highland Pathfinder was launched in September 2006 with a remit to address all aspects of children's needs from birth to 18 years (The Scottish Government 2009).

What appears to be lacking is an in-depth exploration of the experience and relationship between social workers from agencies or teams with an adult focus and social workers in local authority child and family teams. These 'adult service' social workers may be employed in voluntary or independent organisations as well as the local authority. This raises the question of whether there is a common understanding from a social work profession perspective about the child's welfare or whether the focus on the adults and their needs clouds this view.

Horwath and Saunders (2005) undertook an in-depth study into the identification, referral and assessment of child neglect. Although based in the Republic of Ireland, the policies are similar to those in England, Wales and Scotland. This study involved a range of 794 professionals using postal questionnaires and 85 in focus groups who worked directly with children or parents/carers in one Health Board area. The study highlighted the following:

- no agreement among professional groups or between the same professionals about the types of neglect that should be referred to social work teams
- no shared common language or baseline e.g. 'good enough parenting' was interpreted in different ways
- lack of an evidence based approach towards practice
- a mixed understanding by professionals referring cases about the operation of the child protection system
- although there were examples of positive experiences of working with social workers, many professionals focused on the negative experiences
- the referring of children was seen as a last resort (pp.108-109).

Harlow and Shardlow (2006), in a small study of core group practice in a northern metropolitan borough of England, found that the turnover and shortage of social workers

in local authority departments can lead to a disruption of relationships between staff in other agencies. This lack of availability can lead to gaps in service, and difficulties in building trust. Laming (2003) also drew attention to the number of social work vacancies and the difficulties for new and inexperienced social work staff joining a department. In their study Harlow and Shardlow (2006:69) found that social workers expressed the view that other professionals had a lower tolerance of risk and that sometimes 'other professionals were worrying unnecessarily and that referrals would be made about relatively minor matters about which they could do little'. Those professionals with adults as their focus were criticised for only seeing the situation from the parent's perspective and there were issues about how much information could be shared.

Parenting

The structure of families has changed in the United Kingdom. There has been an increase in remarriage and cohabitation leading to reconstituted families and complicated family ties. Pugh (2005:45) draws attention to these changes in family life: two-thirds of children are born outside marriage, one in five live in a lone parent family and one in four will experience their parents' divorce with a large majority losing contact with their fathers. Families are becoming smaller and more geographically dispersed which can lead to a sense of isolation for both parents and children. These factors may lead to complications regarding the present and future care of a child when a parent is dying.

Studies of parenting in poverty agree that living in poverty can affect all involved (Tuck 2000). Poverty brings with it a sense of apathy and feelings of powerlessness and helplessness (Blackburn 1991). Poverty and health are linked in terms of intertwined, physiological, psychological and behavioural processes 'by which poverty may influence a person's susceptibility to a disease or condition' (p.44). Blackburn provides evidence

to show direct connections between poor diet and ill health and, poor housing conditions and ill health. Physical symptoms can affect emotional behaviours. Parents in poverty may 'have to make health choices that serve to protect one aspect of health or the health of another family member whilst undermining another aspect of health or the health of another person' (p.46). However, Stevenson (2007) points out that the physical health of parents is rarely raised as an issue in Serious Case Reviews[11].

The capacity of parents to care for their children is now one of the three key areas in the assessment of a child's needs and vulnerability. However, up until the refocusing debate, research had focused on the concepts of abuse, risk and need and not on the detail of parenting skills (Woodcock 2003). Now that parenting has become a matter of public concern, recent research has looked at family support and a response to need. Although parenting has been an aspect of these research studies, Woodcock puts forward the view that social workers' construction of parenting is generally a missing dimension. In a small exploratory study of social workers in one local authority department, Woodcock's (2003:100) analysis revealed four types of expectations that underlie judgements of what was or what was not good enough parenting. The social workers' expectations of parenting were to prevent harm; to provide routinized and consistent physical care; to know and to meet appropriate developmental levels; and, to be emotionally available and sensitive. The overriding concern was the capacity of the parent to prevent harm.

Hoghughi and Speight (1998) consider that parenting can be referred to as a relationship, a process, a group of activities and anyone concerned with the care of a child may be seen as part of the parenting process. They describe parenting as a

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[11]   Serious Case Reviews are undertaken by LSCBs in England and Wales and Child Protection Committees in Scotland when a child dies and abuse or neglect is known or suspected to be a factor in the death (Welsh Assembly Government 2006; Scottish Executive 2007; HM Government 2010).

'process that adequately meets the child's needs, according to prevailing cultural standards' (p.294). Donald and Jureidini (2004:8) include in their definition of the quality of parenting the 'ability of the adult to recognise and adequately provide for, in a developmentally and emotionally appropriate manner, a child's current and anticipated needs'. Factors in the child and environment shape the quality of the parenting but the determinant of the experience resides with the 'parenting capacity'. This capacity they argue 'is not a measure of how people go about the task of parenting but the psychological qualities they bring to those tasks'. An example given is whether parents give priority to the child's needs over their own (p.12). When caring for children in the family, some parents have reported that losing some aspect of their health 'tips the balance between managing to be a good enough parent and not managing at all' (Segal and Simkins 1996:17). This resonates with findings in the literature discussed in the previous chapter regarding parents who are terminally ill.

The concept of 'good enough parenting' was first used by Winnicott (1965) to describe an environment facilitated by parents that enables a child's needs to be met. He recognised that the vast majority of parents are 'good enough' to meet their child's needs. In *'Child Protection: Messages from Research'* (Department of Health 1995) various studies drew attention to the fact that parenting which is lacking warmth and consistency, and which is excessively critical and punitive, is particularly harmful to children. The bonding between a parent and child and the subsequent attachment is now recognised as an important element in our understanding of parenting (Daniel and Rioch 2007) and secure attachment relationships are considered to be key (Howe 1999, 2005). Assessment of parenting capacity needs to take into account the power structures within families (Stanley et al. 2003) and not to concentrate solely on the mother's role; the role of fathers should not be overlooked (Daniel et al. 2005). A parent's own experiences of abuse and neglect may shape their capacity to parent (Woodcock 2003). As a result of an audit of cases, Macpherson (2009:483) surprisingly

discovered that of the 59 families with a terminally ill or deceased parent who had direct responsibility for a dependant child under 20 years in their home, in 49% one or both parents had experienced sexual abuse in childhood. This may mean that this group of parents are particularly vulnerable during the terminal phase of their illness.

Being alert to current and previous behaviours in the family can be important when shaping a picture of the quality of parental functioning, including how children and parents have related to each other, sources and types of stress and disadvantage, as well as sources of support (Woodcock 2003:91). The impact of domestic violence for example, can reduce a mother's self esteem and undermine her confidence (Mullender et al. 2002).

A diagnosis of terminal illness of one partner in a long-term relationship, however, may not change a negative relationship overnight (Altschuler 1997). Altschuler goes further by stating that although illness may alter experiences of abuse, neglect and marital disharmony it may also 'determine the availability of family members to one another' (p.77). She also differentiates between 'parenting' which she describes as the emotional responsibility parents have for children and 'parental activities' which is what people do as parents. She believes that it is important for a parent to remain 'emotionally available' for the child for as long as possible as this will contribute 'most powerfully' to the child's well-being. When a parent can no longer provide this support, particularly in the case of one parent families, it is important that there are other adults either within or outwith the family who are able to take this on.

Segal and Simkins (1996), writing from their experience as counsellors for people with multiple sclerosis, describe how each family member has to deal with feelings of aggression and control. In their experience disabilities and illness can exacerbate these feelings and also the need or wish to control those around them. Children and adults

may be a danger to each other: 'destructive and self-destructive behaviour always poses multiple problems for professionals, especially when children are involved' (p.89). They describe how an illness may cause extremes of parental behaviour. The parent may just wish to withdraw from their responsibilities leading perhaps to unintentional cruelty and neglect, or they may attack their children in some way in order to cause suffering as they are suffering. A parent may continue to provoke a child in order to elicit behaviour so that 'punishment' can be claimed to be 'justifiable'. Certain types of ill-health and treatments can also change people's behaviour, personality and characteristics which may result in a variety of negative responses towards their children, putting them at risk. Segal and Simkins (1996:99) also describe a 'more concealed kind of cruelty' occurring when attempts are made to punish and control children by 'intentionally exaggerating' the effect of the behaviour by saying for example, 'You'll kill your father if you go on like that'.

The existing literature on the potential impact of terminal illness on parenting, coupled with the prevalence of maltreatment in the general population, suggest the need for palliative care social workers to be alert to the indicators of the need for action in relation to children.

Assessing children in need

I criticised the literature reviewed in the previous chapter for either not considering or not considering enough the wider social context of families affected by the terminal illness of a parent. Whilst the psychosocial aspects of the impact of the illness on family members are important, so are the other factors which will have an influence on the way the family functions.

In England and Wales, the *Framework for the Assessment of Children in Need and their Families* (Assessment Framework) (Department of Health et al 2000) is a conceptual framework for assessing and identifying vulnerable children and children 'in need' and their families. It draws on an ecological model (Bronfenbrenner 1979) and provides a systematic way of looking at and analysing what is happening to children and young people within the context of their families and the wider community. This framework, Horwath (2001:33) believes 'should ensure that practitioners, managers and policy makers maintain a child focus, irrespective of how the world of the child changes and develops over time'. In Scotland, the *Integrated Assessment Framework* (IAF) follows similar principles to the Assessment Framework, setting them within the Scottish context, and is seen as the cornerstone of Scottish children's services policy (The Scottish Government 2005). The frameworks are conceptualised as a triangle with three domains: the child's developmental needs; the capacities of the parents or caregivers to support their child's development and respond appropriately; and, wider family and environmental factors which may impact on development and parental capacity. Each domain is divided into dimensions that describe the key aspects that should be assessed under each domain (Adcock 2001). Houston (2002) describes the Assessment Framework as a 'watershed' in three ways. It emphasises the connection between poverty and child developmental delay, advocates a systemic approach and moves away from the preoccupation with child abuse as opposed to children's needs.

The frameworks are considered to be the most used ones in the UK (Crisp et al. 2005:42), mostly within the statutory services, to locate risk within the broader context of children's needs (Helm 2010). In keeping with the move towards a more multidisciplinary approach to the welfare system, the frameworks have been designed to be used by any practitioner, irrespective of discipline, at the first sign of emerging vulnerability about a child (Horwath 2007a:1286). The guides and supporting tools (HM Government 2006a; 2006b; 2006c) make clear that the frameworks are a generic

assessment of needs which aims to help early identification of need and promote co-ordinated service provision. Horwath (2010b:57) describes them as maps to help practitioners across all disciplines organise their thinking about what is happening to a vulnerable child in order to assess and meet their needs. Indeed, they would be helpful to palliative care social workers, particularly as they may not work with families on a regular basis where there are concerns about a child.

The child's voice

In whatever setting they work, professionals are likely to miss signs that something is wrong if they are not able to hear the child's voice or consider their view point. Again, the literature from child protection and safeguarding children research provides useful pointers for palliative care social workers both for being alert to concerns about a child's welfare and more generally in relation to providing support to the child and parents.

Earlier, I drew attention to children not having agency. Finding out the child's wishes and feelings is a significant aspect of the Children Act 1989 and Children (Scotland) Act 1995. These Acts draw on Article 12 of the United Nations Convention on the Rights of the Child (United Nations 1989) laid down that:

> States Parties shall assure to a child who is capable of forming his or own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

It is not only what children say, but their behaviour, demeanour and general appearance also need to be taken into account when listening to them (Adcock 2001). Observation is therefore an important tool for gathering information and this is particularly true for younger children (Alderson 2008). However, Archard and Skivenes (2009), based on findings from a small research study show how there can be a gap between the ideal and reality in the actual practice of social workers. Although the social workers

demonstrated that they use child-friendly approaches when gathering the views of children, there was little evidence of workers seeing the views making a 'real difference to what happens' (p.397). In Alderson's view (1992:175) 'treating children with respect can markedly increase their competence'. Whilst studies (Butler and Williamson 1994; Hallett et al. 2003) have found that confidentiality and trust are of the utmost importance for young people when deciding whether or not to tell someone about a problem, informal networks, particularly friends, could usually be relied upon to provide confidentiality more than formal agencies like social work.

A paternalistic perspective (Fox-Harding 1991) evolves where adults speak for the children, giving meaning to their experiences and making decisions regarding their future without necessarily consulting them (Smith et al. 2003). Holland (2010:115) claims that studies suggest that whilst adults tend to focus on the 'bigger picture', for children the 'everyday' is more likely to be their priority. Workers may have limited training (Luckock et al. 2007) and experience of talking to children and be anxious about doing so at such an emotional time (Fearnley 2010). When parents and professionals collaborate together regarding the well-being of children, the children may be seen as vulnerable and unable to put forward their own interests (Wattam and Parton 1999); it being easier and less discomforting to concentrate on the needs of adults rather than children (Butler et al. 2002:98). A review of Serious Case Reviews 2001-03 (Rose and Barnes 2008) confirms this view.

I have already described research findings in the previous chapter about children wishing to be informed about the state of their parents' health. Children in a study into children's involvement in their parents' divorce (Butler et al. 2002) echoed this wish and further stated that they wanted to be consulted on the key decisions that were to be made regarding their future. This involvement would be particularly applicable to

children being cared for by a lone parent who is terminally ill when decisions are being made about their future care arrangements.

There is, therefore, useful literature regarding listening to children and hearing their voice that is relevant for palliative care social workers. However, there was no research found which explores palliative care social workers' views about, or skills in, listening to children and this gap is addressed in this thesis.

Conclusion

The emphasis in England, Wales and Scotland is that all children should have the best life chances in order to achieve their potential. The literature explored in this chapter has highlighted the broad range of issues that are involved in safeguarding and promoting the welfare of children that may be of particular relevance to the role of the palliative care social worker in adult services. However, there was minimal literature found that related specifically to them.

The literature does not imply that workers in adult services should act as 'child protection' workers. Rather they should be able to recognise indications when a child's needs are not being met and also recognise aspects of parental behaviour that can reasonably be expected to have an impact on children. They then should consider how these needs can best be met. Whether palliative care social workers consider the welfare of children to be part of their role, and if so in what way and how they go about it, is the focus of this study. The next chapter describes how the study was undertaken.

Chapter Five

The research journey

> The excitement resides not so much in reaching the destination,
> for we can never completely enter the world of the other, but in the
> voyage and what might be found on the way.
> Darlington and Scott 2002

Introduction

In palliative care it is not uncommon for the experiences of a service user to be referred to as a journey. The metaphor is widely used in literature and on occasion by service users themselves (Kristjanson and Ashcroft 1994; Beresford et al. 2007). It therefore seems appropriate to also consider this piece of research into an aspect of palliative care as a journey. It certainly felt like a rather long journey with its ups and downs, twists and turns, stops and starts. In this chapter I will consider the various stages from the selection of methodology, the research design, research methods used, the ethical issues and, the conduct of the analysis. Finally, I will consider my 'self' in the research journey. However, as 'a journey begins before the travellers depart' (Charmaz 2006:1), I will briefly locate this research project in the context of social work research and describe the theoretical perspective taken.

Social work research

The primary purpose of social work research is generally considered to 'promote the development and improvement of social work practice' (Powell 2002: 21). Social work research has endeavoured to become more relevant to practice, mainly through the inclusion of, and collaborative inquiry with, service users (Powell 2002; Beresford et al. 2007). Butler's (2002:24) view is that social work research is about 'social workers, what they think, what they believe, what knowledge they claim and what they do with it'. What makes it distinctive, he believes, is 'its relationship with the lived experiences and practical concerns of those engaged in social work' (Butler 2006:8). This study sets out

to do just that: to find out what are the experiences of a particular group of social workers in their work with children and their families in a particular set of circumstances with the aim of improving services.

Theoretical perspective

It seemed appropriate to use a systems approach to explore the role of the palliative care social worker in safeguarding children for three reasons. First, palliative care social workers operate within a team, an organisation and wider societal systems. The systems approach allows for the study of horizontal interactions between agencies as well as vertical interactions within them (Fish et al. 2009). Second, in exploring the workers' role with families, systemic thinking can help in the consideration of the ill person in all their significant relationships and networks and in the wider context of society (Oliviere et al. 1998:55). Third, an ecological perspective can assist when considering the needs of the child (Rose 2010:40). Whilst the systems approach is not without its critics (Houston 2002; Payne 2005), I could see strengths in using it, not as an underpinning theory, but as a broad framework to help me explore the various 'layers' involved and their impact on one another.

Systems theory has had a major impact on social work since the 1970s (Payne 1991:134). General systems theory is a biological theory proposed by Bertalanffy (1971), and also used in engineering, in which all organisms are systems, composed of sub-systems and in turn part of supra-systems. Bodies and engines are seen as either open systems (influenced by factors outside themselves) or closed systems (self-contained and impervious). Pincus and Minahan (1973) have been the most influential interpreters of the application of systems theory to social work practice based on an understanding that social systems are open systems. The significance of open systems is that all parts of the system are connected and what happens in one part will have an

effect on others. The system requires to be kept in a steady state, adjusting itself to try to maintain that state and there is a feedback loop which provides the capacity for change (Coulshed and Orme 2006:55).

People, as Pincus and Minahan (1973:4) argue, depend on three kinds of systems: informal or natural resource systems such as family, friends, work colleagues; formal systems such as community groups; and societal systems such as hospitals and schools. The focus of the work does not have to be on bringing about change in the individual; other parts of the system may be the target for change. The approach allows workers to be innovative in the way they assess situations. Pincus and Minahan (1973:63) identify four systems within social work:

- *Change agent system:* social workers and people in the agency in which they work.
- *Client system:* people who seek help from the change agent and are the expected beneficiaries of the service. *Actual clients* are those who have agreed to receive help; *potential clients* are those whom the worker is trying to engage.
- *Target system:* people with whom the change agent needs to change or influence in order to achieve the goals.
- *Action system:* people with whom the change agent works to achieve the goals.

The phases of planned change require identified practice skills[12] and different social work methods may be used at various points, for example counselling or task centred work. They also consider it important to analyse the type of relationships the worker forms with the systems encountered and identify three types: collaborative, bargaining and conflictual.

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[12] Eight practice skills identified: assessing problems; collecting data; making initial contacts; negotiating contracts; forming action systems; maintaining and co-ordinating action systems; exercising influence; terminating the change effort (Pincus and Minahan 1973).

Hudson and Payne (2009:Preface) describe dying as 'a family affair, its impact ripples out to affect close friends, neighbours and the wider world' and palliative care is generally seen to be concerned, not only with the patient, but also with the patient's family (World Health Organisation 2002). The family is considered to be who the patient says it is and therefore can include not only blood relationships, but others including friendship, care and duty (Kissane and Bloch 2002). A systems approach to working with families has been recognised as a helpful way to see the family as a 'set of interacting parts with a particular purpose' (Coulshed and Orme 2006). Families have sub-systems: marital, children, sibling, mother-daughter, father-son and so on (Barker 1981). However, families today are becoming more complex due to divorce and remarriage and so the family system is redefined, creating new sub-systems. There are also supra-systems to which families may belong including the extended family, neighbourhood, and societal systems such as health care. Families are open systems and are constantly changing in relation to internal and external forces. Each system and sub-system is defined and understood by its boundaries (Barker 1981) and hierarchies (Mehta et al. 2009). The boundary defines the system and highlights the type and amount of communication that occurs between them. Mehta et al. (2009:237) argue that it is an understanding of the family's boundaries and the degree to which they are 'permeable' that allows professionals to 'make an impact on the family unit'. The reasons behind the boundaries' existence are also important: culture may be an influence as well as previous negative experiences with health and social work professionals. It is also advocated that the family must be understood as a whole, rather than examining individual members or sub-systems in isolation from each other, or from the supra-systems of which the family is a part (Wright and Leahey 2005).

A family systems approach is promoted by several authors in the palliative care arena (Knapp and DelCampo 1995; King and Quill 2006; Mehta et al. 2009; Munroe and Oliviere 2009). A significant change such as a diagnosis of a terminal illness means that

a family has to reorganise itself and individual members may not function as they did previously. Rolland (2005:2585) has devised a conceptual framework (Family Systems-Illness Model) for evaluation, formulation and intervention with families coping with chronic illness or disability based on a family systems framework. This model is based on a strength-orientated perspective which views family and relationships as a potential resource and emphasises the possibilities for resilience and growth. Rolland believes it is important to consider the type and stage of the illness together with the individual and family life cycles as well as the family's belief systems. He points out that when a parent develops cancer during the child-bearing phase of life, a family's ability to 'stay on course is severely taxed' (p.2591). As well as helping with social and relationship problems, palliative care social workers endeavour to develop the capacity of families to manage future adversities (Payne 2007). They enhance the resilience of patients and their families by not focusing on them as individuals, but as members of a wider system using their knowledge to mobilise resources and support (Monroe and Oliviere 2007).

The ecological model applied to child development was first outlined by Bronfenbrenner (1979) where the development of children is seen to be influenced by the factors and interacting processes at individual (micro), family (meso), community (exo) and societal levels (macro). He focuses on the 'balance of stresses and supports in the family environment and the interactions between them' (Jack 2000:704). The development of children and their life chances is seen to be influenced by the factors and interacting processes at individual, family, community and societal levels. For example, poor health and disability are significant factors that can contribute to a family experiencing poverty, which in turns impacts negatively on family functioning. As described in chapter four, this model is the basis of the Assessment Framework and is also seen to be 'consistent with a strength's perspective that looks to the whole community as a resource' (Ward and Rose 2002:215). The child's attachment network also needs to be considered in an

ecological approach; this includes the nature of a child's attachments to adults and to peers and siblings (Daniel et al. 2010:38).

Reflecting on his work, Bronfenbrenner (1992) drew attention to an earlier lack of a time dimension. The 'chronosystem' model focuses particularly on developmental stages triggered by life events or experiences. These may have their origins either in external environment, such as going to school, or within the organism, such as puberty and severe illness. Whatever their origin, the critical feature of such events, he argues, is that the existing relationship between the person and environment is altered, thus creating a dynamic that may prompt developmental change. Therefore, this model is helpful for the understanding of situations where children are living with a dying parent. These children may face two or more experiences at the one time, for example going through puberty, changing schools, as well as coping with the terminal illness of a parent. It is this accumulation of adversities that is the threat to healthy child development (Garmezy 1994). However, many children and families display degrees of resilience despite the overwhelming situation, the components of which, Jack (2000:708) argues, should feature in any ecological assessment made.

Choosing the way to go

This study adopts a qualitative research methodology. There are various ways of defining qualitative research (Silverman 2000; Bryman 2001) and no real consensus has been reached. Denzin and Lincoln (2000:3) describe it as involving:

> an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.

Taking these and similar understandings (Whittaker 2009) of the primary focus of qualitative research, I considered it to be the most beneficial methodology to adopt. In

order for me to take the 'interpretive, naturalistic' approach, it was important to select data collection methods that would allow me to 'hear' what the palliative care social workers had to say about safeguarding children from their own experiences. The gathering of specific practice examples, I considered, would help me to understand their interpretation of this aspect of their role as well as some of the difficulties that they may encounter in carrying it out. Questions would require to be framed to allow this to happen. Methods needed to include interactive opportunities so that workers would be able to explain their approaches and I could ask follow-up questions as required. During the subsequent analysis of findings, I would need to ensure that themes emerged from what the workers had said rather than starting with a preset range of issues.

Taking an inductive approach and looking at specific instances of palliative care social work practice would help me to understand how the findings might be applied to the palliative care social work community as a whole. The use of small, purposively selected samples and interactive data collection methods would, I hoped, provide close contact between the participants and me as the researcher (Snape and Spencer 2003), as well as generating rich data providing an in-depth understanding of the 'world' of the palliative care social worker. As was shown in the literature review, little is currently known about palliative care social workers' involvement in safeguarding children and an advantage of qualitative research is that it can be useful in 'opening up' a new area in order to identify notable issues (Fitzpatrick and Boulton 1994). I did, however, consider two other approaches: case study research and the Delphi technique.

A case study is an empirical inquiry that investigates a phenomenon within its real-life context (Yin 2003:13). This approach is appropriate when context is particularly important and where multiple perspectives need to be taken into account (Walshe et al. 2004). It is an intensive investigation of a single 'unit' that may be a person or a setting (Gilgun 1994; Bowling 2009). Whilst there were many aspects of the case study

approach which could be applicable in this study, case studies require multiple sources of information, and as revisiting cases is a desired feature of the approach, the geographical, time and resource constraints made this difficult to achieve. Also, as this was a new area of study, it was my intention to gain a breadth of views from many 'units'.

The Delphi technique seeks to obtain consensus on the opinions of 'experts' or 'participants' through the administration of a series of structured questionnaires which is continued until a group consensus is reached (Hasson et al. 2000; Powell 2003; Keeney et al. 2006; Bowling 2009). It combines qualitative and quantitative methods (Stewart 2001). I was attracted to this technique after reading how it was applied to an aspect of multidisciplinary child protection research (Gabb et al. 2006). However, after a closer examination of the technique and potential results, I decided that the in-depth and rich data I was seeking could only be provided though a variety of other approaches.

Starting out

In order to discover some of the possible issues that might arise, frame specific research questions, and challenge some of my assumptions, I conducted a small exploratory study (Mason 2002; Sarantakos 2005) after undertaking an initial literature review (Hart 1997). I was also interested in whether the proposed research would be of value and interest to palliative care social workers (Lewis 2003).

This initial exploratory study involved a single interview and a paired interview with palliative care social workers. I had previous contact with all three workers, two through APCSW as I had become an associate member, and one through previous research. Thus, they were 'hand-picked' (O'Leary 2004). One worker was employed by a local authority but working within a NHS setting; one of the pair was employed by a combined

in-patient and day hospice for adults, and the other by a children's hospice. The pair of workers already knew each other, which allowed on this occasion for a stimulating and safe environment (Lewis 2003). Both interviews produced interesting and helpful information that highlighted some of the dilemmas they faced when working with families. The palliative care social worker from the children's hospice also identified aspects of concerns about children's welfare in her engagement with families. Whilst this was an important area, incorporating it into this study would have made it lose focus and become unwieldy. However, I believe it is a topic that should be explored. The fact that there was interest in the proposed study and a range of identified issues led me to feel confident about taking the research forward.

Moving forward

Having refined the research questions as a result of the initial literature review and exploratory study, the next stage was to finalise the research strategy itself, bearing in mind that a good design should be sensitive, flexible and adaptive as well as manageable both in terms of time and resources (Flick, 2007a). In this section, the research design is explained, with information on the methods of data collection and analysis selected, the reasons why they were chosen, the sampling used and the ethical issues that shaped the process.

In order to answer the questions posed by this study, it was important to understand the complexity of the factors and processes that influenced the actions of the palliative care social workers in safeguarding children. I was seeking to deepen understanding about the different experiences of palliative care social workers rather than establish fact. I was also aware that my research would be one-dimensional. This research study was an initial investigation which, depending on the outcomes, could be further investigated

in different ways by seeking the views of service users and other professionals with whom palliative care social workers are involved.

I was mindful of Charmaz's (2006:15) opinion that 'methods wield no magic'; rather, what is important is how a researcher uses the methods chosen. The challenge for me was to understand the reality from the 'inside' (Alston and Bowles 2003). At the outset, I considered that a mix of qualitative approaches would provide both breadth and depth and the process would be iterative (Froggatt 2001). Using focus groups at the initial stage would help confirm some of the issues identified during the exploratory study and also to help identify new ones (Lewis 2003). The findings would inform the survey stage: the administration of a questionnaire using mainly open-ended questions would gather a breadth of opinion. The final stage: a series of in-depth, semi structured interviews to obtain more rich data, would be informed by the findings of the previous two. Thus I embarked on a cyclical process of data collection, analysis, further data collection and re-analysis. Using these three methods also provided a 'within methods' triangulation (Flick 2007b).

Stage one: focus groups

The strength of focus groups is seen to lie in their ability 'to explore topics and generate hypotheses' via group interaction (Morgan 1988:21) and they are increasingly used in social work research (Linhorst 2002). Indeed, Kitzinger (2005) refers to this group interaction as a 'defining feature'. Morgan (1997) sees focus groups being used in three ways: as a 'self contained' method in studies; as a supplementary source of data; and in multi-method studies. In this research study, focus groups with palliative care social workers were used as both a supplementary source to inform the development of a questionnaire and to aid in the planning of semi-structured individual interviews, as well as in their own right as part of a multi-method approach.

The specific purpose of the focus groups was to seek views of palliative care social workers on what, if any, role they considered themselves to have in relation to safeguarding children and to analyse the way they spoke about the issues. In setting up the focus groups, I was influenced by Krueger and Casey's (2000:5) definition of a focus group: 'a carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment'. I was mindful too of the quality factors identified by Krueger (1993)[13] in all aspects of the process, as well as recommendations made by authors who have undertaken health-related research (Sim 1998; Kitzinger 2005). Views appear to vary on optimum focus group sizes (Morgan 1997; Krueger and Casey 2000). The reasons given are that it might be difficult to stimulate discussion with under six people and to control with over ten (Bloor et al. 2001). Four to eight is usually considered ideal (Kitzinger 2005). I aimed for six members.

Recruitment and sampling of participants

Recruitment of participants and the focus group fieldwork took place over a three month period from July to September 2007. An initial contact was made with the Chairperson of the APCSW to inform her of the research study and to ask permission to contact the membership (271 members at January 2008). This was granted and interest was expressed in the study.

The first focus group was held in a hospice in England and the second and third groups during the APCSW Annual Conference. For the first focus group, the recruitment was facilitated by an intermediary who was a palliative care social worker based in England. I had contacted this worker to arrange a meeting to discuss her

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[13] Krueger's ten quality factors in focus group research include: clarity of purpose; appropriate environment; sufficient resources; appropriate participants; skilful moderator; effective questions; careful data handling; systematic and verifiable analysis; appropriate presentation; honouring the participant, client and method (Krueger 1993:67).

extensive experience of work with dying parents and their children. It was her suggestion that she invite other workers in her geographical area to form a focus group; an offer that I accepted. This approach, Patton (2002) would identify as 'opportunistic'. I sent her information leaflets (Appendix 1) to be forwarded to potential members of the group. The intermediary kindly made all the arrangements and 12 members were expected and attended the group. Although this was double my target number, I was pleased that so many workers were interested and did not wish to miss an opportunity of gathering views from as many people as possible. Bloor et al. (2001) advocate the use of pre-existing groups and an intermediary as a way of reducing the recruitment effort, although they recognise that this may lead to a loss of control. In the event, the latter did not prove to be the case.

Recruitment for the second and third focus groups was different. I had previously contacted the Conference Organiser to ask permission to hold focus groups and this was readily given. Two time slots on the second day were identified in the programme. On the first day, I gave a short presentation about the research, explained the purpose of the focus groups and made a general invitation for people to attend. I was aware that an issue of 'volunteer' sampling is that only those most interested are likely to attend (O'Leary 2004) and I was competing with 'free time'. Ten people attended in total, five in each group. 'Piggy-back' focus groups, such as these, may erode quality as they might be influenced by the climate of the conference and responses might be shaped by its stimulus (Krueger 1993). However, there is also a view that they can be productive with meetings of professional associations (Krueger and Casey 2000). When comparing the content of these two focus groups against the first, it did not appear that the quality was eroded or shaped by the Conference.

Profile of research participants

A total of 22 palliative care social workers participated in the three focus groups. All were qualified social workers, although their work titles varied. In the first group, all 12 people worked in England and were female. The second group of five people comprised two male and three female members, all working in England and the third group, also of five people comprising one male and four females, included people based in England, Wales and Scotland. The high female membership of the groups reflected the overall membership of the Association: at March 2010, 94% of the membership was female.

There are advantages and disadvantages in acquaintances being members of a focus group (Morgan 1997). In the first group, most members already knew each other. Acquaintances are generally seen to talk more easily to each other but can rely on 'taken for granted assumptions' (Morgan 1997:37) which the researcher is hoping to investigate. Having strangers in a group avoids a 'polluting' and an inhibiting effect (Kitzinger 2005), but Morgan (1997) believes that the important issue is to recognise that each mix produces different group dynamics. All that is required according to Hudson (2003:203) 'is a group of people with sufficient interest in the issue or question to contribute to the discussion'. This proved to be the case.

Conduct of focus groups

Groups usually last between one and two hours (Brown 1999; Bowling 2009) and Morgan (1997) suggests the optimum length of a focus group discussion is 90 minutes. The first focus group lasted 1 hour and 40 minutes; the other two groups for an hour each due to size and time restrictions. Members in all groups, however, did not appear to be flagging nor need any encouragement to contribute.

A discussion guide (Appendix 2) was developed as a result of the exploratory study and the literature review (Stewart and Shamdasani 1990; Morgan 1997) and I endeavoured to bear in mind that 'quality focus groups depend on quality questions' (Krueger 1993:76). At the first group, I did not use all the topics on the schedule due to lack of time. The questions I did use were not always in the prepared format as the discussion was free flowing, providing information on the areas that the questions were designed to cover. After this first group, I reviewed the topic areas and decided not to make any changes, considering that they were broad enough to allow for the issues to be covered in a naturalistic way. If necessary, more probing questions (Litosseliti 2003) could be used to refocus the discussion.

Despite the size of the first group, the group members were courteous to each other, rarely interrupting each other and not holding side conversations. Group interaction was relaxed and insightful. Throughout there was humour in the group and members supported each other by non-verbal cues and by verbal agreement. They spoke to each other rather than focusing on me as the moderator, indicating my low level of involvement (Morgan 1997). All members made contributions. The 'host' member, who was a line manager for two other members, contributed slightly more than the others but this did not seem to inhibit the general discussion. The other two groups were just under half the size of the first, the group atmosphere and process were similar, with all members making more or less equal contributions. In the second group two members were from the same hospice and one was the line manager of the other. However, nobody appeared to be intimidated by other members of the group and all seemed to be interested in what others had to say.

An assistant moderator, if present, would have been able to take notes during the discussion, with particular reference to the non-verbal content of the discussion (Krueger and Casey 2000). Resources, however, did not allow for this. All of the

groups were audio-recorded (with the permission of all the participants) and I made field notes as soon as possible after each event that included my thoughts and observations as well as a reflection on the atmosphere and interaction. I personally transcribed the recordings and the findings from my initial analysis helped me to move on to the next stage of the research, the development of the questionnaire.

Stage two: survey questionnaires

Brace (2004:5) usefully describes questionnaires as 'A medium of remote conversation between researcher and respondent'. As this was an emergent qualitative research study, a postal questionnaire was considered to be the best option to ascertain the views of as large a sample of palliative care social workers as possible. It was hoped that this would provide a range of practice examples from a variety of work settings in different parts of the UK (Darlington and Scott 2002).

Although questionnaires are a popular method in quantitative research, it is possible for them to be used as part of a qualitative study, if a semi-structured interview schedule is used (Bowling 2009). However, I recognised that there are particular difficulties in using postal questionnaires in an explorative study (Foddy 1993; Birchall and Hallett 1995; Graham 2000) and these needed to be taken into account when planning this part of the fieldwork. The first was obtaining a high enough response rate. People's commitment to completing a questionnaire is known to vary for a range of reasons (Bowling 2009). However, one of the features of qualitative research is the use of a relatively small sample and whatever number is received, the researcher cannot consider that respondents' responses are typical of the whole population and make generalisations. This led to the second difficulty: depth of views. One of the reasons for using a qualitative approach in the questionnaires was to obtain as much depth of information as possible from the respondents in order to understand any variations in terms of views and experiences. Although Birchall and Hallett (1995:10) consider that the 'subtleties of

people's experience, understanding and motivations are unlikely to be conveyed even in open-ended responses', I did hope that palliative care social workers would be sufficiently motivated and feel able to share anonymously as much information as possible. The third difficulty was designing a questionnaire that was clear and precise for every respondent at every point, as people can have different preconceptions as they interpret the questions (Foddy 1993). The fourth was structuring the whole questionnaire in terms of length versus adequate specificity, for, if it was too long, the likelihood was that people may choose not to complete it. These difficulties were taken into account when planning this second stage.

Development of survey

The purpose of the questionnaire was to gather information that would help clarify the views of palliative care social workers about their role where an adult is receiving specialist palliative care and there are concerns about the children in their care. In developing the questionnaire I took account of the various good practice guides, for example Denscombe (1998); Thomas (1999); Graham (2000). Consideration was given to the use of vignettes,[14] which are believed to engage participants and elicit more meaningful and considered answers than the typical questionnaire (Birchall and Hallett 1995). This might possibly be seen as less personally threatening, and allow sensitive topics to be discussed in a more neutral way (Lee 1993). Vignettes have been successfully used in social work research about child protection (Birchall and Hallett 1995; Horwath and Saunders 2005). However, as there is currently little literature on the work of palliative care social workers with children and families, I chose to seek examples of actual experiences, and therefore decided not to use vignettes in this study.

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[14] Vignettes are a simulation of real events depicting hypothetical situations (Wilks 2004:80) and come in various forms, from two lines devoid of context to several paragraphs of a story unfolding over time (Giovanni and Becerra 1979).

In keeping with the iterative nature of the research, I devised a draft questionnaire based on the findings from the three focus groups. For example, issues of supervision and training had been raised in the groups and I wished to gain a clearer picture of their availability. Also, examples had been given in the groups about how children first came to the attention of palliative care social workers, and I sought to examine this in more detail. I conducted a pre-test of the questionnaire with a local palliative care social worker. This included a 'think-aloud' testing (Bowling 2009:301). A revised draft was then read by that worker, plus my two supervisors and a past PhD supervisor, who were all non-palliative care social work specialists. They specifically checked that there was no apparent confusion, assumptions or ambiguities (Thomas 1999). In the light of feedback the questionnaire was further revised. It was then piloted by a small number of people who represented the target group of palliative care social workers (Thomas 1999; Graham 2000; Brace 2004). Four members of the APCSW, whom I had met at different events and who were aware of my research, agreed to take part. Three completed the questionnaire and returned the material as requested. The fourth chose to give her responses and views by phone.

The final anonymous questionnaire (Appendix 3) consisted of 25 questions, nearly all being open-ended questions with two Likert scale questions using a visual numerical scale. The questionnaire was divided into five sections. The questions were designed to elicit information about the respondents' perceived role in safeguarding children including brief examples from practice. On reflection perhaps the questionnaire was too intimidating to complete in terms of the amount of time and effort. On the other hand, those who did respond supplied detailed, thoughtful information about their practice. Once all the questionnaires were received, I commenced the data analysis. The information gathered from the focus groups and survey helped me to formulate the interview schedule for the next stage and focus on areas that were least well explored previously. Areas included aspects of the palliative care social worker's place in the

multidisciplinary team, relationships with the local authority children and family social workers, and the influence of the parents' illness on decisions regarding their care of their children.

Recruitment and sampling of participants

Recruitment of participants, preparation and fieldwork took place over a four month period from November 2007 to March 2008. I had already gained permission from the APCSW to administer a questionnaire to the membership. This was a purposive sample (Mason 2002:124). A total of 271 questionnaires, together with a covering letter, participant information sheet (Appendix 4), and pre-paid return envelope, were sent out in January 2008, using pre-printed labels provided by the Association.

Profile of research participants

A total of 57 palliative care social workers returned 56 questionnaires[15]. Seven returned the questionnaire indicating that they did not work in palliative care for adults. Although there is no agreed standard of an acceptable response rate it appears that a response rate of 50% from a sample not known to the researcher is generally considered to be satisfactory (Graham 2000). The response rate of 21%, therefore, is a much lower rate than the usual expectations of postal questionnaires. However, similar qualitative surveys of health and social service professionals have produced a comparable response rate (Darlington and Feeney 2008).

Fifty respondents were female and seven were male, reflecting the composition of the total membership. Fifty were based in England, two in Wales and five in Scotland. As shown in Table 5.1 there was a range of work locations with the most common being combined day/in-patient hospices. There was a spread of palliative care social work experience with four respondents having 20 plus years experience as Table 5.2 shows.

Table 5.1   Profile of survey respondents by type of work-base

Type of work-base	Number of respondents
In-patient hospice	2
Day hospice	1
Combined day/in-patient hospice	31
Community service	5
Hospital	7
Hospital/community service	2
In-patient hospice/community service	3
In-patient/day hospice/community service	2
Other	3

Table 5.2   Profile of survey respondents by number of years in palliative care, in current post and since social work qualification

Number of years	Number of respondents in palliative care	Number of respondents in current post	Number of respondents since qualification
0 - 4	22	33	3
5 - 9	18	15	9
10 - 14	8	6	5
15 - 19	5	1	13
20 – 29	4	2	11
0ver 30	0	0	14

Stage three: semi-structured interviews

Interviews are the most favoured method in qualitative research (Bryman 2004; Sarantakos 2005). A semi-structured, semi-standardised interview was the chosen method in this study because this allowed some flexibility over the direction of the conversation during the interview as well as the opportunity of gathering rich data (Mason 2002; Patton 2002). It would help me to achieve 'a depth and roundness of understanding' (Mason 2002:65). A feature of in-depth interviews is their focus on the individual and their personal context, as well as being a vehicle for expressing feelings and understanding motivations and decisions (Lewis 2003). They would allow me to

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[15] Two workers at the same hospice returned a combined response on one questionnaire.

explore the meanings workers attach to their role and their perceptions of the processes involved in, for example, their relationship with the multidisciplinary team and other professionals (Mason 2002). Such interviews enable people to talk about past events and ensure that the information is not idealised or general but a description of what was actually done (Arthur and Nazroo 2003). In addition, they are a way of helping interviewees to think, consider and make explicit matters under discussion (Robson 2002). As I was particularly interested in hearing about examples from practice, this method seemed to be particularly relevant and would build on knowledge already gained. Using this combination of opening up areas and exploring details has been referred to as 'content mapping' and 'content mining' (Legard et al. 2003:148).

In order to hear about practice examples, it seemed appropriate to incorporate a narrative approach within the interviews (Kvale 2007). This is an event centred approach which focuses on 'the spoken recounting of particular past events that happened to the narrator' (Andrews et al. 2008:5). Hall (1997:177) points out that social work accounts make use of narrative methods of plot, character and point of view. Workers are able to demonstrate that their work is in accord with responsible and justifiable professional activity. Narratives are also a common genre from which to retell or come to terms with a sensitive time or event (Coffey and Atkinson 1996:56) such as work with families where a parent is dying. They are subject to change and re-interpretation over time (Riessman 1993:64). A central element of the approach is to ask the participant to present narratives of situations which can be complemented by questions that ask for the person's 'subjective definitions' (Flick 2007b:57). This combination of question and answer sequences, together with narratives of situations that the interviewee has experienced, Flick describes as an 'episodic interview' (Flick 2007b:58).

Recruitment and sampling of participants

Recruitment of participants, preparation and fieldwork for the interview stage took place over an 11 month period from January to November 2008. Palliative care social workers were invited to volunteer to take part in the interviews and information about the process was included in the letter accompanying the questionnaire sent to all members. A pre-paid reply post card was also included which allowed workers to express an interest in taking part in the interviews and could be returned separately from the questionnaire, thus ensuring that anonymity would not be compromised. Thirty-two post cards were returned. A participant information sheet was sent out with an accompanying letter (Appendix 5) and a form asking for information about their place of work. Twenty forms were received (one later withdrew). I was concerned that some potential interviewees, especially those who were relatively inexperienced, might have perceived an interview with me as being similar to a supervision session and thus were reluctant to take part.

The overall selection was based on geographical location and mix of work settings in an endeavour to ensure that the sample population was as diverse as possible. Plans were made for the first rounds of interviews based on geographical proximity and a total of 13 interviews were held between June and September 2008. My initial thought was that I would interview about 12 workers. However, after consideration of the material gathered and discussion with my supervisors, a further round of four interviews was planned to secure saturation and a further spread of geographical locations. The selection of the sample in the second round was pragmatic, based on geographical, time and financial constraints. This final round of interviews was conducted in November 2008.

In return for their assistance, time and thought the participants were informed that they would receive a copy of an executive summary of the thesis when the research was completed.

Profile of research participants

A total of 17 palliative care social workers participated in this stage of the research. Two participants were male and fifteen were female[16]. All three countries were represented; the majority being based in England. They were located in a range of work settings (see Table 5.3). Twelve served in urban communities, two in rural and three in mixed rural and urban communities. Again there was a spread of palliative care experience as Table 5.4 shows.

Table 5.3   Profile of interviewees by type of work-base

Type of work-base	Number of interviewees
Combined day/in-patient hospice	6
In-patient hospice/community service	2
In-patient/day/community service	4
Hospital	2
Community service	3

Table 5.4   Profile of interviewees by number of years in palliative care, in current post and since social work qualification

Number of years	Number of interviewees in palliative care	Number of interviewees in current post	Number of interviewees since qualification
0 - 4 years	6	7	2
5 - 9 years	7	8	2
10 - 14 years	2	0	3
15 - 19 years	1	1	3
over 20 years	1	1	7

Conduct of interviews

The interviews lasted between 54 and 120 minutes and the average length was 96 minutes. The length of the interview appeared to depend on the length of the narration of the practice examples that the participants chose to share. There were those participants who appeared to have limited experiences to talk about and others who spoke at length, with very little prompting about their chosen practice examples.

All the interviews were held at the participant's work base (during work hours for all but one) and conducted in rooms that were private. The aim of the interview was to ensure that the overall research question would be answered, whilst encouraging a flow of conversation and allowing the participant to talk in a relaxed and open manner (Whittaker 2009). A fairly flexible approach was adopted regarding the phrasing of the questions but they were asked roughly in the same sequence to facilitate the organisation and analysis of data (Patton 1990). At the heart of the interview was the recounting of the examples from practice. Questions about feelings and attitudes then followed (Arthur and Nazroo 2003). But before asking participants to disclose examples from their practice, it was first necessary for me to gain their trust (Holloway and Freshwater 2007). This was taken account of in the planning of the interview guide (Appendix 6) by asking for more general information at the beginning. The topics were similar to those covered in the questionnaire, but the vehicle of the interview allowed for a more in-depth discussion. All the participants were willing to answer all the questions.

Establishing rapport and developing trust was therefore an important feature of the interview. However, I recognised that too strong a connection between a researcher and participant could cause difficulties (Darlington and Scott 2002). The participant may take it for granted that the interviewer understands what they are speaking about and, as a result, miss aspects from their narrative. There was an additional risk of my making assumptions due to my previous research and not checking them out. In addition, I had to maintain my role as a researcher during the interview and be aware of when I was slipping into a previous social work tutor role (Alston and Bowles 2003). On the occasions when this did occur, any advice sought was given after the interview was completed. I saw the interview as a collaboration (Oakley 1981; Legard et al. 2003). I considered it was possible for me to show feelings as long as it did not hinder the

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[16] The two male participants were the only two who agreed to be interviewed.

participants' account. Some interviews evoked sensitive issues and I acknowledged any distress displayed by participants.

Whilst there does not appear to be any research that shows the 'Hawthorne' effect, i.e. participants benefiting simply by taking part in the research project (Allmark 2002; Payne and Payne 2004), feedback gathered from various research studies indicate that participants frequently acknowledge how positive they found the experience to be (Beresford et al. 2007; Kennedy 2008; Brooks 2009). This study was no exception. Whilst I did not ask for any specific feedback after the interviews (or the focus groups), there were participants who voluntarily commented that the interview had been enjoyable and mentally stimulating.

All of the interviews were audio-recorded (with the permission of the participants) and I made field notes shortly after each interview which described the physical context of the interview, non-verbal responses and my thoughts about the interaction together with my immediate reactions to the content. I transcribed the recordings as soon as possible after each interview, giving me an early opportunity to reflect both on the process and content, with particular reference to my interactions with the participants and their perspectives.

Ethical issues

As I commenced this study at the University of Dundee, a research protocol was submitted to the University Research Ethics Committee (UREC) of the School of Education, Social Work and Community Education in June 2007. This included the design of the study, recruitment strategy, methods to be used and data protection measures. Overall approval and full approval for stage one (focus groups) was granted by UREC in August 2007. The University of Stirling Department of Applied Social Science (DASS) Ethics Committee granted approval for stage two (survey) and

recruitment for stage three (semi-structured interviews) in December 2007. Approval for the outstanding aspects of stage three was granted in February 2008.

Care was taken to ensure that informed consent was obtained from all the participants. For those taking part in the focus groups and interviews, this was done both in writing (Appendices 7 and 8) and verbally before the group or interview commenced. Completion of the questionnaire was taken as consent being given. Prior to giving their consent, all participants had received a participant information sheet outlining the nature and purpose of the study and the interview or focus group. Participants were also given the opportunity to request further information but no one did so. All were informed that they could withdraw from the study at any time without giving a reason for doing so. None did so.

The researcher as a 'whistle-blower' is a particular issue when conducting social work research in the field of child protection (Darlington and Scott 2002). Confidentiality is overridden when researchers have a legal or moral duty to report incidents of harm (Social Policy Association 2009:4). Interview participants were informed that, if during the course of the interview, it appeared that a child under discussion might be at risk and the situation seemed to require intervention, then the researcher and participant would discuss what action should be taken. If any participant, as a result of the interview, wished to make a complaint about any aspect of the interview stage, the contact details of a named, senior person at the University were also given in the information sheet.

Confidentiality and anonymity were addressed at all stages of the research and focus group participants were reminded to keep the discussions confidential (Litosseliti 2003). There was no identifying data requested in the questionnaire. I did however struggle, as have other researchers (Macpherson 2010), with how best to anonymise the rich

information provided about the children, their circumstances and the work of the

palliative care social workers. The stories, often poignant, I considered should be

included in some way to highlight the diversity of the work and it took several

painstaking attempts before I achieved a satisfactory outcome. Details have therefore

been removed or altered in order to preserve confidentiality, but not I hope at the cost of

losing important information about process. I also decided not to provide social details of

the sources of the case and practice examples in order to protect the identity of this

small community of palliative care social workers.

Data collected has been stored securely during the study in compliance with the Data

Protection Act (1998). Upon completion of the study, data will be destroyed or kept in

secure DASS archive facilities for ten years.

Nearing the end, but still a long way to go

Data analysis

> In many respects, analysing your data has similarities with social work practice.
> In both roles, you are faced with rich and complex accounts and your task is to
> make sense of them. This involves seeing patterns and meaning in the accounts
> and it is inevitable that this involves you exercising your judgement (Whittaker
> 2009:89).

Within and after each stage of the data collection, a preliminary analysis of the data of

one stage helped to inform the next, and progress within the current one. The

discussions in the focus groups, for example, were wide-ranging and the interesting

looking themes from the focus groups were tested in the survey with specific questions.

If the answers seemed to require further clarification, then they were followed up in

more detail during the interviews. The findings also provided useful background

information on different aspects of palliative care and palliative care social work, giving

me a firm platform on which to base my approaches to the potential interviewees. There

were many areas that I had initially considered exploring during the semi-structured interviews. However, the findings from the preliminary analyses helped me to focus on those that could most productively be achieved within an interview and its restricted time-frame: examples from practice and a clarification of particular issues to help me achieve a better understanding of the workers' role. Illustrations of this process are provided in Appendix 9. The interview process was also a developmental one; later interviews explored more fully those aspects that seemed to be germane to themes produced by the preliminary analysis of early interview data.

At the end of each stage, I immersed myself in the data and began a more detailed analysis. This was conducted manually as the numbers were manageable. Also, I had no experience of computer packages and did not wish to become anxious about learning a new process to the detriment of the analysis.

For the focus groups, I used the 'The Long Table Approach' described by Krueger and Casey (2000:132) in my search for themes and sub-themes within and across the questions. The core elements of the approach are cutting, sorting and analysing through comparing and contrasting the data (p.137). For the questionnaires, again a thematic approach was taken for the responses to the open-ended questions, taking one question at a time across all the questionnaires (Graham 2000). When categories for each question had been identified they were then compared across questions leading to a greater consistency (Fielding 2008).

The analysis of the interviews presented me with some particular challenges. During the interviews, and particularly during the transcription and subsequent readings, I was aware of the richness of the information contained in the practice examples: the stories. I decided to use a non-cross-sectional data organisation (Spencer et al. 2003:203) of this narrative part of the interviews as they highlighted some of the difficulties faced by

children and their families, as well as the dilemmas for the palliative care social workers. I was anxious that the stories about the children were not lost. However, I did recognise that the perspectives of the children and family members were second hand and may be seen as paternalistic in nature (Fox-Harding 1991). Their circumstances had been described and interpreted by palliative care social workers, based on what they remembered, and then further interpreted by myself. It took several attempts before I was able to produce thematic summaries about the stories, as there were many ways I could categorise this material. Eventually, I decided that as children were a focus of the whole study, I would consider the material first from their perspective, then from that of the parents' before moving on to the perspective of the palliative care social workers. Re-reading the practice examples from these perspectives provided a more coherent approach from which to progress. I compared these examples by the use of tables (Gibbs 2007), which seemed particularly suited to the narrative part of the interviews as it seemed to 'ground perspectives in the situations of clients and social work practice' (Woodcock 2003:93). In many ways my approach had the characteristics of the 'immersion/crystallisation method' (Borkan 1999; Crabtree and Miller 1999). This is when the researcher, after a 'prolonged immersion into and experience of the text …and concerned reflection' enables the researcher to emerge with 'an intuitive crystallisation of the data' (Crabtree and Miller 1999:23).

I took an idiographic approach to the remainder of the analysis of the interviews (Smith et al. 1999:220) by looking at individual cases in some depth. I began with three transcripts chosen at random. I read one a number of times in order to become 'intimate' with the account, noting in one margin aspects that appeared to me interesting and significant. Then I re-read the transcript this time noting in the other margin emerging themes using 'in vivo' coding (Buff 2005:154). Using participants' own words as labels kept me grounded in what the participants had said. In searching for themes, I was mindful of capturing something important about the data in relation to the research

question (Braun and Clarke 2006). Having listed the themes, I looked for connections between them. I repeated this exercise with the other two transcripts and consolidated a list of themes. This process was continued for all the transcripts. I then moved on to use the 'Framework' analysis method (Ritchie et al. 2003:220), which suited my way of thinking and working, to compare instances and individuals. This is a matrix-based approach which allows data to be synthesised and charted so that the researcher can read across data without losing sight of the individual participants. In addition, I referred to my field notes in order to take account of the non-verbal aspects of interview.

Once the data from all three stages of the data collection had been analysed, it was possible to make cross-comparisons, looking for similarities and differences in the findings. Writing memos (Robson 2002; Fielding 2008) helped me to develop my thinking further. I then discovered the voice-centred relational method of data analysis (Mauthner and Doucet 1998) and was excited by the possibilities it afforded (Deery 2005; Paliadelis 2005; Fairtlough 2007; Byrne et al. 2009). It is 'voice-centred' in that it explores the individuals' narrative account of experience and 'relational' as it recognises that these accounts are situated within a wider network of relationships and social structures.

The method involves reading each transcript four times (Mauthner and Doucet 1998; Fairtlough 2007). At the first reading I reflected on the story: the plot, the people, the words and metaphors used as well as my reaction to what had been said. During the second reading, I read for the voice of 'I'; how the workers spoke about themselves, their experiences and feelings to gain insight into their identity and role. At the third, I was looking at interpersonal relationships, how they described their interactions with others. The final reading concentrated on the broader context: the social, political, cultural and organisational aspects that impacted on their role. Returning to the transcripts in this way helped me to refocus my attention on the individual workers in

their situations. Whilst I have not reported my findings using this method specifically, it did enhance my thinking about the language used, the relationships and the context. I have been able to weave the information gathered into my writing.

As I talked to more palliative care social workers, my impression was that I was hearing about palliative care social workers playing an important role in children's and their parents' lives. Those I spoke to cared about the children, their current situation and their future. Many spoke fluently and at length about the children, their families and the work undertaken. It was as if this was the first opportunity they had to share, and even unburden themselves, about the issues involved. I regret not asking why the workers had selected the particular families to share with me as it would have provided an interesting dimension. One of the difficulties in using a questionnaire is that the results are 'one-dimensional'. The printed word does not always carry the passion, although there were instances when it did shine through. However, this is not the same as having the opportunity to observe a person's reaction to the questions and the way in which they tell their 'stories'. Whilst it was possible to discern some of this passion in the focus groups, I was aware that some people may feel uncomfortable and therefore be reticent in showing their emotions in front of others.

My 'self' in the research journey

'Research design should be a reflexive process which operates throughout every stage of a project' (Hammersley and Atkinson 1995:24). Qualitative research particularly requires a high level of reflexivity about the phenomenon under study (Darlington and Scott 2002:18) due to the immersion of the researcher in the research. Self-reflection has become increasingly significant in social work, particularly in social work education. Its roots are to be found in the early psychotherapist approach, where an understanding and use of self were integral to practice learning (Schön 1983). The term 'reflectivity'

has emerged from the professional practitioner and educational discourse: the process of reflecting upon practice. 'Reflexivity' comes more from social science researcher discourse, from qualitative and ethnographic researchers. It has, according to Finlay and Gough (2003:ix), 'exploded' into academic consciousness.

Being reflexive appears to be more complicated than being reflective: not merely searching for implicit theory, but searching for an understanding of the many ways in which one's own presence and perspective influence the knowledge and actions created. There are many definitions of reflexivity in research (Fook and Gardner 2007) but, at its simplest it is 'to have an ongoing conversation about experiences whilst living in the moment' (Hertz 1997:vii). Birch (1998) also sees research as a journey, particularly in terms of reflexivity. She divides the journey into three phases: going there; being there; and, being here (p.162). *Going there* refers to what is happening before the field of study: entering into the research, defining what to study, and gaining access into the field. *Being there* relates to being in the field: the actual taking part in the research. This includes the participation, the involvement and relationships made. *Being here* is the creation of the text: the final stages of analysis and the writing up. I will use these phases to share my aspects of my inner dialogue during the research process.

Going there

I came to this research study after a long career in social work education together with practice experience in child care and particular interests in medical social work. I was excited about this new phase in my life, determined to do well, but also anxious about proving my capabilities, not only to the academic world but also to myself. In addition, I had to cope with a role reversal, now **I** was the student. The first supervision sessions felt strange, particularly as they were with staff who had previously been work colleagues, but this strangeness soon disappeared and the sessions felt supportive and challenging. Reading is a passion and undertaking the initial literature review was

conducted with enthusiasm. As my experience of conducting research was limited, I also read widely about the various methods of conducting qualitative research and attended relevant lectures on methodology. At times, all this seemed rather bewildering as I grappled with some of the philosophies and concepts, but gradually an understanding emerged.

I felt confident about gaining access to palliative care social workers after attending the launch of *Palliative Care, Social Work and Service Users: Making Life Possible* (Beresford et al. 2007) where many people expressed an interest in what I was proposing to do. I was delighted when the Chair of the APCSW gave me permission to contact the Association members. However, I now felt that I had also to prove my capabilities to palliative care social workers since they were granting me the privilege to enter into 'their world'. Being a qualified social worker, I hoped, would be an asset in conducting this research; there could be a shared understanding about the values of social work. However, I recognised it might also be hindrance as it might lead to my making assumptions and introduce bias and this was something I needed to take into account in my contacts and also later during the analysis.

From the beginning, I documented my journey keeping a personal diary of events and thoughts (Moch 2000). This was not only in order to keep an audit trail (Huberman and Miles 1998) but to remember and understand the decisions made along the way that might otherwise be lost in memory as other events took over. I saw this as a positive tool (Payne and Payne 2004). Sometimes, there were no entries for days or weeks on end. However, when a particular difficulty (for example, the move of my principal supervisor to another university) or momentous event (for example, gaining approval from the Ethics Committee) occurred, I took the opportunity to reflect back over the time since the last entry. Events that happened in my personal life were also noted and it

was interesting to look back and see how these had impacted on my 'research based

self' (Reinharz 1997).

Being there

The first focus group was both exciting and daunting. Exciting, because I felt that I was

at last beginning the research 'proper'. Daunting, because of the large size of the group

and wanting to ensure that the time would be productively spent, not only for me but

also for the palliative care social workers who had taken the trouble to attend. In the

event, the group functioned well, the discussion was stimulating, and workers spent time

informally afterwards talking about their experiences and interest in the research. The

final arrangements for the second and third focus groups were more daunting because

of the 'unknowns': would the participants at the Conference be interested enough to give

up their free time to attend; would there be enough to hold two focus groups as

planned? I was relieved that five people attended each group and that once again the

discussions flowed well. Being a moderator was a relatively new experience but my

years of experience running seminar groups gave me some confidence.

Just after the completion of the focus groups, I moved from the University of Dundee to

the University of Stirling to follow my principal supervisor. This entailed adjusting to a

new location, new 'rules', a new student group and new second supervisor. People were

very welcoming and I soon felt settled. Having a new supervisor, who was not a social

worker, brought a different perspective to the research. Her challenges in particular

about social work issues that I had perhaps taken for granted, opened up new areas of

thinking.

The questionnaire was planned to reach a large audience but its design was not as

straightforward as I had originally thought it might be and I had to weigh the advantage

of obtaining detailed information against a possible low return rate. The richness of data received was more than enough compensation for a low return.

I looked forward to the interview stage: getting out, meeting palliative care social workers at their work base, and hearing their stories. After talking to each participant to make the final arrangements for the interviews, I felt confident about what lay ahead. All were very welcoming and positive about the research. I had been anxious to demonstrate that I had an understanding of social work issues and did so by stating in the participant information sheets that I was a qualified social worker. I hoped that this would reassure the potential participants as well as reduce the power imbalance (Skinner et al. 2005). I was aware that my role was to be a researcher, not a social worker and certainly not a social work educator! The latter particularly, as mentioned earlier, was something that I had to guard against. There were times when follow-up questions were required, but I had to check myself on many occasions to ensure that they were being asked for the 'right' reasons; that they were important for the research study. Most participants did not appear to have any difficulty in telling stories with detail and colour and I frequently felt humbled and often very saddened by what was told to me.

Being here

> Analysis is a challenging and exciting stage of the qualitative research process.
> It requires a mix of creativity and systematic searching, a blend of inspiration and
> diligent detection (Spencer et al. 2003:199).

After trying various ways of looking at the data, writing up my ideas, and having discussions with my supervisors, a picture began to emerge that I felt represented the findings in a meaningful way. I had been heartened and reassured when I read the words of Mauthner and Doucet (1998:122) regarding the early phases of data analysis:

they can 'feel messy, confusing and uncertain because we are at a stage where we simply do not know what to think yet'. I had feelings of panic and wondered whether themes would ever crystallise (Borkan 1999). I realised too that the participants' words could be interpreted in many ways and felt a strong sense of responsibility in what I was undertaking. I also recognised that there were occasions during the interviews when I failed to ask follow-up questions to clarify points which meant I might be making assumptions.

During the various analysis stages, I wondered how necessary it was to go through all the steps with each transcript. How thorough did I have to be? Is there a 'right' way to use a particular method? The words of Froggatt (2001: 434) were consoling: 'There is no one right way to work with the data, and it is a process best learnt by doing'. I recognised that my interpretation of the data would be influenced by my belief that children should be 'looked out for' and their voice heard. I felt a great responsibility when interpreting the data and writing up my findings. I was not only presenting it for academic scrutiny but to the social work community. I did not want to let myself down and particularly not the children whose lives I had heard about, nor all the palliative care social workers who had contributed at various points along the way. Whose 'voice' (Hertz 1997) was I selecting to put forward in the write-up? How would I chose which extracts to quote to illustrate my themes (Humphries and Martin 2000)? I was also conscious of the fact that I could be judging the reality of others in relation to my own (O'Leary 2004). Supervision sessions and feedback on my writings were extremely constructive and helped me to take a fresh look at my findings. *Being here* was, at times, a lonely existence but also a heartening and rewarding one.

Conclusion

This chapter has explored my journey through the research, charting the stages and phases within it, together with my inner dialogues. In chapters seven to eleven I present the analysis of my findings together with a discussion as an integrated whole (Holloway 2005). As I saw children to be at the centre of the study, it seemed important to first present a picture of their experiences at this difficult point of their lives, as described to me by the palliative care social workers. This picture acts as a backcloth to the subsequent chapters: a reminder of the children, their circumstances, difficulties, challenges and needs. The palliative care social workers' perceptions of their role in safeguarding these children follow in chapter seven, with an examination of what safeguarding means to them generally and specifically in their own work context. It seemed important to present these findings early in order to gain a picture of how this understanding impacts on their work with children, their families and also their colleagues both in their own and other agencies. Chapter eight importantly considers how children come to the attention of the palliative care social workers; in particular, who makes referrals and why, as this process is likely to determine which children may be safeguarded. Chapter nine then concentrates on the findings that relate to the work palliative care social workers undertake with children and their parents. It contains examples of their safeguarding practice and shows the range and diversity of work undertaken. These examples highlight the relationship between palliative care social workers and social workers in local authority children's services and these findings are examined in chapter ten. The final findings chapter concentrates on what informs the palliative care social workers' practice in safeguarding children, including information on their knowledge base, any supervision and training received and the influence of previous work and life experiences on their practice.

The following chapter describes the experiences of children where a parent is dying as told by the palliative care social workers during the interviews.

Chapter Six

The role of the palliative care social worker:
the children's experiences

Each child is an individual and each child's story is unique.
Daniel et al. 2010

Introduction

The literature review drew attention to the many difficulties and issues which can face children and their families when a parent is dying from a terminal illness. This chapter aims to illustrate the variety and complexity of the issues that, in turn, face palliative care social workers working with adults in their involvement with families. It also highlights those aspects that did not feature in research studies. The aim is to put children at the centre, ensuring that their voices are heard, albeit second hand and as interpreted by the palliative care social workers and then by me.

During the individual interviews, palliative care social workers were invited to describe at least two practice examples of their involvement with families where there had been concerns about the present and future care of the children. These examples provided a richness of material that allowed me to consider issues from the perspectives of both children and their parents, helping me to more fully understand some of the apparent needs of children. This understanding, I hoped, would also help me keep the child at the centre whilst reflecting and promoting reflection on the role of the palliative care social worker. Many examples were described in depth, others less so. This seemed to depend mainly on the amount and duration of contact between the family and the palliative care social worker. Whilst three main themes emerged: the effects of the parent's illness on the children, the relationship context around the illness, and the broader social and economic context, there was not a clear subdivision between them.

As will be seen there was often an overlap, demonstrating the complexity of the circumstances faced by children, their parents and palliative care social workers.

First I will provide a brief description of some of the characteristics of the practice examples. I will then consider each of the three themes with some short extracts from the practice examples to illustrate particular issues. Details have been removed or altered to ensure anonymity and preserve confidentiality. I conclude with a brief discussion on what the examples appear to tell us about the needs of children and the issues facing palliative care social workers.

Description of practice examples

There were a total of 45 practice examples which included palliative care social work involvement with 29 families pre-bereavement, 12 both pre- and post-bereavement and 4 post-bereavement. All age groups of children were represented in the sample as shown in Table 6.1. Information about the parents' country of origin was not specifically sought; some details were gained from the narratives (Table 6.2) but to ensure anonymity specific countries where known have been grouped together. There were more mothers than fathers who were dying or had died and approximately one third of parents were lone carers (Table 6.3).

Table 6.1   Age and gender of children in practice examples

Age in years	Boys	Girls	N/K	Total
0 - 4	2	8	2	12
5 - 10	14	14	5	33
11 - 15	13	16	7	36
16 - 18	4	3	0	7
Total	33	41	14	88

Table 6.2   Country of origin of ill parents in practice examples

Nationality	Number	Nationality	Number	Nationality	Number
Britain	21	Asia	3	Europe	2
Africa	5	South America	2	West Indies	1
Not specified	11				

Table 6.3   Relationship of terminally ill carer to child and number of lone carers

Relationship of terminally ill carer to child	Number	Number of lone carers
Mother	28	15
Father	12	1
Grandmother	4	0
Grandfather	1	0
Not specified	1	0
Total	46*	16

* In one example, a child was sequentially cared for by a mother and grandmother.

Effects of the parent's illness on their children

The research studies in the literature review identified various ways the terminal illness of a parent may affect the children in the family. The practice examples provided by the palliative care social workers particularly illustrated children's awareness of the illness; how they were informed about it; its impact on them; and, how parents' coping abilities influenced the care they provided to their children.

Child's awareness of the illness

A child's awareness of the parent's illness seemed to depend on the age and level of understanding of the child and also whether, or how well, the parents hid the fact that they were ill. In general, children were not encouraged to ask questions about the illness, a cloak of secrecy prevailed. There were examples of children who had lived with their parent's illness all their lives, whereas for others the illness represented a sudden and unexpected intrusion. There were children who had witnessed or experienced a variety of incidents related to the illness. Examples included children coming home from school and finding their ill mother in bed on a regular basis; a parent haemorrhaging or collapsing in their presence; a parent behaving in an uncharacteristic and perhaps frightening way due to either the illness itself or the medication; and, children reading letters from hospital for a parent who was not able to understand English. Children were often present when palliative care staff visited the home and might have overheard or misunderstood conversations.

A young mother, who had come to the UK on a work permit together with her husband and young children, was diagnosed with cancer and later developed brain metastases. The mother had continued to work for as long as possible and her husband had to continue working when she became ill, as he was not entitled to benefits due to his immigration status. The mother, either because of her illness or medication, was exhibiting confused behaviour and possibly hallucinating whilst the youngest child aged under five years, was in the house with her. This caused the youngest child to be extremely frightened and distressed.

There was a variety of examples of children who were very aware of the illness, wishing to be involved in what was happening. This included being with the ill parent whilst they died; seeing the parent's body immediately after the death; giving advice regarding the preparation of the body and helping with the rituals; and after the death, welcoming people to the house to view the body, and being part of the funeral.

Informing children about the illness

Children were usually informed about the impending death of a parent by the parents themselves. Generally, all the children in the family were told, but young children were frequently excluded in the belief that they were not of an age to understand. Accounts suggested that the communication process was often difficult, ad hoc and buffeted by events. Some children were prepared for the fact that a parent was dying months before hand and others a matter of weeks or days before. This latter time-scale might be determined by circumstances where a parent's condition suddenly deteriorated leaving very little, if any, opportunity for the children to be prepared and for the family to make plans. There were accounts of parents intending to tell children about the illness but delaying doing so as they were unsure how to go about it or when would be the best time to do so. There were examples of parents refusing or being unable to tell their

children right up to the last moment and, in rare circumstances, not even by the surviving parent after the death. In many instances, the children were reported to know that their parent was ill but not the extent of the illness.

Whilst the mother was working, the father who had cancer was caring for their children of various ages. The father's condition deteriorated very rapidly and he died shortly after a referral to the palliative care services. One of the children attended a special school and had severe communication and learning difficulties. The parents had wanted to help all their children know what was happening but were unable to find a way to let this child know or help her understand what was happening to her father.

Parents' coping abilities

There were suggestions in the accounts that the ill parents adopted either an active or passive style of coping with the illness, particularly in relation to their children. In the latter group not all were able to come to terms with the likely outcome of their illness and some refused to accept how ill they were. These parents tended to be unable to make plans for themselves or for the future care of their children, on occasion refusing to tell people about their illness. Ill parents who felt physically weak and tired tended to opt out and had no strength to care for their children either physically or emotionally, raising the question 'should I be a parent first or a patient?'. Parents in receipt of personal care services were known to ask the individual care staff coming to the house to undertake tasks with their children instead. This was either to allow them some respite or to meet the children's needs, assistance for the children not otherwise being provided by the local authority child and family services.

A mother, a lone carer, had made care plans for her two children. The youngest was to be adopted by a friend and the older child, a teenager, was already in foster care due to an earlier breakdown in their relationship. The mother was now an in-patient in a hospice and feeling that she had done all she could in regard to the future care of her children, did not wish to see the local authority social workers anymore to discuss their care. She felt very tired and needed to have it recognised that she was dying.

There were other examples of ill parents who, whilst accepting what was happening to them, were determined to remain alive for as long as possible in order to 'be there' for their children. This was particularly apparent in situations where there were difficulties surrounding the family's immigration status and when the ill parent's survival meant that the children and well parent could remain in the UK. There were also reports of parents who were isolated due to limited access to family members, again this was particularly significant for those families whose country of origin was not the UK.

There were accounts where children were a support to the ill parent who might be encouraging their child not to attend school but remain at home to be with them. Feelings of inadequacy and helplessness were described with ill parents being unable to cope with their own needs let alone those of their children. A late diagnosis, a rapid development of the illness, a late referral to the palliative care service all influenced how much time parents had to adjust themselves to the situation let alone consider the needs of their children.

A mother with advanced cancer lived with her teenage children. The father's whereabouts were not known. The children knew she had cancer but she was only referred to palliative care services at a very late stage when her condition was deteriorating very rapidly. She died two weeks later before the concerns about the

behaviour of the children and their future care could be assessed and plans made as a family.

Different coping styles were described in relation to the surviving parent and the ill parent, often affected by gender. These included a father returning to his native country for a while as he could not cope with his wife's illness as well as the children; a husband giving up work to look after his sick wife and children; parents attempting to work for as long as possible despite their illness.

Impact of a parent's illness on the children's behaviour

The examples highlighted a range of behaviour which included descriptions of children who were appearing to cope extremely well, being supportive and continuing to enjoy school to those who were bed wetting, not attending school, being suspended from school, not speaking at school, sleeping badly, drug taking, becoming 'naughty' and, being withdrawn, uncommunicative, hyperactive and confrontational.

Two primary school aged children were living with both their parents. Their father had cancer and had been ill for several years. His condition was deteriorating and he had a tendency to be aggressive. The younger child had become confrontational and preoccupied with thoughts of violence. Parents found the behaviour of both children difficult to manage.

There were also implications for the children as a result of the nature or the speed of the progress of the illness. If the illness was developing slowly, the family and the children were aware of the changes and either adjusted to them or resented them. There would be times too, when a parent was admitted to hospital or hospice and the child, when visiting, would be aware of the treatments being given to the parent as well as to other

patients. This could cause the child distress. One young boy was reported to be unable to visit his father because he was frightened of the change in his father's physical appearance.

Care arrangements for children following the parent's death

Respondents described parents making decisions about the children's future, both with and without their involvement. The age of the child and their perceived understanding appeared to influence whether or not adults considered they had a contribution to make. On occasion children took an active part in helping to sort out their own future care arrangements. However, sometimes a parent was unable to decide what was best for the child and died before reaching a decision; sometimes the decision was made in the very last days of the parent's life. There were descriptions of children moving to live with grandparents, aunts and uncles, older brothers and sisters, foster carers and friends, sometimes prior to the death. There was an example of a very young child being taken to another country by the father to live with his relatives after her mother had died. In some cases, no arrangements were made before the death of the parent.

A lone mother, dying of cancer, was caring for her pre-teenage son. The mother died before making any arrangements for him, as she could not decide with whom he should live. In the event, the boy went to live with the grandparents who had previously been involved in his upbringing and lived locally, despite previous concerns with respect to the quality of the relationship between the grandmother and grandson. The grandparents began to complain about the boy's behaviour - they were unable to control him and he was described as causing problems. The grandmother became ill also with cancer, deteriorated quite quickly and died. The grandfather accused his grandson of causing the cancer because of his behaviour. He no longer wished, or was able, to

continue caring for his grandson. As no other family members were able or willing to take responsibility for the boy, the local authority placed him with a foster carer.

In about a third of the practice examples, the parent who was dying was a lone mother caring for her children and in some instances there was little or no family support during the illness. The father might no longer be in contact with the family. However there were instances where lone mothers decided to re-involve the estranged father; or fathers, on hearing of the illness, themselves took the initiative to re-engage with the family and offer future care for the children. Sometimes the father returned to live in the family home before the mother died. One lone mother refused to tell her children about her terminal illness, neither would she inform their father because of her bitterness about the ending of their marriage. On occasion, the current or future carers were thought by various parties, including the palliative care social worker, to be unsuitable to look after the children.

A mother with young sons was an in-patient in a hospice and her health was deteriorating. She had an unhappy childhood, brought up with her siblings by her father in a very deprived area and had previous partners who were physically abusive to her. A family member disclosed to the palliative care social worker that the mother had been sexually abused as a child by her father who was now caring for her boys.

Lone parents of children between the ages of 16 and 18 years, where there were no family members available to provide care, faced particular difficulties in attempting to sort out future living arrangements. Local authorities were generally not receptive to the young person taking over tenancy agreements and there were concerns that such a young person might therefore become homeless on the death of the parent.

Relationship context surrounding the illness

Changes to family functioning and the relationships between children and their parents were a feature of many of the research studies discussed in the literature review. As can already be seen from some of the above practice examples, the quality of relationships in the family had significant implications for the current and future care of the children and role changes within the family.

Impact of relationships on child's care

The relationships that the well parent in particular had with their children, depended on their ability to cope with the changes that the impending and actual death of the ill parent might bring. The accounts suggested positive outcomes with support from friends, family and agency staff and less successful outcomes if the relationship between the child and the surviving parent was already poor, or the parent was unable to meet or did not understand the child's needs, or considered their own needs as more important. There were examples of families where there was a history of domestic violence or alcohol problems. The changing nature of the illness could lead to aggression or the withdrawal of a parent or worsen an already difficult relationship between a parent and a child.

A teenage daughter lived with her father who had cancer with brain metastases. Her mother had died some time previously. There were angry clashes between father and daughter regarding the daughter's social life of which he did not approve. The daughter admitted she was scared of her father and the relationship had not been good prior to his illness. The father accused his daughter of being the cause of his illness and threatened to kill her.

Role changes in the family

Changes to the roles of nuclear and extended family members occurred both during the illness and after the death of a parent. During the illness, particularly in the situation where the mother was the ill parent, there were examples of children having to take more or full responsibility for themselves and for their siblings, and perhaps providing physical care for the ill parent.

In one family, a father returned to his native country leaving his dying wife and children for a period of time. The adolescent daughter had to cope with the care of her mother and younger siblings. On one occasion when the mother's condition deteriorated, necessitating an emergency admission to hospital, the ten year old was left to care for the frightened younger siblings whilst the older daughter accompanied the mother in the ambulance.

A commonly reported feature was children being looked after by others whilst the ill parent was an in-patient in a hospital or hospice. This care was usually provided by relatives or friends. During the illness, the well parent might take on new responsibilities for the children as well as the caring role for the ill partner. However, this was not always an easy transition to make for all parties. There were also examples of families struggling with a lack of support.

A mother had cancer and had been ill for some time. The relationship between the parents had broken down before the diagnosis but they remained together. There were four children of varying ages. The mother had returned to work after her treatment but when the illness returned the father gave up work to look after his wife and youngest child leading to difficulties. The mother felt 'so flat, so wretched' and was disengaged

from what was going on. The atmosphere in the home was described as one of

'absolute gloom and despair'.

After the death of a parent, there were families where children took on the responsibility

of providing practical and/or emotional support to the surviving parent. There were

instances of older children, sometimes themselves under the age of 18 years, taking

over the parental duties for their younger siblings, there being no surviving parent. This

on occasion caused role conflict. The re-introduction of a parent, usually the father to his

children, meant the making of new relationships. How well families adjusted to their new

circumstances was reported to be influenced by various factors. These included to what

degree the surviving parent was 'caught up' in their own grief; the previous family

history; the desire to respect the dead parent's wishes; their determination to succeed;

the amount of support provided by family, friends and other agencies; the bureaucracy

of various agencies; the gender of the surviving parent; and, the parent's ability to take

on new roles. It was easier to cope and make plans if the parent felt secure in terms of

employment and finance and there were not too many practical obstacles to overcome.

Broader social and economic context

As discussed in the literature review most of the existing studies into the child's

experiences of living with a dying parent are 'psycho-social' in approach but appear to

pay little attention to the social context. Three sub-themes relating to a broader social

and economic context were identified in the examples: poverty, gender roles, and

immigration status. These are inter-linked and references have already been made to

aspects of these issues in earlier cited examples.

Poverty

Being concerned about finances was seen as an extra burden carried by parents which in turn impacted on the children. There were children who had experienced financial hardship in the family as a result of the parent being unable to work due to their own illness or to looking after the ill partner and children. There were families who were described as living in areas of deprivation and poverty and severe financial difficulties were identified as an issue for many families. A number were reported to live in poor quality housing and the home conditions of one family were described as 'appalling'.

A very isolated lone mother with a poor prognosis lived in a deprived part of the city with her pre-teenage child. Both were victims of anti-social behaviour: damage had been caused to the house and there were also incidents of name-calling. As this was so frightening they kept the curtains closed at all times. The mother had a very limited amount of money and refused to go into debt, preferring to do without; she had not realised that she was entitled to Disability Living Allowance.

Gender roles

In various examples there were fathers who were described as taking on roles previously undertaken by the ill mothers. Attitudes to gender roles impacted on the provision of practical support given to a family. There were reports of instances where local authority staff would not provide resources for families where a mother was dying and the father was working. Fathers were considered to be 'responsible adults' and it was thought they should 'be there' for their children even if this meant taking time off from their work or working reduced hours. This might have meant a loss of income or even the job itself for the fathers concerned and some, because of their immigration status, would not have been entitled to receive benefits.

Immigration status

There were practice examples given of families where the immigration status of the family was dependent on the dying parent. There were reports of the Home Office allowing the well parent and children to remain in this country only until the ill parent died, causing great distress and uncertainty. Families had come to this country with a view of obtaining a 'better life' for their children and the children had generally settled well, making friends and wishing to remain in the UK. There was sometimes a great uncertainty about what a return would mean and the notice of departure often appeared to be very last minute allowing no time for preparation and goodbyes. Not only had the child lost a parent but also friends and a familiar way of life.

A mother had come to the UK with her pre-teenage children. She was determined to make a life in this country primarily for them. She was diagnosed with cancer shortly after her arrival, which was treated. She continued to work and remained well for a period but then the cancer returned. The children's father arrived in the UK before she died to look after the children. The mother had been determined that the children should remain in UK and the father was happy to comply with her wishes, but the Home Office refused to extend his visa, which he appealed. The children were very distressed about the death of their mother and the uncertainty surrounding their future. The behaviour of the younger children in particular was a cause of concern. There was no financial support available and the family had received an eviction notice.

Discussion

The practice examples provide a wealth of information about the apparent needs of the children. The palliative care social workers' accounts suggest that it would be reasonable to believe that, to varying degrees, the children would be feeling bewildered, frightened, unhappy, threatened, lost, guilty, depressed, scared, unsupported and

perhaps even unloved. It would perhaps be appropriate to speculate that children in the circumstances described needed consistency and continuity, to be informed, supported, listened to, protected, taken account of, respected and to be prepared for what is and might be happening to them and the people around them.

The circumstances of a parent's terminal illness clearly 'rippled out' (Hudson and Payne 2009) to affect many people, but particularly children, and it is evident from the practice examples that the family system changes as a result. From an ecological perspective (Jack 2000), the development of children and their life chances may well be affected by the changes in the socio-economic circumstances that illness can bring. There was evidence that children's development and well-being were already being compromised prior to the illness; the illness compounded it.

Whilst the examples highlight many aspects featured in the literature discussed in chapter three, they also highlight those that were either not featured or very minimally so in research studies. These aspects include children who were living in neglected or abusive situations; families where there was existing conflict between parents, including situations of domestic violence; families suffering from financial hardship and those living in poverty either prior to or as a result of the illness; and, the uncertain immigration status of the families which impacted on every aspect of decision making pre- and post the parent's death.

Conclusion

Within this chapter there have been illustrations of some of the complex issues that can come to light after the involvement of a palliative care social worker in families where there is a child under the age of 18 years. These issues will be explored in future

chapters. First, I will examine how safeguarding children is perceived by the palliative

care social workers in this study.

Chapter Seven

Palliative care social workers' perceptions of their role in safeguarding children

> All those who come into contact with children and families in their everyday work, including people who do not have a specific role in relation to child protection, have a duty to safeguard and promote the welfare of children.
> DfES 2006

Introduction

As indicated in chapter four, safeguarding children encompasses a wide spectrum of concepts and activities from the broad promotion of welfare to the sensitive and extreme aspects of child protection. Government guidance makes it clear that anyone who works with adults who are parents or carers of children has responsibilities towards those children (The Scottish Government 2005; HM Government 2010). In this chapter I will focus on what the palliative care social workers understand about safeguarding children and how they see it impacting on their work. This chapter will therefore act as a back-cloth to the subsequent chapters that will both describe and analyse the palliative care social workers' involvement with children and their parents and also with the local authority children's services.

The first part of the chapter concentrates on the specific responses of all participants about what safeguarding means to them, how the interviewees viewed their agencies' general attitude to children and all the participants' views on how a parent's illness may impact on their capacity to meet children's needs. The second part considers what all the participants in the study understand their role to be in safeguarding children, its emotional impact on them, how confident they consider themselves in the role and how they might become more effective. In the third part, there is a discussion on the emerging issues.

Safe in the widest sense

When asked to describe what safeguarding meant to them, the overwhelming response from the palliative care social workers in the survey, focus groups and interviews was that safeguarding children carried a much broader remit than child protection. One worker in a focus group described it as:

> Ensuring children are safe in the widest possible way and not just at risk from a particular person.

Another described safeguarding as 'less of a word than protecting' which I took to mean that safeguarding was a more general term; protecting was more specific. A similarly broad view was taken by one interviewee who said that:

> I think there is a subtle difference between child protection and safeguarding children. We talk very much about safeguarding, literally keeping children safe and I think of being much more aware of the impact of things like domestic violence, or a parent with mental health issues, and I think having a parent who is dying increases the child's sort of risk of emotional abuse. The practicality of keeping a safe environment for them.

The prevailing view was that emotional harm was more frequent than other types of harm and that it was generally 'unwitting' emotional harm brought about by the impact of the illness on the family. The broad brush of safeguarding was described by one worker in an interview, which included having regard to the emotional needs of a child:

> … safeguarding them in a general way, even just the right to feel safe and have a routine and not to be moved from pillar to post. Absolutely crucial if you work with the family. It is an absolute. You need to be making sure that their child is looked after and safeguarded when they are gone and also be aware of helping the child emotionally to get through the difficult experience.

Palliative care social workers generally saw the family as their priority with the focus being on the children, being alert to their needs and ensuring that they were not 'forgotten'. One interviewee, for example, specified that safeguarding children was about

protecting a child from being harmed and working with the family as a whole system. Another considered that protecting children from harm was a 'tiny, tiny piece of the puzzle'. She was more concerned about the impact of loss on a child's development and in her experience was aware that a difference could be made if some 'deliberate preparation' was made in partnership with the parents.

Neglect, as a particular aspect of harm, was rarely referred to except in a general sense, something to be aware of. 'Unwitting emotional neglect' was mentioned by one interviewee, where parents might be so caught up with their own emotions and difficulties that they were not aware of their children's emotional needs. However, there was evidence that palliative care social workers recognised when children were emotionally vulnerable but did not seem to rush to describe or perhaps even see them as being 'neglected'. There were two examples in the survey where young children were considered to be emotionally neglected and at risk. However, the local authorities concerned refused to become involved, as there was 'no tangible proof' for them to do an assessment in one situation and 'nothing specific had happened' in the other. Relationships with the local authority will be explored in chapter ten.

Whilst child protection, in terms of physical, emotional and sexual abuse, was seen to be an important part of safeguarding, it was considered to be a rare occurrence in the experience of the palliative care social workers. One respondent in the survey gave the following opinion:

> Coming from a child protection background I am amazed how infrequently we 'come across' or are 'exposed' to issues of protection except in the form of emotional support, readiness for the dying, and my suspicion is whether issues are submerged by the situation [dying] the family are experiencing.

This view was echoed by an interviewee who also wondered why this should be the case. Another palliative care social worker kept a record of referrals to the local authority from her hospice and in 2007, five referrals were made and in 2008, one.

Putting 'a universal responsibility' into practice

The widespread view of the palliative care social workers in the interviews was that in-patient hospices were generally 'child-friendly'. They illustrated this claim by describing how children were encouraged to visit their dying parent and a room was provided for children with a range of toys, DVDs, videos and games. A selection of information leaflets and books on aspects of bereavement were also available that could be shared with children, including culturally specific resources. There were four examples given of children being invited to live in the hospice so that they could spend more time with their dying parent. For one hospice, this resulted in a large financial cost and an emotional experience for the staff. However, as the palliative care social worker involved explained in a focus group:

> It was very draining but that has actually set a benchmark for us and it has made us less frightened of it and it really was a very positive experience and actually now we are more child-friendly. … we are much more confident about preventative work.

Attitudes have changed over time as one worker based in a hospice explained in her interview:

> Certainly when I came here 21 years ago nobody thought about the children - the impact on them. There was no service. Very much forgotten.

There were hospices where a specialist children's worker was in post. The main emphasis of their work appeared to be in relation to the provision of support to children post-bereavement by way of group activities or individual work. There were fewer examples of some individual pre-bereavement work jointly planned with palliative care

social workers. The specialist workers also provided support and advice to any hospice staff as required.

Safeguarding children was seen by the participants as a universal, collective responsibility. One palliative care social worker summed this up by writing:

> Everyone who has contact/knowledge of children has an important role to play in ensuring their safety. We must prioritise this and be vigilant at all times.

However, in a small minority of interviews there was a view that the response of the medical and nursing staff, and the workplace as a whole, to children was poor. Nurses, one hospice based worker considered, would be 'shocked' if they realised that the child's welfare should be a primary consideration. Another palliative care social worker spoke of the medical and nursing staff feeling that children were 'difficult' and that contact with them required someone with special qualifications; another, of the fact that there was no strategy to meet children's emotional needs. Indeed, there was one hospital based palliative care social worker who recognised that not much work was done with the children by any member of staff and that it 'spooked' the consultant. At one hospice it was recognised that the needs of children were not well met and although there was a plan to appoint a specialist worker progress was too slow in the view of the palliative care social worker. There had been an effort to make general information available to children by use of a display board but the management considered this inappropriate, saying information should be put into children's hands via the parent.

This universal responsibility was seen to extend to all who had a role in the workplace. In order to raise awareness within hospices, the general practice described by the interviewees was that all staff, including voluntary workers, received training on safeguarding children. The five palliative care social workers in the interviews and focus groups who identified themselves as the designated child protection officers for their agency had been responsible for drawing up the safeguarding policy and procedures for

all the staff. They, and other palliative care social workers, were also involved in the training on awareness, policy and procedures. Such training often provoked discussion about standards and one worker specifically mentioned that, as a result, staff had come to understand that it was acceptable to discuss a family's situation where they had concerns.

There was a discussion in one focus group about how much palliative care social workers should say to families at the initial stages of contact with regard to their responsibility about 'looking out for' the needs of children. There was a range of views expressed: highlighting this aspect of their responsibilities at the start was useful if a concerning situation were to arise later; explaining was an honest approach to take; doing so raised a barrier and it was better not to explain this aspect at the outset; and it would depend on how it was done. Generally it appeared that there were also clear agency procedures about making a referral where child protection was an issue, although two workers in one focus group were unsure whether there was a policy in place in their agency. One interviewee reported that despite one being in place, she received no advice or direction from the hospice in which she worked about whether she should report some specific information about children's safety to the local authority. The line manager was unavailable and there seemed to be a feeling amongst the medical and nursing staff that making a referral would be too upsetting for the patient; the thought of doing so, according to the worker, 'disturbed them immensely'. In the end, the worker drew on her own experience in local authority work and made a report, but wondered afterwards whether she had delayed too long. There was an echo of this for another worker who was not sure in hindsight whether she should have acted sooner with one family and commented:

I think sometimes on your own in a situation you can feel very isolated.

This highlights the particular difficulties where there are lone workers, or a lack of personnel who can give appropriate guidance, particularly in situations where decisions are needed to be made quickly.

Impact of the parent's illness on parenting capacity and meeting children's needs

The concept of 'good enough parenting' discussed earlier might be challenging to apply with families when a parent is dying. Indeed, there was no clear response to the question *'What is good enough parenting?'* asked during the interviews. There was a recognition that standards differed. There were those who avoided giving a definition saying it was 'hard to do', 'subjective', 'a terrible value laden issue', 'never an expression I have used kind of regularly or think of'. There were those workers who accepted that there were families who operated in different ways and perhaps not in a way that they would want for a child. One thought it important to consider whether the parenting was good enough for <u>that</u> child and another similarly that it needed to be 'contextualised', it being difficult to decide what was the minimum level particularly in relation to families living in very deprived areas. The provision of emotional warmth and support as well as physical care and protection from harm were specifically mentioned by three people. There were those who were more specific in terms of situations where a parent was terminally ill, saying that being 'good enough' meant communicating with and appropriately involving a child; ensuring a child still had a feeling of belonging and being loved.

There was an acknowledgement that illness might prevent parents from parenting in the way they had previously. Workers had witnessed young mothers who were dying withdraw emotionally from their children in order to cope with their own emotional needs. Supporting parents in order to help them provide emotional warmth was

therefore considered to be an important element of safeguarding children. A worker, who had prior experience in local authority child protection work, spoke of the differences in attitudes in relation to parenting:

> In local authority it is usually parents who can't parent and then you get involved and assess risk but in these kind of cases it is parents who can parent but the illness prevents them from doing so. They are still good parents but they need support.

This apparent split between 'our' families and 'their' families is interesting as it highlights a crucial dilemma raised in many of the interviews: the balance between the needs of the ill parent and the child in terms of safeguarding the children. Discretion, it seemed to be suggested, was sometimes required. The importance of not allowing the illness to be the primary focus was mentioned, as well as the need to look at the strengths within and outside the family. One palliative care social worker in a focus group described the dilemma by saying:

> Have compassion with the person who is dying but if you take it too far you can miss the child who is at risk – need to protect the child. We have to hold the balance – not be judgemental and protecting children.

There was a view that parents often struggled particularly as they came near the end of their life, because of the burden they felt they had placed on their children. The impact on teenage children and their behaviour was considered by one palliative care social worker to be particularly difficult as teenagers often struggled in any case, trying to deal with their own understanding of themselves as individuals. Trying to untangle what was general teenage behaviour and what behaviour was in relation to the parent's illness was immensely difficult. The general view was that children were able to understand a parent's changed behaviour if explanations were given together with reassurances that they were not to blame for what was happening.

However, specific medical conditions could cause extra dilemmas for the worker. Sometimes a child could be in danger because of a change in personality in the ill parent due, for example, to a brain tumour. The resulting change in behaviour might cause the child to be at risk. The prevailing view of the interviewees was that this is not a straightforward matter and the context of the situation needed to be taken into account. In coming to a decision, one worker described how there were times when she had 'dithered and hovered' about whether to make a referral because she was aware that such action might destroy family relationships and alienate the patient from using the hospice services in the future. If the situation were to last for some time then the impact of this on the children would need to be taken into account. One worker stated this starkly in an interview:

> If you have a troubled parent that is likely to abuse for the next ten years, it is very different if you have one that might be dead in three weeks.

Where these circumstances occurred, palliative care social workers explained that they tried to ensure that the children would not be left alone with the ill parent. This might be discussed with the well parent, or at a family meeting, and care packages organised as necessary to cover crucial times of the day to ensure the child was not solely in the care of the ill parent.

Whilst about a quarter of the survey respondents clearly stated that the child's welfare was paramount regardless of the parent's illness, others were less categorical. The overall impression was that the palliative care social workers would be attempting to understand what was happening and endeavouring to provide appropriate support to the parents. Here too there was recognition of the dilemma of balancing the needs of parents and children in what was known to be a short-term situation. One palliative care social worker wrote:

> The illness would have no influence on the decision made. We would be sensitive to the needs of the family at the time but our concerns would be raised

with social services irrespective if the parent was ill. We would work proactively and preventatively with such a family but recognising that part of the prevention might involve social services.

Safeguarding and promoting the welfare of children is therefore not a straightforward matter. By being part of an adult service, a few palliative care social workers saw themselves looking primarily at the needs of the patient with children as 'add-ons'. Others were clear that children's needs should be the primary focus. There could be a conflict of interest with parents wanting their life to continue as normal as possible and with children needing to know what was happening. The worker might on occasions be advocating for the child with the parents, which one worker described as being 'a delicate line to walk'. One palliative care social worker described how, for her, the child's welfare was something to hang on to when everything else was in a muddle and staff were emphasising the difficulties the family were in. The worker would then point out that for this child the standard of life was not good and the welfare of the child was paramount. There was another view that this was too simplistic - the whole family's welfare had to be paramount and adults had to feel strong and capable and resilient in order to provide parenting for children. However, it was apparent from many of the practice examples shared in the interviews that this was something that parents often struggled to achieve.

Other workers found that standards sometimes varied between other professionals in the team. There were some who were more forgiving of parents' behaviour because of the nature of the illness which could sometimes lead to conflict between them and the palliative care social worker.

How palliative care social workers perceived their role in safeguarding children

When asked about how they saw their role in safeguarding children, the responses generally reflected the palliative care social workers' descriptions of specific work with children and families which will be considered in chapter nine. About half of the respondents in the survey described their role, or part of their role, in safeguarding children as offering support to parents and undertaking preventive work. One worker wrote:

> The safeguarding of children is one element of many in supporting a parent with a life limiting condition.

Being in a special position to look out for children came through many of the responses and was summed up by one worker:

> I feel I have a unique opportunity to assess a family situation and offer input to improve things if there are concerns about a child's welfare. However, I also see my responsibility as including a need to report a situation if abuse is suspected.

Being alert to the needs of children, their safety and behaviour, and undertaking a risk assessment were other, though less often mentioned aspects. One worker described it by writing:

> I think it is an extremely important role in that as a palliative care social worker I often come to know the family very well. This means we, as social workers, are often placed to recognise any child protection issues or to recognise when a child may be vulnerable … We may also realise when a bereaved parent may be vulnerable to letting other (abusive) adults become involved in their family life.

However, there was one worker who appeared to stand back a little from children when she wrote:

> I don't make decisions about child care, but I can provide advice to child care professionals.

Liaising with other agencies, especially social services, and making a referral to child protection agencies if there was any suspicion, evidence or concerns about a child being at risk also featured in about half the descriptions provided in the survey. The need to follow agency procedures and guidance was included here. However, one worker wrote:

> My primary role is to support patients and their families through their illness and on into bereavement as necessary. I have a duty to report concerns, which I do, but I am not a key worker in child protection. I think the role can easily become blurred, particularly when the child protection concerns are low key.

It is not entirely clear what this worker meant by the 'role can easily become blurred' and as this was a survey response, I was unable to ask for clarity. One interpretation could be that she saw a clear separation of roles, one as a supporter and the other as a protector and that there should not be an overlap. Another could be more straightforward in that she saw herself as primarily a worker for adults rather than children. In either case, the blurring was something that was uncomfortable for her.

In the focus groups, palliative care social workers also described the various ways they were able to safeguard children by undertaking preventative work with a whole family perspective. This included supporting and enabling parents to understand their children's needs, mediating and advocating on behalf of parents and children in order to obtain services, and counselling. Working with aspects of risk was generally recognised, as well as being aware of the need for children to be prepared for the death of a parent. Educating other members of the multi-professional team about safeguarding children through training, discussion both in meetings and on an individual basis, were also seen as part of their role.

In the interviews, whilst protecting and ensuring children were safe from any sort of abuse or harm were mentioned, protecting them from emotional harm was seen as an important dimension of the role. One worker went on to say:

> To see that their emotional needs are met and not neglected I think that is the hardest part really.

Looking after the child's needs, alleviating emotional distress, making things clearer, keeping them informed, helping them say their goodbyes and supporting them afterwards were all aspects of this protection. Having direct contact with children varied depending on agency policy and circumstances and will be discussed in chapter nine. Again, the role of an educator to other members of staff was also seen as an important task as well as being a supporter to enable them to undertake work with children.

Emotional impact of the safeguarding role

Caring for people with cancer and their families comes at an emotional cost (Faulkner and Maguire 1994). Children facing the death of a parent can arouse strong feelings in the health care and other professionals involved, as they may be reminded of themselves as children or of children to whom they are close (Monroe 1990). This can cause a tentativeness in approaching families by not wishing to add to the stress and a concern 'not to transgress family values and child rearing practices' (Macpherson and Cook 2003:398). The dilemma of having compassion for the dying parent, whilst at the same time being alert to a child possibly being at risk, was highlighted by one worker who said: 'having to hold the two bits takes a lot out of us'.

During interviews and focus groups workers displayed warmth and compassion when they spoke about the families and occasionally came close to tears: 'I can feel myself welling up' remarked one interviewee. There was much detail in the descriptions, which indicated how workers would often go 'the extra mile' for the families. One worker

movingly described how, when a mother appeared near to dying in a hospice and wanted to write something for her children:

> I dashed down to the gift shop - and all they had were get well soon cards but I found a Monet water lily sort of thing.

Although workers felt able to 'switch off' there were some circumstances that made it more difficult to do so. One person summed it up by saying:

> Some people touch you and you can't let everybody or you would just be a wreck.

Another worker described feeling 'raw' after the Home Office refused the application for the father and his children to remain in the country after the mother had died. Other examples of the difficulties regarding the immigration status of families also resulted in feelings of frustration and heartbreak for palliative care social workers who, despite their efforts to advocate on the family's behalf, failed to secure the remaining family members' right to stay in the UK.

Workers did not often tell children themselves that a parent was dying or had died, preferring to support the parent to do so. However, when they have been asked to do so they found it extremely emotional; one worker described it as 'harrowing' telling a little boy that his father had died. Palliative care social workers rarely attended funerals but there were examples of where they had decided that this was in the best interest of the child for them to do so. One worker explained her feelings about attending funerals when describing her long involvement with a mother who had died:

> I don't have a blanket rule but you know - if I feel I need to - I get a feeling I need to go and I didn't feel that I needed to go but in a way it was weird because sometimes even I can't believe she has gone after four years so may be I needed some closure and should have gone.

The general impression though was that despite the high emotional level of their work, palliative care social workers were able to find ways of coping with the distress and gain from it.

Confidence in their safeguarding role

The survey asked a specific question about how confident the respondents felt about working in situations regarding safeguarding children. Workers ranked themselves and two thirds were confident or very confident and one third less confident or not at all confident. Eighteen workers did not respond when asked what they considered would make them more confident. Of the remainder, more training scored the highest response (n=20). Interestingly, having more experience was thought to be beneficial for five people. Other responses included having more time to spend with families, having a more appropriate response from the local authority and receiving regular updates on local working practices with liaison available. One heartfelt plea came from one worker:

> I need to be in a context (organisation) that is confident – it can't be left to me or any other one / individual professional to keep instilling such confidence. Regular training seems key but also a reflection for colleagues how much they are doing already and how much they do know.

There was no mention of supervision giving confidence or more or different supervision being required to provide it.

During the interviews and focus groups, the general impression was that workers appeared confident as they talked about their work with children. Those workers who had previous experience of child-care commented that they felt more confident about working in families where there were children, comparing themselves to those workers whose background was with adults: One interviewee explained:

> I think because of my background I am probably more geared up than a lot of people to deal with this, because a lot of people are adult social work trained and I do feel that is why I am more confident than a lot of people.

One worker without a child care background spoke of going into situations feeling she had a lack of appropriate skills:

> I think it is very frightening for any of us to go into a situation when we don't feel very skilled and especially if we think that our role should be this and it feels like because nobody else is responding that we are being expected to also do this. In that area that we may not be comfortable - it is easy to move on to a level of panic that may not be just for us as social workers but across the multidisciplinary team.

Also mentioned was the need to keep up-to-date in regard to safeguarding children by attending training, where this was available, or by reading. This is the dilemma: how much training and experience should workers in adult services, and palliative care social work in particular, have in regard to safeguarding and promoting the welfare of children?

Palliative care social workers' thoughts on how they could be more effective in their role

The interviewees were asked what would help them to be more effective in their role with children and families. The responses echoed those given in the survey regarding confidence; there was not a majority view and training interestingly was not seen as a panacea. The range could be grouped into three areas: issues concerning their own practice, their workplace and other agencies particularly social services. In relation to their own practice, having more time to get to know the families and to follow up; having more experience of working with children; and, receiving more training in child welfare matters in order to keep up to date were all thought to be beneficial. Within their workplace, aspects considered to be important were having the social work role and expectations clarified in general, with their role with children in particular affirmed, and having a more child friendly environment. The ways that other agency practice could help them be more effective included more multidisciplinary and 'joined-up' working, especially with social services; all professionals speaking 'the same language'; having a

named person in the local authority child and family team to contact for advice;

obtaining a response from social services when contact was made; and being informed

about available resources.

Discussion

The findings show that being alert to the needs of children in families where a parent

was dying was perceived to be an important part of palliative care social workers' role.

Personal feelings can influence a professional's practice in matters of child protection

such as fear, guilt and sympathy (Pollak and Levy 1989; Horwath 2007a). Fear of

physical aggression was mentioned in this study, where a parent had threatened to kill

his daughter but in the event he was not aggressive. The main fear expressed was that

a dying parent might withdraw from the palliative care service as a whole or from the

palliative care social work service in particular. This fear could be linked to feelings of

guilt and shame, which, according to Pollak and Levy (1989), centre on professionals

wishing to be seen as trusting and supportive by service users, something which the

palliative care social workers strove to achieve. Workers stressed the need to gain the

parents' permission to make a referral whenever this was possible. Indeed, in the few

examples given where workers did decide to refer without permission because of their

concern for the child, the ill parents did subsequently withdraw from their service and

even from the palliative care service as a whole.

Feelings of sympathy, compassion, or over-empathy with the dying parent might also be

reasons for non-referral. These could be linked to not wishing to put a parent under the

additional stress and anxiety that a referral to the local authority might bring. Parents

may not be able to provide the best care for their children because of circumstances

beyond their control, including poverty (Srivastava et al. 2005). Stevenson (2007:11)

argues that these struggles with 'major environmental deficits' combined with an

uncertainty about thresholds may lead to a 'kind of passivity' on the part of workers. Horwath (2007a) also found that professionals made excuses for parents' behaviour in order to avoid making a referral.

This issue of parental capacity was one that obviously challenged workers in the study. A child's health and development rests with the ability of parents and caregivers to meet his or her needs appropriately (Department of Health 2000b:20). For every social worker, the construction of parenting will influence their practice (Daniel 2000; Woodcock 2003). However, in palliative care, it could be argued, there is an extra dimension: how you expect a parent who is dying to parent. What is considered to be 'good enough' or reasonable in these circumstances? Parents may lack the physical or emotional reserves to engage with their children (Rauch and Muriel 2004; Morrison 2010). If the general view is that 'parents need to be able to prioritise the child's needs above their own' (Sidebotham and Weeks 2010:96), parents who are dying are clearly at a disadvantage. Moyers and Mason (1995) demonstrated that the greater the combination of circumstances that seemed to weaken parents' capacity, the more the children were likely to be 'in need'. The literature suggests therefore that there is a need to discover what other social supports are available from the wider family and friends, the quality of the environmental factors, as well as factors that influence culture including ethnicity and religious beliefs (Rolland 2005; Rose 2010). Indeed the findings in this study point to a range of supports that some children called on outside the family including school friends, teachers and palliative care social workers. All will have an impact on the parents' capacity to respond to their children's needs. The findings here show that this exploration was something that workers endeavoured to undertake, albeit often within a tight time-frame.

Whilst child neglect was rarely specifically referred to, workers were very alert to the emotional vulnerabilities of children. It appeared that they, unlike local authority social

workers (Horwath 2005; Buckley 2003; Horwath 2007a), did not focus on specific incidents but on the overall impact of neglect on the socio-emotional development of the child. However, there is very little written about the link between neglect and physical health of parents, but it has been recognised that physical illness can have an impact on their capacity to act effectively as parents (Stevenson 2007), especially when associated with finance and partnership problems (Berry et al. 2003). This means that there could be competing priorities as well as an ignorance of a child's needs. This neglect is not deliberate and the parent is unaware of the damage being caused (Golden et al. 2003). The dilemma for workers here appears to be whose needs should take priority: those of the dying parent or the child? There is a tension of accepting less than adequate care for the child, knowing that it is likely to be short-term, against taking action and alienating the parent. Unlike social workers in other settings, e.g. mental health (Taylor and Kroll 2004), palliative care social workers are not balancing a parent's capacity to change with the risk to the child, as in palliative care it is expected that the parent's medical condition will deteriorate. Rather, short-term measures need to be found to assist the parents in the care of their children and this was the view here. The ill parent's needs may fluctuate so that support might be required at different times of the day as well as week to week. However, it is not just the ill parent's availability, physically and emotionally, that should be considered but also that of the well parent, if present (Morrison 2010). A matter of future concern could be the ability of the well parent to undertake the full parenting responsibilities. The dynamics in the family will change without the presence of an adult carer previously present.

As palliative care social workers are part of a palliative care team, how that team looks at thresholds of concern around parenting and child-care might influence an individual worker. Workers may adjust their own standards to meet those of the team, the 'group think' (Janis 1972 cited in Horwath 2005:93). However, there were workers in the interviews who appeared able to challenge their professional colleagues about family

situations and were prepared to do so; others less so. Palliative care social workers therefore depend on information from other professionals in their team about children and also from parents themselves. However, as noted earlier, parents may be frightened of their children being removed if they disclose any problems (Stanley et al 2003; Beresford et al. 2007); disclosure being perceived as a threat rather than a potential avenue of support.

Conclusion

This chapter reveals a multitude of complex issues and dilemmas for palliative care social workers in their duty to safeguard and promote the welfare of children. The general view was that safeguarding children embraced a wider range of aspects than child protection alone, reflecting current government policies. Safeguarding was also considered to be an agency-wide responsibility and safeguarding training was reported to be in place. Generally, agencies were considered to be 'child friendly' and 'child aware', although a minority of staff were thought to be less aware than others. Whilst all workers in this study accepted that safeguarding children was part of their responsibilities, there was a difference in how it was embraced: some did so with reluctance, but most with confidence. Although there are dilemmas for all workers in any adult care service regarding priority of needs, for palliative care social workers there is the added dimension of the imminent death of a parent and the emotions that this brings to the family and the workers involved.

The next chapter explores how children come to the attention of palliative care social workers.

Chapter Eight

The role of the palliative care social worker:
how children come to their attention

New patients bring a new set of stories,
often emotive and horrific.
Oliviere et al. 1998

Introduction

This chapter explores how children and families, such as those described in chapter six, are referred to palliative care social workers. From the range of responses gathered from the survey, focus groups and interviews it was apparent that children of service users came to the attention of palliative care social workers for a variety of reasons and in a variety of ways. I will describe the processes involved, including information about who makes referrals, the reasons for them and the rate of occurrence. This is followed by a consideration of the views of the interviewed palliative care social workers about the referral process. Finally, I will discuss these findings in the light of relevant literature.

Who makes the referrals?

The vast majority of referrals to the palliative care social work service for general social work support and child care concerns were reported to come from a member of the palliative care team. Nursing staff were usually the first people to pick up concerns about children and young people. Generally, they were the ones who gathered information about patients on admission to the palliative care service and had ongoing contact with them. Doctors too were involved in admissions to in-patient and day hospices and would sometimes make referrals.

The multidisciplinary team and referrals

As is normally the case, all the palliative care social workers interviewed were members of a multidisciplinary team. The interviewees described how new and current patients were discussed at team meetings generally held once a week. These discussions could lead to a palliative care social worker becoming involved with families where there were children. The composition and numbers of the staff attending the team meetings varied, but they were usually comprised of representatives of the medical and nursing staff, and sometimes included occupational therapists, physiotherapists, complementary therapists and chaplains. The numbers attending ranged from 6-17. There was a commonly held view that these meetings were medically orientated, frequently chaired by the consultant or a senior member of the nursing staff, although there were examples of the chairing role being rotated around the members. There was also mention of the tensions that the medical model could create within the team meetings; one worker observed in an interview: 'power lies in the medical hierarchy'. There was a general feeling that palliative care social workers considered themselves to be undervalued, low in status, and having to 'fit in' and work hard to prove their worth.

Further, there was a range of opinions as to how family-focused the palliative care social workers considered the multidisciplinary meetings to be. At the one extreme, just under half the interviewees described their team colleagues as being sensitive, family-focused and 'holistic', with patients being seen in their context. One palliative care social worker commented 'even the doctors will be asking about the family'. At the other extreme, and less frequently, there were descriptions of how teams sometimes needed 'reminding' and to be 'nudged' to move from the medical side to social aspects in discussions about patients. Palliative care social workers found themselves routinely asking questions in meetings about the family composition and future care needs of children, seeing this need to remind their professional colleagues as an important task. There was a feeling, one worker thought, that working with children was a specialism,

something she disagreed with. There was a less commonly held view that some staff, particularly doctors, tended as one interviewee remarked to 'get a bit panicky where there are children involved'.

The composition of the team was found to make a difference to the discussions about family matters. One interviewee positively described the team:

> It is consultant-led. She will always go through psychosocial needs and there is a lot of staff support in there and I give support to the community nurses, reassuring them they are doing the right thing, advising them when to refer on.

Another explained how a change of team leader in a community team to someone with a health visiting background had led in her view to a positive difference in the language used and the type of information about the family raised. There were examples too of how teams had become more aware of the needs of children over time. In-house child protection training was highlighted as a way of making a positive difference to the staff's awareness. Listening to discussions at the multidisciplinary team meetings about new and existing service users also provided an opportunity for team members to hear a variety of perspectives about family matters, helping them to understand that there were different standards regarding the care of children. Such interactions raised the team's awareness about when it would be appropriate to talk to a palliative care social worker regarding any concerns about a family.

The perceived understanding of the role of the social worker in the multidisciplinary team in relation to children

In order for team members to make an appropriate referral to the palliative care social worker, it might reasonably be assumed that they had an understanding of the worker's role, particularly in relation to families where there are children under the age of 18 years. However, there was a range of views from the interviewees about whether this was in fact the case, and very often difficulties were reported. For example, there was

sometimes a lack of clarity as to responsibilities within the team and to what social work could bring. There were reports of team members sometimes specifying what they thought the social worker should be doing; one worker ruefully saying 'everybody thinks they can do social work'. Lone workers spoke of feeling particularly vulnerable. As a focus group member commented:

> As a single worker within a medical team, it's sometimes a bit lonely when you have tricky situations.

One palliative care social worker based in a hospital was described as an 'extended' member rather than a core member of the team. She consequently considered herself to be at the bottom of the hierarchy, leaving her feeling devalued.

Although there were three participants who specifically stated that they did not believe their role was understood, the impression from the interviewees and focus group members was that generally palliative care social workers felt comfortable about their place within the palliative care team. The workers' expertise in childcare matters, at whatever level, was recognised by the other members, even if there was some lack of clarity about social work per se. About a third of the interviewees volunteered that they felt confident they had been able to make their role clear, especially two who had set up the palliative care social work service in their agencies. They considered they had worked hard to build up their reputation, helping the team understand what they could offer service users and their families. One of these two interviewees commented:

> I feel that the role of social workers within the team is probably respected more and probably understood better than it used to. And that is something that has happened only over time.

This view was echoed by a focus group member who commented that to begin with in a multidisciplinary team 'you do have to actually prove your worth and fight for your position' and 'earn trust', but she believed she was seen as the 'expert' concerning child protection issues.

Referrals by nursing staff

There were a small number of less than favourable comments in the interviews about the ability of the nursing staff on in-patient units to pick up issues regarding children. Comments included doubts about the nurses' awareness and also their anxiety about certain situations: 'some nurses get a bit panicked by certain families to begin with'. One palliative care social worker had felt it necessary to remind staff at one in-patient unit to pass on information if there were children involved. Two interviewees described nursing staff who saw the patients as the sole focus of their work, and whilst they recognised the welfare of the family was important, did not consider children unless they appeared on the ward. The emotional impact of seeing the child seemed to trigger an emotional reaction that something should be done.

The characteristics that palliative care social workers used in the interviews to describe nurses working in the community (generally referred to as clinical nurse specialists, home care nurses or Macmillan nurses) varied from highly positive to very negative. At the positive end, just under half the interviewees gave praise for the initial assessments that usually included genograms as well as the patients' social circumstances. Trust was expressed in the nurses' assessment skills and there was a feeling that the clinical nurse specialists were family focused, picking things up from what parents had said or what they had observed during their visits. One palliative care worker particularly commented that nurses saw themselves as providing a holistic service not just a medical one. Examples were also given of where nurses would phone the palliative care social worker from outside a house for advice if they had immediate concerns or would later approach the palliative care social worker if they needed some help with family dynamics. There were also reports of nursing staff being 'very good' at family work but still needing some encouragement to undertake work with children.

At the negative end, concerns were expressed by a small minority that community nurses concentrated only on the needs of adults and, that the standard of assessment skills was poor, particularly where small children were concerned, showing a noticeable lack of knowledge about child development. One comment was that assessment could be 'a bit hit and miss'. Another worker explained that she sometimes looked at the files before nurses made their visits 'to see if I could pick up anything'. This appeared to be a checking up process and it would be interesting to speculate how the nurses viewed this action. There was an opinion that some nursing staff tended to link into the emotions of the child's mother and prior judgements about parents' capabilities might have been made based on where people lived, their backgrounds, and any mental health or dependency issues. There were reports too of nurses who had visited homes many times but never been able to see the children, although it was recognised that this was not always possible because of the timing of the visits during school hours. There was also the view that some nursing staff seemed to act as gate-keepers and filtered families away from the palliative care social worker.

Referrals from other sources

There were examples of referrals in the interviews from other ancillary staff within the workplace as well as from other agencies in the community. In one hospice, for example, a palliative care social worker described how she had received a referral from a hospice shop driver regarding a family to whom he had made a delivery. Mention was also made of referrals from staff in oncology departments, district nurses and general practitioners. One palliative care social worker based in a hospice covering a large rural area received phone referrals from a variety of sources which often led to the worker offering advice and support to workers and/or families over the phone rather than face to face. There were also instances where relatives or friends of service users made a referral regarding their concerns about the care of children. Less common were referrals

from schools. Similarly, there was little mention of local authority social work staff making referrals to a palliative care social worker regarding children.

Self referrals

The number of service users referring themselves to the palliative care social worker was low. This reflects the findings in the Beresford et al. study (2007) where it was considered that this was possibly due to service users' ignorance about social work and that 'it had not occurred to them that there was such a thing as a palliative care social work service' (p.53). It was suggested by one interviewee in this study that those who did self-refer had heard about the social work service from someone who had already received help, or they already had a positive experience of social work. The literature about the specialist palliative care service made available to new service users was reported to describe the family care support or social work service but no mention was made during the study about self referrals from this source.

Reasons for referrals

There were various circumstances that prompted a referral to a palliative care social worker. However, once a palliative care social worker engaged with a family, further areas of concern might well become apparent relating to the progression of the illness, ongoing assessment, the ability of the family to share their concerns, and/or the development of trust in the worker. Overall, reasons for referrals fell into four main categories which are described below and illustrated with examples from the survey and interviews.

Advice and support to parents about informing children about a parent's illness and imminent death

There were parents who were uncertain about how and when to tell their children about what was happening and likely to happen and sought advice.

A clinical nurse referred a husband and wife who were asking for advice about how to tell their two primary school aged children that their father was dying. The parents were also concerned about the children's behaviour. *Interview*

A clinical nurse was concerned about a family where the mother was dying and there were four young children in the family. The mother had been ill for some time, but the parents were unable to tell the children that their mother was now very ill and dying.

Interview

The daily care of children during the period of the illness and beyond

This broad category applied to situations where there were concerns about parents' capabilities to care for their children that might result in them either being in need or at risk in some way. A decreased lack of ability may have been due to the nature and progress of the illness itself, including the effects of treatment; the emotional impact of the illness on the ill and/or surviving parent; poor parenting skills; domestic violence; or, a lack of understanding of the parents regarding their children's needs. There were children with learning difficulties or special needs who required particular care which parents were no longer so able to provide. Referrals were received regarding the inappropriate physical chastisement of children, parents with mental health issues and, parents who had alcohol or drug related problems. There were also requests for benefit advice due to financial difficulties impacting on the daily care of children.

A nurse referred a young mother with a terminal diagnosis who had three young children. The mother was terrified of the implications of dying and leaving a young family. The father was coping practically, but emotionally struggling.   *Survey*

A community nurse expressed concern about two small daughters of a patient, a single mother with cancer. There was evidence of very poor parenting skills, a chaotic home and use of non-prescribed drugs.   *Survey*

A doctor raised concerns that a mother who had a young son was arriving at the hospice drunk.   *Survey*

Planning for the future care of children following a parent's death

This was particularly relevant in situations where a parent was a lone carer and there were no future care plans in place or, plans already made were being contested. Also included here are families whose immigration status was in question.

A single mother, who was terminally ill, expressed concern about the care of her daughter when she died. Her ex-partner did not have parental responsibility but wanted to maintain contact. The maternal grandmother did not want the ex-partner involved.

Survey

A community nurse specialist expressed concern about a single mother with a poor prognosis who had a son of 10 years who was autistic. The mother had a poor relationship with the child's father and the contact was not good. The nurse believed the mother was 'not facing issues' about the child's future care.   *Survey*

The home care service referred a lone parent with a short prognosis who had a 16 year old boy with a poor school attendance record. There was no involvement with the father and no other family members were available to help.   *Interview*

Advice and support to parents regarding children's behaviour

Included here are situations of children refusing to attend school, being bullied at school, and being beyond their parents' control.

School and hospice staff expressed concerns about a 16 year old whose father was very ill. The relationship with the mother was 'very stormy'. The child was not attending school because of relationship issues with peers.   *Survey*

A team member identified that a 13 year old daughter was providing a lot of care for her father who had a long standing degenerative disease. The mother worked night shifts to finance the home. The daughter was unhappy and bullied at school.   *Survey*

Incidence of referrals

The incidence of families with children under the age of 18 being referred to palliative care social workers varied widely. There was no mention made of any audit of these types of referrals and the numbers given were impressionistic and generally low: five or under a year. One interviewee described setting up a working group within the hospice to audit how much contact the various professionals in the team have with children in order to advise the management group about the need for appropriate resources and perhaps a specialist children's worker. Another, who reported low numbers, was surprised that the referral rate was not higher due to the increase in the number of younger patients with cancer. Another worker commented that her referral numbers of families with children had steadily increased to about 15 a year, which she too had linked to the changes in the pattern of illness, particularly a rise in the incidence of

breast cancer. There being a younger population in the catchment area was also considered to lead to a higher referral rate. Overall, the general view among those interviewed was that the number of families with children coming to the attention of palliative care social workers was increasing. However, there was a small minority within the survey who commented that it was rare to have referrals about how children were cared for and they were not able to give examples of any recent involvement. The number of incidents where palliative care social workers were involved with major concerns of neglect or abuse was described as being particularly small in proportion to the total number of people referred to them.

Types of referrals

Formal referrals

Included here are those referrals made in writing, in multidisciplinary team meetings and by telephone. An example of a formal referral approach was described by a palliative care social worker attached to a day hospice which included a multidisciplinary assessment undertaken by a doctor, nurse, physiotherapist, complementary therapist, occupational therapist and chaplain working in pairs, and the palliative care social worker individually. The prospective patient and main carer were therefore interviewed four times during the course of an afternoon. A pro-forma was then completed leading to a comprehensive care plan. Feedback from both patients and staff was reported to be positive.

There was a variety of examples given in the interviews of written referral systems. In one hospice any worker could complete a referral card or pass it on to someone who wished to self-refer. The card asked for basic contact details and the reason for the referral, for example practical advice like housing, benefits or for an emotional or counselling assistance. These referral cards were dealt with as they came in, although

there was a formal allocation session once a week. One hospice had moved from a paper referral system to an electronic system whereby all new referrals came to the palliative care social worker.

One community based palliative care service team comprised nurses, occupational therapist and the palliative care social worker employed a duty system whereby each member of the team took it in turn to spend a day receiving phone referrals from various sources including general practitioners and hospitals. It was believed that this ensured a good quality of information on referral. Approximately 4-8 referrals were received daily. The referrals were allocated the next day at a team meeting according to the identified need and issues regarding complex family dynamics, children and benefits were passed to the palliative care social worker. One palliative care social worker based in a hospital visited the appropriate wards twice a week to discuss all the patients with the senior ward staff.

There was also an example of 'care review meetings' at an in-patient hospice (which had previously been called 'family meetings'). On admission, patients would be invited to nominate one or more family members to attend such a meeting to be held a few days later, the purpose being to discuss aspects of care important to the patient and family. These meetings were seen as low key and would normally be attended by the patient, a nurse, sometimes a doctor and facilitated by the palliative care social worker. If there were children under 18 years in the family, then issues about their care could be discussed.

Referrals from other health professionals external to the agency, such as district nurses, general practitioners and outreach workers, came mainly by phone.

Informal referrals

One palliative care social worker in a focus group described the informal approach used in a hospice:

> Most of the work I pick up in this unit is when the nurses will say [to a patient] we have someone from the family support team do you want to say hello to? And I go along, or I meet people in the kitchen and I set up formal situations, but sometimes it is a bit tricky.

Here I understood 'tricky' to mean that not all people welcomed the worker making such a direct approach. Spending time on the wards and routinely meeting families that come through the hospice were recognised as positive ways to proactively engage with people but time was not always available for this to take place. This was easier within in-patient hospices or day hospices, less so in community services. There were examples of patients and families being referred to the palliative care social worker 'in passing' by a doctor or nurse. This apparent 'hit and miss' approach seemed to be an acceptable process. Informal meetings with the family of an in-patient were also described where a palliative care social worker and nurse together explained what the hospice could offer.

Information received on referral by palliative care social worker

The quality of information received varied due to the formal or informal nature of the referral. Genograms appeared to be widely used by nursing staff during the admission process and were considered to be a helpful tool. However, their lack of completeness in terms of names and ages of children was occasionally criticised by palliative care social workers.

Referrals post-bereavement

Whilst this was not a focus of the study, there was evidence of a more pro-active service being offered post-bereavement. Families were contacted and provided with information

about the counselling services available, which in some agencies included those specifically for children and young people.

Palliative care social workers' views about the referral process

The general view was that palliative care social workers were clear about their role in the referral process. Their comments about the appropriateness and timing of referrals, as well as what might influence service users in accepting or refusing help, are analysed below.

Appropriateness of referrals

The widespread view was that referrals were generally appropriate and it was clear that families were not referred to palliative care social workers solely because there were children under 18 years. One worker explained:

> I'm not going to push myself to get involved unless it is clear that there are needs.

Workloads varied due to the nature of the referral process. It was rare for palliative care social workers not to accept a referral and it appeared that there were no waiting lists in operation. In those agencies where there was more than one palliative care social worker, referrals were allocated at their own team meeting, or earlier if the referral was judged to be urgent.

Timing of referrals

One worker commented on the difficulties where, for example, referrals were not made to the specialist palliative care service in 'good time'. This in turn tended to leave a referral to the palliative care social worker almost too late for work to be productively undertaken with the family. There were reports about nurses who, because of their ability to hold on to the 'difficult emotional stuff', tended not to seek advice until matters had come to a crisis point. This again could mean leaving a referral too late for the

palliative care social worker to help sort out child care concerns, especially legal matters such as guardianship.

Service users accepting or refusing help

There was a recognition that the stress parents were under might influence how they perceived the possible involvement of a social worker. It was the general experience of those interviewed and in the focus groups that many parents appeared unhappy, worried, anxious and fearful about the thought of seeing a social worker, and some 'reeled back in horror' at the suggestion of doing so. Often, parents were described as 'resistant', refusing any help offered by a social worker because they were anxious that, as a result, their children would be taken away. This resistance was reported to be particularly noticeable in families where there were current problems or a history of abuse or domestic violence. One palliative care social worker explained her way of managing such a situation:

> I have a title 'Macmillan social worker' and sometimes I follow up by saying 'I haven't come to take the children away'. And I will do this quite light-heartedly because some people have had awful experiences.

A worker in a focus group gave her explanation for the reluctance to take up the offer of help:

> The most complex and vulnerable families are the families that are the least able to take your services, not always because you are a social worker but because they are so overwhelmed with other issues in their lives.

Others considered that perhaps parents might be concerned about 'letting the floodgates open' or they were feeling that they were coping and doing the best for their children.

There were also comments on the issue of parents 'gate-keeping' their children's accessibility to services in relation to childhood bereavement because of their fear that

social workers may be disapproving of aspects of family life which might be revealed. However, if a palliative care social worker had concerns about a family situation, one route was to keep in touch with other team members who did have contact until such time as the family might be prepared to accept help.

In contrast, there were those palliative care social workers who believed that if they were 'taken along' by the nursing staff, introduced to the patient and then explained what they could offer, they were not seen as a threat and their services accepted. Indeed, one focus group member explained her experience:

> I've seen parents who are relieved when we know things are wrong regarding the children and we have stepped in - they have not had the capacity to do anything. The relief is on the parents' faces when someone has had the courage to say - 'I'm concerned about your children'.

There were also those who considered that their services were often 'sold' to the family by nurses in particular who would say to family members: 'Our social workers are different', compared, presumably, to the negative public image of local authority social workers.

Use of the title 'social worker'

There was a difference of opinion between palliative care social workers in the focus groups about how they should describe themselves to family members, particularly at the point of referral. There was a recognition that although it may be a barrier, referring to themselves as a 'social worker' was a more honest approach that defined their profession. For example, one palliative care social worker commented:

> I do stick resolutely to the title of social worker. We are not going to be ashamed of it. We will work through that prejudice and it is often the nurses who are introducing the idea of myself to families and they do struggle and they say 'can't we call you something else?'. And I say 'no, that's what we are and it's deceitful to go in on any other platform.

In saying this, the palliative care social worker demonstrated a very strong sense of pride in her profession. Another supporting view was that if the title social worker was not being used it was somehow 'fudging' the issue, misleading people and denying their social work profession. One worker explained that when using the title 'social worker', she would make it clear that she was employed by the hospice rather than the local authority because in doing so 'they trust you that bit more'. Another described the dangers of being 'too pally' with the family and the need to define the boundaries, a view supported by others.

In contrast, there were workers who, because of the many negative first reactions of families to the title 'social worker' and the refusal to take up services, had changed their title to 'family support worker' finding that this was a more neutral term that appeared to relax family members. However, parents had on occasion been found to see this title as threatening too. One person described how they might 'emphasise the counsellor bit and sometimes emphasise the social worker bit' or 'play down the social worker bit' depending on the circumstances. Overall, across all three focus groups there was a mix of titles used, with the title 'social worker' being used by about two thirds. In the interviews two of the seventeen had job titles of 'family support worker' and in the survey approximately 90% had social worker in their job title. However, one interviewee whose work title was 'social worker' explained that she introduced herself to families as a 'family support worker' and another whose title was a 'family support worker' who made clear she was a social worker when contacting outside agencies believing that this made her status more clear.

Discussion

There is minimal research regarding referrals to palliative care social workers in general (Beresford et al. 2007). This study highlights the complexity of such processes where

there are concerns about children and the influence of, and the dependence on professional values, personal beliefs, intuition and knowledge, as in child protection generally (Dent and Cocker 2005:153). The findings in this study show that palliative care social workers are very dependent on others, mainly health professionals, for referrals to their service. This gatekeeping role was also identified by Beresford et al. (2007) in their study of palliative care service users. They also found that social work support was offered in an inconsistent and non-systematic way before a person died compared to a more systematic and proactive way post-bereavement. Whilst being dependent on others for referrals is true for social workers generally, this study highlights particular issues for palliative care social workers.

Record keeping itself was not a specific topic in the interviews. There was no mention of an audit of referrals regarding child care concerns or the involvement of palliative care social workers with families with children. It is therefore difficult to estimate with any accuracy the amount of involvement that occurs. There was also no mention of numbers of users of the specialist palliative care service with children to know the proportion of those referred to palliative care social workers. Overall, there was no evidence of social work support being offered consistently or systematically, but neither was there evidence to suggest that workers turned down the referrals that were made to them.

Palliative care social workers are part of a system: the change agent system (Pincus and Minahan 1973:54). As already stated, whilst this study did not explicitly examine the workings of palliative care teams, it became apparent that how they function can impact on the referral process. The differences between multidisciplinary and inter-disciplinary teams were explored in chapter two. The findings here suggest how the role of the palliative care social worker may be compromised by the dominance of the medical approaches to palliative care and to a limited understanding of the social work role within the team as suggested by various authors (Oliviere 2001; Firth 2003; Raymer and

Reese 2004; Beresford et al. 2007). Whilst the differences in professional cultures and values impacting on inter-professional working described by Fitzsimmons and White (1997) were evident in the current study, there were also descriptions of workers displaying 'professional adulthood' (Laidler 1991 cited in Molyneux 2001:33). Palliative care workers in Beder's study (2006:53) described themselves as the 'emotional arm' of the team. The findings here showed that workers who regularly raised questions in the team about the presence of children saw it not only as their duty but also as a way of helping the other professionals to recognise the needs of children. In these situations, palliative care social workers spoke of being sufficiently confident in their own roles and professional identity to work productively with other team members, sharing ideas and expertise, particularly in situations that involved children. They were therefore viewing their own agency as targets of change and trying to change the system from the inside. They are not, however, able to stand apart from their own system and have to recognise that their ongoing relationships with colleagues and status may affect, and be affected by, their efforts to bring about change.

In Sheldon's (2000) opinion, working with people who are dying can bring emotional distress and anxiety that has been described as 'hard work' for all the people involved, including professionals (James 1993). Adding the dimension of children to this already stressful situation could be experienced as an extra burden to the staff involved. One way perhaps for staff to deal with this would be to focus on the patient rather than consider who else may be affected within the family. However, this approach would be contrary to the ethos of palliative care, which is clear about the place of the family within the care umbrella (WHO 1990), and does not appear to recognise the concept of family systems. Nevertheless, how each palliative care team interprets the 'total care' ethos can be expected to influence how the individual professionals practise. The findings here reflect a range of interpretations and practice in the referral process.

Confidentiality as a barrier to sharing information within the team (Egnew 2004) was not raised as an issue in this study. This is a little surprising in comparison with other adult services, for example in drug services (Taylor and Kroll 2004), but perhaps the holistic approach of palliative care allows for a sharing of information.

Of all the staff involved, nurses were the main source of referrals regarding child care concerns because of their initial and ongoing contacts with the patients, both in the hospice and in the community. Nursing staff, therefore carry a responsibility for ensuring that children do not lose out on appropriate support at a critical time in their lives. Their ability to look beyond the patient and pick up issues about children may be dependent on several factors: awareness, knowledge and confidence. A study conducted by Heaven and Maguire (1997) found that hospice nurses failed to pick up or register correctly both emotional concerns and those concerns that were important to the patient. It is perhaps more understandable in the hospice setting for nurses to be less aware of children where it might be a question of 'out of sight, out of mind'. However, for those in the community, it would be reasonable to expect that there would be tangible reminders of children in the home, either through their direct presence or through toys and photos. There was evidence in this study that nurses were 'child aware'. The completion of a genogram, something that appeared to be a regular part of the assessment process (to be discussed in chapter nine), can raise awareness of the existence of children and used as a starting point for discussion with the patient (Oliviere et al. 1998). Research would suggest however, that medical practitioners do not always feel equipped or competent to engage in conversations with children themselves nor with the parents about how they might communicate with their children (Turner et al. 2007; Fearnley 2010).

In order to work productively together, professionals should understand not only their own role but that of the other professionals involved. Barriers to making full use of the

palliative care social worker by medical and nursing staff were discussed in chapter three (Reese and Sontag 2001). The debate around the title of social worker is interesting in this context. There is evidence from other studies that the social work role is not always well understood by health professionals (Bywaters 1991; Davies and Connelly 1995; Bliss 1998; Bliss et al. 2000). However, these studies were generally considering professionals who worked for different agencies such as district nurses and social workers based in social service departments. Here the opposite was true; the professionals were working for the same agency and yet there were still difficulties. This lack of understanding might lead to some professionals not always being helpful or knowledgeable about referring people on to a palliative care social worker. There may be 'competition' between nurses and social workers; nurses believing that they can take on the psychosocial roles and social workers perceiving that they were taking over their duties (Reese and Sontag 2001; Hudson 2002). There was evidence in this study that rather than being on equal terms palliative care social workers believed that they were perceived as an 'internal consultant' or 'resource' (Monroe 1998; O'Connor et al. 2006). Nurses, especially those in the community, were seen to have overlapping competences and shared responsibilities, sometimes welcomed though sometimes not. Such overlaps are referred to as 'role blurring' (Falk 1977 cited by Hall 2005:192; Sheldon 2000; Reese and Sontag 2001) which was evident here; this may be positive where the focus is rather on the needs of the patient and the family (O'Connor et al. 2006).

The value that palliative care social workers themselves place on the significance of safeguarding the needs of children can also be expected to affect whether or how they influence and encourage team members to raise concerns. In addition, how much confidence palliative care social workers have in their own level of knowledge and expertise in working with and for children may also have a bearing on their

encouragement of such referrals in this area. These aspects will be discussed in future chapters.

Conclusion

This chapter has examined the issues relating to the referral of families to the palliative care social worker where there are concerns about the children. The findings revealed a complex process, frequently affected by professional roles and team functioning which has not previously been addressed in the literature. Nursing staff were the main source of referrals and although the numbers fluctuated they were generally low. However, just because there is a child in the family, it should not be assumed that there is a need for a social worker to be involved. What is perhaps required is for professionals to be alert to the needs of children and for there to be an enhanced understanding of the role and expertise of the palliative care social worker so that families and children who do require support do not 'fall through the net'. There is evidence in this study that palliative care social workers do take it upon themselves to remind other team members to be 'child aware'. The next chapter will examine the process of the palliative care social workers' involvement once a referral has been made.

Chapter Nine

The role of the palliative care social worker:
the work they undertake with children and their parents

Far more people are affected by disease than are infected by it.
Anderson 1995

Introduction

In the previous two chapters I explored how palliative care social workers perceived

their role in safeguarding children and how children came to their attention. The first part

of this chapter explores how workers viewed their engagement with children and their

parents and identifies the key themes of the work they described in the interviews, focus

groups and survey. The second part illustrates the process of their involvement through

the presentation of five practice examples taken from the individual interviews. These

examples illustrate the key themes as well as the breadth and depth of their work and

highlight some of the dilemmas and tensions that it brings. The third part contains an

analysis and discussion of the process of the work undertaken by palliative care social

workers with children and their parents. It also focuses on the practice approaches to

this work as well as on the organisational constraints, ending with a section on how the

immigration status of families can impact on families and the work.

Engagement with children and parents

The palliative care social workers considered that the starting point for their work should

always be with the parents. There was a predominant view that it was important to

support the parents, working with them first rather than immediately becoming involved

with the children, if indeed at all. It was recognised however, that parents, in dealing

with their own grief, could be struggling to help children cope with theirs. Finding out

about the parents' awareness of the children's needs, how much the children knew,

what they might be experiencing, any changes in their behaviour and, what supports

were already in place were all considered to be part of the palliative care social worker's initial assessment of the situation regarding their children.

As discussed in chapter seven, this capacity 'to juggle different needs and vulnerabilities' was widely considered to be an important aspect of the work. This meant that when working with the family as a whole there was a balance to be struck when considering the needs of the individuals within the family whilst, at the same time, respecting the wishes of the dying parent. This was considered to be particularly evident in circumstances where either a child did not know about the illness, or knew about the illness but not its implications. One worker ruefully commented that she knew 'she will only get one shot at it' when visiting some families, as it would be too painful for them to ask her back.

Involvement with children

As discussed in chapter four there has been a growing emphasis in policy documents, literature and research regarding the need to hear the voice of the child. Whilst many palliative care social workers said obtaining children's views was important, there was a limited amount of reported direct work undertaken by palliative care social workers with children and young people. This came as a surprise, as it did to Beresford et al. (2007) in their study because, over the years, palliative care social workers have been reported as developing services for children (Monroe 1998; Oliviere et al. 1998; Chowns 2006). The amount of direct work seemed to depend on agency policy, general circumstances and the preference and confidence of the worker, as well as the willingness of the parents and children for the work to take place.

There were barriers to direct work being undertaken. In one hospice, the worker felt that she was not encouraged to work with children; in another, the worker was told that she was a social worker for adults and should not undertake work with children. A few

workers commented that they tended not to even see children unless they came to visit their parent in the hospital or hospice during the day and that there was little opportunity to meet children of day patients unless a home visit was specifically made. Community-based workers were generally only able to see school children if home visits were made during holidays or after school hours. No one claimed that they were uncomfortable about working with children, although there were some who stated they preferred certain age groups. It could be that workers did not wish to become too involved because of the emotional distress it might cause them, preferring to only work with the parents although this was not stated directly.

One worker commented that although children were not her 'special interest', she was happy to work with the family but would pass any direct work with children to the children's worker in the hospice. Another worker, based in a hospital, who was not so confident about work in this area, referred a father to a palliative care social worker in a nearby hospice for advice about how to tell his children that their mother was dying.

Most of the work with children would best be described as informal; for example, seeing children, particularly young ones, when visiting the family home or showing children round the hospice. Observing a child in their home allows a worker to see that child in context, providing the opportunity 'to enter the child's world' (Helm 2010:56) and there were many examples given in the interviews and focus groups where observation had been an important part of the worker's assessment of the situation. One practice example shared in a focus group is a clear illustration of an observation process:

> I think I would be looking at the way the children in the family are behaving and picking up clues about their behaviour to see if something is wrong and also observing interactions between parents and children. I can think of one case … where it's the grandmother who is ill. … She has responsibility for caring for her two grandchildren … and she is having tremendous problems with the behaviour of the younger child, and those problems seem to be around the lack of her

parenting skills. And we have come to the conclusion there are problems there just by observing the interactions between the grandmother and the child.

In the opinion of Sidebotham and Weeks (2010:96) all professionals who have contact with parents are in such a position to comment on their observations of parents' behaviour and interaction with a child. This should include positive as well as negative behaviour or interaction (Glaser 2002).

More formal engagement with children ranged from a single meeting to sustained work on an individual basis as well as joint work with their parents. There were examples of workers giving advice to children, advocating on their behalf, assisting them to re-engage with school, as well as helping children talk about their feelings. Workers stressed that it was important for parental agreement to be given before they became involved in any direct work with children. One worker remarked:

> I tend to prefer to work with the family rather than an individual child anyway because it tends to be about the family rather than the individual child.

A minority of palliative care social workers said they preferred to work indirectly with the children, through the parents. As one worker explained:

> I don't dive into direct work immediately (with children). I don't reach for the crayons and the paper. I reach for the adults in the situation. That is who the child knows best, that is the people who should be communicating with that child. The adult closest to that child should be doing that work and I will do it if they can't or won't or along side but empowering them is where I am at.

Another echoed this by saying:

> I feel strongly that you support the parent - no good doing games and interesting things with the child if the mum is sitting in the corner completely depressed because that is going to be the issue, that is going to make the difference for that young person.

Working with children was described by one interviewee as: 'hard work and time consuming work', referring in particular to the time it took to get to know the children. Another worker who welcomed the opportunity to do so, summed up her thoughts about working with children by saying:

> I think children are amazing - when you do get to talk to them their understanding surprises us and their ability to cope surprises you as well.

However, as stated earlier it is not suggested that every child of a dying parent will require professional help and support (Worden 1996) or is at risk of significant harm. Indeed, legislation emphasises that the rights and responsibilities of parents should be respected. What perhaps is required is an understanding about the lived experience of the children in the family, so that workers can feel confident that every assistance available has been offered. Palliative care social workers therefore should be alert to the cues and clues provided by parents, by the children themselves if seen, and by the environment in which they live, as well as professionals who have had access to the family. As Helm (2010:56) points out:

> It is not the child's responsibility to communicate their needs; it is the practitioner's duty to listen and use the means of communication and engagement that best allow the individual child to express their lived experience and needs.

Continued work post-bereavement

This study focuses on the work of the palliative care social worker prior to the death of a parent, but there were examples of practice where engagement, initiated before the death, continued afterwards. Sometimes the young person initiated contact, on occasion after a gap of several years. This was welcomed by the workers and was not seen as a dependency issue. Indeed, it highlights the value the children had placed on their previous contact and the importance of consistency and availability. However, whilst some palliative care social workers reported that it was possible for them to engage with

children directly prior to the death of a parent, not all were encouraged or able to do so afterwards due to agency policy. Rather, the workers' role was perceived as offering support to the surviving parent and other adult family members in order for them in turn to support the child in their grief. However, parents might not be in a position to do this due to a previously poor, neglectful or abusive relationship or they might be incapable for other reasons. Such support tended to be offered on a one-to-one basis and available for a period of up to one year, although some workers were restricted to a lesser period of weeks or months after the death. In some hospices there was a dedicated children's worker or specialist bereavement counsellors who could take on post-bereavement work with children. Children might be invited to join group activities with other bereaved children and in 'Remembrance Days'. Workers' views about organisational constraints on engaging in this work will be examined later in the chapter.

Key features of the work with children and their parents

Weaving through the descriptions of the work undertaken by the palliative care social workers with children and their parents were the following five key themes.

1   Children need to know what is happening

2   Planning for the future care needs of children is essential

3   Practical support is crucial

4   A family does not exist in a vacuum

5   Joint work with others can be beneficial.

1   *Children need to know what is happening*

An underlying premise to the work as described by the respondents was that children whose parents are dying should be kept informed about what is happening; a view widely supported in literature (Christ 2000; Chowns 2006; Christ and Christ 2006; Kennedy 2008). The general view among the respondents was that it was better if the

news about the illness and its expected outcome came from the parents themselves. However, if parents felt unable to do so, and studies show that parents do struggle to do so (Houldin et al. 2006; Kennedy 2008), then palliative care social workers explained that they would either be present to support the parents or, more rarely, would do the explaining in the parent's presence. Those workers who had been asked to tell a child about a death or impending death of a parent spoke of the emotional challenge involved.

The literature points to two main reasons why parents do not tell children: their belief that children are not aware of what is happening or are too young to understand (Beale et al. 2004; Christ and Christ 2006). This was supported by the respondents in this study. One interviewee described how she tried to encourage the parents to tell their children about their mother's illness and prognosis:

> They kind of accepted that the older boys needed to know but they just thought it was hilarious that I would suggest that the three year old should. They actually laughed out loud.

Workers recognised that for a parent to tell a child that they were dying was not an easy task and one described it as 'the most major thing for them to do as parents'. They saw themselves as facilitating these difficult conversations by finding out from parents what they believed the children already knew and understood, as well as the reasons for their reluctance to share information with the children. There were many reports from the participants of parents who were often unsure about how to explain what was happening to their children and therefore needed guidance. Both Barnes et al. (1998) and Turner et al. (2007) highlight these difficulties, particularly where a child has learning needs and behavioural problems. Palliative care social workers provided leaflets and other written material, including activity books and directed parents to relevant information on the internet. In an example where there had been a late referral

to the hospice, the children had been told that their mother was ill but not that she was dying. The palliative care social worker commented:

> …and this is very often the way. At every point up until the last treatment was stopped and she knew she was going to die, I think the family said things like 'the doctors are doing what they can'. You know those adult truths but they are avoiding the central truth which is that we all know that mum is going to die. Parents don't intend to put their children under this - they are trying to protect them from the awful news.

2 Planning for the future care needs of children is essential

There were children whose future care after the death of a parent, usually the mother, was uncertain, not known, not considered safe or, in dispute. These situations were usually where the mother was a lone carer. Palliative care social workers encouraged these parents to discuss the options in order to help them come to a decision, ensuring where necessary that it was legally secured. This might involve the palliative care social worker in negotiations with estranged parents. In one family, the worker, at the request of the mother who was dying, contacted the father who had not seen his children for two years. After many discussions he contacted the family, resumed contact and took over the care of the children when their mother died.

Palliative care social workers, however, may not always understand the importance of such planning or lack the confidence to engage in it. Not every palliative care social worker wished to initiate a discussion with parents about the future plans for their children. One worker stated:

> I think in a way I wait and see if people begin to drop clues about that [plans for children after parent dies] rather than being too proactive.

However, not engaging in such discussions could cause difficulties. It might be the case that a parent was putting off making a difficult decision but postponing it could cause uncertainty for the child and lead to a lack of preparation for all parties concerned and

there were examples where this had occurred. Nurses who had been working with the family might leave a referral to the palliative care social worker regarding legal matters too late for wills to be discussed and completed, particularly in relation to the future care of children. A worker wrote:

> At times my colleagues and I feel a great sense of <u>urgency</u> [respondent's emphasis], especially re future planning/guardianship, as we are keenly aware of short prognosis for some clients, yet a significant number are not able to make plans.

3   *Practical support is crucial*

A further significant aspect of the work concerned the family's living circumstances. Many families were described as living in poor accommodation and struggling financially, which could lead to their sense of security becoming even more threatened (Walsh 2005). Parents who were no longer able to remain in employment due to their illness or caring responsibilities often had extra financial burdens as a result of treatment. Mcleod and Bywaters (1999) draw attention to the health inequalities and how already marginalised groups face extra difficulties in the event of ill health. Palliative care social workers recognised that these difficulties could inhibit a family from engaging with the more emotional aspects of care resulting from the illness. This in turn could impact on the parents' care of the children. One worker summed it up by saying:

> I am a firm believer that you can't get anyone to sit down to talk about their feelings if they have no roof over their head or no food.

Children's lives are not only affected by the immediate financial position of the family but also by other resources to which the family has access such as housing and community resources (Jack and Gill 2010).

Palliative care social workers generally do not hold budgets and therefore could not offer direct financial support but were able to apply for funding from relevant charities.

They also offered advice and practical support which included assistance related to care packages, housing, benefits, education and immigration status. A worker described her role as:

> A Jack of all trades - filling in a form one minute and doing intensive therapeutic counselling the next.

4   A family does not exist in a vacuum

Chowns (2006) and Rolland (2005) observed that children and their parents were not only part of a family system but other systems too, and these may impact on the way they cope during the period of illness and post bereavement. This is evidenced here through the workers' explanation of the process of individual pieces of work or by direct general reference, as one interviewee commented:

> It is very much looking at individuals as part of a system and the roles that they play, which is why I wouldn't put a false demarcation around family members - they are all part of the patient's system - and that would include the school, the church, just that sense of network.

Palliative care social workers helped parents to negotiate the health and welfare systems upon which they depended. Indeed, workers saw liaison with other agencies to be an important part of their task. Within the family system, other relatives may be involved in the current and future care of the children as well as family friends. These relationships were generally positive, but on occasions were seen to be unsuitable for children or causing difficulties. Mention was also made of a family's cultural heritage and religion having an influence on family functioning as well as creating challenges for the worker in finding appropriate resources to meet the needs of parents and children. There were also examples of families who faced particular difficulties in ongoing negotiations with and appeals to the Home Office because of their immigration status and these will be explored later.

5 *Joint work with others can be beneficial*

Palliative care social workers provided many examples of productive joint work where they and others became the action system to achieve the goals (Pincus and Minahan 1973). A common area was work in conjunction with other members of the multidisciplinary team. Such work included visits with nurses to families in the community, the running of family meetings together with medical and/or nursing staff, participating in a joint assessment process and, participating in case discussions at the team meetings. These activities allowed team members to draw on each other's knowledge and skills and to keep a wider perspective. The occasions when children were invited to live in the hospice enabling them to spend more time with their dying parent was very much a combined venture for all the staff in the hospice. There were examples too of successful joint work with local authority child and family social workers and education staff that enabled children's needs to be met in a satisfactory way. The relationship between palliative care social workers and local authority child and family teams will be explored in chapter ten.

Practice examples

In chapter six, I illustrated the children's experiences of living with a terminally ill parent with brief scenarios from the workers' stories. Here, in order to illustrate the key features of the work undertaken by palliative care social workers with children and their families such as those described in that earlier chapter, I have chosen to present five practice examples. However, selecting five out of the forty five was not an easy task because all the stories were important in different ways. The examples here are selected because they include children in differing circumstances, illustrate different approaches and a range of practice. Several involve direct work with children, which is slightly unrepresentative as just under half of all the practice examples involved working with children directly. They also highlight some of the complexities, dilemmas and tensions in

the work. I will explain why each has been chosen before giving an account of the work undertaken as described to me by the palliative care social worker during the interview. Names have not been used and details have been removed or altered to ensure anonymity and confidentiality. Care has been taken to ensure that this does not detract from the process as described.

Family A

This example was chosen because it exemplifies a palliative care social worker taking a family systems approach, gaining an understanding of the boundaries and hierarchies (Mehta et al. 2009) by working with parents, with children and parents together, and also with children on their own. The palliative care social worker here interpreted her role to be a supporter to the parents, listening to their concerns about their children, observing the children's behaviour, and forming and carrying out a plan of work that involved herself and other professionals. It is an example of contact maintained over a longer period of time than perhaps is usually the case and of a palliative care social worker exhibiting confidence in her work with children.

> A community nurse specialist had been visiting a family where the father had cancer and had been undergoing treatment. He lived with his wife and two primary aged children. The parents had asked for advice and guidance about what to tell the children and so the nurse passed the request on to the palliative care social worker.

> The social worker's initial impression of the children was that they were polite but exhibited hyperactive behaviour which the worker described as chaotic. The father explained that he could be aggressive at times due to a reaction to his medication. Both parents were very worried about the children and felt that they could not do

anything to manage their behaviour and consequently had lost control of the situation.

During her visits, the social worker set up a pattern of seeing the couple first, then the family as a whole and then the children individually or together and finally back to the family. Her real concern was the younger child who was 'acting out', being very confrontational, trying to shock by use of language and outrageous behaviour. The social worker was very worried about the child's mental health. She asked the parents' permission to contact the psychological services, which was given, and the social worker prepared reports. The child was offered help and the social worker continued to meet with the family. After several months, the child had calmed down and was performing well in school.

The social worker continued to work with the family, reducing her visits to about every 5-6 weeks. Family members were now more able to talk to each other and managing to cope with their problems. Both children had responded well to the social worker throughout her contact with them and they very much wanted her to continue seeing them.

When reviewing her work with the family, the social worker explained:

> I was feeling a bit overwhelmed in there at one point and was really glad that [the child] had somewhere else to go. … I know I was the catalyst for getting that moved so much quicker.

Family B

This example shows a palliative care social worker involved in the future planning for a young boy normally cared for by his grandparents. The palliative care social worker

engaged with the adults involved both individually and as a group in a family meeting. The example illustrates collaborative working, on this occasion with a doctor who was part of the multidisciplinary team. It shows how a family's previous negative experience of social work can act as a barrier to engagement with a palliative care social worker, and how engaging in memory work can ensure that a child receives a more rounded family history.

A grandmother, the main carer for her grandson, aged 9 years, was a hospice in-patient. The ward staff had referred the grandmother to the social worker because they were aware that she was concerned about the future well-being of her grandson. When the social worker began to talk to the grandmother it transpired that there had been many past difficulties. He was four years old when he was moved from his mother because of her lack of care. The mother had since died and the whereabouts of the father were not known. The local authority were involved and did not want the boy to stay with the grandfather but to live with an aunt and uncle, and for this to happen before the grandmother died. The timing of this planned move had made the family angry and distressed.

The social worker first had to gain the trust of the grandparents because they associated her with the local authority. The social worker considered it was not her place to tell the grandparents what to do but to encourage them to look at the issues. The grandmother was concerned that the family would not in future talk about the child's mother in her absence. The grandmother explained to the social worker about her wants for her grandson and her concerns about her husband. She agreed her husband was not able to look after their grandson.

The social worker described how both she and the doctor spent time with the grandmother talking over her concerns. The social worker helped the grandmother make memory boxes for her grandson that included material about the boy's mother. The idea of holding a family meeting at the hospice was raised at a multidisciplinary team meeting. It was proposed that the social worker and the doctor would facilitate the meeting to help the grandmother talk about her concerns. The grandmother was in favour of this idea. Both grandparents and the aunt and uncle attended. The grandson had not been invited but knew the meeting was being held and the basis of what was being discussed. The social worker had briefly met the grandson and was aware that he too had negative views about social workers.

At the meeting, it was agreed that the grandmother should return home, the grandson spend increased hours with the aunt and uncle and the grandfather collect him from school. Social services were to be informed of the plan. However, the grandmother's health deteriorated very quickly and she died the following day. The social worker remained in contact with the family. The grandson had moved to live with the aunt and uncle, remained in the same primary school and had daily contact with his grandfather who continued to play a major part in his grandson's life.

When I asked the social worker what she thought of the outcome she said:

> … disappointment - in that we were not able to facilitate the plan we had put in place ... I think it was probably successful and I think the family meeting had joined together not a fractured family but a family where there were issues ... so there was stability there for the child. That was our main concern.

Family C

This example is again one where direct work was undertaken with the children before their mother died. It illustrates how the palliative care social worker, restricted by agency

policy regarding 'post-bereavement' support to children, chose to be flexible in her approach. The emphasis here was very much on the needs of children in a family where there has been a history of domestic violence.

The social worker first met the family when the mother was dying at home. She had been asked to visit by the community nurse because of child protection concerns. There were two teenagers living at home. A single older son lived nearby. The family had been known to social services because of a history of domestic violence.

Shortly after the initial contact, the mother was admitted to the hospice as an in-patient. The social worker came to know the children quite well and talked to them about their relationship with their parents. The youngest was particularly close to her mother but hated her father because of his violent behaviour.

In the light of this, the social worker met regularly with the father trying to balance her own working relationship with him and with the children. The youngest child very much resented this. The mother had previously refused to believe how ill she was and had not made provision for the children and there were no relatives who could help. The mother became very withdrawn and when she died the children were very distraught. They invited the social worker to attend the funeral, something she did not do on a regular basis, but did on this occasion to support them. As the hospice did not offer bereavement support to children under the age of 18 years, the social worker was unable to continue supporting them directly; something she felt very unhappy about particularly in this instance. However, she was able to provide bereavement support to the father and chose to visit him at his home so that she was better able to monitor the situation.

A little while after, the social worker received a distraught phone call from the older child who said his father had punched him and he wanted to run away from home. The social worker contacted the local authority duty team and also the older son who agreed to take his brother for the night. Shortly afterwards, he returned home saying he did not have much choice but it was better than being in care. The social worker again had to explain to the children that she was no longer able to work with them and liaised with the local authority social worker.

Some time later, the younger child called the social worker to say that her father had physically hurt her. The social worker contacted social services and asked them to follow this through. According to the procedures of the local authority concerned, the social worker should have been kept informed of the outcome; she felt let down when this did not happen.

There was further contact when the social worker later received a phone call from the younger child's school. Apparently the child was in a distressed state, had become quite depressed and did not want to go home. Once again, regretfully the social worker said, she had to direct them to the local authority and reflected:

> I find that a dilemma sometimes, getting children to work with me closely, to trust me, knowing that I can only take things so far.

Family D

This example highlights how a late referral to palliative care can create difficulties in making future care plans for children. In this situation the parent was a lone carer and the family's situation illustrates the complexities of negotiating and liaising with various local authority services to secure supportive services for the children. It also shows the

importance of considering the children's views as well as those of the parent and demonstrates how a family's resilience can be enhanced once support is provided.

A lone mother had been receiving treatment for cancer. Her condition had deteriorated and the hospital had consequently referred her to specialist palliative care services. The community nurses visited and discovered that the mother was very ill indeed and in their opinion had only a few weeks to live. The family consisted of a teenage daughter who had not attended school for several months having stayed at home to look after her mother. An older son was still at school. The nurses were so concerned that the family was not prepared for what was happening that they asked the palliative care social worker to visit with them.

The social worker first ensured that all the necessary practical arrangements including benefits were in place. As the social worker came to know the family she learnt that the mother had become withdrawn over the past few years and had left the children to their own devices. The worker also realised that there was no father involved or any other family member who could help. The son appeared to be mature for his age, but she became particularly concerned about the daughter's future care.

The doctor explained to the mother that she was terminally ill and had only a very short time to live. Once the son was made aware of this he said that he wished to look after his sister. The social worker talked to the mother about her wishes for her children. The mother said that she also wanted her son to take responsibility for his sister. The mother had a few weeks to spend time with the children and to write down her wishes for them. The mother died a few weeks after the social worker became involved.

After many phone calls the social worker managed to involve social services. Education services organised specialist remedial input for the daughter. She attended school regularly and made good progress. Her brother continued to attend school and became the guardian of his sister with social services monitoring the situation. The palliative care social worker ensured that he received all the benefits available and negotiated with the housing department that he take over the tenancy at age 18 with the proviso that social services continue to monitor the situation in the meantime. 'Children in need meetings' were held after the mother's death, which the social worker attended together with the children. Bereavement support was provided for both children.

When asked what she now thought about the situation, the social worker explained:

> The son is so amazing, I have a lot of admiration for him and so determined from the beginning. I didn't know the mum that well and the kids, I think they are wonderful, just fantastic.

Family E

I selected this example because it illustrates a family coping with the threat of having to leave the UK once a parent has died. It highlights the importance of rituals surrounding a death and how a hospice was able to meet the family's requirements with the support of the palliative care social worker. There is evidence too of collaborative working among the hospice staff when the children were invited to stay in the hospice with their mother.

A terminally ill mother was living with her husband and two mid-teenage daughters. They had come to the UK seeking asylum and had been in the country for several years. The Home Office had refused their asylum application and as the appeal

procedure had been exhausted the family were to return to their native country. However, because of the mother's terminal illness, the Home Office had agreed that the family could remain until after her death.

When the social worker first visited the family with the community nurse, she was unsure how much the girls knew about their mother's illness. They encouraged the mother to tell her daughters but the mother refused. The girls were able to understand English but the social worker needed to use the services of a translator when talking to their mother. The social worker again explained to the mother that the girls needed to know and to have the opportunity to talk things through. The mother agreed, and when told, the children said that they had known all along because they had been reading the letters to their mother sent from the hospital.

The social worker visited the family regularly. The girls were attending school and enjoyed doing so. The social worker described the father as being very quiet; the children described him as a loving father. The mother's condition deteriorated and she was admitted to the hospice which, being some distance from the family home, meant the girls were not able to visit very often. When their mother was close to dying, the girls were invited to stay in the hospice. The social worker helped them to prepare memory boxes and the mother wrote letters for the girls. In addition, the children talked to the social worker about how they wanted to stay in the UK as they had come to see it as 'their country'. They said there were scared about returning to their relatives who had not been supportive to the family, although they were looking forward to seeing their grandparents.

The social worker linked with the school. The girls' friends came to visit them at the hospice. The social worker spent time with the girls talking and understanding about the cultural needs and requirements surrounding death. The social worker contacted

the Home Office asking for information about how long the girls could remain in the UK after their mother's death so that they could plan some bereavement work. The Home Office could not give a date and explained that decisions were made on a daily basis. The girls also wanted to write to the Home Office, asking for help from the social worker, which was given.

The mother died and the girls helped with the rituals involved in the preparation of her body. The social worker talked regularly to the girls on the phone and when she was unable to get in touch with them anymore assumed that they had left the country. She had attempted to find out if there were any resources or services that the girls could be referred to in their country of origin, but found it impossible to do so. About a month or two later she received a letter from the girls saying that they were all right and there was no need to worry about them.

When asked, the social worker explained how she had felt about her work with this family:

> I feel good about it because I think we achieved a lot. It felt like we could do work and we could prepare and the children were very involved and we could do things according to what their needs were. If the Home Office could just give us an indication, if we had a week or two in terms of planning. They could not bend the system and I think that is the frustrating part. With death and dying, life goes on without realising the impact and the additional needs for children at that time - just kind of seems it is not being acknowledged.

Process

What came through all the narratives concerning work with children and their parents was the importance of process. Process can be seen as 'a systematic series of actions directed toward some purpose' (Pincus and Minahan 1973:85). Process and purpose according to Pincus and Minahan are related concepts. To understand the process it is

important to know what determines the worker's purpose and how and why purposes change. The start of the process is the referral and initial engagement but what directs it subsequently is not only the relationships developed and the assessments undertaken, but the illness itself.

Impact of the illness on time available

Life expectation is not predictable, and for some their condition may worsen and they die sooner than was expected. This may mean that plans for the future care of their children have not been made or finalised or the wishes of the parent are not known, as in Family D. There were other examples in the study where this was the case. In one family, the mother unexpectedly died two weeks after the referral leaving a complicated family situation with no time for any assessment or planning which involved the mother. Palliative care social workers recognised that time was needed to assess the potential strengths of the family and its ability to change (Jackson 2000b). Oliviere et al. (1998:25) are also of the opinion that it is important to take time when assessing to ensure that 'one is not drawn into the strong emotion surrounding the ill person'. Time, however, was something that palliative care social workers frequently mentioned as a rare commodity in their work subsequently hampering their assessment of a family situation. This was graphically described by one worker:

> I think that one of the things that I notice about working in this environment, you have to think on your feet a lot of the time because you don't have the luxury of being able to do a thorough in depth assessment. And when somebody in the family is dying, then you know there are kind of much bigger issues that they are trying to deal with and so you are very much standing on the perimeter and just using all your senses in trying to make sense of what is going on. So rather than being able to do several visits, and talk about this and play with the children and see what kind of level of development they have - I don't think you always have the time to do that.

Consequently, this is particularly true for palliative care social workers who may be going into situations where they do not have the luxury of postponing decisions until they have a wealth of information; they 'must often act on the basis of incomplete information' (Pincus and Minahan 1973:103). A sudden deterioration in the patient's condition can lead to minimal information being gathered. Assessment and work then tends to be intensive (Trevithick 2005).

If there was an early referral to the palliative care service and then on to the social worker, there was more opportunity for the worker to be involved with the family as in Family A. This was regarded as positive, particularly for those workers who wished to encourage parents to be involved in making memory boxes (to be discussed later). It also allowed the worker opportunities to help the parent or parents make plans for the children both in the preparation for the bereavement itself and care arrangements post-bereavement.

An earlier than expected death can also have an impact on the process of the engagement. For example, in Family B, the process of holding the family meeting was important in terms of clarifying what was to happen, when and why. Although the grandmother died the next day and all aspects of the agreed plan could not be put in place, this did not detract from the importance of the meeting itself. The lady died knowing that the future of her grandson was clear, her views about the importance of family history heard and respected and, family relationships repaired. In Family D, where the mother was very ill when the worker first became involved, the emphasis of the involvement, after immediate practical help was given, was to ascertain the wishes of the mother and together with her and the children begin to make plans for their future.

Building relationships and trust

Having a good relationship with a client in social work has historically been important (Beistek 1961; Harlow 2003) and essential to good practice (Trevithick 2003). According to Sudbery (2002:151), the primary resource in social work practice is the social worker and 'their use of relationship'. This 'relationship' was seen as 'the primary tool' in social work in the 1970s, but increasingly and particularly within the statutory services, building relationships and trust is now less possible due to the ways in which services are delivered (Parton 2008:258). This was highlighted in Family B where the family felt let down by the local authority worker and in Family C in regard to the children's fractured contact with the child and family team. Howe (1998:45) believes that the value of building relationships has become 'confused and ambivalent'. However, Cree and Davis (2007) found in their study that carers and service users wanted workers who would listen, treat them with respect, as well as seeing them in the context of their families, as the palliative care social worker demonstrated in Family B. Indeed, in palliative care there continues to be an emphasis on the service user being at the centre and the need to have a holistic approach to practice (Oliviere 2000). Service users in palliative care themselves place great emphasis on the relationship element of practice (Beresford et al. 2007). Mullard (2005:55) writes about the importance of 'presence' - the unseen therapeutic relationship in palliative care that requires an openness of all the participants involved. Other studies (Howe 1998; Leigh and Miller 2004) have found that service users generally value empathy, good listening skills, humour, respect, warmth and honesty in their social workers. From the way the palliative care social workers in this study spoke of their relationships with the families it was clear that they strove to achieve these qualities and is particularly evidenced in the practice examples described above.

One of the essential features in each of the practice examples given in the interviews was the importance that the workers themselves placed on building relationships and

trust as opposed to going in to a family situation and being directive. There was, for example, clear evidence of the social worker working in partnership with the parents in Family A and after time with the grandmother in Family B.

Getting to know families during such a time of stress and distress could mean that palliative care social workers might become very close and emotionally involved. It became apparent across all the practice examples that in some circumstances, often in their encounters with children, the worker was viewed as a friend, as in Family A and particularly in Family C. This finding resonates with those in the Beresford et al. (2007) study. Where this was raised specifically, workers stressed the importance of reminding people of their role and maintaining boundaries. One worker summed it up by saying:

> In the past some people have said you are kind of a real friend and I am always careful to say that is really kind of you. It's nice in some ways that you can see me in that way but actually I am a social worker and I am coming from the hospice and this is what I do - this is my supportive role and try to put that boundary back on it because I just worry when kids do say - oh you are not going to go away are you - you will always be around and I am sure what they are doing is stating their fears for the future.

This may also demonstrate the particular value children place on having someone outside the family for support as research in chapter three indicated.

Literature supports the view that working in partnership with parents is generally considered to be beneficial (Thoburn et al. 1995) because of the link to better outcomes for children (Department of Health 1995; Cleaver 2000). This was evident here, for example for the children in Family A. However, the picture of partnership is less clear in Family C where there were issues of domestic violence within the family. Here, it appears that the worker endeavoured to work alongside the father in an effort to obtain better relationships within the family but there is no sense of a partnership. Indeed, in this situation a directive approach with the father might, from the outside, seem to be

warranted in order to safeguard the children. In Family D, the mother died a very short time after the social worker became involved and there was no father present, but a partnership evolved instead with the adolescent children. In Family E too, there was more of a partnership between the worker and the children than with the worker and the parents. For the mother, there were perhaps language difficulties as it is not clear how this was managed in the hospice. The father is portrayed as a caring person but there is little evidence of a working relationship between him and the social worker. This could have been due to cultural or language issues, or the lack of opportunities for the worker to see the father, rather than to a low value being placed on the need for engagement.

Involvement with fathers

There were proportionately more examples given in the interviews, focus groups and survey of situations where mothers were dying. In the interviews, for example, the ratio of fathers to mothers dying was 1 to 2.3. Views were expressed by the palliative care social workers about the different losses there might be if it was the mother, rather than the father, who was dying. One worker in an interview commented:

> This may be sexist, but if the mother is dying, I just think it is a bigger impact on perhaps the emotional, not necessarily the financial. I just tend to think that children grieve very differently for a mum than a dad.

Mothers seemed to be regarded as the lynch pin of the family and whilst there might be financial difficulties after the death of a father, it was considered that there were more chances of the emotional and practical concerns being managed. Studies have shown that fathers may be less likely to be aware of their children's emotional state and children may be less likely to talk to their father (Kennedy 2008). This could be because mothers are generally seen as the expressive leaders of the family (Cohen et al. 1997) and children generally behave more obediently towards their fathers and hide their emotional state from them (Visser et al. 2005). Studies have also shown that fathers are

less likely to offer closeness and support (Cawson et al. 2000). Three workers in this study specifically described how, when a mother was dying, they would be looking to see what the relationship was like between the father and the children. One gave her reason for doing this:

> … as fathers fall roughly into two categories - either they are really going to rise to the challenge and be brilliant or, they are useless.

Mothers, it was assumed, were used to the caring side; fathers, it was thought, struggled with this aspect and tended to put their own needs above those of the children. These views seem to reflect the more traditional views of the roles of mothers and fathers, men and women (Featherstone 1997; Turney 2000; Christie 2001; Featherstone 2003). They also support the view expressed by Daniel et al. (2005) that gender divisions in parenting are still present and that gender assumptions about parenting roles appear to continue (Daniel and Taylor 2006).

Daniel and Taylor (2005) wrote about a recent 'explosion' of interest in the role of fathers together with a recognition that mothers tend to be the focus in child care and child protection work. Indeed it is mothers, not fathers, who are considered to be the perpetrators of child neglect based on the breakdown of nurturing, historically attributed to mothers (Scourfield 2003; Daniel and Taylor 2006). There is also evidence of fathers not being involved in assessments and a general 'failure of policies, procedures and agencies to find ways of engaging with fathers effectively' (Gilligan and Manby 2008:183). Some men avoid social workers and health visitors which, Scourfield (2006:445) speculates, they see as 'women's business' and social workers and health visitors are criticised for concentrating on the mother (Daniel and Taylor 2001). If social workers in general see women as ultimately responsible for children and men 'as no use, irrelevant and as absent' (Scourfield 2006:443), was this also true of the palliative care social workers in this study? To what extent were fathers involved in the process?

Indeed, the telling of the stories rarely focused on the fathers unless they were the sole carers of children.

The five practice examples show different levels of involvement of workers with the fathers of the children. In Family E, for example, the social worker described him as 'very absent'. There was little evidence that the worker discussed the emotional needs of the children with the father, or in fact, the father's own emotional state and I failed to pursue the issue. The worker made reference to the fact that 'we involved Dad at some point' but did not make it clear why or what the outcome was. The emphasis of the work appeared to be with the dying mother and the children who were more readily accessible during the day and appeared to wish to have contact with the worker. In Family A, the father was at home during the day and so was available to meet with the worker. In Family C, the worker offered bereavement support to the father but there is no clear information about whether his behaviour towards the children was questioned or challenged in any way by the palliative care social worker. In Families B and D, there were no fathers to be involved, although there was limited involvement with the grandfather and uncle in Family B.

Assessment

Assessment has been described as being a 'crucial feature of social work' (Jackson 2000a:20) and 'at the heart of all good social work practice' (Watson and West 2006:30). In the Beresford et al. study (2007:62) the assessment process, as described by service users, was presented as a picture of 'a subtle process where the emphasis was placed as much on building the relationship between the social worker and the service user as on finding out the facts'. Service users had welcomed this informality as it made them feel at ease and gave them a sense of being listened to. From listening to how the workers described their practice in this study, this informality appeared to be present and they approached assessment with an emphasis on relationship-building.

There was, for example, little mention of the completion of checklists or forms as part of their own assessment. The informal approach was illustrated by a hospice based worker:

> I would have talked to the patient - both the patient and partner, and wider family or friends and then perhaps talk to the children if they are around - come and get a biscuit in the kitchen … and then ask if anyone is involved with them in the community, nurse-wise. I would ask them how things are functioning at home.

In this way, palliative care social workers are constructing their 'own narrative' about the situation (Fook 2002:118).

Whilst there are many definitions and ways of undertaking assessments described in social work literature, the accepted view is that assessment should be an ongoing process (Crisp et al. 2005), particularly in the case of dying people (Beder 2006). It should be a 'video' not a 'snapshot' (Oliviere et al. 1998). Pincus and Minahan (1973) developed a process model of assessment in their systemic approach to practice that recognised that the worker must continually assess situations to inform their decision-making. This would include the context as well as the individual, as described by one survey respondent:

> There should always be an assessment of the individual and of the context to avoid assumptions. Such an assessment invariably includes issues such as history of the child care offered prior to diagnosis/symptoms of illness, levels of mental capacity/likelihood of this being impaired (temporarily/permanently).

This approach was generally reflected in the study. One palliative care social worker particularly remarked that assessments needed to be continually reviewed because 'not everybody reveals everything to begin with'. There were, however, depressing comments made, both relating to hospital rather than hospice care. One focus group participant commented:

> The danger is that you become an assessment machine to enable a discharge if you work in a hospital setting and you lose the wider dimensions - thinking about children and their needs is one of them really. The holistic bit.

For this worker, the demands of the medical setting appeared to take precedence, which meant that concerns about children might be missed. Another palliative care social worker in a focus group made a similar observation with emphasis on the difference between hospital and hospice care:

> The one great advantage to me is that if you are in a hospice you have more time, but having moved to the national health recently it has struck me that in hospitals you have no time. Hardly getting to know anybody to pick up concerns and worries and suddenly they are out again.

As Buckley (2003) found in her study, it was not always easy to gain a clear picture from the information gathered across the data about how palliative care social workers undertook their assessments in relation to children and their parents, and therefore what informed their practice in this aspect. One interviewee, for example, explained that she did not use any assessment tool but relied on her training and experience. Sometimes how the worker approached the task was implied in the narrative, for example:

> I talk to the patient and partner, wider family and friends, children. Ask anyone else involved.

Overall, the data suggests that workers tended to use the 'exchange model' of assessment (Smale and Tuson 1993). This model views everyone as 'experts in their own lives' and there is an emphasis on exchanging information. The aim is to identify people's internal resources and potential and discover how best to use these as well as identified external resources to meet needs and achieve goals (Milner and O'Byrne 2002). Indeed, from the way the palliative care social workers spoke about their contact with families, it would also be reasonable to assume that a narrative approach (Fook 2002) was often used in gaining a picture of what was happening in the family. Here

again, the emphasis is on natural exchange, encouraging people to talk about their experiences and any questions used should be open to help build a reflective story (Parton and O'Byrne 2000). This recognises that service users have 'agency': they have responsibility for making decisions and being involved in 'the sense making activities of assessment' (Coulshed and Orme 2006:35). This links back to the concept of working in partnership described earlier.

There were, however, workers who were specific. One interviewee spoke of the strengths perspective (Trevithick 2005:72) in her explanation of how she approached a family:

> These are capable people who are dealing with an extremely difficult situation. I am working with people's strengths, resilience, their capacities to cope.

Another spoke of how she used a 'solution-focused' approach to assessment and she also commented that she liked to look at possibilities and strengths in situations. There was also mention of the use of psychodynamic assessment and a family-focused assessment. Another referred to having a systemic approach, looking at people's networks and family dynamics - how people actually communicated with each other. A more detailed list was provided by another worker who described herself as acting as a change agent, listening, being flexible and having a systemic non-judgemental approach. She said:

> It is very much looking at individuals as part of a system and the roles that they play, which is why I wouldn't put a false demarcation around family members - they are all part of the patient's system - and that would include the school, the church, just that sense of network.

Another interviewee both echoed and developed this by saying:

> I tend to look quite systematically, looking at people's support networks, family dynamics, not just what they say to each other but how they actually communicate with each other and just building trusting relationships with them

so they can feel they can talk honestly about what is happening. I do look at development issues.

These two workers are clearly describing a family systems approach, not just how the family functions 'internally' but also how the family relates to other systems 'externally'.

In just under half the interviews, specific mention was made of genograms being drawn up during contacts at initial assessments, usually by nursing staff, which explained the inter-relationship family system (McGoldrick et al. 1999; Parker and Bradley 2003). These were considered by the palliative care social workers to be a helpful tool and although not always complete, they were the bases from which to start their engagement. However, it was not always clear whether the genograms referred to were merely a family tree, e.g. names of parents and children with dates of birth, or a more specific picture of the strengths and weaknesses of family relationships (Thoburn et al.1985). Detailed genograms have been found to help clarify who the ill person and family members are close to, from whom they receive support, their relationships with other agencies, how they coped with previous losses (Oliviere et al. 1998; Stokes 2005), as well as building up a 'story of the illness' (Kissane and Bloch 2002).

What is missing is a clear picture about how workers recognise or assess the level of abuse and neglect of children. One interviewee spoke about looking at children's behaviour, and another the stress and pressure in families. Only one worker specified she would undertake a risk evaluation of a child as part of her assessment, although references were made by other interviewees in different ways about the need to be alert for children being at risk. A third of the survey respondents also referred to children who might be at risk.

Surprisingly, there was little mention of the Assessment Framework in England and Wales, or the Integrated Assessment Framework in Scotland to assess children's

needs[17]. Whilst it would be very unlikely for palliative care social workers to be nominated the lead professional in such an assessment, they may be called upon to make a contribution. Indeed, an awareness of the aspects within the three domains[18] might help workers in making their own initial assessment of a child's vulnerability and needs. One worker in reply to a question about possible use of the Assessment Framework remarked:

> I am probably aware of the triangle. I think it is probably in-built. I don't sort of think about it. I am aware of the sort of things and where a child is struggling and you just throw in the illness of one of the parents.

There was, however, an example in the survey where a senior palliative care social worker, in her supervision of another worker, had applied the framework in a specific way:

> A colleague reported to me that a father of three revealed to her that he had hit one of his children. He is dying of cancer and lost his wife (and mother of the three children) to cancer also, recently. I explored with the colleague whether the father could identify any possible 'solutions' (approaches) to the increasingly tense family situations. He could, to some degree, but he was reported to be in denial about his prognosis and also not clearly able to think through the children's needs. We explored the child concern model[19] as a possible framework particularly for one of the three who seemed at [the] brink of disengaging from education all together.

Here the worker in supervision was assisting a colleague to think about the child's circumstances in a more structured way. However, being able to apply aspects of the Assessment Framework would be dependent on how much the workers or their supervisors knew about the framework, whether they had received any training on its

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[17] These frameworks were described in chapter four.
[18] The domains are: child's developmental needs; the capacity of the parents or care givers to support their child's development and to respond appropriately; and wider family and environmental factors which may impact on development and parental capacity.
[19] The child care concern model is based on the Assessment Framework and defines different levels of vulnerability which should then trigger particular actions by staff in the relevant agencies.

use, how confident they might be about using it and what support they might receive when doing so. Aspects of supervision and training will be explored in chapter eleven.

Practice approaches

During the sharing of practice examples in the interviews, some palliative care social workers were specific about the practice approaches they employed in their contacts with children and families; others less so. Here, the term 'practice approaches' is used to describe approaches, models and methods drawn on a body of theory (Trevithick 2005:79). Those workers who were more specific named the methods and theories they utilised in their work which assisted them in their understanding of situations. Those who were not specific tended to describe what they did but did not attach a 'label' to their work: indicating an implicit use of theories rather than an explicit one which other studies of social work practice have shown (Monroe 1998). This supports Hawkins et al. (2001) who found in their study of social workers' use of language that little use was made of terminology. However, as Sheppard and Ryan (2003:168) point out, just because a social worker refers to a particular theory, it does not necessarily follow that they know what it means. Milner and O'Byrne (2002:69) consider that how any worker uses theory is 'a matter of great uncertainty'. Paley (1987) argues that although there is sometimes an assumption that social workers do not use theory, he believes that it tends to be 'situation specific'. Rather than using an 'empiricist style' where practice could be accounted for theoretically, a more 'contingent' repertoire is used which gives a natural account of their practice. This was certainly the case in almost all of the practice examples and supports Hawkins et al. (2001:2), who argue the way social workers talk about their practice is actually *part* of their practice. Parton (2003), reporting on a study of social work practice, also highlighted the lack of formal theory demonstrated by practitioners, but commented that it was clear that the workers used their own frameworks. This appeared to be the case in this study.

Those practice approaches that were specifically mentioned included having a task-centred approach; a psycho-dynamic perspective; crisis intervention; bereavement counselling; and a casework approach. (A brief description of these approaches in this section is given in a glossary in Appendix 10.) One worker spoke of recently attending a cognitive behaviour therapy course. Although the approach to the work described by the palliative care social workers appeared to be psycho-social in nature, it was not described as such by any of the workers. There were those who specifically referred to systems theory. One worker who advocated 'brief solution' approaches commented that:

> I am very much a believer in brief solution approaches, so my approach is to go in and do the work and come out again. I am not someone who necessarily wants to have an ongoing relationship; this could be a problem actually. I don't think that part of my role is a dependency relationship.

Her approach was to offer people six sessions of focused counselling which was reviewed before any further action was planned. This was a more unusual approach as for other workers, building a relationship appeared to be the most important feature of their work and this was particularly apparent in their described work with families.

Communication with families is seen to be a key aspect of palliative care and working with families is considered to be an important part of the task of palliative care social worker practice generally (Beresford et al. 2007). Workers in this study displayed skills in family work which included giving consideration to the emotional, physical and financial strains drawing on the families' resources. This included couple counselling particularly in situations regarding the care of the children during times of stress, as was seen in Family A. The literature shows that family meetings, which draw on family systems theory, are recognised to be an important aspect of palliative care (Fineberg 2010) and there were examples in this study of family meetings being held. These were for a specific purpose (for example, the meeting held with Family B) or to resolve more complicated issues. One worker wrote in the survey:

> Two children of my patient being cared for by their father (my patient's partner) were often being left with her sister to feed, get to school etc. A family meeting was convened, with the outcome that my patient, supported, tried to elicit her partner's long term intentions towards her and the children. With time this proved he wished little role and certainly no caring responsibility.

Here, an outcome was reached which enabled the mother and sister to make realistic plans for the children's future.

'Memory boxes'

Palliative care social workers gave information and encouragement to parents about how to prepare the children for what was happening through the use of already prepared material, for example, from Winston's Wish[20]. Advice was also given on the writing of letters and cards to the children, the taking and gathering of old photos, and on ten reported occasions, the preparation of memory boxes as in Families B and E. The importance and value of biography and memories as part of the process of grieving has now been recognised (Walter 1996) and is much promoted as a way of helping children pre-and post-bereavement (Stokes 2004; 2005). Helping dying parents (and it was mothers who were talked about in that context) to complete memory boxes or books was undertaken by five palliative care social workers in their practice examples and two in the survey. They were seen by them to be an important aspect of the work and valued by the dying parent. For them it might be described as a 'practice rule' (Sheppard and Ryan 2003:165): collecting memories can help children acquire a realistic sense of the person who has died and so it should be done. However, as I did not specifically ask about memory boxes it is difficult to comment on their overall use, although there were two workers who particularly sounded a note of caution. One spoke of families who had heard about this approach through the Channel 4 series 'The

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[20] Winston's Wish is the charity for bereaved children which helps children and young people re-adjust to life after the death of a parent or sibling by providing professional assistance before, during and after bereavement. For further details see www.winstonswish.org.uk

Mummy Diaries' aired in November 2007. The programme had followed five families

'facing the unthinkable - life without mum' (Winston's Wish 2007). After the programme

was screened, some families had commented that they felt guilty because they could

not be like the people on the programme and this had annoyed the worker. Another

worker commented:

> I have never met a mother who could bring herself to do one [memory box]. Two
> mums said when I am well enough I want to enjoy being with the children and do
> things and keep life going and when they feel awful the last thing they can face
> is the memory box. I think it is too much for some people.

In the examples provided, the emphasis appeared to be on the compilation of memory

boxes when a mother was dying. This could reflect on the proportion of women's deaths

to men's at this stage of life or to the attitude to fathers generally.

Organisational constraints

In all the practice examples, there seemed to be a high level of activity with the service

users and their families. No workers mentioned being burdened with recording or

bureaucratic procedures, even though mention was made of minimum administrative

support being provided. Nearly all workers were based in the voluntary sector. Their

experiences mirror those of other social workers in the voluntary sector, as described in

the *Social Workers' Workload Survey* completed on behalf of the Social Work Task

Force (Baginsky et al. 2010).

It has been found that palliative care service users value 'a sensitive, participative and

responsive model of social work practice' which includes being given time, the social

worker being available and accessible, and the provision of continuity and support

(Beresford et al. 2007:93-101). In the five examples, these qualities are present, except

for the situation of the two children in Family C due to the boundaries placed on the

worker's role where continuity could not be provided. The feeling of betraying children

was echoed by other workers in the study who found themselves to be in similar situations. The ability to continue to work with a bereaved parent, but not directly with a bereaved child under the age of 18 years, with whom a positive relationship had already been formed, appeared to go against what children themselves wanted. This placed the workers in a dilemma. Should they follow the 'rules' of the organisation or find ways of circumventing them? There was recognition that resources were limited but those workers who found themselves in some conflict with their organisation were frustrated by the policy. Aldgate and Statham (2001: 93) found that children are clear about the qualities they look for in social workers: reliability, practical help, ability to give support, time to listen and respond, and the ability to see children's lives in the round. If children feel let down by social workers at this crucial time in their lives, what will their image be of social work in the future?

Impact of the family's immigration status

Cohen (2001:18) put forward the view that everyone who has a professional contact with children and families regarding welfare provision will 'probably be confronted with immigration control issues'. Families in close contact with social workers for any reason may 'coincidentally' be under threat of immigration controls (p.19). This was true for four of the 45 practice examples described in the interviews; there were no examples given in the focus groups; one was given in the survey.

In one family the mother was very ill and there was a 14 year old child who had been excluded from school. The father was waiting for definite leave to remain in this country and the social worker was in the process of writing a supporting letter. In another, it was the mother who had a work permit to come to the UK with her husband and three young children. When the mother became terminally ill she was clear that she wanted the children to remain in this country, but shortly after her death the father, whose status

was not secure, decided to return to their country of origin with the children. The

circumstances of the third family have already been described in chapter six, where a

father joined his dying wife to look after the children and remain in the UK, but the Home

Office refused a visa for him to extend his stay once his wife had died. The children

were very distressed and exhibited concerning behaviour. Help did not seem available

from the local authority, and the asylum team, who became involved for a short time,

withdrew as the father was not an asylum seeker. An appeal had been lodged and the

worker had written letters of support to the Home Office. Family E, the fourth family,

were asylum seekers who knew they could only remain in the country as long as their

mother was alive. The example from the survey concerned an adolescent girl of a dying

father and a mother who did not have a right to stay in the UK long-term. The

relationship between the girl and parents was problematic, as well as between the girl

and her school peers, resulting in her non-attendance at school.

These examples illustrate the additional stress placed on the parents, who were only too

aware that their children could only remain in the UK as long as they were alive. The

well parents had to cope with their own loss, that of the children, plus all the future

uncertainties as well as the bureaucratic procedures of the Home Office. The children

too were bewildered about what might be happening and were faced with multiple

losses not only of their mother, but of their friends and way of life to which they had

grown accustomed. In these circumstances deportation or removal overrides the

provision of the Children Act 1989 (Cohen 2001:166). The Court of Appeal in 1998 (Imm

AR cited by Cohen 2001:168) stated:

> In the field of immigration, particularly in relation to deportation, the interests of
> the child are not, and cannot be paramount or primary … if it were otherwise it
> would be difficult ever to make a deportation decision in relation to children.

The Court added:

> The interests of the child are of great importance and must be given separate consideration, including consideration of child's family ties in this country … and adults' ties with the child must be taken into account in the balancing exercise.

However, as Cohen (ibid) points out 'great importance' is 'inadequate'.

The poor physical and financial situation of families in these situations is due mainly to the lack of benefits available to the family on account of their status in the UK (Cohen 2002). Humphries (2004:93), writing about the role of social workers implementing immigration policy, described people subject to immigration controls as 'some of the most oppressed people on the planet'. The experiences of children of refugees and asylum seekers show that they are 'a particularly vulnerable group even compared to other black and ethic minority children' (Dutt and Phillips 2010:357). The workers involved in the above families did not appear to see themselves colluding with the government (Briskman and Cemlyn 2005:721) by putting a 'human face on to inhuman practices' (Unison and BASW Scotland 2006:7) but were endeavouring to safeguard the children in very emotional circumstances. However, there was a sense of 'helplessness' in the face of the Home Office bureaucracy.

Conclusion

Due to the holistic nature of palliative care, social workers in this service have a remit to consider the needs not only of the patient but also the patient's family which includes the children. Work concerning the care of these children was wide-ranging, although engagement with parents was the main vehicle for promoting children's welfare. Children were not always seen but the main emphasis appeared to be on ensuring that they were informed about what was happening by providing advice and support to parents. A family systems approach was in evidence, however. Direct work with children depended not only on the willingness of the parents and children for this to happen, but

also on agency policy, general circumstances and on the preference and confidence of the worker. However, in some instances, agency policy prevented a minority of workers from providing continuity of support direct to children post-bereavement.

Whilst there was engagement reported with fathers, it was mothers who mainly featured in the examples provided in focus groups, surveys and interviews. In the majority of the situations described it was the mother who was ill reflecting the national statistics. The future care of the children was often a focus of concern, particularly where the dying parent, nearly always the mother, was the lone carer. Whilst many parents were able to make plans, there were others who were unable to do so.

The plight of children in families where the immigration status of the parents was in question was particularly concerning. Not only did the family have to cope with the uncertainties and distress associated with the parent's illness but also the uncertainties and distress of the likelihood of moving to another country against their will. It was apparent that palliative care social workers found working with these children and their families distressing but they saw themselves as striving to do all they could to support and assist them.

If one accepts Searing's view (2003:318) that the essence of good social work is helping, not hindering, and bringing something human to the relationship, then the evidence here goes some way to demonstrate that this is what palliative care social workers strive for and achieve. Because of the time constraints that the illness of the parent can bring, much of the work is intensive and short term in nature. All the practice examples highlighted not only the range of work undertaken by palliative care social workers where there are concerns about the care of children but also the value they put on their engagement. Agencies that had policies restricting direct contact between children and palliative care social workers after the death of a parent caused challenges

for the workers and apparent disappointment for the children. If trust had been

established then it is understandable that the children would wish to turn to someone

familiar for help and support at such a difficult time. Workers were concerned not to let

the children down.

The following chapter will describe and analyse the palliative care social workers'

perceived relationship with local authority children's services.

Chapter Ten

The role of the palliative care social worker:
liaising with local authority children's services

> Children's services have a different agenda and priorities to us.
> Survey respondent

Introduction

In their work with children and families, palliative care social workers identified liaison
with other agencies as an important part of their task. Local authority departments were
the most frequently mentioned agencies, in particular the child and family teams of the
social service departments. There was limited mention of contact with other local
authority services, for example education, adult services and housing, in connection
with their work with children and families. As well as contact relating to specific families,
there was other involvement too, namely in relation to training and the Local
Safeguarding Children Board to be discussed in the next chapter. This chapter therefore
concentrates on the relationship between palliative care social workers and social
workers in child and family teams. The information is gathered from the interviews,
focus groups and the survey. I will describe the amount and reasons for contact before
exploring communication and making referrals. This is followed by an analysis of the
relationships between these different types of workers as perceived by the palliative
care social workers together with their suggestions for improving working relationships.
This is followed by a discussion of the emerging themes.

Amount and reasons for contact

All those palliative care social workers who were interviewed and participated in focus
groups spoke of having contact with child and family teams. In the survey, however,
about three quarters of the respondents reported that they had contact while the

remainder had either no contact or very minimal contact with these teams. One respondent wrote:

> I have not needed to contact the teams regarding child protection issues in the 10 years that I have worked here.

The main reasons for contact fell broadly into two broad areas: one was seeking advice and guidance regarding individual family situations and the other involved making referrals. Advice and guidance covered a broad spectrum including guardianship issues and child care resources. Reasons for making referrals were diverse and included issues relating to the future care of children; parents who were unable to physically cope with the care of their children due to illness; behavioural problems in children; inappropriate care of children; and, suspicions of abuse or neglect. There was a minimal number of reports of referrals from the local authority, except in one hospice where there was a bereavement service which was open to referrals from other agencies in the area and no requirement for a previous contact with the hospice.

Contact with local authorities could be a very complex issue. Hospices and hospitals generally serve a wide geographical catchment area. This meant that a palliative care social worker might be involved with more than one local authority as can be seen from data gathered from the interviews in Table 10.1.

Table 10.1   Palliative care social workers' potential involvement with local authorities

Number of local authorities in catchment area	1	2	3	4	5	6	Not given
Number of workers reporting involvement	3	3	3	0	2	2	4

So, for example, there were two palliative care social workers who could be involved with up to six local authorities. However, it was not just a question of negotiating with

more than one local authority; usually there was more than one child and family team in each authority. One palliative care social worker, for example, spoke of there being six teams in one of the local authorities in her area. The general view was that working with more than one local authority presented difficulties and confusion for a palliative care social worker, particularly as the political outlook in each authority could lead to differing policies, attitudes and resources. Palliative care social workers, therefore, encountered varied responses, making it difficult for them to engage in longer term planning with families. This could lead to feelings of confusion. One authority might be very flexible in its approach and prepared to participate in joint working, while another might refuse to consider any involvement unless a child was judged by them to be 'in need' or subject to abuse. One survey respondent illustrated the difficulties:

> I work with a number of local authorities. Some are very flexible about when they can offer and understand the need for early intervention and joint working to avoid a crisis later. Others refused to take any cases that aren't
> child protection or children in need. Difficult to do long-term care arrangements without their involvement. Parent has to become very ill before they'll get involved.

Communication

It might be reasonable to assume that in order to successfully seek advice or make a referral there should be good communication between parties. Evidence from this study would suggest that good communication often did not exist between palliative care social workers and social workers in child and family teams. Whilst there were examples of palliative care social workers considering that referrals had been taken efficiently and action successfully put in place, these were in the minority. One palliative care social worker commented:

> One local authority refused to talk to us even though children were already known to them.

There were difficulties reported in getting through the 'gatekeepers' in the social services when searching for advice and making a referral and this felt less than satisfactory. Before gaining access to duty workers, palliative care social workers had often first to go through call centres, sometimes talking to up to three people before reaching someone who could actually help. One worker had solved the problem by missing out the call centre; over the years she had collected the direct numbers of several local authority social workers. She commented:

> If I get through to them and then say, put me through to somebody else - at least I am in the office and not the call centre.

There were other palliative care social workers who also saw a need to build up a web of contacts to bypass official systems. Use was made of past connections, experience gained from previous employment in the local authority, practice teaching links, friendships, and from a previous positive joint working relationship. As the following quote describes:

> Fortunately, I have extensive statutory experience or I would have felt very much unsupported by my social service colleagues.

The few palliative care social workers currently employed by a local authority considered they had better links to children's service workers and were also able to access the local authority database if necessary.

The difficulties involved in gaining the attention of the social services were often mentioned and frequently called for perseverance on the part of the palliative care social worker. One worker reported that it took about five months to arrange for someone to collect children from school. She succeeded after completing 'children in need' forms, writing letters, and sending a complaint to the manager and finally the director of the service: 'it was just tearing your hair out sort of stuff'. Another made three referrals over a period of one month regarding a family before an offer to make an assessment was

made. However the case was closed without a social worker meeting the family. This worker commented:

> … the statutory services almost didn't understand why I was concerned and I kept trying in lots of different directions to get assistance for this family but feeling like doors were being shut everywhere that I looked.

There were also reports of communication being very one sided. Palliative care social workers would leave messages but the call back rate was poor. Similarly, a lack of feedback about a referral once made was regularly commented on which led to feelings of frustration. 'I have never had an easy or successful interaction' wrote one worker. Summing up her thoughts about contact with the local authority, one worker said:

> Things have changed very dramatically over the last three or four years in that staff members in the community in the children's teams have changed incredibly and no continuity ... but if I were only dependent on trying to get some understanding of what to do or where to go from a duty social worker in children's services, we would frankly be up a creek.

Seeking advice and guidance

The ability to seek advice appeared to depend on the quality of the communication between parties. A palliative care social worker might wish to make a referral but would be unable to do so for a child 'in need' unless parents first gave their permission. On these occasions, palliative care social workers endeavoured to seek advice from social services regarding possible resources so that this could be discussed with the family. However, there were several reports of occasions when social services refused to give advice unless a referral was actually made. One palliative care social worker wrote:

> Contact re family with four children and terminally ill father. I was asking what may be available - respite care? family home care? before [writer's emphasis] discussing with Mum. Duty worker refused to discuss resources, said I must make a referral first - I felt Mum unlikely to agree unless she knew what help she might get.

However, there were also reports of advice having been willingly given and this generally appeared to be in situations where there was already a positive connection between the workers. There were also occasions when local authority workers would be supportive and give advice even if they were not able to provide a service themselves. One worker felt when she said she was from a hospice: 'people seemed to go that extra mile'.

Issues around referrals

Once a referral had been made by palliative care social workers to child and family teams, the latter did not always become involved, especially in situations where children were not seen as being in immediate risk or danger by the local authority staff. This led to feelings of frustration on the part of palliative care social workers who were unhappy about the different standards that seemed to be operating between themselves and the local authority staff. One palliative care social worker commented:

> Children in need seem always to take second, third, fourth, fifth place behind child protection.

This issue of thresholds was a frequently reported difficulty. The local authority staff would appear not be concerned about the situation described and would ask palliative care social workers to make contact again when there was a crisis. This was particularly the situation in one family where there were guardianship issues regarding two children whose mother was dying. The palliative care social worker wrote:

> Service user had concerns about arranging guardianship for her children after her death and made a referral to social services; one child diagnosed with learning disability and the other's father was abusive. Children's services were reluctant to be involved until her prognosis was such she had a few weeks to live.

It seemed that the local authority staff were 'too busy' to take their complaints seriously and concerns were minimised. One palliative care social worker wrote:

> I referred a young child … for assessment /care as seemed to be neglected (grandmother dying). The team felt there was no need to get involved. I was told they had worse cases to deal with and didn't have the time as nothing specific had happened.

There were times when palliative care social workers were very worried about children's circumstances and felt responsible for them, particularly when a local authority was reluctant to become involved. One described it as feeling 'really scary' when trying to talk to a member of the duty team 'to make them understand what was happening'. Another described how a family's circumstances caused her concern not only because of what was happening but because of her own agency policy which meant that she could only be involved for three months post-bereavement. She did, however, manage to extend this for a couple of months but had to withdraw before any resolution was made. She wrote:

> An ill parent died in hospital leaving two teenage daughters in the care of their much older brother. I attempted to get input from the local authority children's services over a four month period when the brother informed me that one daughter was depressed and suicidal and the other was spending nights away from home, smoking dope with friends. While waiting input, I met with the family several times, to try to assist in discussing the tremendous impact of loss of mum, while also trying to engage young people to reduce risk. Children's services never got involved, even when months later the family faced eviction.

There was less certainty about referring a child who was 'in need' rather than a child who was 'at risk'. There was a view that often such decisions were difficult to make, particularly when past experience had led the palliative care social worker to believe that such referrals would not be acted upon. One worker described herself as being 'behaviourally conditioned' by social services and subsequently had referred 'less and less'. Workers would try to find resources in other ways and 'sort things out' themselves.

Referrals regarding older teenagers, particularly those between ages of 16 and 18 years, caused palliative care social workers particular concerns, as it appeared that social services were less inclined to be involved. There was an example of a 16 year old boy who was living with his mother who was dying. She was a lone carer and there were no other relatives available to help. The palliative care social worker was questioning her own level of responsibility in this matter, as social services told her that they 'might find him somewhere for him to live' when his mother died. He could not take over the tenancy of the flat due to his age. The palliative care social worker was concerned that not only would this young man lose his mother but also his family home. There was another example in the survey of a 16 year old girl described in the previous chapter who was not attending school because of relationship issues with her peers and had a poor relationship with her parents. The palliative care social worker was involved with advocacy and negotiation work with school, parents and daughter. Social services were reported to be aware of the situation but considered the girl was old enough to access her own help.

Regardless of previous responses from the local authority, there was a general opinion among palliative care social workers that it was important to make referrals sooner rather than later, recognising that the parents' permission was required before doing so. However, making a referral to the social services where there were concerns about the safety of a child could, it was recognised, damage the relationship between the family and the worker as well as the agency and examples were given where this had been the case. For one worker, having to put a dying woman through a child protection investigation was a difficult decision, but she considered the children's welfare was paramount and made a referral to social services. The patient was subsequently extremely angry and verbally hostile to the worker and refused to have any further contact with the worker and, after discharge, with the in-patient hospice.

There was also some evidence of palliative care social workers 'giving up' on social services because past negative experiences had coloured their decision; they were reluctant to make a referral at all. One palliative care social worker spoke of her lack of trust in the abilities of local authority social workers to understand and work with families where a parent was terminally ill. This made her reluctant to make referrals. Another worker considered that making a referral would give the parents an 'extra burden' because of the uncertainty of the agency becoming involved. Another worker summed up her views by saying:

> I was trying to think why you perhaps don't go more to social services and it is because, you know, you are not going to get a response in terms of a preventative, supportive service. You tend to look around and sort things out yourself.

One interviewee described this lack of resources as being the hardest part of being a palliative care social worker. In her view, if practical support could be offered to the family, then all the pre-bereavement work 'which could be such a value to the family and children' could then be undertaken, as parents would have more energy to take part. The worker commented: 'it's like it's not important enough'.

Relationships with local authority social workers

There was an overall feeling of disappointment in the interviews about the quality of the relationships with local authority social workers based in child and family teams. Opinions ranged from tenuous to very good; excellent to very, very bad. However, it was recognised that it was difficult to form working relationships when there was minimal contact.

Several workers described their relationships with the local authorities in a combative way. One was vigorous in her assertion that as a qualified social worker her assessment was appropriate and that those to whom she was making a referral needed 'to

understand that my assessment is experienced, expert and valid'. Others spoke of their lack of faith in the child and family workers. Those who had previously worked in child protection in a local authority shared examples about their ability to negotiate their way to obtain services and even on occasion to 'manage' local authority staff. The quality of communication and knowledge of the 'system' was seen as having an impact on the nature of the relationship.

There was a view that local authorities appeared to be 'bogged down in all their procedures'. Workers were concerned about the changing standards and thresholds regarding access to children's services with, as they saw it, a lack of emphasis on prevention and services for children in need. They found it difficult to keep up-to-date with the current thinking and felt let down by the lack of support from their social services colleagues. As one palliative care worker expressed it: 'It rather undermines what you are trying to achieve'.

Most of the negative aspects of relationships centred round issues of referrals and communication discussed earlier. Examples were given where palliative care social workers took on the role of mediator between local authority staff and the family, particularly where it appeared to the palliative care social workers that the local authorities were being 'draconian' in their approach. Those palliative care social workers who had experience in local authority child protection work were particularly able to explain to families what was happening and why. One palliative care social worker described how she attempted to make social services act in a more appropriate and sensitive manner by building up trust with the social worker who was under pressure from her manager. At the same time she explained to the family that social services did have legal rights and a duty to care.

It was almost like having a family that was fighting actually - the two parties.

Sometimes a family seemed to fall between services for adults and those for children and families when it came to the allocation of resources. There were reports of disputes about funding and providing services for children when it was the adult who had care needs. One worker spoke of this as:

> … the disconnect between adult services and children's services … many adult social workers these days who seem to not know anything about children's needs - not only not to be very skilled about those things but also to not see it [as] a priority to get skilled up.

Workers gave examples of the divide between the services, particularly where support workers provided by the adult services were not prepared to undertake care of the children; for example, to prepare a meal for them or collect them from school, even though this would assist the terminally ill parent. There were, however, also examples of individual support workers who had undertaken these tasks once they had become involved with the family.

In contrast, there were examples of positive experiences with work in partnership and an acknowledgement of how much some local authority social workers had struggled to provide what children required. However, these amounted to a small minority compared to the total number of experiences shared. One respondent wrote:

> We haven't had a bad experience in many years. We think this is because of our commitment to safeguarding children by being involved with joint training. Also two members of our team worked a significant number of years in child protection and so understand policies and procedures of protection agencies. We have established good rapport with social services and our concerns are respected. … We are included in case conferences, children with additional needs meetings and make contributions to the assessment framework. There we have input to needs assessment and action plans and our contributions are taken seriously.

In such circumstances, joint working was welcomed and, when undertaken, warmly reported, as one worker explained during an interview:

> I got a child and family social worker involved and interested - it was fabulous. I was so pleased … we actually did manage to progress plans for the future and that felt safer to me.

There were two mentions of positive examples of children's social workers attending case conferences for patients, enabling constructive action plans to be made. Often though, joint working meant that the palliative care social worker continued to work with the parent who was dying and the local authority worker with the child. A survey respondent provided an example:

> School concerned about a 15 year old boy with behaviour problems whose single parent mother was dying. I liaised with children and family team who had contact in the past. Worker in team became involved and focused on child's needs whilst I continued to support mother. The boy became closely involved in caring for his mother and her death, though sad, had a profound effect and initially he appeared to cope much better than expected by all concerned. Follow up was by child and family team.

There was a further example of co-operation and collaboration when two primary age children had moved into a hospice to be with their dying mother and stayed for several months. Their father had died a few years previously and there was no else who could care for the children whose behaviour had become concerning. The palliative care social worker spoke positively about involving social services and 'getting them on board'. Social services arranged transport to and from school and provided carers for the children as well.

Perceptions of role

At various points during the study, palliative care social workers made comparisons between their role and those of social workers employed by local authorities. The narrowness of the role of local authority social workers was particularly highlighted. In

contrast, palliative care social workers considered that they were able to look at the family as a whole. Those workers who had qualified several years ago believed that their role, being generic in nature unlike that of local authority social workers, was more like the one that they had been trained to carry out. One worker observed:

> I know my colleagues in the local authority would think we are kind of dinosaurs here really.

In fact, those workers who had been qualified for some time spoke of the need to return to the model before children's services and adults' services were split and two specifically mentioned the return to neighbourhood services. One of them commented:

> It is unbelievable that one person in one office is looking after the mother and someone else somewhere the children.

Palliative care social workers' perceptions of local authority social workers

There was an understanding that local authority social workers had a vast job and it was the general impression that they were only able to react to child protection situations and to crises. There was very little evidence of preventative work. This was very much a matter of regret and frustration for many palliative care social workers who saw children in need coming way behind child protection. There was, however, recognition that changes in children's services due to re-organisations, inspections, staff suspensions and a large staff turn-over resulted not only in low morale amongst the staff but also a lack of continuity. There was also recognition that local authorities struggled to provide adequate resources and were over-stretched. A worker who had moved from local authority child protection work into palliative care explained how she had viewed the work:

> I was aware that I was not practising with children and families in the way I wanted … I had to seek to work in some other way where I could bring a standard to what I was doing. I thought I was merely working at such a superficial level I just didn't have the time. I didn't get to know the kids. I was being asked to make huge decisions that would have a huge effect on children's lives … and I just thought it was awful and wasn't the way I wanted to work.

Another worker who had also moved reflected:

> I think when you work in child protection it is very much a tick box thing - what
> are the risks, what is the risk reducing practice, is the child safe, is there a
> responsible adult around? It is kind of tick box things but not really thinking about
> the subtleties or the intensity. It may be that dad is around but dad is also losing
> his wife and will be a single parent soon and working and caring and so
> emotionally he may not be that available for the children.

One palliative care social worker thought that some children and family workers saw themselves as the ones 'who do the really important work and are the cutting edge' implying that palliative care social workers do lesser work. Another pleaded that social workers generally 'should not fall into the trap of being isolated within their roles', believing that this could easily happen. Change, she believed, could occur and explained:

> It requires a lot of insight and a lot of constantly re-examining, reflexive practice,
> and it takes resources to do that but it is also a cultural shift.

Palliative care social workers recognised that they had more opportunity to talk to people, especially within a hospice and that this was something local authority social workers did not generally have the time to do. They also felt that families trusted them more than the local authority social workers because of their non-statutory basis and the fact that they kept people informed about what was happening, leaving them in control of what they wanted to do. There was also a belief that local authority workers generally only saw people with low incomes or who were in poverty, whereas, in their specialist posts, palliative care social workers had the opportunity of working with people from a range of backgrounds.

Whilst a minority of palliative care social workers themselves admitted to not being up-to-date with all the changes in child protection terminology and policy, they were less

tolerant of staff in local authorities who were not clear about the palliative care needs of parents and the emotional needs of their children. There was a perception, often repeated, that social service social workers did not fully understand the impact of bereavement on children and families. There was also an apparent lack of understanding regarding the nature of the illness itself and the needs of families where a parent was dying. There was a failure to recognise the need for a prompt response, whether it was for information or service provision. One respondent described how social services were involved with a family, and had placed three young children with grandparents. The grandmother was later diagnosed with breast cancer and was receiving daily treatment but could not cope with the children and required assistance. The palliative care social worker found that obtaining this was quite difficult.

There were two examples where workers from children's services appeared reluctant to make face-to-face contact with a dying parent, giving the impression that they were unsure of how to approach the task or perhaps unable to cope with what was happening to that person. One palliative care social worker wrote:

> Sensed a marked reluctance to see the patient face to face, because of her medical condition.

These difficulties of understanding illness and bereavement were attributed by the workers to lack of experience and a gap in the qualifying and post-qualifying social work training.

There was a sense of palliative care social workers feeling protective about the families they referred to children's services. This was apparent in the way they spoke about certain members of staff. One worker spoke of her lack of trust in the ability of novice field staff taking over work with a family:

> Felt children and families social workers very young, inexperienced and harsh.

Another worker remarked: 'I thought they would go in and make a hash of it'.

Palliative care social workers' understanding of how they are perceived by local authority social workers

It was a prevailing belief that the vast majority of local authority workers did not understand the role of the palliative care social worker and had different priorities and concerns. One palliative care social worker in a focus group reported being referred to as the 'Macmillan nurse' at case conferences regarding children, even when they had been introduced as a palliative care social worker. However, it was considered that social work staff in the adult services might have more of an understanding compared to those workers in child and family teams. This was because palliative care social workers had more regular contact with these staff members, particularly when arranging care packages for patients either living, or returning to live, in the community.

Improving relationships

In the individual interviews, palliative care social workers were asked how relationships with social work staff in the local authority might be improved. The most favoured approach was having an opportunity to talk and explain their role. This might mean going out to visit social workers in their teams to talk about what they do and share ideas about how they might work together. One worker expressed it succinctly:

> They need to learn from us and we need to learn from them.

Other suggestions made included meeting with managers of child and family teams and inviting staff to visit the hospice so that, as one palliative care social worker explained:

> They can come and experience it and see what families need to juggle with.

Shadowing was another strategy put forward - in both directions. One palliative care social worker thought that spending time with a child and family worker would help her to understand more clearly the various procedures and statutory responsibilities. Where it had taken place, joint working was also seen as productive way of learning about each other's role. However, one worker sadly commented:

Child protection and family teams would often gain a lot from working in conjunction with us, but they seem just not interested.

Some palliative care social workers who, because of the number of authorities they were linked to, struggled to make contacts and thought that concentrating on the largest authority would be a good starting point. One respondent who had attempted this commented:

…getting better as I am proactively finding individuals I can ring who I can talk to. Used to feel isolated.

Networking was therefore seen as beneficial, although there were time constraints that hampered its productiveness. Having an identified person in the local authority as a liaison contact and meeting periodically with that person to keep up to date with developments in practice, was described as a positive experience but not one universally available. Joint training on child protection, children's needs and current thinking was a particularly favoured avenue. A further suggestion was that this should also include staff from adult services. There were questions about the adequacy of qualifying social work training on the subject of bereavement. One worker suggested that the impact of bereavement on life cycle issues should be made more explicit in training. Taking student social workers on placement was believed to be a productive, but slow method, as it would not only help to influence the individual student's thinking, but the learning gained might be shared with fellow students and, when qualified, with staff in the local authority.

Discussion

Overall, the findings present a rather depressing picture of palliative care social workers' struggle to ensure that children's needs are met. However, the findings are not new. There is much congruence with those from other studies, particularly around issues

connected with communication, the referral process and relationships generally (Birchall and Hallett 1995; Calder and Horwath 1999; Buckley 2003; Horwath and Saunders 2005; Horwath 2007a). Overall these studies considered the views of other professionals, for example, staff from education, health care and the police in their contact with local authority child and family social workers. In this study the views considered are those of social workers in one setting about social workers in another. Consideration will be given later as to why there might be difficulties in single-profession communication and collaboration.

In Horwath and Saunders' (2005) study four issues emerged which appeared to have a negative influence on referrals to local authority workers: lack of communication and feedback; poor continuity of local authority staff; lack of access; and, perceptions of social work practice. Certainly all these issues were present in this study. There were feelings of anger and frustration at the perceived lack of response from local authority workers, which left palliative care social workers worried and anxious about the future care of the children, together with the feeling of letting down the child and family. This lack of communication after making a referral can also leave the referring professionals feeling powerless and unsure as well as concerned about the consequences for the child (Cleaver et al. 2004; Holland 2004). Local intake procedures contributed to the tension due to the inability to talk directly to a child care worker. There was a sense of powerless in many of the situations described in this study by the workers when referrals were 'not accepted'; one worker described it 'like doors being shut everywhere I looked'. This left workers with feelings that their assessments and concerns did not count and that the children with whom they were involved were not 'important' enough to warrant enough concern for services to be provided.

However, local authority staff may hear a message of concern about a child as a demand for them to do something when they lack the resources to do so (Taylor and

Daniel 2005:16). Reder and Duncan (2003:96) drew attention to the 'the complex interplay' involved in communication. It is not surprising that palliative care social workers reported that they were often reluctant to make a referral for a child in need because of a previous lack of response to requests; a view reported in other studies (Buckley 2003; Horwath and Saunders 2005). In contrast, while issues of confidentiality as a barrier to communication have been raised in other inter-agency studies (Darlington et al. 2005; Horwath and Saunders 2005), they were not mentioned in this study.

Palliative care social workers hoped that when they did refer a child 'in need' it would be a catalyst for intervention; nurses had similar views in a study by Fitzsimmons and White (1997). However, this was frequently not the case. The reported attitude of local authority social workers that there had to be a crisis (as if a parent dying was not crisis enough) before any action could be considered, is concerning. Many workers queried how aware local authority workers were about the impact of living with a dying parent on a child. There were examples of the apparent avoidance of involvement with a dying parent. This may be due to a discomfort about death and dying, a lack of confidence, being unclear about the social work response to dying and bereavement (Currer 2002:211) or to a gap in their training referred to earlier.

The issue of 'thresholds' was a recurring one and is replicated in other studies (Buckley 2003; Horwath and Saunders 2005). However, 'thresholds' have no statutory basis (Laming 2009:29). Despite the requirement that local authorities should provide a range and quantity of services appropriate for children in need, this is clearly difficult to achieve. How decisions are made about which children and families should receive a service is not clear. Literature shows that escalating demands and inadequate resources mean that local authority workers ration the number of cases they can accept and work is dominated by child protection (Scott 1997; Buckley 2003). It is apparent that

there is a 'filtering' system in operation (Buckley 2003:123), particularly in relation to child neglect. Buckley argues that child protection workers struggle with this aspect and prioritise situations that are apparently more urgent and possibly 'dramatic' (p.124). Thus a gatekeeping exercise takes place before a family is able to receive services. There appears to be a greater variation in how children who are exposed to adversities outside their carers' control are supported (Srivastava et al. 2005:131). These are 'children in need' whom local authorities are expected to identify and assist (Children Act 1989 s.17). However, there is a wide variation in how or whether assistance is provided and it was this 'bottleneck' (Daniel et al. 2010:254) that caused palliative care social workers so much frustration. Children between the ages of 16 and 18 seemed to be particularly disadvantaged. It was not clear who had ownership of responsibility for such young people, which could lead to workers taking defensive positions (Buckley 2003:188).

Workers reported wishing to discuss a situation before considering making a referral. Given that many of the palliative care social workers had limited experience within their agency of working with families where there were children under 18 years, this would seem to be a reasonable step to take. They did not wish to raise expectations with a family until they were clear what, if anything, might be available. An informal discussion could clarify thinking about the needs of the children. However, there was a reported reluctance on the part of local authority social workers to engage in this way, insisting that a referral be made before any discussion could be had. A joint inspectorate report in England had also found a reluctance to provide advice, guidance and support to agencies raising concerns about children (Department of Health 2002). This refusal is contrary to Government guidance (HM Government 2010).

The relationships as described by palliative care social workers appeared to be very much a 'them' and 'us' situation. There were reports of some local authority workers

giving the impression that they were undertaking the 'important work'. Buckley (2003:53) referred to statutory social workers seeing themselves taking the 'nasty bits' and others doing the 'nice (therapeutic) work'. This 'outside looking in' (Horwath 2007a:1294) perception of others is particularly interesting in terms of workers who are in the same profession. Scott (1997:73) argues that in these situations it is important to consider the 'culture, structure, mandate and imperatives' of the organisation. Local authority social workers, for example, have been reported as wishing to take on a more welfare approach (Spratt 2001) but are constrained from doing so at an organisational level, a view supported by Parton et al. (1997). Social workers, they argue, mainly carry out their duties as defined by their employing organisation and are anxious to avoid being blamed when something goes wrong. The culture of the organisation therefore, has an impact on the different ways issues may be looked at, how problems are reacted to and procedures and rules interpreted (Murphy and Oulds 2000). All this shapes the way professionals work rather than the knowledge, skills and values of the profession (Peck and Dickinson 2008). Banks (2006:122) argues that the social work professional code that describes the duties to service users and the profession should have 'primacy' but agencies require that policy and procedures have precedence. The social worker's role is determined by legal and professional rights and duties, moral duties and social duties (Downie and Loudfoot 1978) as well as procedural rights and duties (Banks 2006). Along with the role come responsibilities to service users, the profession, the agency and society, and these can conflict with each other.

Palliative care social workers are part of much smaller organisations where children are 'secondary' clients (O'Sullivan 1999). They may be seen as more autonomous professionals, operating within a 'professional' model (Banks 2006:138) where their guidance comes more from the professional code of ethics. Local authority workers, on the other hand, are described as following a 'technical-bureaucratic' model, carrying out the tasks and role required by the agency and, as Banks suggests, becoming 'de-

professionalised' in the process. Palliative care social workers therefore display characteristics of 'individualism' (Peck and Dickinson 2008:93) and are able to exercise 'individualised professional discretion' in their decision-making (Carrier and Kendall 1995, cited in Peck and Dickinson 2008:93). But this autonomy was not always welcomed; one worker felt vulnerable in this position as she was 'now more muddied' about her responsibilities compared to her position in the local authority where 'she knew exactly where she was'.

In summary, it is possible to describe palliative care social workers as being able to take a more holistic and generic approach to their work which is in an emotionally charged environment with people from varied socio-economic backgrounds. They have very limited direct access to resources and are able to exercise professional autonomy having fewer organisational constraints on how they operate. Local authority social workers on the other hand, were seen by palliative care social workers to be more narrow in approach, have high workloads, work in a publicly exposed context, be subject to increased bureaucracy, have a less than adequate resource base, work with people in poverty or low incomes and restricted by organisational policies and procedures. In addition, the nature of the work and decisions they have to make can lead to high levels of stress (Stevens and Higgins 2002: Morrison 2007).

Whilst there were many criticisms about the relationship between workers, positive accounts were also reported. Successful joint working was particularly mentioned and although reasons for success were not always made clear, good communication appeared to be a crucial element. Hallett (1995) observes that the chance of success in multidisciplinary work is greatest when personal relationships between professionals are strong. Stevenson (2005:111) calls for improved inter-personal awareness, believing that 'agencies affect but do not determine the process'. Being able to see the perspective of other workers is an important skill (Stanley et al. 2003). However,

bringing about change takes time and effort (Darlington et al. 2005), and is made even more complicated by the number of local authorities and teams with which the palliative care social workers could potentially be involved. Ways of improving relationships suggested by the workers here echo those made in other studies (Horwath 2007a) and found to be effective in others (Murphy and Oulds 2000; Darlington and Feeney 2008). Workers suggested two broad approaches for improving interagency relationships: effective communication both at organisational and individual case level and an improvement in the knowledge base of all workers. The appointment of a 'link' person to promote inter-agency co-operation and to ensure an exchange of communication can only work if consistent and regular efforts are made to maintain the relationships (Buckley 2005:127).

The Local Safeguarding Children Boards in England and Wales and Child Protection Committees in Scotland are responsible for the co-ordination of policies and for promoting and commissioning inter-agency training for personnel in their areas who work with children to meet local needs (Scottish Executive 2005b; HM Government 2010). Making contact and ensuring that they are kept 'in the loop' would enable palliative care social workers to keep up to date with local developments and training initiatives. Palliative care social workers have knowledge and skills they can pass on to local authority social workers in order to encourage a wider awareness of good practice with people who are dying or bereaved (Sheldon 1997; Quinn 1998; Currer 2002). For 'bridges to be built', workers in both services need to work together in a 'spirit of respect, appreciation, and understanding and eagerness to learn' (Tye and Precey 1999:171). Issues relating to training will be discussed in the next chapter, but appropriate joint training can, according to Murphy and Oulds (2000:120), be 'very effective in promoting inter-system collaboration and understanding'. Such training allows participants to learn about each other's 'worlds' and to explore how their systems cross each other. However, as palliative care social workers are likely to be engaged with more than one

authority, understanding organisational strategies and taking part in multiple training events would inevitably take time and effort which they may not have.

From a systems perspective, palliative care social workers can be seen as endeavouring to involve social workers in children's services as part of their action system in order to achieve the goals for the family. There is clear evidence of both collaborative and conflictual relationships, with the latter unfortunately predominating. When a service is not forthcoming, the children's services system becomes a target for change and palliative care social workers strive to exercise influence in order to bring about a resolution. However, the amount of influence palliative care social workers can exert is often not enough. It would seem that they can only draw on their knowledge of and expertise in the effects of pre- and post-bereavement as well as established relationships. Communication patterns appear to be travelling one way - from the palliative care social workers to the local authority.

Conclusion

Professional behaviour does not exist in an organisational vacuum; the outlook of each organisation sets the priorities. Agency differences can result in the inability of workers to agree on the seriousness, or indeed existence, of a concern about the care of a child. In this study, palliative care social workers and social workers in child and family teams appeared to have unrealistic expectations of each other. Although the palliative care social workers were aware of the pressures that their local authority colleagues were under, they did hope that there could be more of a common understanding regarding the situations that this community of children faced. The repeated negative rebuttals regarding service requests meant that palliative care social workers were extremely reluctant to engage with the local authority, perhaps to the detriment of children and their parents. This study therefore confirmed findings from other studies that inter-

agency co-operation is not a regular feature in everyday practice. There appeared to be a range of impediments to productive, joint work between palliative care social workers and local authority social workers. Occasionally this came from a lack of information about each other's tasks and responsibilities. There was a danger, as one palliative care social worker noted, that the behaviour of professionals resembled in some ways a dysfunctional family. It was, however, heartening to hear about positive experiences. Workers from the two agencies, palliative care social workers believed, could learn from the other. It is hoped that Professor Monro's review on behalf of the Government (Department of Education 2010) into how early intervention and interaction between social work teams and universal child and family services can be improved might shed some light on the way forward.

In the next chapter, I will consider what informs the palliative care social workers' practice with children where there are concerns about their present and/or future care.

Chapter Eleven

The role of the palliative care social worker:
what informs their practice with children and their parents

If social workers are to act clearly, competently and usefully in
practical situations, they need to think theoretically.
Howe 2008

Introduction

The previous chapters considered the process of the palliative care social workers'
involvement with children and their parents as well as the local authority children's
services. In this chapter, I will examine the information gathered mainly from the
interviews but also from the focus groups and surveys to draw some understanding of
what informs the palliative care social workers' practice in this work. It will include an
analysis of their knowledge base, any supervision and training received, and
consideration of the influence of previous work and life experiences.

Knowledge base

Practice wisdom has been defined as 'the accumulated knowledge practitioners are
able to bring to the consideration of individual cases and their practice in general'
(Sheppard 1995:279). Sheppard suggests that there are three main sources: knowledge
gained from everyday life: 'a common sense framework' (Munro 1998:97); from social
sciences; and, from the conduct of social work practice. Mixed into this may also be an
'intuitive awareness' as described by Ling and Luker (2000) in their study of health
visitors engaged in child protection work, although surprisingly in this study only one
worker specifically mentioned having 'gut feelings' about situations but maybe others did
not wish to share this 'publicly'.

Although not a direct question raised in the interviews and focus groups, palliative care
social workers described in their examples and discussions particular aspects of

knowledge and values that informed their practice when working with children and their parents. In respect of children, this included knowledge in relation to loss and grief and the impact of bereavement; being aware of how children show distress; the concept of resilience; knowledge of child development; children's needs; the role of young carers and the impact this role may have on the children's lives and development. In relation to child protection it seemed that workers were generally aware of the signs and symptoms of abuse but there was no real sense from the data about the depth of knowledge regarding neglect. Carew's (1979:361) study of social work practice found there were few times when responses about practice were overtly based on theoretical knowledge or generalisations from research. Similarly, in this study where theory was mentioned, it was reported in a piecemeal way or provided as a result of my prompting.

One description of work with a family showed how a palliative care social worker used her awareness of child development and children's needs, as well as the impact of terminal illness on the parenting capacity. The worker wrote:

> Parent's reduced abilities to do 'active' things with child and sometimes could not be bothered with child. Discussed quality time, utilising network of family/friends to exercise child. Normalised child's anger and suggested safe ways he could work this off under supervision of responsible adult. Gave literature and links to useful organisations and web sites.

This was a response taken from the questionnaire and is a good example of where workers tended to use more official, technical and colloquial language when writing about their practice than talking about it, as referred to in chapter nine.

Workers recognised particular issues in situations where children were being cared for by a lone parent, especially where there were no family members able to care for the children after that parent's death. Knowledge of family dynamics, particularly in the area of management of change, was recognised as important, as was knowledge of

attachment theory. Included here was the impact of estranged relationships after death as well as the impact of the stress caused by the illness and impending death on the family. The legacy of past abuse in the family was considered to be a dynamic in some situations, particularly where this concerned someone who was currently a grandparent and who may have contact with the children.

Knowledge about managing conflict, being able to say 'really difficult things' to families, working in partnership with families and other workers whilst keeping within the boundaries of confidentiality and social work values, featured in the focus group discussions and interviews. Person-centred work that appears to be such a feature of palliative care social work, places importance on the values of unconditional acceptance, non-possessive warmth and empathy (Sudbery 2002). These values, although not specifically mentioned, were evident in the way palliative care social workers described their practice. They appeared to see the whole person. This included having knowledge about and an understanding of other cultures and how different religious beliefs can impact on the care of the dying person and the family. There was evidence of workers endeavouring to practice in a 'culturally safe' way as described by Oliviere (1999), as for example in Family E in chapter nine.

Two palliative care social workers specifically mentioned that a major part of their theoretical underpinning was Maslow's (1970) hierarchy of needs. In their view, basic needs had to be met before achieving other needs of a 'higher order', for example belonging and self-esteem. One worker explained:

> You have to attend to the practical safe things first before thinking about counselling because until you have got all of that in place you can't be offering counselling as a solution.

However, Walsh (2005:96) has put forward an alternative view that when a person is dying it may be more relevant to invert the needs. For example, food may no longer be

a motivator due to illness but self-fulfilment may be. The person may need help to reconcile past events and relationships to be able to make sense of their lives.

I did not specifically ask about the participants' knowledge about the relevant child care and child protection legislative framework. There was minimal reference to Children Acts specifically and only very occasional reference to the term 'children in need'. A minority of people both in the focus group and interviews volunteered that they did not consider themselves to be as up-to-date with regard to legislation and policies as they would have liked.

A palliative care worker who was relatively new to the post and to working with children, explained how she had prepared herself for the new tasks:

> I have done quite a lot of reading on developmental work and understanding of issues around bereavement and children. As a new worker to that area that is where I focused my learning. I have certainly gone back to child development work, gone back to social work theory again recently to look at movements in that, attachment theory and other issues. I have really tried to underpin what I am trying to do from a theoretical place.

Two other workers spoke of undertaking literature reviews on bereavement and loss, particularly in relation to children, as well as gathering together relevant literature and materials that could be used in direct work with children. Direct reference to research findings was rare. One worker spoke of research on the best predictor of a child coping being the parent's coping ability; another, on the gender link between the parent who was dying and the child, together with the name of the journal; and another that when support is given to a parent the result is better outcomes for the child. However, whilst direct reference was limited it may not reflect the frequency of research on which practice was based. Buckley (2003:68) in her study found little evidence of social workers using theory to inform their practice, particularly in regard to child development and family dynamics. However, findings here present a different view as palliative care

social workers appeared more able to articulate a theoretical base for this aspect of their work. The areas of knowledge that are identified here support the literature discussed in chapter two.

Supervision and support

Supervision in social work is generally considered to be essential (Coulshed and Orme 1998). Indeed, the Social Work Task Force (2009:29) stated that it is 'an integral element of social work practice, not an add-on'. It recommends that there should be a 'strong supervision culture' in all organisations that employ social workers, and where a line manager is not a social worker, professional support should be provided. In Lord Laming's (2003:211) view: 'effective supervision is the cornerstone of safe social work practice. There is no substitute for it'. Lishman (1994:39) considers it is different from management accountability and it should be built on a 'professional relationship'. The general consensus is that it should be a reflective analysis (Darlington et al. 2002) with an emphasis on how a worker forms judgements, a consideration of ways 'worker bias' can be reduced (Coulsed and Orme 1998:35) as well as a review of how decisions are made (Milner and O'Byrne 2002:177). Pritchard (1995) adds that supervision should ensure that practice is sensitive to the needs of service users. It should also be an important part of workers taking care of themselves (Hawkins and Shohet 2006). In palliative care there is an additional dimension that should be recognised in supervision: the acknowledgement and management of strong feelings that can occur when working with people who are facing death (Currer 2002:211). It is Chowns' (2005) view that working with children can be as demanding as working with death and dying and so doing both at the same time is likely to be stressful. Supervision should provide an opportunity for these feelings to be recognised and appropriate support given. The Social Work Task Force (2009:29) sums up all these views in its statement on the purpose of supervision:

… to review day to day practice and decision-making, plan their learning and development as professionals, and work through the considerable emotional and personal demands the job often places on them.

The topic of supervision was explored in the focus groups and interviews and it appeared that a variety of models of supervision existed. Everyone received supervision in some form. This could be from an external person (someone not employed in their work place), for example, an experienced social worker, a lecturer in social work, a counsellor or from someone inside the agency, usually the line manager who was either a social worker or someone with a nursing background. One worker described how she had to arrange her own supervision, and the hospice agreed to pay. Out of the 17 palliative care social workers interviewed, 10 received supervision from a social worker. One worker in a focus group spoke very highly of her external supervisor, particularly in relation to work with children and families:

I am really lucky because I have external supervision and the social worker I see has worked in child care for a long time and she is also a qualified counsellor and supervisor – I dread her retiring because it would be jolly hard to find someone who has that breadth of knowledge.

Those palliative care social workers who described their supervision arrangements seemed satisfied with what was provided, although one worker did comment that it was sometimes difficult to get together with the line manager when both were busy. Recognition was given to the importance of sharing their thinking with someone and checking out attitudes to find out if 'they were getting over-involved and not seeing the wood for the trees'. For immediate discussion regarding a child, those with external supervision would turn to their line manager (often a nurse), or the person who drew up their agency's child protection policy, or staff in the local authority children's services. Another source of support was the 'named nurse for child protection'. If there was an issue they were struggling with or for information and advice, contact might be

made with the social services, either with a team leader or a duty team. So, unless the internal supervisor him or herself had a child care background, finding someone who could assist was not always straightforward. The breadth of the job made it difficult to find someone who could sufficiently supervise all aspects.

Palliative care social workers who were located in a palliative care social work team spoke of the importance of peer support, being able to discuss situations in an informal way or at specific case presentation sessions. There were those who were themselves managers of other palliative care social workers in the team and provided supervision. There were particular difficulties for those palliative care social workers who were lone social workers in their agency and had no opportunity to share concerns with social work colleagues and, in these cases, mention was made of contacting colleagues in other palliative care agencies. One lone hospital worker met with a hospice worker for peer support every six weeks and another with a group of hospice social workers every three months. For these lone workers, and indeed for some others, there was a feeling of vulnerability and the lack of backup that a social work team could provide. This vulnerability regarding child care concerns was succinctly described in a focus group by one lone worker:

> You know that there is abuse and when you are a lone worker it is hard to see round it until someone outside the system comes in and you are able to talk it through with them and they are able say to you 'Well actually I think it is abuse' and you can say 'Yes I think you are right we need to do something about it'. And sometimes it is quite hard to do, isn't it, when you are stuck in it?

In the survey, palliative care social workers were asked*: '*If you ever have cause to be worried about the care and welfare of a child of a service user, who would you discuss this with?' Out of the 56 responses there were five main groups of people identified; people indicating more than one. The line manager or manager of the team was the predominate group, followed by the staff in the local authority child protection team or

children's services. There was an even spread among the remaining groups of supervisors, colleagues in the multidisciplinary team and social work colleagues in their own agency.

As palliative care social workers cover the whole range of age groups it may be that not every supervisor has an interest and/or expertise in child care matters. If there was no recognition that working with children was part of the palliative care social worker's responsibilities then it would be unlikely to be a topic for supervision. Helm (2010:57) points out that supervisors need to have 'a sound, contemporary, understanding of theory'. Supervision, according to Haringey LSCB (2009:24) in its review into the death of Baby Peter, 'will not improve the quality of the practice unless the manager has competent knowledge and skills which are relevant to the case'. In addition, supervision should provide an opportunity for the worker to reflect on their work and discover new learning that can emerge from difficult situations and be a crucial part of self development (Hawkins and Shohet 2006:5). It should be a vehicle for considering the worker's professional development and what further training might be required to enhance the worker's knowledge base and effectiveness in practice (Lishman 2002:15). It was difficult to gain a clear view in this study of how well supervisors were able to support the palliative care social workers in their work where there were concerns about children.

Training on safeguarding children

'The recognition of the need for child protection training is not new' (Baverstock et al. 2008:64). There has been a stress on the importance of training in the various inquiries into the deaths of children through abuse over the years (Laming 2003). Statutory guidance on staff development and training now exists (2010:91) which includes 'being able to recognise when a child may require safeguarding, and knowing

what to do in response to concerns about the welfare of a child'. In particular those

who work with adults who are carers and who may be asked to contribute to

assessments of children in need:

> … should have a higher minimum level of expertise: a fuller understanding of
> how to work together to identify and assess concerns and plan, undertake and
> review interventions (p.95).

In England and Wales, Local Safeguarding Children Boards (LSCB), and in Scotland,

Child Protection Committees, provide a range of inter-agency training. Section 11 of

the Children Act 2004 places a duty on NHS Trusts in England to ensure that all staff

working with children and families have a regard to the need to safeguard and promote

the welfare of children. This includes training. There has been an emphasis on the

need for inter-agency training in order to help develop a shared understanding of the

roles and responsibilities of the various professionals. This, in turn, it is argued can

contribute to more effective and integrated services; improved communication

between professionals; effective working relationships; and, sound decision-making

(DfES 2006:4.3).

The evidence base for the assumption that inter-agency training enhances inter-

agency working is 'rather slim' (Ogilvie-Whyte 2006; Taylor and Daniel 2006:179). The

evidence from a multidisciplinary interagency training in one London Borough (Barker

1998) however, suggests that child protection awareness was raised and

communication between agencies improved. The training highlighted the complexities

of the work and the demand on professionals, particularly in terms of how they defined

need and risk. There has also been a recognition that whilst task and process are

important elements in the training, in order to facilitate better working relationships,

there should be more emphasis on process (Glennie 2007:174). Evidence from a

recent substantial evaluation of inter-agency training to safeguard children in England

(Carpenter et al. 2010) shows that there were positive outcomes in terms of increased knowledge base and 'very substantial improvements' in self-reported understanding of the role of other professionals involved (p.ii). Participants 'very highly valued' the opportunity to learn together.

The emphasis in policy and guidance documents is that all staff who have contact with children should have ongoing training, both single and multi-agency which 'is tailored to address the identified needs of staff in terms of their level in the organisation and stage of professional development' (Department of Health 2004:170). The non-statutory guidance *The Common Core of Skills and Knowledge* (National Collaborating Centre for Women et al. 2010) covers six areas of expertise that everyone who works with children and young people, even as only part of their job, should be expected to have. It is recommended that these should be used in induction, training and staff development.

In this study, the need for training and keeping up to date in child care matters was generally recognised as important, even if could be quite an effort to achieve. Where training was not immediately available, there were palliative care social workers who spoke of gathering information from the Internet or by reading articles and books. The need for good quality training in safeguarding children, including the relevant legislation was considered to be important, although the latter aspect in particular was not always forthcoming and many workers felt out of date.

From the responses in the survey, the amount of training workers had received on safeguarding children ranged from none during the previous two years to two days a year. A quarter of respondents had not received any training on safeguarding children in the past two years. Of those who had, about a quarter had found the training not very supportive and about half generally supportive or very supportive.

Findings from the interviews showed that child protection issues were generally first raised in agency induction training which included terminology, signs of abuse and agency procedures. This training was generally followed by multidisciplinary training provided in-house and there were examples of palliative care social workers being responsible for its planning and delivery. The training was generally mandatory, although one worker commented that in her experience it had become 'a bit jaded' and needed revising. If the in-house training was not provided by a palliative care social worker, then it was generally led by a medical member of staff. One worker in a focus group described her experience:

> It was health who came in. We had nothing till last year and then somebody from health came in - it would be the child protection officer, Acute Trust - and did some talks. And my understanding is that they should do that every year but I am sure it is over 12 months since the last. And they haven't come back … it should be mandatory every 12 months, like your fire lectures.

This view that it should be mandatory and within time limits was repeated regularly.

Whilst there were palliative care social workers who acknowledged that accessing training was easy or relatively easy, others found it relatively difficult to do so. There were reports of workers funding their own training. There were workers who could access courses delivered by local authorities and LSCBs. This training was generally provided free of charge. Those courses supplied by the LSCBs in English authorities were singled out for particular mention by some, whereas others were not aware of the Boards' existence. One worker however described how she was the hospice representative on the local safeguarding children's panel and also part of its training pool.

Those who had a link with the Boards spoke positively about being kept up to date and accessing their web sites for information. Gaining access to or having knowledge of

training provided by local authorities was a particular difficulty for some whereas others had positive experiences in this area. There were views that the local authority training departments did not know that palliative care social workers existed, or if they did, did not understand their role and did not include them in their circulation lists.

Various Primary Care Trusts also provided training on child protection which members of the multidisciplinary team were expected to attend. There was a wish expressed that training be more 'joined up' with adult and child and family social workers attending as well as medical and nursing staff. Separate training, it was believed, perpetuates the gaps between the services as well as the gap of understanding. The split between adult and children's services meant that some palliative care social workers missed out on training on safeguarding children. One worker spoke of her training being 'very out of date' due to this split and the non-expectation that palliative care social workers would be involved with children. The emphasis was rather on adult protection. In contrast, there was one worker who described a positive experience when she attended a two-day joint training event between social services and health aimed at people working primarily with adults who may come into contact with children.

It is possible that this view that palliative care social workers' involvement with children is very limited means that the workers themselves and/or, their managers do not seek or are not encouraged to attend safeguarding training. In the survey, there were comments to this effect and one person, employed by the NHS and working in a combined in-patient and day hospice, wrote that she was not encouraged to access such training and that in fact she was prohibited from working directly with children. Another described how she had to specifically request such training and provide a rationale for the request. There were also palliative care social workers who considered that they

needed to be more proactive in finding out what training was available and accessing it themselves.

In the survey, respondents were asked about their future training requirements. About half felt that an annual or regular update would be beneficial and this would reinforce their basic training. Updates on legislation were particularly mentioned, as was information on local policies, procedures and practices along with services available. Four workers commented that they were happy with the present situation already receiving sufficient training, regularly updated, which met their needs. Seven either gave no response or said 'none'. Three asked that the training be palliative care specific. The other responses were wide ranging, for example, how to talk to parents where there appeared to be a real concern, how schools support children facing death and, dynamics of the dying phase on child protection. Interestingly, no mention was made of direct communication with children.

Other influences on their practice

Those who had previously worked in the local authority, particularly in child and family teams or child protection, found this experience very beneficial in their current posts in terms of their confidence and knowledge. Of the 17 palliative care social workers who were interviewed, seven had local authority experience of child care work; three as generic workers and four in specific child care teams. One worker still described herself as a child care worker. Another explained that frustration was the reason for moving from local authority child care services where she had been well aware that she was not practising with children and families in the way that she wished to because of the 'enormous' case loads.

There was a spread of other previous work experiences with children including daily minding, youth work, residential child care, teaching, and working with children with disabilities. Those who had worked in the mental health field or more general work with adults found their understanding about anxiety, loss and depression relevant and endeavoured to fill gaps by attending relevant courses as well as reading on child care issues.

Those palliative care social workers who had children of their own saw this personal experience as an asset in helping them understand and communicate with children; those who did not spoke about their experiences with children of friends and family in a similar way. There was also mention by some of the losses in their own lives that had helped them have some understanding of others' grief. Workers recognised that their own upbringing and values shaped their current thinking and was summed up by one worker:

> I bring my whole self when I am doing this work. I have a great sense of social responsibility and justice and all of those old-fashioned social work values.

All spoke in various ways of their commitment to children and their interest in families. One worker explained:

> I enjoy working with children and I think my influence comes from the fact that I feel that everybody has the right to have a decent death, to be told the truth, including the children.

Conclusion

It was apparent, although not always referred to directly, that the practice of palliative care social workers in their involvement with children and families was informed by various factors. There appeared to be a good knowledge base about the impact of bereavement on children and about child development and attachment as well as what constitutes child abuse, although in contrast, neglect was not so frequently referred to.

However, there were workers who felt less confident about recent child-care policies, guidance and legislation. Basic training on child protection, mainly on terminology and recognition, was provided with some palliative care social workers providing this themselves for other staff in their workplaces. Knowledge about and access to training outside the workplace on safeguarding children varied. There was acknowledgement that personal and previous work experiences gave palliative care social workers confidence in their work with children.

As supervision for social workers is now considered to be an essential requirement, it was interesting to note that there were palliative care social workers who did not receive regular supervision from another social worker. This was more frequently the case for the 'lone' practitioners. Having someone to share professional concerns about the care of the children was considered to be important but not always available, which left some workers feeling vulnerable.

Chapter Twelve

Conclusions

Children are precious … they are entitled not just to the
sentiment of adults but a strategy that safeguards them
as children and realises their potential.
DfES 2003

Introduction

The aim of this qualitative study was to explore the role of palliative care social workers

in safeguarding and promoting the welfare of children of adults who are receiving

specialist palliative care. This study was comprised of focus groups, a survey and semi-

structured interviews involving a sample of palliative care social workers. The purpose

of the study was to both draw and analyse the picture of their 'real-life' work with

children and their families. I believe that this wide-ranging examination of their

involvement has illustrated not only the dedication of the workers involved and the

dynamic nature of their task, but also the benefits and difficulties in carrying it out, as

well as the 'swampy territory' in which it is situated. This concluding chapter presents

the main conclusions and a summary of the key findings. It is followed by a reflection on

the systems perspective, the strengths and limitations of the study and a consideration

of the implications of the findings for practice and future research.

Main conclusions

Safeguarding and promoting the welfare of children is not a straightforward task,

particularly with regard to children of adults who are receiving specialist palliative care.

Palliative care social workers considered it to be part of their role, but generally it was a

very small element of their total workload. Whilst the focus of the work is the adult who

is terminally ill, in keeping with the holistic nature of palliative care palliative care, social

workers in the study were mindful of the impact of the illness on children in the family;

reference was made to 'unwitting emotional neglect' of children by their parents.

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 cover a wealth of practical and emotional issues. There was a general feeling of working without support; to a lesser extent in relation to their own agency and to a greater extent 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 all parties as well as the quality of relationships between them.

Whilst there was evidence of direct work being undertaken by palliative care social workers with children, support was mainly given to the children via their parents. This seemed to depend on the workers' own interpretation of their role, as well as that of their agency and colleagues, plus any previous experience, training and their confidence in this aspect of work.

Key findings

In order to achieve the aim of the study, six key research questions were developed. I will first summarise the findings for each of these questions before presenting four other key findings that came to light during the analysis.

The first question concerned the palliative care social workers' understanding of the term 'safeguarding children'. It transpired that the workers generally saw the term as embracing a wider range of aspects than child protection alone. Certainly the welfare of children concerned them generally and particularly because of the children's emotional needs during their parent's terminal stage of illness. The findings suggest that whilst palliative care social workers are 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 competently, others less so. However, not all agencies were supportive of direct work being undertaken with children; the emphasis being rather on work with parents. These agencies perhaps did not fully understand the implications of the governments' safeguarding policies.

The second question related to how palliative care social workers identify situations where there are concerns about the care of children and how the palliative care teams are involved in that identification. In the main, palliative care social workers as social workers generally, are dependent on others for referrals who may not be child-centred or aware of children's needs. Almost all referrals come from members of the multidisciplinary team. There were some instances, however, when workers did proactively engage with a patient, but this was in a minority of situations and only in in-patient or day hospice care. Palliative care social workers are in a unique position by being in a medically-orientated setting where there is an ethos of holistic care. This involves seeing the family as the 'unit of care' (WHO 2002) which gives 'authority' to the multidisciplinary team to consider the needs of children as well as the ill parent. Unlike other social workers in adult care, being part of such a team means that palliative care social workers are in a position to exert some influence on the 'child awareness' of their professional colleagues and to ensure that children's needs are not lost in the particular concerns about the patient-parent.

In general, palliative care social workers did not have a clear profile of their caseload or pattern of referrals. Compared with 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. Many palliative care social workers were therefore not working on a regular basis with these families; indeed, for many, their experience was very minimal. Consequently, there was a lack of opportunity to build up knowledge,

understanding and expertise, not only about child-care practice itself but also the underlying legislation, policies and guidance.

The third question inquired into how palliative care social workers go about their work with children and their families. The study established that the work is wide-ranging, although generally with parents rather than directly with children. This was a surprise. Palliative care social workers claimed ownership of a child-centred approach to their work. However, where there were concerns raised about the care of particular children, it appeared that they were not always seen, let alone spoken to by palliative care social workers. The workers did not always deem this to be necessary and work was undertaken through the parents or other health care workers. There were also those who considered that they did not have the skills and/or experience to offer a suitable service to children directly.

Palliative care social workers have a large amount of professional autonomy in how they conduct their work, particularly those who are lone workers in their agency. Many, therefore, are in the position of deciding how much they can or should do themselves in terms of direct working with the children of dying parents. This could be due to inclination, ability, confidence and resources, as well as appropriate support within and outside the agency. What was apparent throughout the study was the amount of time, energy and thought that was expended by workers in their efforts to assist children and their families.

The fourth question centred on the palliative care social workers' view of the quality of their relationship with social workers within the local authority children's services. The findings here 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. There was a danger, as one palliative care social worker noted, that the behaviour of professionals resembled in some ways a dysfunctional family. Whilst there were pockets of co-operation and productive joint work, these were in the minority.

There appeared to be a range of impediments to productive co-operation between palliative care social workers and local authority social workers in child and family teams. For some palliative care social workers, there was a dread of 'devastating' a family (Buckley 2003:182) by involving child and family local authority services, perhaps indicating a reluctance to take on the social control function of child protection activity. Occasionally difficulties occurred because of 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 but these tended to fall by the wayside due to lack of time and effort. A commonly held view by palliative care social workers was that local authority social workers did not have a thorough enough understanding of death and dying and its impact on families, particularly in relation to children, and hence shied away from involvement. This lack of understanding was considered to be due to deficiencies in contemporary social work qualifying training.

The fifth question referred to the amount of support and training palliative care social workers receive about safeguarding children. Palliative care social workers participated in basic agency training in child protection and some, further inter-agency training in safeguarding children. However, there were those who had difficulty in knowing about and accessing relevant training. In some agencies, 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.

The amount and type of professional supervision and support varied: not all had access to supervision from another social work professional.

The final question asked for insights from the views of the palliative care social workers which may improve how children may be safeguarded in the palliative care setting. These are included in the following section on 'Implications of the findings for practice and future research'.

There were four other key findings. First, having a parent who is dying is a stressful life experience for any child. For those children where a parent's immigration status was in question there were additional stresses that challenged not only the family, but also the palliative care social workers in their task of endeavouring to promote the children's welfare.

Second, children of lone parents who were dying could also be placed in an uncertain situation. Not only do they have to cope with the terminal illness of their parent and the subsequent loss, but also their future care may not be known or secured.

Third, 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 parents. This would seem to suppose that the relationship between the parent and child will be a positive one, which may not always be the case. This was particularly evident in Family C described in chapter nine. Research has established that children welcome continuity of support and this would seem to be particularly important in a time of loss.

Fourth, there is a neglect of consideration of socio-economic issues in much of the literature, especially given that the incidence of cancers among younger people, who

are likely to have young children, is increasing (Cancer Research UK 2009). Work on health inequalities suggest that this increasing incidence will primarily impact on those in the lower socio-economic groups (Bywaters 2009) where children may already be disadvantaged. Indeed, there were examples provided in this study where this was found to be the case. At the time of writing, the economic climate means that public services are being reduced, benefits reviewed and the cost of living rising, all of which will have an impact on all those who are ill, but particularly those in the lower socio-economic groups.

Reflections on the systems perspective

It has been helpful to keep a systems perspective in mind as I journeyed through this study, especially during the data analysis stages. I took the view that 'the meaning of behaviour has to be understood in context' (Oliviere et al. 1998:55) and systemic thinking therefore helped me to consider the effect of the wider systems and influences on the ill person and their world, including the multidisciplinary team of the hospice or hospital. These contexts include those in which the ill person lives: their work-place, friendships, religious group, neighbourhood, and the reaction of all these to the ill person and family. This view particularly assisted me in my contemplation of the children's and parents' experiences, how children come to the attention of palliative care social workers, the workers' subsequent engagement with parents and children, their interaction with local authority social workers in children's services, and finally the influences on their practice.

In particular, when considering the experiences of children and their parents, I was mindful of Rolland's (2005) Family System-Illness Model. He likens the impact of the more serious and debilitating forms of cancer to the addition of a new member to a family, one with 'special needs', that can compete with the needs of the 'real children' for

potentially scarce family resources (p.2591). One way of considering a family's ability to cope, Rolland believes, is the consideration of the impact of past illnesses, losses and prolonged adversities, for example unemployment and asylum seeking, on the individuals and the family as a whole. The family's belief systems will also have a bearing on this, including those about health issues. This historical view would help explain and predict the family's current style of coping, adaptation and 'creation of meaning' (p.2589). Those families with past unresolved issues or dysfunctional patterns of communication are likely to struggle under the strains that a dying parent can bring. Within many of the examples provided by the palliative care social workers there were these different factors present, resulting in stress which impacted on the children and the parents' coping abilities. The illness therefore does not come alone and palliative care social workers appeared to be aware of the multi-layers in families.

It was very apparent, particularly from the narratives, that dying is a 'family affair' (Hudson and Payne 2009). There were changes in the micro-systems (Bronfenbrenner 1979) in the family, for example brothers or sisters took over the parental role for siblings; estranged parents became re-involved with their children; and relatives such as aunts, uncles and grandparents became carers of the children whose parent had died. The quality of the past and present relationships in a family also impacted on the present and future care of the children.

There was evidence that some palliative care social workers generally approached their work in a systemic way, although they did not always state this explicitly. There were those who demonstrated an awareness that systems theory locates the patient and their family within a number of systems that can have a negative or positive impact on individual members. They recognised that societal systems could both have a hindering or enhancing effect on a family and used their knowledge to mobilise resources and support. However, whilst there was evidence that workers did consider the children and

their needs, the study did not look in depth at the assessment process and so it is not possible to judge to what extent workers considered the children from an ecological perspective. Parenting capacity was a consideration but the knowledge that a parent is soon to die is an extra dimension that workers had to take account of. This dimension is very seldom discussed in the literature.

Palliative care social workers do not work in isolation. They are part of the 'change-agent system' (Pincus and Minahan 1973) which employs them. When endeavouring to bring about change within that system, for example in relation to referral practice or on-going work with children post-bereavement, the workers' continuing relationships with other people in that system and their status will be factors in whether and how this can be achieved. Lone palliative care social workers may feel particularly vulnerable in a medically-orientated setting and this was reported to be so in this study. Pincus and Minahan (1973:247) draw attention to the exercise of influence that underlie the activities of social workers in their engagement with different systems. From the study it was possible to see that the palliative care social workers' bases of influence derive from their knowledge and expertise, their reputation, their status and established relationships. Their status is linked to that of the agency and is considered to be viewed differently by service users to those workers in local authority children's services. The main area where there were difficulties in exercising influence was in relation to social workers in the children's services of the local authorities. Here the relationship could be described in the main as 'conflictual' although there were a few examples of 'collaborative' relationships between workers. Palliative care social workers seemed to generally believe that they were unable to exercise influence in their efforts to secure the support for children and their families that they thought was appropriate.

Palliative care social workers are themselves influenced by their knowledge, value and practice base, their profession, the multidisciplinary team, the agency, and society as

well as the family with whom they are working. Society here includes legislation and government policies and guidance as well as the general population's expectations of social workers and health care workers with regard to the care of children.

Strengths and limitations of the study

This thesis 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. Whilst the experiences and views are from a group of specialist social workers based in a particular setting, there are themes that are relevant to other workers in other settings. It also continues the debate around the extent to which services for adults are child-centred, and how staff may be supported in their task of safeguarding and promoting the welfare of children.

This study extends the knowledge about the practice of palliative care social work in a particular aspect of their work which is currently under-researched. As the experiences, opinions and insights presented are based on those of a limited number of palliative care social workers, it cannot be assumed that the findings are representative of all. Indeed, as people self-selected and volunteered their time, there is an assumption that they had an interest in the topic. However, those who did participate supplied rich data which was gathered in three ways in an effort to widen the information base, which is a strength of the study.

This is a 'one-dimension' study rather than a 'multi-voiced' reconstruction (Guba and Lincoln 1994:115) in the sense that no children or parents were involved in the research process. I am aware that throughout, and in particular in chapter six, I have interpreted children's voices through an adult lens: the palliative care social workers' (often via parents) and then my own. However, I have endeavoured throughout to ensure that, as

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far as possible, there has been a child-centred approach on my part and children's circumstances represented. The study also lacks information from the other professionals involved with the palliative care social workers in their duty to safeguard and promote the welfare of children, in particular members of the agency multidisciplinary teams and social workers based in local authority children's services. The roles that these professionals play have been seen in this study to have an influence on the way in which palliative care social workers are able to carry out their role and responsibilities with regard to children of adults receiving palliative care.

Implications of the findings for practice and future research

If the argument is accepted that children are to be more centrally located in the family then I would support Chowns' (2006:265) recommendation that palliative care should have a culture that is genuinely 'family' rather than 'adult-family-focused'. This means that all the settings that provide palliative care services should acknowledge the presence and involvement of children. If all staff think in this way, it would help to ensure that children in the family are acknowledged from the start and their circumstances and needs taken into account both before and after the death of a parent. Children need to be recognised as social actors with their own views and concerns that may differ from those of their parents. At the same time, as child protection has now widened to encompass not only preventing abuse but also promoting the welfare of children, agencies 'need to find ways to form a protective network around all children' (Taylor and Daniel 2005:299). This is a challenge not only for palliative care social workers but also for all workers across agencies.

Further, in order to undertake direct work with children, palliative care social workers need to be equipped to have 'open conversations' with children to enable their voice to be heard (Oliviere et al. 1998). There are dangers in assuming that the perceptions of

adults accurately and adequately represent those of a child. Workers should also be willing to 'be alongside' children in all circumstances, particularly when they are sad, and acknowledge their own feelings that this generates. If there are gaps in the palliative care social workers' skills leading them to limit the service they offer to families where there are children, there should be mechanisms in place to enable them to be filled. These would include appropriate training, as part of continuing professional development, and ongoing professional support from someone knowledgeable about child care matters. Indeed, the findings suggest that there is a particular need for inter-agency training whereby social workers in local authority children's services and those in palliative care participate together in exploring ways of working with children who are living with a terminally ill parent. There is a role here for the LCSBs in England and Wales and the Child Protection Committees in Scotland to encourage such training, and to identify those palliative care social workers in their area in order to ensure that they are kept abreast of training opportunities and up-to-date information about safeguarding children.

In their study, Beresford et al. (2007:152) highlighted the problems of access and referral to palliative care social work. They recommended that workers undertake a systematic audit of referrals to their service. I would support that recommendation with the proviso that there are audit categories that include reference to children under 18 in the family and also to lone carers. I would also recommend that the audit be widened to include the number of referrals to the palliative care service where there are children under 18 years in the family. This would allow a picture to emerge regarding the onward referral rate to palliative care social workers. It would also provide palliative care social workers with information to assist them in arguing for specific resources to assist them in their work with children and families, including training and support.

Future research might also benefit from a case study approach to explore the work of one or two palliative care social work units. This should include children and parents, palliative care social workers, palliative care team members, senior management of the agency, local authority social workers in child and family teams, an analysis of documents and observations of team meetings. This would ensure a more 'rounded' picture in order to highlight the dilemmas and tensions as well as positive outcomes. Exploring two different units would allow for comparisons to be made. The Delphi technique might be usefully applied to a part of the research to determine a multi-professional understanding about safeguarding children in palliative care practice with adults.

There were reported instances of collaborative relationships between palliative care social workers and social workers in the local authority children's services. Research into what makes these collaborative relationships work would be constructive, not only in relation to the work described here, but also to that between other agencies and children's services.

The impact of the immigration status of the family on the children's welfare during pre- and post-bereavement is a key finding of this study. This aspect has not previously been researched and therefore is 'hidden' from public scrutiny. The amount of distress and stress that children and their surviving parents experience calls for an urgent need for research. Doing so would provide another dimension to the literature on the implications of immigration for children and inform the agencies with whom they are involved.

Concluding remarks

It is my belief that all social work practitioners, in whatever work setting, should be able to recognise direct and indirect indications of a child being in need of help. Combined

with this they should be able to recognise aspects of parental behaviour that might be expected to have a negative impact on their children. This does not mean though that palliative care social workers should become 'child protection officers'. Rather they should consider if a child's needs are being met and, if not, whether their development is being, or is likely to be, impeded as a result. Such an assessment should include what they themselves are able to provide in terms of direct support to children and their parents and what assistance might be required from elsewhere.

This study adds to the limited existing knowledge about the practice of palliative care social work. If the scope of the work is not promoted and acknowledged more widely, then it is likely that it will remain a 'service in the shadows'.

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71.

PARTICIPANT INFORMATION SHEET   *Focus Groups*

TITLE OF PROJECT

Safeguarding Children: The Role of the Palliative Care Social Worker

INVITATION TO TAKE PART IN A RESEARCH STUDY
You are being asked to take part in a research study, which is exploring the role of the palliative care social worker in situations where a main carer has a terminal illness and the child/children in the family may be vulnerable and at risk.

Carole Comben is undertaking this research as a PhD student based at the University of Dundee in the School of Education, Social Work and Community Education. Carole is a qualified social worker with over 30 years of experience in social work education with particular emphasis on child care. The study is expected to be completed by October 2009. The main data collection phase will be taking place between end July 2007 and April 2008 and will involve focus groups, the administration and analysis of questionnaires and semi-structured interviews.

PURPOSE OF THE RESEARCH STUDY
This study aims to consider the impact of recent policy and legal developments regarding the safeguarding and protection of children and young people on the work of palliative care social workers. Recent UK research, [Beresford et al. (2006) *Palliative Care, Social Work and Service Users.* London: Jessica Kingsley] shows that prior to meeting the palliative care social worker, patients and families tended to have negative views of social workers in general associating them with the removal of children and loss of independence. Once engaged with each other, this view changed and the psychological support role was seen as particularly significant to them. This study will consider whether this therapeutic relationship has any bearing on the decisions made about the care of children in the family of the patient.

Participation in this research would enable there to be a clarification of the role of the palliative care social worker with regard to safeguarding children, an identification of training required to enable them to carry out their role competently and confidently and, the development of good practice guidelines.

TIME COMMITMENT
This part of the study will require attendance of a small number of specialist palliative care social workers at focus groups. Each participant is invited to attend one group meeting of approximately 6-8 workers. The maximum time for the group session will be 1.5 hours.

TERMINATION OF PARTICIPATION
You may decide to stop being a part of the research study at any time without explanation.

/RISKS

RISKS
There are no known risks for you in this study.

COST, REIMBURSEMENT AND COMPENSATION
Your participation in this study is voluntary.

CONFIDENTIALITY/ANONYMITY
The focus groups will be recorded with the consent of the participants. The recording and transcripts will be kept securely within the School of Education, Social Work and Community Education and will be destroyed two years after the end of the project.

The data we collect will not contain any personal information about you except your professional qualifications, place of employment and length of time in this field of work.

No one will link the data you provide to your identity, name or place of work.

The results will be contained in the PhD thesis. An executive summary will be sent to those workers who participate in the focus groups and semi-structured interviews and also to Association of Palliative Care Social Workers for dissemination. It is anticipated that articles will be submitted to the relevant professional journals. Participants will remain anonymous and will not be identified in any way.

FOR FURTHER INFORMATION ABOUT THIS RESEARCH STUDY
Carole Comben will be glad to answer your questions about this study at any time and her contact details are given below.
If you want to find out about the final results of this study, you should also contact Carole Comben.

You may contact her at <u>C.R.Comben@dundee.ac.uk</u> or write to:

Carole Comben
Post Graduate Research Office
OTI Building – Room 107
School of Education, Social Work and Community Education
University of Dundee
Nethergate
Dundee
DD1 4HN.

FOCUS GROUPS   **Discussion guide**

Note that the terms safeguarding and protecting are both used due to the different use of terminology in Scotland and England/Wales.

Introduction
Explanation of the purpose of the study and confidentiality aspects.

Specific question

1   Each member will be invited to state where they work, how long in post, their employer (e.g. local authority or hospice) and how long in post/this field of work.

General questions to group as a whole

2   What is your understanding of safeguarding/protecting children in general?

3   How do you think this understanding applies to your role as a specialist palliative care social worker?
         • Is this part of your remit?
         • Are there guidelines in your agency on child protection/safeguarding children?

4   What training have you received on the topic of safeguarding and protecting children?
         • How easy has it been to access this training?
         • Did you find the training relevant to your position?
         • Can you identify any gaps?

5   To whom do you go for supervision/professional support regarding matters in relation to child protection/safeguarding children?
         • What are your views about this?

6   How do you identify situations where a child might be at risk?
         • Any examples of situations you are able to share?

7   How would you describe your links with your social work colleagues in the relevant local authority child and family teams?

8   What is the role of the specialist palliative care team in relation to safeguarding/protecting children?
- Any examples of dilemmas?
- Any examples of positive practice?

9   Do you think the nature of the illness of the carer may have any influence on your decisions about the child care offered by the family?
- To whom are you responsible?

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Safeguarding Children

The Role of the Palliative Care Social Worker

Questionnaire

Carole Comben
Postgraduate Research Student
Department of Applied Social Science
Colin Bell Building
University of Stirling
Stirling
FK9 4LA

Notes

The research study is exploring the role of the palliative care social worker in situations where an adult service user has a terminal illness and the child/children in his or her family may be vulnerable and at risk. By completing the enclosed questionnaire you will help to clarify this role, identify the support and training required to enable workers to carry out their role competently and confidently, and assist in the development of good practice guidelines.

All the information you are able to give will greatly assist in the mapping of current working practices and identification of any dilemmas. You are not asked to identify yourself in this questionnaire and therefore no one will be able to link the information you provide to your identity, name or place of work.

It is estimated that the questionnaire will take up to 45 minutes to complete.

Please go through the questions and answer them in the light of your normal practice, perceptions or experience.

When completed, please return the questionnaire in the postage paid, pre-addressed envelope by 19 March 2008.

If you have any queries about the questionnaire or the research study please contact Carole Comben at c.r.comben@stir.ac.uk

If you are not currently working with adults in palliative care please tick the box at the bottom of the page and return the questionnaire in the pre-paid envelope provided.

Terminology

Please note that the terms 'safeguarding', 'child protection' and 'protecting children' are all used in the questionnaire to reflect the terminology used in the four countries of the UK.

'Child' refers to children and young people up to the age of 18 years.

I am not currently working with adults in palliative care.   ☐

GENERAL INFORMATION

This section asks for information about yourself and your job.

1   What is your job title?………………………………………………………………

2   When did you gain your social work qualification?……………………………………

3   How long have you been in your current post?………………………………….……

4   How long, approximately, have you been working in palliative care social work?

        …………………………………………………………………………………….…

5   Where is the location of your workplace? *(Please tick)*

Day hospice	☐
In-patient hospice	☐
Combined day and in-patient hospice	☐
Hospital	☐
Community	☐
Other	☐

        please state …………………………………..

6   Who is your employer? *(Please tick)*

Hospice	☐
NHS	☐
Local authority	☐
Other	☐

        please state…………………………………….

7   In which country do you work? *(Please tick)*

England	☐
Wales	☐
Scotland	☐
Northern Ireland	☐

8   Please indicate your gender. *(Please tick)*

Male	☐
Female	☐

YOUR ROLE IN SAFEGUARDING CHILDREN / CHILD PROTECTION

9   What is your role when working with service users who are parents with children?

10   Please describe a recent example where you have initiated discussion with a service user regarding the care/parenting of his or her child/children.

11   Please provide a recent example of what you did in each of the following three circumstances, briefly describing how concerns were raised, what happened and how the situation was dealt with.

         (a)   A service user expressed concern about his or her child/children's care.

         (b)   Another family member expressed concern about the care of the child/children of a service user.

(c) Another professional expressed concern about the care of the child/children of a service user.

12   What influence do you think the nature of the illness of a parent may have on your decisions about the child care offered by that person and the family?

13   Overall, what do you see your role to be in safeguarding children?

SUPPORT AND JOINT WORKING

14   If you ever have cause to be worried about the care and welfare of a child of a service user, who would you discuss this with?

15   If you are a member of a Palliative Care Team, how do other members view your role within the team in relation to safeguarding/protecting children?

16   Please describe your contact with social workers in the local authority child and family and child protection teams in your area. (*Where possible, please illustrate your answer with an example of where this contact has had a positive outcome and an example of where the contact has been less successful.)*

17   How easy is it for you to access services for children?

TRAINING

18   What training, if any, have you received in the last two years in relation to safeguarding children?

        In general, how supportive to you in your role did you find the training to be? *(Please circle number that most closely matches how you feel.)*

        Very supportive   1……2……3……4……5……6   Not at all supportive

19   How easy is it for you to access training on matters regarding children?

20   Please describe any training on safeguarding children/child protection that you
         believe would be of benefit to you in your work.

IN CONCLUSION

21   Overall, how confident do you feel about working in situations regarding safeguarding
         children/child protection? *(Please circle number that most closely matches how you feel.)*

         Not at all confident   1……2……3……4……5……6   Very confident

         What, if anything, would help you to feel more confident?

22   If there is anything else you would like to add regarding the role of the palliative care
         social worker in relation to safeguarding children, please write it here.

Thank you for taking the time to complete this questionnaire.

Please return the completed questionnaire in the envelope provided.

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**DEPARTMENT OF
APPLIED SOCIAL SCIENCE**

14 February 2008

Dear Member

Safeguarding Children: The Role of the Palliative Care Social Worker

This letter asks you to participate in a research study. The enclosed questionnaire is
designed to obtain your views on your role as a palliative care social worker in situations
where an adult service user has a terminal illness and a child/children in his or her family
may be vulnerable and at risk. All the information you are able to provide will greatly assist in
the mapping of current working practices and identification of any dilemmas. The Association
of Palliative Care Social Workers has given permission for the questionnaire to be sent out to
all its members and the study has been approved by the University of Stirling Department of
Applied Social Science Ethics Committee. Attached is an information sheet giving more
details about the study and how the results will be disseminated. If you are not currently
working with adults in palliative care, please tick the box on page 2 of the questionnaire and
return the questionnaire in the pre-addressed envelope provided.

It is estimated that the questionnaire will take up to 45 minutes to complete. You are not
asked to identify yourself in this questionnaire and therefore no one will be able to link the
information you provide to your identity, name or place of work. Please complete the
questionnaire as fully as possible and return it to me in the postage paid, pre-addressed
envelope by 19 March 2008.

The next phase of the research will be individual interviews with a sample of palliative care
social workers. These are scheduled to take place between June and August 2008 at a date,
time and location to suit each person being interviewed. The interviews will explore in some
detail examples of situations where there have been concerns about the vulnerability of
children. The emphasis will be on the outcomes for the child, family and worker. If you are
interested in taking part in this important part of the research, please complete the enclosed
post card and return it separately from the questionnaire – postage is pre-paid. Full
information about the interviews will then be sent to you.

Should you require any further information about the study, or if you have any questions,
please do not hesitate to contact me at c.r.comben@stir.ac.uk or write to me at the above
address.

Thank you in advance for your assistance.

Yours sincerely

Carole Comben

PARTICIPANT INFORMATION SHEET   *Questionnaire*

TITLE OF PROJECT

Safeguarding Children: The Role of the Palliative Care Social Worker

INVITATION TO TAKE PART IN A RESEARCH STUDY

You are being asked to take part in a research study, which is exploring the role of the palliative care social worker in situations where an adult service user has a terminal illness and the child/children in his or her family may be vulnerable and at risk.

Carole Comben is undertaking this research as a PhD student based at the University of Stirling in the Department of Applied Social Science. Carole is a qualified social worker with over 30 years of experience in social work education with particular emphasis on child care. The study is expected to be completed by October 2009. The main data collection phase will be taking place between July 2007 and August 2008 and will involve focus groups, the administration and analysis of questionnaires and semi-structured interviews.

PURPOSE OF THE RESEARCH STUDY

Palliative care considers the needs not only of the patient but also of the patient's family. This study aims to consider how palliative care social workers engage with families where children and young people may be vulnerable and at risk, exploring those aspects of their role which may have a bearing on decisions to be taken regarding the care of children. It will also consider how recent policy and legal developments regarding the safeguarding and protection of children and young people may impact on the work of palliative care social workers.

By participating in this research you will assist in clarifying the role of palliative care social workers with regard to safeguarding children, in identifying the training and support required to enable them to carry out their role competently and confidently and the development of good practice guidelines.

TIME COMMITMENT

The questionnaire will be distributed to all members of the Association of Palliative Care Social Workers at the beginning of February 2008. It is expected that the questionnaire will take up to 45 minutes to complete.

TERMINATION OF PARTICIPATION

You may decide to stop being a part of the research study at any time without explanation.

/RISKS

RISKS
There are no known risks for you in this study.

COST, REIMBURSEMENT AND COMPENSATION
Your participation in this study is voluntary.

CONFIDENTIALITY/ANONYMITY
The questionnaire does not ask for any identifying data and therefore no one will be able to link the information you provide to your identity, name or place of work.

The results will be contained in a PhD thesis. An executive summary will be sent to the Association of Palliative Care Social Workers for dissemination to its members. It is anticipated that articles will be submitted to the relevant professional journals. Participants will remain anonymous and will not be identified in any way.

FOR FURTHER INFORMATION ABOUT THIS RESEARCH STUDY
Carole Comben will be pleased to answer your questions about this study at any time and her contact details are given below.
If you want to find out about the final results of this study, you should also contact Carole Comben.

You may contact her at c.r.comben@stir.ac.uk or write to:

Carole Comben
Post Graduate Student
Department of Applied Social Science
Colin Bell Building
University of Stirling
Stirling
FK9 4LA.

The Department of Applied Social Science Research Ethics Committee of the University of Stirling has reviewed and approved this research study.

UNIVERSITY OF STIRLING

Dear

Safeguarding Children: The role of the palliative care social worker

Thank you for returning the card indicating your interest in taking part in the interviewing phase of the study.

The interviews are planned to take place between June and October 2008. They will explore situations identified by you where you have been engaged with families where there are children and young people. The emphasis will be on a 'solution focus approach' to identify reasons why a particular intervention was successful and to learn from situations where there was a lack of success. The discussion will concentrate on the process of the work and the outcomes for the child, family and yourself. No identifying names will be asked for and no one will link the data you provide to your identity, name or place of work or anyone else involved in the work. It is expected that the interview will last between 1½ and 2 hours. A participant information sheet providing more details is enclosed.

I am planning to interview up to 20 palliative care social workers from a range of work settings and geographical locations. If you are still interested in taking part, please would you complete the attached form and return it to me in the enclosed postage paid envelope as soon as you are able. If you do return a completed form, I will contact you again after 5 June regarding possible interview dates.

Please contact me at the above address or at c.r.comben@stir.ac.uk if you have any queries. I look forward to hearing from you.

Yours sincerely

Carole Comben
Post Graduate Research

Enc: Form
             Postage paid return envelope
             Participant Information Sheet – Interviews

PARTICIPANT INFORMATION SHEET   *Interviews*

TITLE OF PROJECT

Safeguarding Children: The Role of the Palliative Care Social Worker

RESEARCHER*:* Carole Comben

INVITATION TO TAKE PART IN A RESEARCH STUDY
You are being asked to take part in a research study, which is exploring the role of the palliative care social worker in situations where the service user has a terminal illness and the child/children in his or her family may be vulnerable and at risk.

I am undertaking this research as a PhD student based at the University of Stirling in the Department of Applied Social Science. I am a qualified social worker with over 30 years of experience in social work education with particular emphasis on child care. The study is expected to be completed by October 2009. The main data collection phase will be taking place between end July 2007 and August 2008 and will involve focus groups, the administration and analysis of questionnaires and semi-structured interviews.

PURPOSE OF THE RESEARCH STUDY
Palliative care considers the needs not only of the patient but also of the patient's family. This study aims to consider how palliative care social workers engage with families where there are children and young people, exploring those aspects of their role which may have a bearing on decisions to be taken regarding the care of children. It will also consider how recent policy and legal developments regarding the safeguarding and protection of children and young people may impact on the work of palliative care social workers.

By participating in this research you will assist in clarifying the role of palliative care social workers with regard to safeguarding children, in identifying the training and support required to enable them to carry out their role competently and confidently and the development of good practice guidelines.

TIME COMMITMENT
This phase of the research - the semi-structured interviews with a small number of palliative care social workers - will take place between June and August 2008. The interview will take place at a date, time and venue to suit you. It is expected that the interview should last between 1.5 hours and 2 hours.

NATURE OF PARTICIPATION
Your participation in this study is voluntary. You may decide to stop being a part of the research study at any time without explanation.

/COST, REIMBURSEMENT AND COMPENSATION

COST, REIMBURSEMENT AND COMPENSATION
No funding is available to cover any costs that may be incurred by you during this study.

RISKS
There are no known risks for you in this study.

CONFIDENTIALITY/ANONYMITY
The interviews will be audio recorded with your consent and will be transcribed and analysed by me. The recording and transcripts will be kept securely within the Department of Applied Social Science; the consent forms will also be kept secure, separately from the recording and transcripts. All this material will be destroyed five years after the end of the project. The transcribed data will not contain any personal information about you except your professional qualifications, type of employment and length of time in this field of work. It will not contain any identifying information about service users. No one will link the analysis to your identity, name or place of work or to any others involved in your work. If during the course of the interview it appears that a child under discussion may be at risk and the situation requires intervention, then we will discuss what action should be taken.

The results of the study will be contained in a PhD thesis. An executive summary will be sent to those workers who participate in the focus groups and semi-structured interviews and also to the Association of Palliative Care Social Workers for dissemination to its members. It is anticipated that articles will be submitted to the relevant professional journals. Participants will remain anonymous and will not be identified in any way.

COMPLAINTS
If at any time you wish to make a complaint about any aspect of the interview phase of the study, please do so by contacting Professor Brigid Daniel in the first instance at the Department of Applied Social Science - b.m.daniel@stir.ac.uk

FOR FURTHER INFORMATION ABOUT THIS RESEARCH STUDY
I will be pleased to answer your questions about this study at any time and my contact details are given below.

If you want to find out about the final results of this study, please contact me at c.r.comben@stir.ac.uk or write to:

Carole Comben
Department of Applied Social Science
University of Stirling
Stirling
FK9 4LA.

The Department of Applied Social Science of the University of Stirling Research Ethics Committee has reviewed and approved this research study.

INTERVIEW GUIDE

1   Introduction

- Thank you for agreeing to participate

- Explain the purpose of interview

- Go over issues of confidentiality, anonymity

- Permission to audio record

- Consent form to be signed

- Any questions

- Structure of the interview: general contextual information, then the main part of the interview exploring two examples from your practice with families where there were children and young people; and finally some more general questions regarding your work with children.

2   General background and contextual information

In order to set the scene it would be helpful to gain a picture of you and your work setting.

Personal information

- What is your job title?

- How long have you been in this post?

- How long in palliative care social work?

- How long (approximately) in social work?

- How would you describe your work place - e.g. hospice (what type, inpatient)?

- Who is your employer, e.g. hospice, local authority, hospital?

- Are you the only social worker in your work unit?

Palliative care team

- Are you a member of a palliative care team?

- If yes, who are the other members of the team?

- How do you as the social worker receive referrals?

> PROBE: are you clear about your own role and responsibility and that of others in terms of referral?

- How would you describe the work of your team with regard to families with children under 18?

> PROMPT - 'family-focused'?

- How is information generally gathered about the family of the patient?

- How are families identified as being 'at risk'?

> PROBE - How does the team perceive children at risk?

3   Practice examples

In this part of the interview, I would like to explore two situations where you had concerns about the welfare of a child/children. One where you believe the intervention and outcome were successful and another where they were less successful. You choose which one you would like to talk about first. I am particularly interested in the process of the work and the outcomes.

- So, please describe a situation where you had concerns about the welfare of a child/children.

- What were your concerns?

- What were these concerns based on?

- How did you carry out an assessment?

- Did you meet with the child?

- How did you feel about the child, the family and their situation?

- What action did you take as a result of this assessment?

> PROBE - did the illness of the parent affect your judgement in any way?

> PROBE - To what extent did you consider development theories or anything else?

> PROBE - To what extent was your decision influenced by past experiences?

- Were other people involved in the assessment/decision making?

    - If so, who and why?

- Can you tell me about the outcomes (as far as you know) for

    -the child?

    -the parent/s?

    -you?

- How would you describe these outcomes?
    - successful: unsuccessful

- Thinking back on this situation now, what are your thoughts about the actions taken and the outcomes?

Thank you. I'd now like to ask you about another situation where the outcome was successful / less successful (depending on choice of first example). Repeat questions.

- How typical were these two cases would you say ?

Thanks for all that information.

I would now like to move on to your links with the local authority.

4   Decision making - referral to local authority

From what you have said and information I have gained generally from the questionnaires and focus groups, workers have differing views about links with the local authority.

- What factors would influence whether or not you would refer a child/family to the local authority child and family team?

    PROMPT - Are your decisions to refer made on the basis of previous responses from the local authority?

    PROMPT - Are they based on the level of risk?

- Do these factors affect your approach?

- How, in general, would you describe your working relationship with staff in the local authority?

    PROBE - Are you able to discuss your concerns about children and families?

(depending on above answer)
- What if anything would help to make these relationships more effective?

Thanks. I would like ask you some questions regarding safeguarding children in general.

5   Safeguarding children

- What does the term 'safeguarding children' mean to you?

     PROMPT - keeping children safe, legal terminology

- How do you see this as part of your role?

- The term 'the child's welfare is paramount' is a legal term - what does this term mean to you in your work as a palliative care social worker?

- The child's views - how are these heard?

- The expression 'good enough parenting' is one that is often used by social workers when assessing child welfare situations. What does this expression mean to you?

- Would this understanding vary in circumstances where a parent has a terminal illness?
-
     PROMPT - behaviour of parent due to brain tumour - pace of disease progression - lone parent

- Are there any other factors, personal or professional, that may affect your work with regard to children?
-
     PROMPT - children of own; personal knowledge/experience of terminal illness

- If yes, how do you think this experience influences your work with families and children?

6   Finally

- Please complete the following sentence:
'I feel I could be more effective in cases of child welfare if………………

- Is there anything else that you would like to add?

Thank you for your time and consideration.

INFORMED CONSENT FORM   *Focus Groups*

TITLE OF PROJECT

Safeguarding Children: The Role of the Palliative Care Social Worker

This research study is an exploration of the role of the palliative care social worker in situations where a main carer has a terminal illness and the child/children in the family may be vulnerable and at risk.

The study is part of a PhD based at the University of Dundee in the School of Education, Social Work and Community Education. The Research Ethics Committee of the School has reviewed and approved this research study.

By signing below you are agreeing that you have read and understood the Participant Information Sheet and that you agree to take part in this research study.

_____   _____

Participant's signature   Date

Carole Comben

_____   _____

Printed name of person obtaining consent   Signature of person obtaining consent

Thank you very much.

INFORMED CONSENT FORM   *Interviews*

TITLE OF PROJECT

Safeguarding Children: The Role of the Palliative Care Social Worker

This research study is an exploration of the role of the palliative care social worker in situations where a main carer has a terminal illness and the child/children in the family may be vulnerable and at risk.

The study is part of a PhD based at the University of Stirling in the Department of Applied Social Studies. The Research Ethics Committee of the Department has reviewed and approved this research study.

I have read and understood the 'Participant Information Sheet – Interviews' and agree to take part in this research study. I give my consent to the interview being audio-recorded.

_____   _____

Participant's signature   Date

Carole Comben

_____   _____

Printed name of person obtaining consent   Signature of person obtaining consent

Thank you very much..

Data collection and analysis: illustrations of process

In chapter five, I describe how the preliminary analysis of data helped inform subsequent stages of the data collection. Three illustrations of this process are given below which demonstrate how the analysis was built up across the datasets in slightly different ways and how, in illustration two, reference was also made to findings from the literature.

Illustration one

The preliminary analysis of the three focus groups highlighted the palliative care social workers' relationships with social workers within the local authority children's services. These were reported to be more negative than positive and there were some very strongly held views about, as one worker described it, the *'draconian way'* the services were delivered. The workers were concerned about the changing standards and thresholds regarding access to children's services with, as they saw it, a lack of emphasis on prevention and children in need. Those who had previously worked in child protection shared examples about their ability to better negotiate their way to obtain services. Whilst there were examples of positive experiences of work in partnership and obtaining appropriate services for the family, these were in the minority.

As I saw liaison with local authority children's services to be an important element of the palliative care social workers' safeguarding role, I followed up this aspect in the survey by asking the following:

> *Please describe your contact with social workers in the local authority child and family and child protection teams in your area. (Where possible, please illustrate your answer with an example of where this contact has had a positive outcome and an example of where the contact has been less successful.)*

By asking for examples in this way, I was inviting workers to share positive experiences as well as those of a more negative nature to help me gain a rounded picture. A preliminary analysis showed once again that there was a variety of experiences; a few workers had very minimal contact. There were those who described their contact as '*varied*' and those who were able to give useful examples of a positive outcome but the overall tenor of the experiences was less than positive.

During the interviews, I hoped through the sharing of practice examples and the asking of particular questions to clarify two issues. The first centred around the factors that might influence the palliative care social workers in their decision to refer, or not to refer, a child to the local authority. The preliminary analyses of the focus groups and survey had shown that these factors might be based on previous responses from the local authority. However, I wanted to establish whether there were any other factors and if so, how they affected the approach the workers might take. The second centred around the working relationships between the palliative care social workers and those in the local authority children's services and what, in their opinion, would help to make these relationships more effective. If, as it had appeared so far, these relationships were less than positive, then ideas about how this might be changed would be important information to share with others.

The analysis from all three data sets helped to form a more composite picture of this aspect of the role of the palliative care social worker in safeguarding children and forms the basis of chapter ten: *The role of the palliative care social worker: liaising with local authority children's services.*

Illustration two

One theme that arose from the preliminary analysis of the focus group data was balancing the needs of the dying parent and those of the child. This was vividly illustrated by one worker who said their role in safeguarding children was:

> *'…to have compassion with the person who is dying but if you take it too far you can miss the child who is at risk - need to protect the child. We have to hold the balance - not be judgmental and protecting children.'*

The literature review highlighted difficulties that other workers in adult services experience when the focus of their work is with an adult who is also a parent. I wondered how far the terminal illness of a parent was a factor that might influence the decisions the palliative care social workers might make regarding the care being offered to the child. In the survey, therefore, I asked a specific question: *'What influence do you think the nature of the illness of a parent may have on your decisions about the child care offered by that person and the family?'* The preliminary analysis of this question, as well as that from information gathered from the practice examples given in response to questions 10 and 11, showed that there was a recognition of the dilemma of balancing the needs of the parent and child in what was known to be a short-term situation. There were those workers who clearly stated that the child's welfare was paramount, whilst

others were less categorical. I considered this to be an important aspect of their safeguarding role and sought in the interviews to widen this issue by asking what the expression *'good enough parenting'* (a phrase often used by social workers when assessing child welfare situations) meant to them and whether this understanding might vary in circumstances where a parent has a terminal illness. The preliminary analysis showed that giving a clear definition was subjective, difficult to do and that standards differed. There was also recognition that the illness might prevent parents from caring for their children in the same way as they had previously. The analysis from the three datasets appears in chapter seven.

Illustration three

During the preliminary analysis of the data from the focus groups on the above theme, it was apparent that palliative care social workers found that the medical and nursing staff sometimes had differing opinions about parenting and children's needs. It was reported that some staff were more forgiving of the parent's behaviour because of the illness and there were others who focused their attention on the parent who was dying and did not consider the needs of the children to be a priority. As the analysis from the focus groups had highlighted that nearly all the referrals to a palliative care social worker were made by a third party, usually a member of the nursing staff, I wondered how their attitudes might influence the referral process. There was no direct question about this in the survey as choices had to be made regarding its length and direction. However, question 15 did ask for the workers' opinions about how other members of the palliative care team viewed their role within the team in relation to safeguarding children. A preliminary analysis showed that the workers considered they were seen as a resource in child care matters and that staff members would come to them if they had concerns.

As children can only be safeguarded by the palliative care social worker if they are known to them, I considered that there should be a place within the interview to explore the issue of referrals in some depth. Specific questions were asked about how the workers received referrals, whether there was clarity about their role in this and how information was generally gathered about the family of the patient. The referral process was also described within the practice examples explored later in the interviews. The analyses from the interviews, focus groups and the survey are presented in chapter eight.

Glossary of terms: chapter nine

Included here are brief definitions of terms used in chapter nine. Further information on social work methods can be found in the following texts:

Coulshed, V. and Orme, J. (2006) *Social Work Practice: An Introduction (4th ed).* Basingstoke: Palgrave Macmillan.

Lishman, J. (ed) (1991) *Handbook of Theory for Practice Teachers in Social Work.* London: Jessica Kingsley Publishers.

Parker, J. and Bradley, G. (2003) *Social Work Practice: Assessment, Planning, Intervention and Review.* Exeter: Learning Matters.

Watson, D. and West, J. (2006) *Social Work Process and Practice: Approaches, Knowledge and Skills.* Basingstoke: Palgrave Macmillan.

Brief solution approaches

'A short-term, strengths based method emphasising the utilisation of existing coping mechanisms/skills to resolve new challenges' (Watson and West 2006:53-54).

Casework

Refers to work with individuals and/or families. This is a common form of social work practice which involves 'a worker engaging with an individual, couple or a whole family, depending on the circumstances, forming a picture of the situation and attempting to move forward accordingly' (Thompson 2010:41).

Cognitive behaviour therapy

Based on learning theory it is a brief and highly structured approach. The aim is to teach coping skills, thus empowering the client and avoiding dependence on the therapist (Coulshed and Orme 1998).

Counselling

The process whereby a trained counsellor explores a difficulty a person is having, distress they may be experiencing or the dissatisfaction they have with their life, or loss of a sense of direction or purpose (The British Association for Counselling and Psychotherapy).

Crisis intervention

'A short term method of intervention utilising a crisis situation as a catalyst for change' (Watson and West 2006:53-54).

Psychosocial approach

Usually linked to the writings of Florence Hollis (1964), the goal is to assist the person or situation, or both, by reducing the internal and/or external conflict. The focus will be on the behaviour but there is also an attempt to understand and resolve inner conflicts by sustaining and modifying procedures. Sustaining procedures include offering support and building relationships; and modifying procedures aim to reduce 'outer' pressures and enable the client to gain insight (Coulshed and Orme 1998:146-148).

Psychodynamic perspective

The value of this perspective is to understand human behaviour. Psychodynamic thinking is seen as predominately concerned with certain key relationships: those between self and significant other people; past and present experience; inner and outer reality. The approach has its basis in psychoanalysis and specifically the work of Freud, but incorporates more recent analytic thought (Brearley 1991:49-62).

Solution-focused approach

Focuses on a person's strengths and solutions rather than the problem areas (Hepworth et al. 2010).

Systems approach

'Considers the impact of social structures, the kinds of help and support provided and access to them have on the ways in which individuals, families, groups and communities respond' (Parker and Bradley 2007:89). [For more information see chapter five].

Task centred approach

'A short-term systematic method focused on the contractual completion of achievable and agreed tasks' (Watson and West 2006:53-54).