Caring for children dying from cancer at home: a qualitative study of the experience of primary care practitioners

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Background. The rarity of childhood cancers makes providing palliative care in the community an unusual event for primary care practitioners. Providing this care requires effective interprofessional collaboration with the team that forms to provide the care often working together for the first and only time.

Objective. To explore the experiences of primary care practitioners following their involvement in the palliative care of a child with cancer at home.

Methods. The study design was a community-based qualitative study. The study location was the West Midlands region. Purposeful sample of GPs and community nurses involved in providing palliative care to 12 children. One-to-one in-depth interviews with 47 primary care professionals (10 GPs and 37 community nurses) and 5 facilitated case discussions were undertaken. Field notes were documented and grounded theory data analysis undertaken: chronological comparative data analysis identifying generated themes.

Results. GPs had minimal input into the preceding care of children undergoing treatment for cancer but sought to re-establish their role at the child’s transition to palliative care. GPs felt they had a role to play and could add value to this phase of care, highlighted their continuing role with the child’s family and acknowledged that they had gained from the experience of contributing. However, lack of specialist knowledge and uncertainty about their role within the team made this more challenging. In contrast, community nurses were routinely involved in both active treatment and palliation care phases. There was little evidence of collaboration between the specialist and primary care professionals involved. There was considerable variation in out of hours provision across cases.

Conclusions. Engaging primary care practitioners needs to be more actively anticipated and negotiated at the transition to palliation. Variation in out of hours care is another cause for concern. Enhancing inter-professional collaboration and planning during both active and palliative care phases may help.

Keywords. Cancer, family medicine, palliative care, paediatric.

Introduction

The provision of palliative care falls beyond the remit of any one professional.1 In contrast to adult palliative care, where health professionals may commonly have established working relationships, those contributing to palliative care to a child with cancer at home may often be working together for the first and only time. The paediatric palliative care team may include GPs, community nurses [incorporating children’s community nurses (CCNs), children’s palliative care nurses (CPCNs), district nurses (DNs) and health visitors (HVs)], Macmillan nurses and allied health professions such as physiotherapists.

However, effective team working may pose major challenges as childhood cancers are rare and community health professionals are likely to have limited experience of care in this context. GPs can expect to see only two or three cases during their whole career, one of which will be leukaemia.3,3 The
rarity, coupled with the fact that during treatment for cancer the child’s first port of call is usually the hospital, can result in the GP having minimal contact with the child and family. GPs can feel excluded during the treatment period, despite the recognition of their role in supporting the whole family. An opportunity for GPs to regain active involvement in the care of the child and family might arise when palliative care becomes appropriate. Parents caring for their dying child at home appreciate the interest expressed by their GP. GPs perceive their main role in paediatric palliative care as offering support in terms of explaining and interpreting, providing reassurance, listening and understanding. In addition, the GP may offer on-going support and medical care of the family as a whole through palliation, bereavement and beyond.

Conversely, paediatric community nursing teams are often involved in the practical aspects of the child’s care, such as taking blood tests and administering chemotherapy. In maintaining contact throughout the treatment period, community nurses have often already developed an established working relationship with the family at the point of transition to palliative care.

There are many barriers to building a cohesive community team that can provide effective palliative care, especially in striving to provide out of hours medical and nursing care. Changes to GP’s accessibility out of hours have resulted in GPs moving from sole responsibility of providing out of hours care to the situation where the majority of out of hours care is organized and commissioned by Primary Care Trusts. The out of hours GP may have little or no prior experience of paediatric palliative care and is likely to have only minimal clinical information and knowledge of family dynamics. Models of community nursing teams vary tremendously across the UK and there is clear evidence of limited 24-hour nursing services.

Paediatric oncology palliative care is often led by specialist teams from regional paediatric oncology centres, working closely with locally based teams. As groups of GPs become responsible for commissioning for their patients groups, the potential impact upon paediatric palliative care will be determined by the commissioning decisions determining which services or teams will be contracted.

This paper reports on the experiences of GPs and community nurses following their involvement in the care of a child with cancer receiving palliative care at home, examining differences and similarities in their roles and work patterns. GPs and community nurses are local and accessible to the family and may be ideally suited to holding key roles in providing paediatric palliative care.

Methods

Design

The study design was a community-based qualitative study using in-depth 1:1 interviews, facilitated case discussion (FCD) and field notes for data collection and grounded theory analysis. The FCDs were group interviews with all the health professionals involved in the care of a child and family. The aim of the case discussion was to identify key beneficial or detrimental episodes in individual cases with a view to identifying methods of improving methods of improving quality of care. It was anticipated that the FCDs would elicit additional information to that collected through the 1:1 interviews as a result of the health professionals having the opportunity to discuss their experiences with each other. Collaborative discussion was seen in the FCDs undertaken along with evidence of participants directly benefiting from interactions.

Setting

The geographical area of the study location was the West Midlands region and parts of Powys in Wales as defined by referrals to Birmingham Children’s Hospital National Health Service Foundation Trust.

Sample

The sample comprised the GPs and community nurses involved in the care of a sample of 12 children (aged 0–18 years) who were receiving palliative care for cancer at home. The sample was selected chronologically as the children died. Cases were selected to ensure that wide ranges of variables were captured; such as cancer type (leukaemia, solid tumour, neuro-oncology), age of child, rural or urban location, range and type of professionals involved (for example, whether GP was involved) and the level of out of hours care provision.

Data collection

Shortly after the child died, the GP and community nurses were sent details of the study and consent to participate was sought. The researcher undertaking the interviews and FCDs was experienced in providing bereavement support to parents in a nursing role and had undertaken training in both depth interview and FCD techniques.

All the health practitioners involved in the care were invited to participate in a one-to-one interview. The researcher introduced herself, explained the purpose of the interview and assured confidentiality before gaining consent from the participant. The in-depth interviews were tape-recorded with an opening question, ‘Please can you tell me about your involvement in the care of x?’ The follow-up questions were raised in response to the answer given in order to gain clarification of a particular point or to explore a new
direction to the research that had not been anticipated. An interview schedule was written as a topic guide, with three main questions selected that aimed to provide a depth to the understanding of the participant’s experience. The three main questions were ‘Can you describe your role in the provision of care?’, ‘How was the palliative care organized?’ and ‘Have you identified any educational needs since being involved in the care?’. Prompts were also identified for each of the three questions. For example, one of the prompts for the question ‘Can you describe your role in the care?’ was ‘How were you informed of the child’s transition to palliative care?’. The tape-recorded FCDs involved the participants most involved in the care talking about their experiences including perceptions of good aspects of care as well as areas of concern. The other participants were then invited to add their observations. The aim was to complete both the individual interview and FCD within three months of the child dying so as to aid accurate recollection of detail. Written informed consent was obtained from all participants for both the interview and FCD.

A pilot study was undertaken with one case comprising six health practitioners undertaking both individual one-to-one interviews and a collective FCD. The pilot did not identify the need to amend the interview or case discussion format.

Theoretical saturation was reached after 12 cases, determined as the point at which new facets arising from the data no longer added to the already collated and well-defined categories.10,11

Analysis

Analysis was on-going throughout the data collection period and, due to the large volume of data obtained from different health professions, the process of analysis was complex. The transcripts were downloaded onto NVivo and open coding undertaken. Open-coding analysis is the process by which the information detailed in the transcripts is examined line by line, sentence by sentence and paragraph by paragraph, with the aim of examining the meaning of each section of text, thereby enabling sections to be grouped or categorized under broad headings. Themes identified in the data from all sources were coded into as many categories as possible and constantly compared and contrasted with new data as it were collected.12–14 Throughout this process, the codes evolved as they were revised until theoretical saturation was reached and the final axial codes (category headings) identified.

Results

One-to-one interviews were undertaken with 10 GPs and 37 community nurses (Table 1) (comprising 22 CCNs, 3 DNs, 4 HVs, 7 CPCNs, 1 home support worker) and 5 FCDs completed. It proved very difficult to organize the FCDs due to the time constraints of each individual professional. This resulted in only five case discussions being undertaken.

Table 2 provides a summary of the cases. Five axial codes, or categories, were identified from the data: Organization of care, Out of hours care, Teamwork, Communication and Emotional impact. Within these categories, 20 subcategories were identified. The category ‘Communication’, for example, had four subcategories: Communication between health care professionals, Talking to parents, Bereavement and Talking to the child. This paper reports on five of the categories or subcategories identified from the data; three relating to role (establishing contact with the family, role uncertainty, role undertaken), one relating to out of hours care and the final category detailing the emotional toll. These categories and subcategories were selected as they portray the primary care practitioner’s journey from re-establishing contact with the family through to the potential emotional impact they endured. Within these categories, the key

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HVA, health visitor assistant and HSW, home support worker.
differences and similarities between the roles of the practitioners are highlighted.

Establishing contact with the family
GP’s described how, following diagnosis, the child ‘... disappeared into the system ...’ (GP 1) and despite comprehensive letters from the hospital, not actually seeing the child and family resulted in them feeling out of touch. In many cases, they had had little, if any, contact with the child and family before the diagnosis. The lack of contact continued throughout the treatment phase as the family was advised to return directly to the hospital should the child become unwell. This often resulted in the child reaching palliation without the GP having had an opportunity for any meaningful contact. GPs identified difficulty in re-establishing their role with the child and family describing a lack of clarity in both in how to initiate contact and in defining what was expected of them:

... you can’t keep ringing especially if it’s bad. You know it just sorts of reiterates how bad it is. (GP 7)

... the family were don’t call us we’ll call you sort of thing ... (GP 10)

I felt it would have been inappropriate for me to cold call the family ... (GP 4)

Conversely, the children’s nursing teams met the child shortly after the diagnosis following a formal referral from the hospital and offered a practical and supportive role through to treatment and palliation.

The nursing teams were also proactive in maintaining contact with the family:

I didn’t see him for quite big gaps really but Mum kept in touch on the phone or I phoned up the (regional centre) to see how he was ... (CCN 7)

...that’s one thing I took away was that to maintain a good relationship and contact the family even if you’re not doing anything active. (009 CCN 2)

Role uncertainty
GPs clearly differentiated their roles into task orientated or supportive. For many GPs, the supportive contact visits proved more challenging as often no practical role existed. It was in offering or undertaking supportive visits that GPs felt most uncertain about their roles, yet this was perceived as important in fostering relationships for future contacts, be they bereavement or for medical needs:

... you get used to doing everything task orientated. You go to see somebody because you’re going to sort out the pain control or you’re going to sort out something ... we’ve got something to say ... actually just sort of going with no reason is actually quite hard and I think actually that might have been a good thing to have done just to have actually gone and said I haven’t got anything to do I haven’t got anything to say ... it’s sort of culturally quite hard to do that because you sort of hide behind your role don’t you? ... I think it’s as much down to us to be sort of making the effort

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to actually try and go and like I say it’s just hard when you don’t have a prompt or a prop. (GP 6)

... the difficulty is being comfortable with handing over large amounts of both personal and technical care to other people who know much more about it and still retaining some sort of input that stands you in good stead for the continuing relationship afterwards ... speaking personally I am absolutely happy to be replaced or to be led by other people who are doing the job in a very specialist kind of way but all that stops in the aftermath, so the fostering of the relationship between members of the family and the GP is important as part of their care. (GP 1)

Role uncertainty was not perceived as an issue by the nursing teams. During active treatment, their interventions were often instigated by a practical need, such as taking a blood sample. These initial practical visits were often seen as an opening to develop a good working relationship with the child and family, paving the way for future visits:

I think if you build up a good relationship with the family it certainly anchors everything else in place. (CCN 11)

... you know one of the things you are doing is investing in a good working relationship with that family. (CCN 2)

Role undertaken
The GPs and community nurses acknowledged that they had both practical and supportive roles to play in the care provision and there was evidence of learning from the experience:

(I see my role) as one of providing medication and support. (GP 11)

My chief role was to listen to them and to talk to them ... It is quite interesting how a visit like that even though it may not end up with writing a prescription or a change of care is just so they have someone else to talk to. I’ve actually gained from it. I now know how important useful you know I can be in that regard ... (GP 8)

Every death that we have experience has been completely different and I take away something every single time ... (CCN 3 (3)

There was a clear understanding that palliative care provision was a team approach but what appeared at times unclear was how each role fitted into the wider team providing the care. GPs seemed happy to let the ‘specialists’ manage the aspects of care that they had less knowledge in but recognized the need to maintain their role, particularly as they acknowledged the importance of their on-going support of the family after the child’s death:

I was very comfortable with my role in it really in terms of feeling that it was appropriate and really it was only a piece of the jigsaw really ... (GP 3)

It’s absolutely right to have people with specialist skills but there is also a role ... for maintaining a point of contact with your GP ... because we have access to other things and skills ... if you look after a patient you look after their family as well, you’re in a good position to be able to counsel them and look after them after the patient has died. (GP 4)

... you feel as if you are treading on other people’s toes or you are duplicating or you are not actually asked to go in because everyone else is going in (GP 11)

For the nursing teams, their ability to fulfil practical roles in the care was at times challenged by their ability to maintain specialist skills. The rarity of childhood cancer deaths sometimes made it difficult for practical skills, such as setting up syringe drivers, to be maintained. These difficulties were often enhanced by the fact that many of the nurses worked alone out of hours.

District nursing teams only became involved when no out of hours children’s services were available. For the three district nursing teams interviewed not meeting the child and family until called out to deal with a problem proved difficult, as did their acknowledged lack of paediatric knowledge and experience:

... the staff don’t always get to practice those skills the symptom control drivers and things and then along comes a child that has relapsed and they lose confidence again. It’s actually quite hard to persuade them to work alone. (CCN 2 /FCD)

I think we’d always be happy to help but it isn’t ever going to be easy for us because we’re not specialist children’s nurses ... (DN 6)

... it’s just the medication side of it with not being pediatric trained we’re not au fait with all the bits and bobs that go with it. (DN 9)

Anticipating the need to support DN teams in providing out of hours care could facilitate earlier discussions, identification of education and training
needs and, where deemed appropriate, introduction to the child and family.

**Out of hours care**
A review of paediatric palliative care services identified that variations in palliative care provision existed and recommended that commissioners promoted the development of effective community teams able to provide end-of-life care 24 hours a day, 7 days a week.8 Providing continuity of care has been described as a ‘central tenet’ of general practice, and was also highlighted by the GPs interviewed.15 The changes in GP out of hours practice was found to be particularly pertinent to their practice with evidence of GPs not feeling comfortable handing total care to an out of hours service provider. Five out of the 12 GPs interviewed provided out of hours care themselves, the remainder handing over the care to their GP out of hours service providers:

We aim to provide service cradle to grave in general practice. (GP 4)

It’s a peculiar situation that we’re just getting used to … having to be on-call forever and then having our contract changed and we just walk away at half past six on a Friday night. It’s actually uncomfortable when you have got people that are terminally ill. So what I do is leave my mobile number with the district nurses so if they feel anything needs changing they don’t have to liaise with the primary care centre who don’t know anything about the patient. (GP 3)

A lot of doctors including me will give personal telephone numbers to patients in these sorts of circumstances. (GP 1)

The benefits to handing over care to an out of hours service provider were highlighted, such as the child being seen with a ‘fresh set of eyes’ (GP 8) and the GP out of hours service provider not having any ‘baggage’ (GP 1) about the case. The potential drawbacks for out of hours service provider GPs were those of their entering a potentially difficult emotionally charged environment often with limited background information and their walking away with no follow-up of the outcome:

There’s no stuff about the diagnosis. You are in fresh as it were to do a job and often that has advantages in itself. (GP 1)

I think that it could be very difficult for out of hours to go and see a case like that because without having contact with the patient without knowing what was going on and so on quite difficult. So I would have felt for the out of hours doctor going out in circumstances like that and at night time too. (GP 8)

Out of hours nursing care was available to 8 of the 12 families, but unlike general practice, out of hours nursing services are not standardized nationally. Nurses were often found to be providing out of hours care while maintaining their day-time workload:

… when we’re on call that isn’t really a part of our working hours … we don’t get paid for it … it is a voluntary basis and you don’t have to do it. (CCN 3 (3)

The impact of being on call was clearly evident:

When you’re on call you go to bed with your clothes by your side (laughs) you don’t really sleep properly … you wake up in the morning and check the pager just to make sure it didn’t go off that I didn’t sleep through it because I was so exhausted. (CCN 8 (1)

(When you’re on call) … you can’t really do anything because you’re waiting for the phone to do or not to go and if it doesn’t ring you’re thinking oh God they haven’t called me, why haven’t they called me … it’s on your mind the whole time. (CCN 8 (2)

**Emotional toll**
The impact of the emotive nature of providing palliative care was clearly evident in many of the interviews. Practitioners highlighted the impact of the visual changes to the child as well the stresses that arose from actually carrying out the day-to-day care:

I have seen pictures as well before the illness but how she was after being ill, it is unthinkable that that girl became like this. (GP 9)

When you have a child so very ill you feel as if you are working with a black cloud over your head. I don’t know whether that’s a professional thing and we should be able to mange that better, but you carry that family’s sadness with you in your working day. (CCN 2)

**Discussion**
It is during the palliative phase of their child’s illness that most families prefer their child to be cared for at home with professional support from those known to them.16,7 Providing palliative care at home not only results in the child feeling happier but also through caring for their child during the terminal illness, parents have been found to cope better with bereavement. This study aimed to examine the experiences of health practitioners who had been involved in supporting parents to provide palliative care for their child with cancer at home, focusing on the experiences
of GPs and community nurses. The described differences and similarities between the GP and community nurses' roles and work patterns have been shown to impact upon the difficulties they face in finding and establishing a role in this rare context of paediatric oncology palliative care.

The rarity of childhood cancers, minimal, if any, contact during active treatment and a lack of specialist knowledge can make it difficult for GPs to re-institute contact at the child’s transition to palliative care. GPs have to ascertain the practicalities of how to re-establish their role at the transition to palliation. Unlike the nursing profession, evidence showed some GPs reluctant to ‘cold call’ the family (visiting unannounced to offer support without clinical input being required) and unclear of what supportive role they could play. Despite describing a lack of role clarity, the GPs interviewed felt that they had something to offer and could add value to the care provision. Ten of the 12 GPs had some involvement with the child and family during the period of palliative care. The level of GP involvement varied from seeing the child and family only once during the period of palliation to seeing them regularly each week. GPs’ previously exclusive role in clinical assessment and prescribing is now often supported by the expanding number of community nurses with these skills, but their clinical and supportive role may remain integral to the child and family’s care.

The community nurses would receive a referral from the hospital when the child was diagnosed. The child and family would be offered a home visit even if no practical task was required at that time. The rationale for the visit would be for the community nurses to introduce themselves and undertake an assessment of need. Although often task orientated, the community nurses role also encompassed supportive care and they often had an established working relationship with the child and family throughout active and palliative care. The community nurses were proactive in maintaining telephone or face-to-face contact even when no practical role existed. For DNs, the level of, and rationale for, involvement was not so clear cut, often arising to fill the deficit in community children’s nursing out of hours service provision.

This study had identified that it is the transition from active to palliative care that needs to be better anticipated and more actively negotiated in order to ensure that practitioners’ knowledge and skills are effectively utilized. Building on the established role of community nurses and their working relationship with the family, collaborative working with the GP could help re-establish and define their role. This practice may facilitate an enhanced role for GPs in both active and palliative care providing an opportunity to improve care and enhance inter-professional communication, mutual learning and support. In addition, recognition of the need to involve DNs earlier in the discussions about care provision has been identified by this study.

The newly formed team of professionals needs to rapidly develop effective working patterns, such as developing efficient communication pathways, if exemplary care is to be achieved. Effective team working can be difficult to achieve as childhood cancers are rare and community-based health practitioners have limited experience in caring for these children and even less in providing their palliative care. Initiating a team meeting at the child’s transition to palliation could prove to be the linchpin for not only clarifying the GP’s role within the team but also re-instigating contact with the family through the organization of visits with community nurses. It is also envisaged that facilitating co-working with DNs at the child’s transition to palliative care will additionally enable knowledge deficits to be identified and addressed in advance of need. This practice supports other study findings that where adult services are required to provide palliative care to children they should work together with paediatric colleagues, sharing knowledge and expertise.21

It is well recognized that paediatric palliative care provision requires 24-hour medical and nursing care from practitioners with palliative care knowledge and expertise and competence to carry out the care.6,7,17,18 The GP may not hold the required specialist paediatric palliative care knowledge and skills but is integral to the care from the stance of providing a holistic approach to the care of the family, providing continuity of care and support in palliation and providing bereavement support and ongoing medical care to family members. It is well recognized that out of hours care is not standardized; prior to the changes to the out of hours care provision in 2004, it was acknowledged that some GP’s gave their home telephone numbers to terminally ill patients or instructed deputizing services to contact them directly and nationally it is acknowledged that there are inconsistencies in the development of nursing services for children.6,7,19 The differences in out of hours care provision between the two professions was marked, with GPs having a formal service whereas the nursing services were often provided informally by individuals within the team. The nursing teams faced an additional challenge of trying to maintain specialist competencies in tasks infrequently performed, such as those required to set up a syringe driver. This study provides evidence of both medical and nursing practitioners providing informal out of hours end-of-life care to families of children dying from cancer in attempting to bridge the gap in service provision. The emotional toll of providing out of hours care was not examined by this study but was clearly highlighted by
many participants. It is well recognized that working beyond remit can result in individuals suffering increased stress levels or even burnout but in addition this practice raises the issue of equity of service provision, whether health practitioners can sustain working enhanced hours to all their patients given the unpredictable duration of palliation and patient numbers.

Study strengths and limitations

A key strength of the study was that it gained access to practitioners in a very unusual setting, paediatric oncology palliative care. Methodological strengths include purposeful sampling that enabled a wide range of variables to be considered. Utilizing FCDs in conjunction with one-to-one interviews enabled additional data to be obtained through discussion between practitioners. Triangulation of data sources also further strengthened the findings.

The researcher’s dual role as both Macmillan nurse and researcher may have inhibited some practitioners from talking openly and freely but was deemed beneficial in that it facilitated ease of access to the participants and provided background knowledge of the setting and the terminology used within the interviews.

The family’s perspectives of the care were not sought in this study but current work is now addressing this knowledge deficit.

Transferability

The findings are important as they are transferable not only to other regional paediatric oncology centres but also to other settings, beyond the arena of paediatric oncology, where inter-professional collaboration forms the mainstay of the care provision.

Conclusions

Providing palliative care to a child with cancer within the family home requires a multi-professional team approach. Establishing effective multi-professional working necessitates defining a shared goal, developing effective communication pathways, ascertaining roles and responsibilities, recognizing individuals with expertise and identifying and addressing areas for learning mutual learning and support.

Although community nurses were shown to often have a clear practical role in the care from the point of diagnosis, there was evidence of their efforts to pro-actively maintain contact even when no practical task was required. GPs’ had minimal input into the medical care of the child during active treatment and acknowledged uncertainty of how to practically re-establish contact with the family at the transition to palliation. This uncertainty, combined with knowledge deficits, can impact upon a lack of role clarity. GPs that participated in palliative care found that they had something to offer and could be of value; furthermore, they acknowledged that they had gained from the experience. Community nurses’ often constant role throughout the treatment period resulted in nurses usually having an established working relationship with the child and family prior to the palliative phase. Better anticipation of the transition to palliative care, negotiation of roles and promotion of enhanced co-working between GPs and community nurses could engage more GPs and have a positive outcome on care provision. The proposed development and implementation of the Gold Standard Framework in paediatrics may help address these deficits through enhancing both the planning of care and inter-professional working.

In addition, recent developments highlighted in ‘Equity and excellence: Liberating the NHS’ may impact upon the provision of palliative care services through commissioning decisions determining standardization in provision of both day and out of hours care.

Declaration

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Conflict of interest: none.

References

Caring for dying children


