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Bereavement Support after the Death of a Child with Cancer: Implications for Practice

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Declaration

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Abstract

The effects of bereavement are unique and support must be individually tailored. The role of the general practitioner (GP) in paediatric cancer palliative care is wide-ranging and challenging, yet little is known about offered bereavement support in this context. We carried out an in-depth secondary analysis of text relating to bereavement support from a semi-structured interview study exploring GPs' and parents' experiences. Findings highlight the importance of early GP-initiated face-to-face contact with parents, exploring opportunities for innovative practice and maintaining close collaboration with hospital-based teams. A coordinated, equitable and sustainable approach to bereavement support may help address identified GP knowledge deficits and time-pressures.

Keywords

Bereavement, Death of a Child, Cancer, General Practitioner.

Word count: 4679

Background

This paper reports on an in-depth secondary analysis of text relating to bereavement support from a semi-structured interview study in which GP and parent experiences of care were sought following the death of a child from cancer (Neilson, Gibson, & Greenfield, 2015).

Parental bereavement has been described as one of the most stressful life experiences and can have a direct impact on parental morbidity (physical and mental health) and mortality (Dias, Brandon, Haase, & Tanabe, 2018; James & Johnson, 1997; Morris, Fletcher & Goldstein, 2019). Whilst medical practitioners are able to identify when normal grief (coping without professional intervention) becomes abnormal (such as a prolonged period of grief), defining disturbed or pathological grief is more complex (Boelen & Smid, 2017). Prolonged Grief Disorder and Persistent Complex Bereavement Disorder (debilitating ongoing intense distress) are recognised classifications of disturbed grief (Boelen & Smid, 2017). There is an acknowledged distinction between the often-greater depth and duration of grief associated with parental bereavement following the death of a child than that associated with bereavement in other contexts, with these parents benefitting from the provision of long-term interprofessional support (Snaman et al., 2017). The often-profound impact on these parents is also evident through the identified high prevalence of post-traumatic stress disorder (Ljungman, Hovén, Ljungman, Cernvall & von Essen, 2015). Whilst clearly evidenced, the identified range (10-94%) of incidence of complicated and prolonged grief in bereaved parents related to types of death, and the dearth of evidence on what should be considered 'normal grief' in this context, highlights the need for further research (Morris et al., 2019).

Each parent's grief is unique and often follows a different trajectory, with their level of long-term distress being influenced by factors such as the pain their child experienced and the care provided at time of death (Jalmsell, Kreicsberg, Onelov, Steineck & Henter, 2006; Kreicsberg, 2005). Whilst bereaved parent's adopted coping styles, rather than circumstances of the child's death, can inform levels of grief and depression (Harper, O'Connor & O'Carroll, 2014), their views on factors such as the quality of last weeks of life can predict these outcomes where their child had a cancer diagnosis (McCarthy et al., 2010). It is well-recognised that there will be those who will manage their bereavement without professional support, those who will require formalised support, and a cohort who will require specialist support and intervention, such as from mental health professional services (Aoun et al., 2015; National Institute for Clinical Excellence [NICE], 2004). Bereavement services, however, have generally been found to be inequitable in their location, quality, and care provision, and health professionals are not always proficient in assessing and addressing the needs of the bereaved (NICE, 2004; Sealey, O'Connor, Aoun, & Breen, 2015).

Despite a recognised international need for specialist children's palliative care (an estimated 8 million children world-wide), access to care is influenced by a range of factors including the health system, economy, and need (Connor, Downing, & Marston, 2017; Knapp et al., 2011). In the United Kingdom (UK) although rare, childhood cancer still causes the largest number of death by disease in children, with an average of 231 deaths in 2014-2016 (Cancer Research UK, 2019). The usual model of community-based palliative care for children with cancer in the UK is care provided within the family home by both community (General Practitioner [GP] and community children's nurses) and hospital-based health professionals (paediatric

oncology outreach nurse specialists), all of whom may play a role in bereavement support (Neilson et al., 2015; Vickers, Thompson, Collins, Childs, & Hain 2007). There are examples of countries with similar community care models for children with cancer, such as Australia and the United States, and evidence of associated benefits such as improved quality of life (Monterosso, Kristjanson, & Phillips, 2009; Friedrichsdorf et al., 2015).

Bereavement support offered by health professionals based in principal childhood cancer centres [PCCCs, formerly known as Regional Childhood Cancer Centres] varies between the 21 UK centres (National Collaborating Centre for Cancer, 2005). The benefits of offered 'closure talks,' (predominantly occurring within 6 months of the child's death) where bereaved families talk to members of the team who provided the palliative care, are recognised (Kreicbergs, Lannen, Onelov, & Wolfe, 2007). Although some PCCCs offer indefinite support to bereaved parents there is recognition that contact with families beyond a certain point would be intrusive and also impractical for the health professional (Vickers et al., 2007). The GP is the only health professional with a defined long-term role providing on-going support and medical care to bereaved parents (Neilson et al., 2015).

The role of the GP in paediatric oncology palliative care has been found to be wide-ranging (often encompassing support of the wider family) and challenging with minimal opportunities to develop effective working relationships with the child and family due to PCCC led treatment and care and the often short duration of palliative care (Neilson, Gibson, Jeffares, & Greenfield, 2017). The GP's role in bereavement care can be described in the context of health promotion, observing for abnormal grief reactions and providing preventative care where problems are likely to occur (Charlton & Dolman, 1995; Haines & Booroff, 1986; O'Connor & Breen, 2014; Woof

& Carter, 1997). Although GPs recognise bereavement support as an important part of their role, little is known about the level of bereavement support offered, nor what a 'bereavement contact' constitutes (Nagraj & Barclay, 2011). Patients see their GP as a provider of bereavement support but GPs do not always routinely make contact with the newly bereaved (Harris & Kendrick, 1998; Main, 2000). Although recommendations for bereavement practice exist, such as national guidance (NICE, 2016) and regional frameworks and guidance (Blackburn & Dwyer, 2017), offering bereavement support to bereaved parents is a distinct and rare experience for GPs in comparison to support more commonly offered after an adult death (Charlton & Dolman, 1995; Child Bereavement UK, 2017; NICE, 2004; Rolf, Machin, & Archer, 2008).

Education and training in grief and bereavement is included in end of life teaching in the UK (Walker et al., 2017) and US medical school teaching (Dickinson, 2012), with an identified enhanced emphasis on delivery of end of life education over recent years (Dickinson, 2007; Dickinson & Field, 2002). However, it is recognised that GP registrars should receive additional planned systematic training focusing on bereavement care and bereavement updates should be included in on-going professional development (Low, Cloherty; O'Connor & Breen, 2014; Wilkinson, Barclay & Hibble, 2006). Despite this recognition it would appear that current interdisciplinary courses in end of life care for GPs fail to include paediatric palliative care (Selman et al., 2017). For example, studies have shown that grief education in Australian health professional courses (including medicine) is often encompassed within wider 'end of life' teaching (Breen et al., 2013). A potential impact of this model is the omission of sociological and cultural context and the impact of rarer experiences, such as sudden death, on grief (Breen et al., 2013). Learning within this

context is, however, influenced by a number of factors, for example formal teaching being underpinned or informed by personal experience and/or religious beliefs, and the application of theory to practice (Balk, 2007) as well as limited time and lecturer confidence (Breen et al., 2013).

A larger study (Neilson et al., 2015) explored the experiences of both GPs who had cared for a child with cancer receiving palliative care at home and the child's bereaved parents and gives an overview of the 5 categories which emerged from the data analysis (GP role, Parent view of GP role, PCCC, Symptom management and Bereavement). The overview identified bereavement as an area for more in-depth exploration due a lack of standardised approach to bereavement care and families being unsure of their GPs role in providing bereavement support. Bereavement support is also an important topic area in general, outside of this specialist context. A review of the data set identified rich descriptive data, confirming validity for a secondary analysis focusing on bereavement support. The benefits of undertaking secondary data analysis in this context, an emotive area of study with hard to reach participants due to the sensitive topic area, are recognised (Long-Sutehall, Sque & Addington-Hall 2011). This paper focuses on bereavement support and extends the analysis and interpretation of data from the larger study on this topic. It reports on the process and findings of the in-depth secondary analysis of the transcripts relating to this topic area.

Method

Design

The data used for the secondary analysis of the topic area of bereavement came from transcripts from a qualitative semi-structured interview study that explored the experiences of GPs and parents following the death of a child from

cancer within the family home (Neilson et al., 2015). Grounded theory provided a systematic approach for the data collection and analysis (Neilson et al., 2015; Corbin & Strauss, 2008). Findings from this study identified that enhanced collaboration with PCCCs might help GPs address the challenges they face (such as role clarity within the wider team and addressing their learning needs) as a result of time pressures and having no access to bereavement guidelines. We carried out a secondary analysis of the study data to identify text relating to bereavement support. To provide context for this secondary analysis, brief details of the original study sample and process are given here and are reported in full elsewhere (Neilson et al., 2015).

Sample

Bereaved parents whose child (aged 0-18 years) died within the family home following treatment for cancer, and their GPs were invited to participate in the study. Eleven families (12 parents) and 18 GPs were interviewed.

Recruitment

Research information inviting GPs to participate was posted three months following the death of a child. An introduction letter was sent to the child's parents at six months, in line with best practice guidance (Dyregrov, 2004; Hynson, Aroni, Bauld & Sawyer, 2006; National Partnership for Palliative and End of Life Care [NPPELC], 2015). Those who had not declined participation were contacted 7 days later by telephone and interview arrangements (date, time and venue) confirmed. Written consent was obtained prior to commencing the interviews and all interviews were completed by the first author.

Ethics

South Birmingham Research Ethics Committee (10/H1207/25) and recruitment site Research and Development approvals were obtained prior to commencing the study. Ethical considerations included timing and mode of contact, potential participant distress from recalling emotive events and support. Mechanisms of support enlisted included a debrief period immediately after the interview, a follow-up telephone call to participants one week later and a printed list of sources of support contact details.

Data collection

Digitally recorded semi-structured interviews were undertaken following a GP or parent interview schedule. Data saturation was achieved after 18 GP and 29 parents had been interviewed. The GP schedule included a question exploring GPs' perceived roles in bereavement. All parent interviews took place within the family home and the GP interviews within the health centres (n=16) and GP's home (n=2). Interviews with the GPs ranged from 14.15 - 46.48 minutes ($M = 30.5$, $Mdn = 46.0$) and with the parents ranged from 25.57 – 64.35 minutes ($M = 45.1$, $Mdn = 46.0$).

Data analysis

The secondary data analysis focused solely on one of the 5 identified final categories in the overall study (Neilson et al., 2015), 'Bereavement Support', and followed a recognised process (Long-Sutehall et al., 2011). Data collection was through re-reading the full transcripts, identifying references to bereavement support. There was relevant text in all of the transcripts, resulting in all the primary data (GP and parent transcripts) being included in the secondary analysis. NVivo was used to organise the data; transcript sections from the first interview were initially categorised

under broad headings and then compared and contrasted with subsequent interview transcripts. A grounded theory approach (Corbin & Strauss, 2008), was used to develop the categories, the transcripts analysed chronologically (in the interview order). The category codes evolved during this process and the resulting final axial codes (category headings) identified (Table 1).

Findings

Analysis revealed 4 categories related to bereavement support: Timing of contact, Mode of contact, Contact enablers/inhibitors and Sources of GP information and learning (Table 1). The categories both aligned with, and built on, the 'Bereavement' open codes in the larger study (View of care provision, Sources of information and learning and Communication). Identifying nuances informed both care provision and receipt in this context and provided a further contribution to knowledge, over and beyond that previously presented. The timing of contact related to how GPs determined the appropriate time to make contact after the death. Although this often informed the mode of communication, other factors also influenced the selection, such as time pressures. Enablers and inhibitors to contact were identified from both GP and bereaved parent perspectives. In addition, GPs identified sources of learning and information to inform their practice. Each main category had a number of key themes relating to practice (Table 2). These are now discussed using quotes from the interviews which reflect the range of views presented.

Timing of contact

The timing of contact was important in communication between parents and GPs with findings highlighting a lack of clarity of when GPs should make contact with the bereaved parents. Those who certified the death used the visit as a means of discussing follow-up support, often with parents being asked to make an appointment at the surgery 2-4 weeks later “so they’ve had the funeral and had a bit of time to think about things” (GP 12). However, where GPs did not certify the child’s death the onus was often left with the parents to make contact if required;

“keep him (*their GP*) informed, let him know how they're doing, let him know if they need any help, don't leave us guessing.” (GP 2)

This practice was attributed in part to a feeling that they were “a bit part-player” (GP 3) alongside the PCCC team who were providing “plenty of support” (GP 3) to the parents and concern that their contact would be perceived as an intrusion by the family who “were grieving in private and didn’t involve us” (GP 2). This practice, however, left them with no knowledge as to how the parents were coping.

Mode of contact

The majority of GPs (n = 8) made contact with the parents after the death: modes of contact included home visits (n = 5), telephone calls (n = 5) and condolence cards (n = 2).

GPs were more likely to undertake a home visit after the child’s death if they had visited and got to know the family during the child’s palliative care.

“I usually telephone but it depends how well I know them, if I know them very well, you know, I might visit.” (GP 3)

Telephone calls, although a means of passing on condolences to the parents and to “see if there’s any way we can help and to listen” (GP 20), were not viewed as formal assessments for abnormal grief in that a policy or guidance was not followed.

“There is not a formal one (*policy*) I did phone just to let them know we’re here really.” (GP 10)

Difficulties with telephone contact were identified by parents, “...you can be having a really good day then somebody phones you ... then it’s hard” (Parent 17), but mobile telephone text messages were appreciated; Parent 4 recalled appreciating receiving “a little text asking how I am,” in between face-to-face contacts. Parents also valued the offer of open telephone contact (being invited to contact the GP as/when necessary) although no evidence of use was found.

Contact enablers and inhibitors

The level of GP contact was determined by each individual GP, influenced by uncertainty in what would be perceived as helpful to the parents, balancing the offer of support with not imposing. Although it was acknowledged that not all parents would need their support: “people have very different needs in bereavement some really don’t need to have our involvement and some need quite a bit” (GP 19), GPs were unclear how to identify those in need of support: “I don’t want to keep pestering them but just want to let them know ... I’m here if they do need help” (GP 11). GPs’ involvement in a child’s palliative care was found to facilitate meaningful bereavement support, the GP understanding, “to some degree” (Parent 17), what they had been through. Certifying the death provided an opportunity for GPs to organise a future meeting with the parents.

“We usually say come and see us in two or three weeks after the death so they’ve had the funeral and a bit of time to think things” (GP 12)

Parents who saw their GP after their child’s death described the contact positively and reported a feeling of being given permission to make contact in the future if needed: “if you need me, come and see me” (Parent 4). Parents were reassured by “just knowing there was somebody there if we needed to go and see them” (Parent 4).

However, some parents reported they did not want to waste their GP’s time. Parental guilt regarding consultation duration (when a double consultation was allocated) was evident and there was an identified need for verbal GP validation. Parent 24 recalled their GP saying, “but I want you to come and see me. I do care about you, you are my patient.” This parent positively reported consultations, not just in terms of the time allocated but also from a feeling of being heard, “she lets me just sit and talk,” and the holistic approach taken: “she asks about all of us you know as a family. She is concerned about us as a family.” Parents who had seen their GP after their child’s death appreciated having the opportunity to talk without feeling rushed: “normally you’re kind of in and out but she was how are you feeling?” (Parent 21). However, parents recognised the impact of the time pressures GPs faced on consultation duration.

“Unfortunately we’re in a world now where you only have so many minutes to spend with a GP because they’re quite busy.” (Parent 21)

Although bereavement support was reported by GP 21 to be provided according to individual need, common practice was for bereaved patients to be visited once at home and then seen at the practice, which may align with the parent’s perception of GP time pressures.

Although 5 families said they had received a home visit, time pressures were also reported to impact on the GP's mode of contact with telephone calls replacing the initial visits.

"I ring them and then ask them to come. There isn't the time to leave the practice because everyday general practice is so busy. It is very busy." (GP 5)

Bereavement support was not universally perceived as a GP's role. Parents who were clearly struggling with their bereavement did not always see their GP as someone they could turn to for help. Psychological support was not recognised as a valid reason for contact "as there was only so much doctors could do really" (Parent 25) and perceived there to be limited specialist support available: 'they've got no counsellors at the doctors, nobody who specialises in bereavement" (Parent 11). There was an identified need for GPs to voice the rationale and means (when and how) for making contact in order to give parents 'permission' when they did not perceive themselves as being 'unwell' and needing to be seen. In contrast, there were parents who, although outwardly seen to be continuing with day-to-day life, "you have to deal with things", acknowledged that they presented an often inaccurate impression "of being okay you know" (Parent 17), demonstrating the need for meticulous assessment. Interestingly, the GP for Parent 17 did not routinely contact bereaved patients but "left the door open" for them to make contact if needed.

Sources of GP Information and Learning

None of the GPs had undertaken courses in bereavement support outside of their basic training.

"I've not had any training. Bereavement care is down to individual GPs." (GP 13)

This limited training determined provision of bereavement support for some GPs, “you do it from the heart don't you? ... as your personality dictates” (GP 17). But there was an element of uncertainty for others, “there’s a part of you that wants to say I’d like to take that pain away from you but is that truly realistic? How much do you try and counsel and what do you say to them?” (GP 12). Training in effective bereavement communication was perceived as being of value and there was consensus that written information detailing what the GP could offer and listing local resources and specialist services for signposting parents would be beneficial.

There was recognition that the rarity of providing bereavement support in this context, and time pressures, impacted on the decision to seek formal learning opportunities. Instead the value of seeking advice from specialists, highlighting the importance of effective communication, was recognised:

“I suppose what I learnt from it is that there is a lot of expertise out there and you don’t have to know everything you just have to be willing to accept advice from people or to listen to people who are doing it all the time give you advice.” (GP 8)

In addition, GP learned through reflective practice both individually, “It’s experiencing it and then perhaps altering your behaviour afterwards” (GP 4), and collectively, “we talked through and wrote some minutes up of it but what we felt had gone well and what we thought could have done better and learning points” (GP 8) was acknowledged.

Discussion

This secondary analysis of data from a study examining the role of the GP in the palliative care of a child with cancer focuses on bereavement support. Findings

add to the literature base and identify new implications to inform this rare (when compared to adult death) area of GP practice. In addition findings support the international growing evidence of current bereavement support and need for evidenced-based practice (Breen, Aroun, O'Connor & Rumbold, 2014). The need for effective communication underpinned all four identified categories (Timing of contact, Mode of contact, Contact enablers/inhibitors and Sources of GP information and learning). Understanding the constituents of 'Communication' (timing of contact, mode of contact, contact enablers and inhibitors) enabled the larger study's 'Communication' and 'View of care provision' codes to be explored from wider perspectives, aiding translation to practice.

Developing the GP: parent working relationship during palliative care (a time when carers should be receiving individualised support (NPPELC, 2015),) can benefit subsequent bereavement consultations, facilitating initial contact and communication. Initiation of family contact after the death of a child provides an opportunity not only to assess and observe for abnormal grief reactions, but to discuss and agree ongoing support, including timing and mode of contact. Clarifying timing of future contact may help address GPs' concerns of 'intruding'. In addition, agreement of mode of contact may benefit both families (for example, sending text messages that do not require an immediate response, unlike a telephone call) and GPs (for example, quick text messages can help GP time pressures). Contact enablers and inhibitors may be beneficial to GPs in identifying those who require support and to families in identifying providers of support (through clarifying the rationale, and opening and formalising the route, for families to contacting their GP). Formalising the recognised need for collaborative working across care settings in

this context (Neilson et al., 2015) could aid provision of seamless integrated bereavement support.

The effects of bereavement on the parent following the death of their child can be profound. For most bereaved people sufficient support may be given by family and friends and GP support may not be required (Woof & Carter, 1997). However, the recognised exceptional stress that can accompany parental bereavement in particular that caused by child death from cancer (James & Johnson, 1997; McCarthy et al., 2010), necessitates a more proactive approach to identifying those who need GP or specialist bereavement support. This paper, reporting on the experiences of bereavement support from the perspectives of the both the bereaved parent and their GP, has identified opportunities for developing innovative practice around communication.

In recognising that the effects of bereavement will be unique to each parent, findings demonstrate the uncertainty GPs can face in determining when (the timing) and how (the mode) to offer support to meet individual needs: a dichotomy between proactively offering support without being intrusive and expecting families to actively seek support. In addition, the expectation that parents would ask for support, rather than anything being offered routinely, a finding which both supports and informs current literature through evidence in this specialist area (Breen & O'Connor, 2011), highlights the need for bereavement contact to be initiated by GPs. The challenge for GPs lies in identifying those in need alongside balancing normalization of what for many might prove to be a normal grief response to bereavement with over-medicalisation (Haines & Booroff, 1986). Proactively initiating a face-to-face consultation with the newly bereaved provides an opportunity for an early assessment and can help tailor future support to meet the needs of both the family

and GP, ensuring realistic and achievable expectations, such as frequency, duration and mode of contact. Through clearly outlining their role, the context of support offered, and the location (home or practice), duration (longer consultations) and validation (not needing to be 'ill') of contact, GPs can help facilitate parents seeking appropriate, timely support.

Developing, and formalising, close collaborative working with PCCC during palliative care will help facilitate delivery of exemplary bereavement support and build on current good practice, such as 'closure talks' (Kreicbergs et al., 2007). The current UK provision of care offered by PCCCs includes indefinite bereavement support from some centres (Kreicsberg et al., 2005). This adds a distinctive dimension to bereavement support in the community for this patient group and highlights a clearly identified need for further exploration of the provision of PCCC bereavement support alongside the recognised longevity of the GP role (Neilson et al., 2015). Enhanced communication between PCCC and GP around bereavement support, such as outcomes of consultations or 'closure talks' (including future planned contacts and referrals to specialist support) could minimise role duplication or task omission due to incorrect assumption of role allocation, ensure a seamless provision of support and provide a means of addressing identified GP knowledge deficits (such as local specialist services).

Embracing opportunities for inter-professional PCCC: GP collaboration and enhanced co-ordination of bereavement support can also potentially aid the identified need for acquisition of specialist knowledge and skills through peer learning. Identified bereavement training requirements align with findings from previous studies (Low et al., 2006) demonstrating the need for continuing professional development in order to facilitate current evidence-based practice.

Although identification of training needs lies with individual GPs and on-line guidance exists, shared specialist bereavement guidelines (covering topics such as timing of contact, writing bereavement cards/letters and the process for referral to preferred specialist child bereavement services (Stevenson et al., 2017) may help standardise support offered and, in conjunction with coordinated collaborative working, address identified knowledge deficits and the time-pressures every GP faces in practice today (Royal College of General Practitioners, 2017).

Limitations from both the larger study from which the data were drawn (reported elsewhere (Neilson et al., 2015) and secondary analysis are recognised. Secondary analysis limitations that need to be considered include the larger study aim not focusing specifically on bereavement support, (although the interview schedule included an interview question on the GP's role in bereavement support) which may have influenced the amount of data collected and subsequently the conclusions drawn. However, this paper has, through accessing the experiences of GPs and bereaved parents and looking in depth at the topic of bereavement support, identified new knowledge and implications for practice in this specialist area of care.

Identified areas for future research include developing integrated, across care settings, collaborative bereavement support and exploring opportunities for innovative practice, such as the wider role of digital technologies in bereavement support.

Conclusion

Findings help address the dearth of research into GPs' experiences of providing bereavement support to bereaved parents and inform practice. The significance of these findings is particularly important given the recognised impact a

child death can have on the lives and health of the parents (Dias et al., 2017) and the need for their early identification and management. GP initiated face-to-face parent contact early in bereavement can provide an opportunity to clarify role, nature of offered support and future contact (timing and modes), aiming to ensure mutually appropriate and accessible mechanisms for identifying and addressing future support needs. Exploring innovative practice, such as novel modes of GP: parent communication may also aid optimal provision of bereavement care. The unique model of care (on-going bereavement support provided by PCCC) that exists for children with cancer provides opportunities for close collaboration between care settings. Formally communicating bereavement support, both that provided and planned by each care setting, will help ensure clearly signposted seamless support for bereaved parents and time-efficient collaborative working for GPs that provides opportunities to meet identified learning needs. An equitable, co-ordinated, and consistent approach to the provision of bereavement support will help address the identified knowledge deficits and time-pressures every GP faces today and ensure that provided support is sustainable over time.

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Table 1: Extract example of categorizing open codes into axial codes

Axial code	Open codes examples
Timing of contact	Timing Clarity Role Principal childhood cancer centre Communication Impact
Mode of contact	Home visit Telephone Communication Card Timing Open
Contact enablers and inhibitors	Time Relationship Communication Individual Role awareness Permission
GP training and resources	Reflection Peer learning

	Training Time pressures Rarity Communication
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Table 2: Bereavement Support: Categories and Themes Related to Practice

Category heading	Key themes related to practice
Timing of contact	Lack of clarity of how and when to make contact with bereaved parents.
	GPs were aware other health professionals were involved in the care and therefore expected parents to ask for support, rather routinely instigating contact.
Mode of contact	GPs contact families by telephone.
	Parents appreciated text messages as they had control over when they were read and responded to, unlike when receiving telephone calls.
	GPs undertook home visits.
Contact enablers/inhibitors	Enablers
	Certifying the death provided an opportunity for GPs to organise a future meeting with the parents.
	Parents required and appreciated validation for making contact with their GP, confirmation of the value of an open door policy.
	Parents felt that GPs who had been involved in the palliative care were better able to support them.
	Inhibitors
	Time pressures.
	GPs lacked knowledge of how the parents were coping unless they had contact with them.
Parents did not always see their GP as someone they could go to for support.	
Sources of GP information and learning	GPs learnt through reflective practice.
	GPs learnt from specialists and colleagues.
	Although welcomed, GPs did not have access to guidance such as local support networks for families.
	GPs had not undertaken any specialist bereavement training since qualifying.
	Training in effective communication in bereavement care was perceived as being of value.