The Think Family project

A project funded by Macmillan Cancer Support

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2. Executive Summary

Up to a third of patients suffering from cancer are parents to young children and teenagers. Bereavement can affect children deeply although not all families and children who face loss are in need of specialised support. Many families report needing support with children in relation to age appropriate information and communication about a parent’s cancer diagnosis. The Think Family project, a collaboration between the University of Surrey, a National Health Service (NHS) trust and two charity organisations in the United Kingdom (UK), was prompted by a lack of knowledge about how specialist oncology and palliative care staff manage families and children who experience pre-bereavement due to parental cancer in the acute sector. The project focused on exploring the experiences and needs of oncology and palliative care staff and on increasing awareness and confidence regarding the needs of families with children.

The study was designed as a collaborative project using case study methodology. A three stage study was undertaken during 2013 - 2014 using focus group and individual interviews, a collaborative data analysis event; and a staff training workshop related to the needs of parents with advanced cancer and dependent children. Three key themes emerged from the data which are: ‘a challenging and complex area’, ‘supporting parents to support children’, and ‘the needs of oncology staff in relation to the support of families’.

The first theme, ‘a challenging and complex area’, identifies how sensitive and challenging it is for staff to support patients and their children, and that there are no ready-made solutions. The intrinsic uncertainty associated with the outcome of a cancer diagnosis contributes to the complexity inherent in providing support to patients and children. Paradoxically staff appeared to find it easier to support patients who are terminally ill and their children due to the relative certainty regarding the outcome of the illness, and there was a perception that there are more resources available for those in the terminal phase of the illness such as palliative care services. Conversely, it was viewed as difficult to provide support in the acute and early stages of the parent’s illness and in the pre-bereavement phase. Most participants in the study were female nurses.
who appeared to identify primarily with their female patients, which raises the question of possible gender specific issues in relation to responses to a cancer diagnosis and the way staff manage their patients and families.

The second theme, ‘supporting parents to support children’, identifies how specialist oncology staff do not normally have direct contact with young children, but instead support children vicariously through the parents. Nevertheless, staff become quickly aware of patients who have children, some of whom have special needs such as autism, although there are no formal screening processes in place to identify patients who have children who might benefit from psycho-social support. Specialist staff, from areas such as breast cancer services, are more familiar with patients with dependent children as they are more likely to have patients with young children as breast cancer has a younger age profile than other cancers. Although some staff describe actively pursuing the issue of children’s well-being with patients/parents, most learn about children’s needs when parents bring it up and there seems to be some reluctance among staff to actively explore children’s situations with parents. This appears to be because staff may not feel sufficiently prepared and the work culture in the NHS predominately focuses on the patient and the hospital environment, which may not facilitate them to engage with the support of children. There is also a perception among staff that patients are acting as ‘gatekeepers’ wanting to protect their children from their illness and the hospital environment, and staff feel they need to respect patients’ wishes because the parents know best.

The third theme identifies ‘the needs of oncology staff in relation to the support of families’. Although nurses were motivated to support families and children they report feeling apprehensive about this sensitive area of communication. They describe a lack of knowledge/guidance around children’s needs and developmental stages. They also report how they adapt to the ‘culture’ of each family since there is no ‘one size fits all’ when it comes to support. The general strategy adopted by staff was that of being approachable and remaining alert to signs that patients or their children might struggle, and then to follow the lead of the parents should some form of intervention be regarded as beneficial by them or the parents. Staff were aware of a network of resources
available to support families but asked for a ‘one stop shop’ approach to updated information and signposting to resources. They also discussed the benefit/lack of regular opportunities to reflect on practice with colleagues regarding families and children.

What is most likely to facilitate change and improve support for families and children is a pragmatic approach, which utilises existing resources in an effective way within health care systems with very limited resources. In addition a broad cultural change is needed using a ‘drip drip’ approach involving education, and explicitly including support of families and children in job descriptions for oncology staff. What would further facilitate change would be to highlight the needs of children and families in future cancer awareness campaigns.

We recommend that there needs to be:

- Regular opportunities for oncology and palliative care staff to reflect on practice with colleagues and peer-support systems put in place. This could be incorporated into the existing clinical supervision process.
- Increasing awareness of the impact on children of parental cancer in oncology staff throughout the cancer illness.
- Provision of one stop updated sign posting/tool for information and guidance.
- Workshops for staff to increase staff confidence; including guidance on children’s developmental stages and age adapted information and support strategies.
- Guidance on children’s developmental stages and age adapted information included in psychology level 2 training and other forms of training for staff.
- Guidance on assessing family needs and the needs of children.
3. Introduction

The think family project was prompted by a dearth of knowledge of acute oncology and palliative care staffs’ responses to children experiencing loss due to parental cancer. The focus of the project was on exploring the experiences and needs of oncology and palliative care staff who work in acute settings with patients who have children; and on increasing awareness and confidence in family needs. The project has involved a collaboration between the University of Surrey, Jigsaw South East, Macmillan Cancer Support and an NHS hospital trust.

There has been some research on interventions to support children and parents both pre-bereavement (Chowns, 2008; Semple & McCaughan, 2013) and following bereavement (Brewer & Sparkes, 2011); however health care staff have been found to lack confidence in supporting children and families experiencing bereavement and this is a productive area for further research and development (Wiles et al., 2002). The think family project extends knowledge of the needs of specialist staff working in acute cancer services and their experience and confidence in supporting families with dependent children.

4. Background

About 24% of adults suffering from cancer are parents to children under 18 years of age and about a third of patients with breast cancer are reported to have young children (Rauch et al., 2003). Most children and families facing loss and bereavement do not need specialist help nor intervention, and bereavement should be considered “part of human experience” (Kennedy et al., 2008: 164). Nevertheless, children with a parent with a life limiting illness can manifest significant distress (Beale et al., 2004) and the remaining parent may have conflicting needs such that recognising the needs of children is very difficult (Thibo Karns, 2002). Some children and families are especially vulnerable to bereavement, especially the death of a parent (Christ & Christ, 2006). Such children have been shown to suffer long term sequelae. The provision of services pre-bereavement remains fragmented (Kennedy et al., 2008) and resources are not necessarily directed to those who need them most. In fact family centred support is
lacking for those affected by parental cancer with little support for parents on how to communicate with their children (Turner et al., 2008).

In a recent study it was reported that parents felt a lack of confidence and skills when talking to their children about cancer and the children of these parents were found to have a number of misconceptions and fantasies related to cancer (Semple & McCaughan, 2013). Parents report needing to have a variety of levels of support including being supported to communicate openly with their children and how to seek additional resources from health professionals who may not be aware of the difficulties experienced by families with children; especially if routine assessment of family coping is not carried out (Semple & McCaughan, 2013; Watson et al., 2006). Children and young people need age appropriate information about their parents’ cancer to enable them to cope with parental illness (Patterson & Rangganadhan, 2010; Semple & McCaughan, 2013). Children and young people may also take on additional roles within families such as caring responsibilities and emotional support thus becoming ‘young carers’ (Macmillan Cancer Support, 2013).

As stated previously bereavement can be considered a normal part of life for children and does not necessarily bring with it longer term problems (Kennedy et al., 2008). However, results from a Finnish study using longitudinal data from health and social care registers show how the negative effects on children from bereavement can be more enduring than previously assumed (Niemelä et al., 2012). Children can be deeply affected in a number of ways even if the parental illness is not terminal, but there is a dearth of knowledge and literature in relation to this; whereas there is some extant literature on bereavement in children (Chowns, 2008; Kennedy et al., 2008). There is a need for further research into strategies for effective support of families and children, particularly in the pre-bereavement stage of the illness in the acute hospital setting. The main aim of this project was to explore the experiences and needs of oncology and palliative care staff who work in acute settings with patients who have children, and on raising awareness and confidence in staff who support families with children.
5. Methodology

The project was designed as a collaborative project using case study methodology undertaken during 2013-2014. A three-stage study was designed using focus group and individual interviews; a collaborative data analysis event; and a staff workshop related to the needs of children and families. The research team at the University of Surrey lead by Principal Investigator Dr Anne Arber assumed overall responsibility for the project and worked closely with collaborators in one NHS trust, with Jigsaw Southeast and Macmillan Cancer Support representatives. The collaborating NHS trust, through the Lead Cancer and Palliative Nurse, recruited staff to the study.

The study proposal was approved and given a favourable opinion by a NHS Trust’s Research Governance Committee and by the University of Surrey Ethics Committee. The first stage of the research involved two audio recorded focus group discussions (n=12) with a broad sample of Cancer and Palliative Care Nurse specialists representing different areas (e.g. breast, gynaecology, lung, chemotherapy, palliative and end of life care) who discussed their experiences and needs in relation to patients who have dependent children. One individual interview was carried out with a member of the medical staff. The interviews were guided by a topic guide (see appendix 1). The two focus groups lasted for approximately one hour each and the individual interview with the member of the medical staff lasted approximately 30 minutes. The audio recordings were transcribed verbatim and closely read by the core research team, and systematically coded by one researcher using the software programme NVivo 10 (QSR International, 2013). The use of NVivo adds transparency to the analysis and increases rigour. A thematic analysis was used to analyse the qualitative data (Braun & Clarke, 2006). The coding from the focus group data resulted in 195 subordinate codes which were then organised in stages into three superordinate themes by the core research team. The initial findings were subsequently discussed, revised and agreed by the steering group during a data analysis workshop. Findings were also presented to, and validated by, participating clinical nurse specialists (CNSs). The transcript from the individual interview was coded and searched for new insights. A draft report related to the findings was prepared and discussed at the final steering group meeting.
An experiential training session (see appendix 2 for an overview of the training session), based on the study findings, was offered to staff who had participated in the project. A two hour training session with six participating clinical nurse specialists was developed and piloted at the research site. The workshop used three case studies as basis for the discussion (see appendix 3) outlining situations involving three different levels of complexity in relation to children with varying needs for support.

6. Findings

6.1 Introduction

All 13 participants in the study (11 female and 2 male) had experience of working with parents who had children and of supporting families and children either directly or indirectly via parents. As is customary in qualitative research there are no strict boundaries between the themes identified (see Table 1) and where themes overlap we have chosen the most suitable theme to present an issue, and have made cross references where applicable.

We present our findings in the light of three key themes which were generated from the data. The key themes are: ‘a challenging and complex area’, ‘supporting parents to support children’ and ‘the needs of oncology and palliative care staff in relation to the support of families’ (see Table 1 for key themes and sub themes). There were no contradictions in the data although staff from areas such as gynaecology or breast cancer were more likely to come into direct or indirect contact with children and to have more experience with a younger age group of patients than other staff (see also Rauch et al., 2003; Semple & McCaughan, 2013).
### Table 1: Key themes and sub themes

<table>
<thead>
<tr>
<th>Key Theme</th>
<th>Sub theme</th>
<th>Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>A challenging and complex area</td>
<td>• Identifying with parents</td>
<td>'I am a mum', 'speaking as a parent'</td>
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<tr>
<td></td>
<td>• Emotional burden</td>
<td>'it was tragic'</td>
</tr>
<tr>
<td></td>
<td>• Uncertainty in the illness experience</td>
<td>'my cancers aren’t terminal'</td>
</tr>
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<td></td>
<td></td>
<td>'there is much less support available for the children [in the acute sector]'</td>
</tr>
<tr>
<td>Supporting parents to support children</td>
<td>• Assessing the family situation</td>
<td>'do you have any dependents?'</td>
</tr>
<tr>
<td></td>
<td>• Keeping the normality of family life</td>
<td>'leave it like that with the parent'</td>
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<td></td>
<td>• reluctance of parents to involve children</td>
<td>'we will see how we get on'</td>
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<td></td>
<td>• Maintaining hope</td>
<td>'there was a positive'</td>
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<tr>
<td>Needs of oncology staff</td>
<td>• Children’s development stages</td>
<td>'what to tell them depending on their age'</td>
</tr>
<tr>
<td></td>
<td>• Apprehension about engaging with children</td>
<td>'blagging it'</td>
</tr>
<tr>
<td></td>
<td>• Sources of support</td>
<td>Daisy’s dream, Jigsaw southeast, community palliative care, Macmillan booklet</td>
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### 6.2 A challenging and complex area

Participants kept returning to how challenging and complex it can be on a number of levels to support families with children and/or young people who have a parent with cancer (see also Turner et al., 2007). Nevertheless, much attention has been given to the value of psycho-social interventions for families and children in the emerging body of literature on bereavement and pre-bereavement support for cancer patients and their families (e. g. Semple & McCaughan, 2013). Many of the participants in this study identified with patients who were parents as they were often of similar ages to themselves, often female patients with children of similar ages. Therefore there was an element of identification with the patient that led to a blurring of the boundary between the staff and patient and to feelings of sadness and emotional distress in staff. This is
consistent with the findings of Turner and colleagues who also found that when staff had patients of their own age this “aroused distressing thoughts” and made staff aware that this could have been them (2007: 152). However, identifying as ‘a mum’ could also be helpful to participants as they felt they could empathise as a mum with their patients.

6.2.1 Identifying with parents ‘I am a mum’

Participant’s reported how they use their own personal experience as a parent to support patients. One participant describes ‘speaking as a parent’ (FG2 - 5). The participant below describes a process of assessment of the family situation when she meets the patient at diagnosis and she also goes on to identify herself as ‘a mum’ similar to her patient:

When they come in you tell them the diagnosis, you then obviously ask about what the family situation is at home, what else they have got going on so recognising that straight away you know, I am a mum as well. (FG2 - 5)

This identification as a mother is important and gives the nurse confidence to assess the family situation early on in the encounter. However, having this connection can also be challenging and a feeling of being out of one’s depth emotionally can emerge, especially where the situation with the parent is changing quickly:

Yeah, our patients are not as young as breast patients so generally the patients aren’t young but we have had a couple of ladies recently in the last year whose children were sort of teenagers same ages as ours (...) So the first person I did that for I had never ever had to sit and speak to teenage children the same age as mine… so that was fairly difficult especially as on that very day the whole situation with their mother changed drastically and then so then another lady I had whose children were similar age so wanted to see me on her own. (FG1 - 6)

The specialist nurse above does not normally have younger patients on her case load like the breast care nurse, therefore the situation described above is presumably uncommon for her to find herself in. However she describes a situation where there was a ‘drastic’ change in her patient’s condition and where the children who were teenagers had asked to see her. It appears that in this situation the nurse may have been called
on to deliver unexpected news due to the drastic change in the mother’s condition which may have resulted in the need to deliver bad news.

In contrast to the nurses above the nurse below does not have children of her own and feels that this is a disadvantage compared to other nurses. She found the prospect of speaking directly to children of a critically ill young mother as ‘daunting’ and ‘hard’ and felt inexperienced when it came to children:

*We [the participant and the husband of the patient] just talked through ways to talk to the different age of children and I must say it’s not something I’ve got a huge amount of experience with, I haven’t got my own children so it was quite a daunting prospect to talk to him actually and think ‘oh gosh if he is going to bring these children it will be quite hard’. (FG2 - 3)*

The specialist nurse above felt ill equipped for talking with children however she was confident to talk through with the husband ways to talk to his children about the mother’s illness. Although it is emotionally draining for staff to identify with patients and draw from their own personal experience, it may also be a helpful strategy and one that can reduce emotional burden in staff by helping them to build a close relationship with the parent.

Eleven out of 13 participants were female and the patients they remembered and talked about were mostly female (n=16), although a few male patients/male cares were mentioned (n=6). Female participants did discuss and empathise with men as partners and fathers of children but they seemed more emotionally engaged and detailed when telling stories about female patients. It might be expected that many patients would be women, given that some of the staff were from areas such as breast cancer. However, it would also be expected that oncology staff come across a number of male cancer patients who have children. A systematic review of studies on the psychosocial effect on children of parents suffering from cancer also highlights that most of the studies reviewed pertain to cancer in women/mothers (Osborn, 2007). Perhaps the reason for the absence of research on the role of fathers might be gender issues related to the traditional role of women as primary carers for children. However it is possible that men’s responses to a cancer diagnosis might be different to that of women in turn
eliciting different responses in staff. Research has, in fact, shown that women’s response to their cancer diagnosis is more emotional than that of men and that women see their cancer as “a disruption to their emotional lives, social and family networks” whilst men focus more on medical information (Seale, 2006: 345). This is reflected in the way our female participants seemed more emotionally engaged with the female patients. On the other hand one male participant appeared emotionally engaged with other males (one patient and one partner of a female patient). In the following quote he worries about the partner of a patient:

_One does worry that it is a tough conversation for a dad to have [telling the children] when mum has got breast cancer._ (I)

A study exploring the negative impact on children of parental cancer in the light of demographic factors found that children appear to have more problems when a father is ill rather than a mother. This suggests that having a mother or father who is ill may impact on outcomes in different ways for children (Visser et al., 2005).

### 6.2.2 Emotional burden

Our data show that working and engaging with patients who have children takes a considerable emotional toll on staff. Participants shared how their experiences affected them deeply and had shaped their practice. One participant expressed the emotional element of care: ‘there is also the emotional element that’s really hard’ (FG1 - 3) and another felt that ‘it is quite draining for one person to deal with’ (FG2 - 5). So this is a challenging, draining and emotional experience for these specialist nurses, especially where younger patients are concerned:

*I am still learning to deal with younger patients with a diagnosis of breast cancer that have children and I do find it quite a learning curve and sometimes a challenge to help to support those patients._ (FG1 - 3)

The above participant describes a learning curve for her when having younger patients with breast cancer on the case load who have children. She describes a challenging situation in terms of offering support to younger patients and as something she needs to learn more about.
Supporting families with children create memories and emotions of a personal nature in staff which can affect their subsequent practice positively or negatively (Turner et al., 2007). Specialist nurses remembered past memories of patients and their situations in great detail which implies a deep emotional involvement with families. The participant below reflects on the ‘very very sad’ situation of a dying patient who was a young single mother which had stayed fresh in the participant’s memory.

I’ve got a memory (...) of a young single mum who had (...) a little girl who at the time was about three years old and my lasting memory was of the patient not taking any analgesia because she didn’t want to miss a moment of her daughter’s life. She was dying, she knew that, and she had a very short time to go and she just would not take any analgesia and it was all very very sad (...) if I’m honest I probably got a bit too emotionally involved with the situation but it was tragic. (FG1 - 5)

This dying young mother’s situation is described as ‘tragic’ as she is so young, her child is very young and she does not have a partner. It was difficult for the nurse not to become deeply emotionally involved in this situation which was further complicated by the young mother refusing to take analgesia as she wanted to stay alert and be with her child in the short time she had left. The emotional burden experienced by staff was connected to the uncertainties they faced in relation to the way the illness progressed and impacted on patients and families.

6.2.3 Uncertainty in the illness experience

Kennedy and colleagues, discussing support for patients who are not in a terminal phase, argue that “supporting children during pre-bereavement is, racked with uncertainty, and has been described as being like wading through swampy ground sown with landmines” (2008: 164). There is a profound uncertainty associated with the progress of cancer which affects how support is provided and accessed by families and indirectly children. A diagnosis of cancer can mean anything from a short stay in hospital for acute treatment to a terminal illness with palliative care support. Modern targeted treatments have also contributed to some types of cancer becoming treatable chronic diseases, if not curable (Morgan et al., 2006). Although a positive development this
creates new challenges for oncology staff who support patients and their families over many years with metastatic cancer. The emergence of the chronic metastatic cancer population brings challenges similar to other chronic diseases, blurring the boundary between living a life and managing a disease (Thorne et al., 2013). There is variability in patients’ experiences and access to resources over extended periods of time with different support needs for self and family members (such as children) at different points in time. What starts out as a relatively hopeful journey for patients may remain so throughout the illness trajectory with a positive outcome, but may also turn into despair at short notice; and staff have to manage the support for patients and children against a quickly changing backdrop of end of life issues. During a workshop discussing the preliminary results from the study with our collaborators from the NHS Trust and cancer charities it was suggested that oncology staff are ‘trying to control an uncontrollable situation’. Jenkins and colleagues also argue that knowledge [about illnesses] “creates new uncertainties” (Jenkins et al., 2005: 17). It could be argued that the uncertainties oncology staff have to manage are perpetual and interactional.

Paradoxically, participants describe how it was ‘easier’ to provide support to terminally ill patients and their children, albeit draining, rather than those newly diagnosed due to the relative certainty regarding the outcome; and the perception that there are more resources available for terminally ill patients and their families from hospice and palliative care services. The data extract below touches on problems with access to support for those newly diagnosed with cancer; particularly financial support for the family is identified:

*You feel like there is more access to support if someone’s diagnosis is terminal because that’s when I feel like I can, I find like [the hospice] really helpful and they have got amazing support teams. So if someone is terminal I feel that's really awful, but it’s great, because I know I can get more support for them whereas if a patient is just diagnosed with cancer and they have got to have six months of chemo and they might not be able to work for six months and they are the main bread winner for the family it is much harder to get them support and for their kids if they are at school and they know that granny died of cancer and there is that association. (FG2 - 1)*

The nurse above is contrasting the support available for those who are terminally ill with those newly diagnosed with cancer. For those that are terminally ill there is the
possibility of further support from the local hospice and palliative care services. However for those that are having active treatment with chemotherapy there is a lack of support for the family and she identifies how hard it is to find sources of support. This same nurse talked about not feeling able to refer children to the palliative care team, which provides support for children, unless the parent’s condition is terminal due to the negative connotations associated with the palliative care services, which in her view would worry children:

_A lot of my cancers aren’t terminal so a lot of mine will survive so a lot, so you, those are the ones, it’s not appropriate to refer them to the palliative care team for support of the children because it would freak them out._ (FG2 - 1)

The nurse above appears to distance herself from the situation described by saying ‘my cancers’ rather than the patient with the cancer. She wishes to protect the children from any difficult news as it would have a negative impact on them and would ‘freak them out’ in her view. To her palliative care is about support for those who are terminally ill; despite the fact that palliative care can be accessed early on in the cancer trajectory so that patients and family members receive the support they need.

A member of the medical staff further highlighted the perceived differing levels of support for families and children between palliative care and acute care:

_I have two very kind of different experiences, the first is the experience of support available in the hospice environment for patients who are referred to a specialist palliative care unit and that can contrast with the experience of patients and families whose care is only in the acute sector. So the hospice environment (...) have got an extensive family service team (...) so the infrastructure there is very very good (...) I have reflected on the difference in care when we sometimes see young adults, young parents who are very unwell, dying in the acute sector who haven’t been known to a specialist palliative care team, there is much less support available for the children._ (I)

In the hospice there are specific services for families and there is a ‘family service team’. Therefore hospice services are geared up to offer specific support to families and children in particular in contrast to the services available in the acute services.

Another participant gave the example of a young female patient who had not wished for
her children to know about the seriousness of her cancer in order to maintain hope and to protect them. Turner and colleagues call this “parental avoidance” (2007: 151). This patient then became acutely ill and subsequently died within a short space of time:

Yeah I had a lady with [a cancer diagnosis] coming in acutely unwell (...) and it became apparent that she wasn't going to survive the admission; met a very distraught husband and it transpired she had [two young children] at home that knew mummy was poorly but didn’t know how unwell mummy was and that mummy was likely to die, and we met with the husband and talked through because he was saying I don’t know how to talk to my children I don’t know what to tell them (...) he had a community palliative care nurse who I think they had met once or twice. They [staff] had been kept at arm’s length all throughout this lady’s treatment she had always had a very positive ‘I am going to get through this, I am going to survive’ so the community palliative care nurse had only met [them] a couple of times. (FG2 - 3)

It is, however, possible that these children had picked up from their parents that something was amiss that they were not told about causing them to wonder or worry. Even quite young children are sufficiently perceptive to understand when something is wrong in their family, such as cancer in a parent, and it is important that oncology staff support parents to give age appropriate information to children to manage their needs in a difficult situation (Forrest et al., 2006; Semple & McCaughan, 2013).

There was an awareness that children are perceptive to what is going on in the family. The nurse below is well aware of this and describes the need for children to be informed about what is happening and that not informing them can have negative consequences:

Children are so perceptive, they worry more if you don’t tell them because often what they perceive is even worse than the worse that is happening. (FG1 - 7)

Knowledge is scarce about children’s own experiences and needs pre-bereavement (Chowns, 2008; Lewis, 2007), particularly those of young children (Osborn, 2007); although psychological and sociological theories of childhood highlight that children are competent actors in their own right in society albeit limited “by structural features of the milieu in which children live their lives” (Hutchby & Moran-Ellis, 1998: 1). Bibou-Nakou (2004: 311) also suggests in the context of support for children of severely mentally ill parents that support for children should not be based on “adult-centric ideas”, but rather
on children’s own needs, and that children are capable of recognising what those needs are; (see also Gladstone et al., 2014; Lewis, 2007). Children’s actual needs may also differ from their parents’ assumptions about those needs (Huizinga et al., 2003; Visser et al., 2005), which is manifested in the data extract below where a male patient had requested counselling for his teenage children:

What we [oncology staff] did was get in touch with Community Macmillan services and put all of that in place but then when they contacted the father and ultimately the children, the children said no they didn’t want it which was fine because, obviously it was the father’s perception of what was needed was different to what the children wanted. (FG1 - 5)

The nurse is highlighting the important role played by palliative care services with support for children and young people. However in this instance the children did not feel they needed support and it seemed to be that the person who needed support was perhaps the father.

A recent paper reporting on the positive impact of a psychosocial intervention for children in relation to parental cancer details that a requirement for participating children was that they had a previous “awareness” of the cancer diagnosis (Semple & McCaughan, 2013: 221). Although it is not clear from the paper exactly what the awareness entailed in this context, the view was that there needed to be some family acceptance of the parental condition and prognosis for the children to be able to benefit from the intervention, as well as parental consent to participate. There is also the important issue of confidentiality, which was highlighted by our collaborators from the Trust and the cancer charities, in that staff are in principle limited in what they can discuss with families of patients, including children, without expressed consent from patients. This has also an impact on support for children and the extent to which information can be shared with them.

6.2.4 Summary

To support patients and their children is very challenging and complex on a number of levels for oncology staff and there are no ready made solutions. Staff find themselves
working in an emotionally charged context which is full of uncertainties. Nearly all participants in the study were female nurses who appeared to identify primarily with female patients which raises the question of possible gender specific issues in relation to support needs and awareness of needs across gender. Paradoxically staff report finding it easier to support patients who are terminally ill and their children due to the relative certainty regarding the outcome of the illness, with a perception that there are more resources available in end of life situations as they can draw on palliative care services. Conversely, it is viewed as difficult to provide support in the pre-bereavement phase as there is a possibility of parental avoidance with some parents being seen to want to protect children from the emotive and distressing situation of the parental cancer. In the early stages of the cancer illness the outcomes are more hopeful and both staff and parents feel more protective about communicating with children.

6.3 Supporting parents to support children

Participants felt very strongly that they wanted to support families and appeared to become quickly aware of patients who have children who might be affected by their parent’s diagnosis; although there are no formal processes in place to identify children’s related needs in the participating trust. Staff become aware of patient’s children through parents initiating discussions about their concerns for their children. Parents may also ask staff for advice on how they should inform their children about having cancer.

6.3.1 Assessing the family situation

Patients are being assessed on diagnosis and admission to hospital regarding dependents, which provides an opportunity for patients to talk about their children; or staff may ask at diagnosis ‘about what the family situation is at home’ (FG2 - 5). However, it is also perceived as difficult to ascertain from patients what the exact situation is like regarding children:

It’s really difficult to tell when you have a patient sitting in front of you talking about their children as to what is actually happening. (FG1 - 1)

The nurse above finds it difficult to assess what the situation is regarding children in the
family and finds it challenging to find out what is actually happening. However another nurse discusses how she establishes if there are concerns about the children:

*Well I suppose [we find out about children’s needs] if the parent tells you there is a concern with the child or if there is another health need for the parent. (FG1 - 5)*

The above suggests that the nurse waits for the parent to disclose if there is a concern over a child, which suggests a more reactive form of assessment. Another staff member working in the chemotherapy unit also describes a more reactive approach, however she describes the importance of building a relationship with patients before bringing up the topic of children unless there are any immediate concerns:

*We build a relationship (...) when we are giving chemotherapy that is the time, and the patient has started to build up a relationship with you, and they have started to open up and we would do something [about any concerns]. (FG1 - 2)*

Some nurses actively explore with parents their children’s understanding of the situation and their related needs early on. This may also reveal any particular vulnerabilities in relation to children which then gets documented:

*We would [identify children] on admissions because our patients come as outpatients for treatment so we would say ’do you have any dependents’ and you would take it on from there, and if I had a patient I would always ask ’do your children know and how do you feel they are coping’. (FG1 - 7)*

In the data extract above the nurse is very specific about her assessment. She would ask directly about dependents in the family and use open questions to assess with the parent the children’s knowledge of the illness and how they are coping with the situation.

The nurse below describes her involvement with patients’ children in terms of keeping ‘the door open’ and ‘being guided by parents’ when it comes to psycho-social support:

*Just keep the door open you can’t be [get too involved], can you because you don’t know their life you don’t know their children you don’t know their circumstances, you don’t you know, for us we tell them they have got a cancer diagnosis and support them*
through the process and if they flag up that they want some involvement with the child then we will facilitate that but we don’t constantly ask or you know we rely on them feeding us that information. You know, obviously if there was a concern for the safety of a child then that is a different matter altogether but in terms of information we are very much guided by the parent really. We give books we give information about how to talk to the schools and things like that. (FG1 - 4)

The nurse above uses a variety of resources to help patients such as booklets, talking with the school teachers and other forms of helpful information support. The limitations of her role is also commented on in that she has a lack of knowledge about the circumstances of the patient’s life.

A number of participants mentioned their role in providing information at a distance to children through the parents (FG1 - 7) and ‘talking to parents about how to talk to your children and giving them information’ (FG1 - 3). One nurse described how she did not want to be perceived as being prescriptive or conducting an “interrogation” (FG1 - 5). It is possible that this nurse saw that asking about children would overstep the mark and would be seen to be destructive.

The nurse below describes being asked about what to tell the children but also sees this as the parent’s role:

Well sometimes they ask should I tell the children; what should I tell the children (...) it’s never my place [as staff] to tell them to tell the children I think. It’s about them [parents] assessing how much information their child needs. (FG1 - 1)

Nurses do identify a role with families in providing relevant information to parents to support their children. Some nurses directly assess and screen patients in relation to the needs’ of their children but other nurses display a more reactive approach to assessment relying on parents flagging up the situation and needs of their children.

The participants identified children through the ‘vicarious lens’ of the patients/parents and there were no discussions around any short or long term impact that parental cancer can have on children. This was because nurses generally heard positive messages about the children:
Most of the stories I hear from my patients are mostly positive, how these children are coping. (FG1 - 2)

And

On the whole recently all of our patients seem to be quite open in discussing things with their children and they say how well their children have adapted. (FG1 - 7)

Although there was some awareness of the negative impact of parental cancer on children it seems that there was a limited awareness of this. The children were reported to generally cope well through information from parents, which conflicts with extant literature pertaining to the long term impact of serious illness on children (e. g. Niemelä et al., 2012). There is also a sense that staff see the support of children mainly as the parents’ responsibility and so leave the psychological welfare of the children ‘with the parents in their capable hands’ (FG2 – 4); with parents perceived to know best about their children. It may be that staff are trying to help patients keep up as ‘normal’ a family life as possible by staying positive about the children and their ability to cope with the situation.

6.3.2 Keeping the normality of family life and avoidance

The support for children described in the study is that of vicarious support; in that staff indirectly support parents to support their children, especially where the prognosis is good and where the family appear to be living a normal life and functioning well. Where a patient has a good prognosis there is the prospect of family life remaining relatively normal and there is reported to be less need for children to need further support:

We don’t see that many children (...) Ours [our patients] is slightly different because they are usually you know good prognosis you know whereas yours [addressing another participant about their patients] is usually probably a slightly different situation you know whereas (...) [our patients] might be still going to work and still functioning and still, and so to the children things are fairly normal. (FG1 - 1)

In the above data extract the nurse who works in oncology breast care is contrasting
her experience of patients with good prognoses to her colleague who works with patients with a poorer prognosis. In her view the needs of the children are associated with the more serious type of illness that her colleague is involved with. This participant also refers to herself and her colleagues as ‘just health care professionals’ which seems to indicate that she feels unprepared to directly support children, and this is discussed further below in connection with staff’s educational needs.

*And sometimes we have to leave it like that with the parent. You know your child best and we are just health care professionals. We are seeing them [children] one or two times and we can’t judge on their behalf and we can’t make any decisions on their behalf. You know your child, you have to talk to them as how they will understand the situation you know, story form or however you tell them that’s how we leave it with the parents in their capable hands as we can’t take over that role. We can only support them and advise the grownups to help the children but sometimes we can’t directly involve ourselves with the children because we are total strangers for them and what we say may be too strong for them, isn’t it, or the words what we interpret for them might be too heavy they probably won’t be able to either understand or tolerate that. (F2 - 4)*

Here the nurse is describing a type of avoidance of the situation with children by identifying the boundaries of her role with a number of negatives about her role with parents and their children (we can’t, won’t be able to, have to leave it). She describes how it is up to the parent to cope with the situation and this is a mirroring of the patient avoidance described earlier with the ‘staff avoidance’ identified here. She does identify different ways that parents can talk to the children and suggests a ‘story form’ as one way for the parent to tackle this communication. The nurse also identifies how it would be difficult to become directly involved with the children as ‘we’ are strangers. She is generalising her comments to all the nurses by her use of ‘we’. She describes that her way of speaking would be too ‘strong’ for children and ‘too heavy’ and would be inappropriate. She identifies a lack of skill to talk with children and feels it is best left to the parents.

The emphasis on vicarious support and ‘staff avoidance’ seems to be the nature of the work culture in the NHS in that the focus remains on the patients and their needs not necessarily the family (see also Turner et al., 2007). Although a dedicated space for meeting children and families had recently been designed and organised in the participating trust.
6.3.3 Reluctance of patients to involve children

Participants describe how patients often communicate that they do not wish for staff to be involved with children but that they will manage it themselves “as a family” (FG2 - 5) and that they wish to be ‘very protective of the children’ (FG2 - 1) and there were recurring references in both focus groups to this effect. Families are also perceived to want to wait and see how they manage on their own before they welcome further support:

Families are very much like ‘oh we will see how we will get on’ and often I have said well link with the community palliative care teams or link with your community if you feel like you do want further outside support. (FG2 - 3)

The importance of palliative care support is identified above and the nurse urges the patient to make links with palliative care support.

The parents are described as needing to identify their needs for themselves:

It has got to come from them [parents] if they need it, if they need support and guidance. You can take a horse to water but, you know, you can only give them information, you can, and offer. (FG1 - 7)

In the data extract above the nurse is primarily identifying her role as one related to information giving. She wishes to facilitate information giving but does not wish to be seen as dictating what her patients should do. However she is willing to give information to the parent on behalf of the child in a similar way to the participant below:

We want to facilitate things, help when you can give the information what will help but you can’t come along and say ‘oh you’ve got cancer, you’ve got to do this’. You can’t dictate, it can only be to try and help and support each individual case. (FG1 - 3)

Another participant gave the example of staff being kept ‘at arm’s length’ by a female patient with children thus limiting what staff could do for the children, although staff seem to have registered that the family had a support network in place indicating that
an informal assessment of the situation with the children had taken place at some stage. Well intended parents can sometimes act as “gatekeepers” which may not be in the best interest of children (Semple & McCaughan, 2013: 228).

*I am thinking a woman we have got in her 40s with children and she has got a husband and supportive family and she wants us at arm’s length so there is not a lot we can do in that situation. (FG1 - 7)*

There was a perception among the participating nurses that patients and their families often want to keep the illness and what is happening at the hospital separate from children and family life as much as possible, to keep the feeling of normality.

The nurse below has offered an information booklet to empower the family to deal with the situation as ‘a family’:

*No I offered you know, we talked she wanted to talk more to her daughter and then next son down the youngest was too young and how much information, and I gave her the Macmillan booklets and we talked through it and offered her if she wanted any help with it and she wanted it kept quite separate. So they wanted to deal with it as a family they didn’t want us intervening with it, they wanted it kept with them managing it. (FG2 - 5)*

The nurse above describes how she has talked with the patient and given a lot of emotional support. She has also given the Macmillan booklet which they have talked through together. The nurse appears to have supported the family vicariously so that the family can deal with the situation in their own way.

### 6.3.4 Maintaining hope

Our data also show how conflicting it can be for staff to help patients maintain hope or at least not destroy hope and, at the same time, try and support and inform patients and their children about the reality of a situation which may involve an impending death (see also Turner et al., 2007). It could be suggested that hope can in a sense compromise acceptance of a terminal condition which in turn means that families and children may not be at all prepared when the time comes. This is not to say that
maintaining hope is not important in this context but rather that the context is highly complex and demanding for staff who need to strike a careful balance.

The participant below describes how she discussed with a female patient how to manage and balance the information given to her adolescent children to keep them aware of the situation with their mother without too much negativity i.e. the information was staged:

*And it’s also going through the diagnostic process. One lady had a child at college and one at university and we only had a little bit of information to begin with. Do I tell them what I know now or do I wait? So we talked that through and we said well actually what’s the point of worrying them let’s get all the results that are back and with the negative, that your mums got cancer, we can also say that however this is going to be done and this is the plan so there was a positive so that was how in the end we you know she decided to deal with it and we talked at length about that and how the best way without worrying them because if you just tell them a load of negative stuff and then you say well you can do this, that’s quite hard and we knew we had time to obviously be palliative. (FG2 - 5)*

Here the nurse describes working closely with the children’s mother to talk through the plan of care and how to inform the children of the parent’s cancer in a carefully managed way to avoid ‘worrying’ the children who were away at college and university. The nurse wished to avoid any sense of negativity for the children and that the children had practical information about the care plan.

**6.3.5 Summary**

Although there are no formal screening processes in place to identify patients who have children who might benefit from psycho-social support, oncology staff become quickly aware of patients who have children, some of whom have special needs such as autism. However those working with patients with breast cancer are more likely to come across patients with children. Some staff actively pursue the issue of children with patients, but most learn about children and children’s needs when parents bring it up and there seems to be some reluctance among staff to actively explore children’s situations with
parents. This appears to be because staff do not feel sufficiently prepared to address the needs of children and the work focuses on the individual patient and their medical needs. There is also a perception among staff that patients are acting as ‘gatekeepers’ wanting to protect their children from their illness and the hospital environment, and staff feel they need to respect patients’ wishes because the parents know best.

6.4 The needs of oncology staff

As previously discussed there was a sense that participating staff felt highly motivated to support families and children who were perceived to need it. Turner and colleagues also found that oncology nurses felt that “psychosocial support was a core part of their role in oncology” (2007: 151). Participants spoke about wanting to ‘relieve the burden’ of families and to ‘help support them’ (FG1 - 3). However, they also described a situation of a lack of knowledge about how to support families with children which is discussed next.

6.4.1 Children’s developmental stages

Participants discussed a lack of knowledge/guidance around children’s needs at different ages and developmental stages such as ‘what to tell them depending on their age’ (FG1 - 5). This is consistent with findings by Turner et al (2007) who found that oncology nurses felt they did not have sufficient knowledge about children’s experiences of parental cancer.

A participant discusses how important it is to understand how the children are responding to the parent’s illness and how they cope with the situation and also the age of the children:

*It depends on how they [children] take it [the parent’s illness] and it depends on what age they are and how they can cope so say for example if they are having other health issues with say autism and things like that and based on that [I would] just leave it with the parents they are best to know their children. (FG2 - 4)*
This participant seems to believe that it is particularly important to follow the lead of the parents when children are vulnerable for instance if children have health issues such as autism. However, the nurse describes leaving these issues with the parents which might also indicate a reluctance to become involved for “fear of making things worse” (Turner et al., 2007: 152).

Sometimes young children are brought in with the patient and material such as paper and crayons might be offered to the child but staff would not normally engage with the child:

*If the child came in we would do things like give her some paper and crayons (...) while mum sat and had something done, a dressing or something like that. (FG1 - 5)*

As discussed most of the existing support that is given to children appears to be vicarious in that oncology staff support parents to support children, however there were a few examples in the data of staff meeting directly with teenagers at the teenagers’ request. One nurse saw this as an opportunity for the teenager she met to ask questions they might not have wanted to ask with the parent present. She found that being truthful and adapting to the teenager’s agenda was helpful.

*I think it was about being sort of adult about it and finding our [sic] own information and asking things that [they] could without [their] parents being there (...) I mean I did read the information because there is a book, isn’t there, about talking to children so I did at night sat and read it (...) before meeting the teenager] so I suppose that sort of thing literature [is good] or something about how to be with them. But I guess you are the same with them as the patients you are as truthful as you can be and you say things gently and you only answer the questions they ask you because you know that they are prepared for the answer that you are going to give. (FG1 - 6)*

The nurse above did some homework before meeting with the teenagers which she describes as helpful in knowing ‘how to be with them’. She describes specific skills that she used such as saying things gently and being guided by the teenagers questions and only answering the questions that they asked. These are specific skills in handling difficult questions and using tactful communication skills to handle a challenging interaction.
6.4.2 Apprehension about engaging with support for children

Although not expressing this directly, our participants also appeared to be somewhat apprehensive about engaging in direct or indirect support of children through parents citing, for example, that families often do not welcome oncology staff initiating support for children, or staff not feeling prepared such as ‘never prepared until it happens’ (FG1 - 1).

Another nurse describes how she is often ‘blagging it’ due to a lack of knowledge and guidance:

*And I suppose [we need] guidance about how much to tell the children, what to tell them depending on their age and things because I suppose half the time we are blagging it aren’t’ we. What we think that we should tell them and, you know. (FG1 - 5)*

The nurse feels unprepared to confront the issues surrounding children such as how much to tell and age appropriate information which comes from her opinion rather than guidance.

When staff engage in vicarious and/or direct support of families and children one recurring issue regarding support was that of the culture of the family. Participants discussed how there can be no ‘one size fits all’ approach to supporting families and children given the varying cultures of families. This is not just referring to ethnicity, language or religion but also to how, for example, family members communicate and behave towards each other in their daily life.

*And culture the family’s culture as well as other cultures [such as ethnicity or religion] and I think what is best [for each individual family]. (FG2 - 3)*

The nurse above shows appreciation for individual family differences and most importantly the cultural issues which she sees are important and therefore affect how support is offered to families.

Another participant describes how important it is to be non-judgmental and to accept
that families differ in how they manage their lives:

*I don’t think there is an absolute wrong and an absolute right way either and I think (...) And some families discuss everything openly and you even, this they will probably take it lighter and they will have their own ways of discussing it with the children. Some families are a bit too close they put children to bed and then only discuss family situations. So in that situation they might find it hard to discuss this with the children because they haven’t dealt with other day to day life issues openly with the children. So they might have a lot of difficulty than families who are discussing it openly with the children. So that is how we have to look at the patients in front of us and go with what they think [is] the best for their children. Again I wouldn’t say I will get involved and say oh I will come and talk to your child, no I think it is totally left to the parents they have the full understanding into their child’s capacity.* (FG2 - 1)

The participant above does not want to take over from the family and she is aware that families have different ways of handing communication with some being open and others wanting to be more discrete and private about how they communicate. Therefore in her opinion it is best to leave the issues regarding the children to the parents. Another participant in a similar vein didn’t want to ‘enforce things on people’.

(FG2 - 5)

Staff did not want to interfere with family functioning by giving inappropriate advice to parents who may have different attitudes and beliefs about communicating with their children with some described as being open and others having more closed communication styles with children. The general strategy adapted by the oncology nurses when dealing with patients with children who might need support was that of being approachable and remaining alert to signs that patients or their children might struggle, and then follow the lead of the parents should some form of intervention be regarded as beneficial by them or the parents.

6.4.3 Sources of support

The nurses seemed aware of a network of resources to help support families and children who they could refer to or liaise with including General Practitioners (GPs) schools, and other resources such as the hospital chaplaincy and dedicated charities such as jigsaw southeast offering support for families and children. However they noted a lack of effective signposting to updated information sources. They liaised with and
referred families to colleagues in the community such as palliative care services and social work services. They also report being aware of tools and techniques used in the support of families and children such as memory boxes and written information such as the Macmillan booklet. One participant expressed a concern that having a large number of professionals being involved with a family at the same time might "make it worse" (FG2 - 5) i.e. this might be intrusive for families at a difficult time.

This nurse describes some sources of support that she is aware of and also notes that the support being offered in the hospital is limited:

_There’s something called Daisy’s Dream which is very good at supporting children. I'm aware of Jigsaw (...) but I think in the hospital environment they don’t often invite people in and we often refer to the community palliative care teams we know they have the welfare team at [the hospice] haven’t they, and they talk to children and I suppose they are going out to their homes. (FG1 - 7)_

Discussions around existing support, resources and needs of oncology staff in relation to the support of children highlighted two major areas where further support is needed. Firstly, given the varying and multi faceted needs of patients/children, participants asked for a one stop signposting through which updated information could be easily accessed to fit in with whatever situation staff are faced with. One participant suggested that ‘all I would need to know is to know where to get information from’ (FG1 - 4). Participants also emphasised that strategies for supporting families should take into account the busy hospital environment, or ‘the time factor’ (FG1 - 3), to ensure implementation and better support for families. One participant said ‘I don’t think [more] paperwork would make it any better’ (FG1 - 7) i.e. routine screening for children who might need support would not be helpful. Another participant suggested that ‘you do it instinctively’ (FG1 - 4) implying that intuition plays an important role for staff when assessing and managing patients’ situations and needs. Results from the study by Turner and colleagues also indicate that oncology nurses feel resources need to be “practical” and easy to implement to support children (Turner et al., 2007: 154).

Staff encounter patients/families with a variety of financial and practical problems as well as issues with the psycho social aspects of a cancer illness, all of which may affect
children negatively. Participants discussed how at certain times other needs than those of a psycho social nature need to be prioritised and how a holistic approach needs to be adapted.

The second major area discussed was a lack of opportunities to reflect on practice with colleagues as well as regular clinical supervision. A nurse highlights that given the complicated context of providing care and support for cancer patients and their children, specific training would be unlikely to prepare nurses for any situation. She does, however, suggest that regularly sharing experiences with colleagues in a supervised and safe environment would be helpful; and she uses the focus group as an example:

*The trouble with us having specific training is that every situation is different and you need to do different things at different times and it would be hard whatever scenario that we train for, the one we deal with would probably be different and I don’t mean that to be a negative thing. I think it is important to just come and talk about experiences and perhaps learn [like] we have done this morning really [referring to focus group] (...) I think that everyone’s experiences we would all do the same sort of thing. I think if we sat here and thought I never thought of doing that then that might create alarm bells might it, but it sounds like we are all doing the same sort of thing anyway which is reassuring isn’t it? (FG1 - 5)*

Another nurse describes how she sought and received peer support from colleagues regarding a particular situation with a patient which had left her reassured that she had managed the situation well:

*It was difficult for me as well [as the patient] (...) I did check with the breast nurse as I know they deal with young families quite often and they felt I had really gone down the right paths with it (...) so it was reassuring for me as well (...) when colleagues have been through something it’s nice to pick up on what they have picked up on. (FG2 - 5)*

Participants describe receiving a great deal of help from colleagues particularly from the breast care nurse who has more contact with young families.

A training session was piloted as part of this study. The session was informed by the findings of the study. The feedback from the workshop showed that nurses felt a great need to share experiences with colleagues and to give and receive peer support. The training session took place with 6 participants recruited from those who took part in the
study. The session which is described in the methodology chapter (chapter 5) mainly consisted of role play around a number of case studies, some around vulnerable children (see appendix 3), and nurses found, that 'discussing in small groups and role play was helpful as [I was] reflecting back on my own practice’ and another participant found that 'learning from experience’ is important. A skill a third participant would take away from the training was ‘confidence to ask them [patients] about their children and offering them support’. Participants describe feeling more confident in relation to asking about children and offering support following the workshop. If staff continue to feel apprehensive about engaging with patients about children’s needs as previously discussed, this could lead to ‘staff avoidance’. However staff engagement with the issues of parents and their children requires support, opportunities for reflection and confidence building.

6.4.4 Summary

Nurses were aware of a network of resources and information to help support families but lacked access to a one stop shop to resources. They also discussed the need for regular opportunities to reflect on practice with colleagues. Staff felt they needed further guidance on how to support parents and families sensitively and responsively so that cultural needs were accommodated and patients felt sensitively supported in relation to the needs of their children. The training workshop was found to be a supportive intervention that developed participants confidence in asking patients about children and their needs and helped staff to feel supported in this challenging work.
7. Concluding discussion

The Think Family project explored the experiences and needs of oncology staff who work with patients who are parents, and also focused on heightening awareness of the needs of children where a parent has cancer. The small sample from one trust means that results cannot be generalised; however, at the same time, the small sample and the methodology used has provided an opportunity to gain a deeper understanding of this area, thus contributing to knowledge and to the wider literature on the subject.

The findings demonstrate the complexity of the issues for staff to provide support to families and children. Staff are concerned that families continue to lead as normal a life as possible and wish to support patients and family in this regard. Mothers with breast cancer have also been found to safeguard familiar routines with a preference to carry on as usual as much as possible (Fisher & O’Connor, 2012). However these mothers also wished to be recognised as mothers not just as patients and to have their responsibilities for the well-being of children to be acknowledged by health care professionals. Fearnley (2010) observes how healthcare staff tend to be medically orientated and issues regarding children may not be discussed.

In the current research some of the nurses described their ability to assess family needs through use of questions exploring dependents, but generally the nurses report a more reactive approach mostly taking their cue from patients regarding the needs of their children, or indeed if any discussion is to take place at all. Fearnley describes how a specialist nurse used sensitive language to assess the family: “very gentle to test out what the children may have been told” (2010: 453). In our research there is evidence that some of the participants felt they do not have the skills to explore issues relevant to patients and children in a sensitive and gentle manner. The complexities for staff reflect the general busy working environment in hospitals where straightforward “off-the-shelf solutions” cannot answer complex emotional and psychosocial concerns (Turner et al., 2008: 1626), and awareness of family needs can be low on the list of priorities. Healthcare staff work in highly charged emotionally loaded situations requiring emotional labour and this is particularly the case when it comes to children. Specialist nurses described how they can identify with their patients (as mothers) and this adds to
the emotionally charged context of care and to the emotional burden on staff.

Participants’ stories were imbued with references to how engaging with patients and their families/children had affected them deeply and shaped their practice. Supporting families can awaken emotions of a personal nature in oncology staff which can affect practice positively or negatively. Although it may be emotionally draining for staff to identify closely with patients and draw from their own experience it may also be a helpful and empathic strategy and one that can reduce the feeling of emotional burden on staff. Turner and colleagues similarly found that for staff to engage emotionally with “a ‘special’ patient” can alleviate the “emotional distress” they themselves experience when supporting patients (Turner et al., 2007: 152). Lipsky also reminds us that health and social care staff may attempt to give ideal care to at least a small proportion of service users, which he refers to as “creaming”, when conflicted by service users’ needs and available resources to increase job satisfaction (1980: 107).

There was evidence of staff avoidance of the needs of children, for example staff used terms such as: ‘leave it like that with the parent’ and ‘totally left to the parents’. This type of avoidance has been called ‘blocking behaviour’ that may limit the extent to which patients can express concerns about sensitive matters regarding dependents and children and the wider needs of family members (Maguire & Pitceathly, 2002). Staff avoidance is understandable as to confront the needs of family and children calls for emotional labour that triggers hard to manage emotions in staff and in patients. Fearnley, however, states: “don’t ignore the elephant in the room” which refers to the needs of children (2010: 450). Much research points to the needs of mothers in particular for support at all stages of the cancer illness regarding their worry about their children and the need for psychosocial support regarding these worries (Rauch et al., 2003; Stinesen-Kollberg et al., 2013). Working with the uncertainties associated with cancer and the chronic nature of some cancers means that patients’ needs will be variable over time and staff will need the skills to respond to these needs over longer and shorter timescales as the acute and chronic cancer illness experiences overlap and are extended through survivorship.
Our findings demonstrate that staff did not normally engage directly with children and that the mainstay of the support was vicarious support in that they offered a way of ‘supporting the parents to support children’. Staff reported becoming quickly aware of cancer patients who have children although no formal processes were in place to identify children’s needs. It was, however, mainly left to parents to initiate/request support. Participating staff often perceived parents to be reluctant to involve their children through parental avoidance because of a wish to maintain hope which can mean that discussions about potentially negative consequences of a cancer illness within the family are avoided. It can be conflicting for staff to help patients maintain hope and at the same time convey to patients and their families the seriousness of their situation. Hope can in this sense compromise acceptance of a terminal condition and lead to withholding of information and support for families; and staff need to strike a careful balance. However, even quite young children can understand when something is wrong, such as illness in a parent, and it is essential that families receive support to enable them to communicate with children (Forrest et al., 2006; Semple & McCaughan, 2013). In fact patients are reported to welcome the interest of nurses in their family life (Fisher & O'Connor, 2012), and low psychological well-being is linked to worry about one’s children (Stinesen-Kollberg et al., 2013). Staff reported how patients are generally coping well with the needs of children. However, there is evidence that parents feel inadequately supported to minimise the impact of cancer on children and to identify a child who may need more support (Rauch & Moore, 2010). Recent work in the US reports a pilot programme for parents on the effect of their illness on their children and this programme was reported to be well received (Rauch et al., 2003).

There is a need to develop more robust family interventions which are theoretically informed and systematically evaluated (Semple & McCaughan, 2013). Less complicated interventions, such as peer support from other children with similar experiences, can be highly valued by children (Semple & McCaughan, 2013). Responding to wider support need involves setting up care pathways to specialised support interventions and family support systems.

An unexpected finding in the study was that female staff identified closely with female
patients by mostly talking about female patients and one male participant identified more closely with male patients by giving examples of male patients. Although the sample was small, this suggests that there may be gender specific issues relative to patients’ responses to a cancer diagnosis and how staff manage families and children (see Visser et al., 2005) which could merit further research. There is a lack of research in the needs of fathers with cancer and the parenting role and the intensity of distress regarding children at different stages in the illness.

Staff appeared highly motivated to provide support for families and children but communicated a need for further training and support in relation to this challenging and complex task. Staff were aware of a network of resources including their own colleagues which they called on regularly including liaison with schools. However, they seemed reluctant to engage with issues of children and reported that they needed more knowledge and support to engage with children’s need and their developmental stages. They were interested in how to adapt the information and support to these stages and one staff member reports directly supporting teenagers by meeting with them and answering their questions. Additionally they felt it was important to show respect for individual family differences and cultural differences and to avoid imposing on parents and to keep a non-judgmental footing about parenting practices.

The data highlighted two major areas where the participants felt more support was needed. Firstly, in order to provide an effective ‘one stop’ approach to signposting updated information sources is needed. Secondly, staff need regular opportunities to reflect on practice with colleagues where they can share experiences with colleagues and offer and receive peer support.
7.1 Recommendations

Firstly, we suggest that what is most likely to facilitate change and improve support for families and children is a pragmatic approach which utilises existing resources in an effective way within health care systems with very limited resources. In addition a broad culture change is needed including interventions involving education, training, clinical supervision and explicitly including support of families and children in job descriptions for oncology staff. What would further facilitate a broader cultural change would be to highlight the needs of children in future cancer awareness campaigns.

More specifically, we recommend that there needs to be:

- Opportunities for oncology staff to regularly reflect on practice with colleagues and peer-support systems put in place. This could be incorporated into the existing clinical supervision process.
- Increased awareness of the impact on children of parental cancer in oncology staff throughout the cancer illness.
- Provision of one stop updated sign posting/tool for information and guidance.
- Workshops for staff to increase staff confidence; including guidance on children’s developmental stages and age adapted information and support strategies.
- Guidance on children’s developmental stages and age adapted information included in psychology level 2 training and other forms of training for staff.
- Guidance on assessing family needs and the needs of children.
8. References


Macmillan Cancer Support. 2013. Let’s talk about you MAC 13009.


Osborn, T. 2007. The psychosocial impact of parental cancer on children and
Patterson, P. & Rangganadhan, A. 2010. Losing a parent to cancer: a preliminary investigation into the needs of adolescents and young adults. Palliative and Supportive Care, 8(3): 255 - 265.
9. Appendices
Appendix 1: Topic guide for staff focus groups

- Welcome and introductions

- Ground rules relating to e.g. confidentiality; and outline of the focus group process

- Any questions before we begin?

- Discussion/sharing around participants’ [recent] experiences of patients with cancer who have children

- How do you learn if your patients who suffer from advanced cancer have children? (probe: would you normally ask if patients have children and what their ages are etc?)

- What are the barriers for finding out about the children?

- What are the processes for recording that there are dependent children in the family?

- What are your thoughts on available support for these children?

- What are the resources and skills needed to support children?

- What do you think children might need when a carer is very ill?

- What internal or external resources are you aware of for the support of the children?

How much children should be told about their parent’s/carer’s illness?
Appendix 2: Overview of training session

- Welcome & introduction
- Learning outcomes
- Key points from focus groups
- Participants’ expectations of the training
- Practical work with case studies
- Vulnerable children/families
- Supporting children of different ages
- Top tips to share with parents
- Signposting of services/support for families
- Feedback/evaluation form
Appendix 3: Case studies

Case study 1
Amy is 8 years old and is an only child. Her Mum has a brain tumour, but after nine months of surgery, radiotherapy and chemotherapy, she is now expected to die in the next few days or weeks. After much deliberation Mum has been admitted to the local hospice. She has never spoken about dying to her husband.

Case study 2
Thomas is 7 years old and is in Year 3. He lives with his Mum, Dad, sister and two dogs. His father has cancer of the kidney and is on “experimental chemotherapy”. Dad looks well, but gets very tired and no longer works. Thomas has ASD and has been running away from school.

Case study 3
Kaley is a 11 years old and in Year 7 at school. She lives with her Mum, her father died in an accident 6 years ago. Her Mum, who is estranged from the rest of her family has had breast cancer treated over a period of 6 years. She has now been told that she likely to have between 6 and 18 months to live. Kaley has survived cancer herself as a child, but is left with a mild left sided weakness. Kaley has no siblings.