Abstract

Background: Many parents report a strong desire to take on information-giving roles, and believe they are best positioned to discuss their child's illness with their child. Healthcare professionals have a supporting role to reduce the burden on parents who feel responsible for conveying information to their child and other family members.

Objective: To examine parents' and healthcare professionals' perceptions of roles in receiving and communicating information when a child is diagnosed with and treated for acute lymphoblastic leukaemia.

Design, setting and participants: We used the principles of a grounded theory approach. This was a single site study, recruiting from a principal children's cancer treatment centre in the United Kingdom. The sample included parents of children receiving and completed treatment for acute lymphoblastic leukaemia (*n=28*), and healthcare professionals (*n=26*).

Methods: Methods included individual interviews, face-to-face and telephone, focus groups, and an online forum.

Findings: Communication 'touch points' are many over the course of a child's cancer journey. We describe often 'mismatched' communication encounters where those seeking information and those providing information have different goals. One participant, healthcare professional, in the encounter has expertise at the outset, the other, the parent, has no expertise, but this expertise grows over time and this can increase the perceptions of this 'mismatch' and create different challenges.

Conclusions: Considered in the context of middle range transition theory, we might suggest that parental foreground (seeking information directly) and background (passive actors) roles are the result of differing levels of uncertainty, and depend on the situation and preferences, child and family need, that may present differently over time in different contexts. Our work contributes to the emerging consensus that communication is more than a core set of skills that a healthcare professionals just need to learn: clear specifications of mutual roles, responsibilities and a shared understanding of goals is also essential.

Keywords: cancer; children and parents; communication patterns; communication intervention

What is already known about the topic?

- Children (primarily between the ages of 4 and 10) have shown a reliance on parents for information, therefore giving parents many important communication roles.

- Many parents report a strong desire to take on information-giving roles within their families, and believe they are best positioned to discuss their child's illness with their child.

- Information provision is not a benign intervention by healthcare professionals, it requires a responsive approach to child and parent needs and preferences.

What this paper adds?

- Parents sometimes felt inadequately prepared for the level of responsibility they were charged with and in the majority they were not offered assistance on how they could communicate the diagnosis to their child.

- Information was protocolised by healthcare professionals, particularly in the 'diagnosis talk', and this established a pattern for all future conversations.

- Assumptions are made about which roles provide particular kinds of information, for example, doctors primarily focussed on the disease and treatment and nurses focussed on care and side effects with parents, while health play specialists talked with children.

- Most parents in our study actively sought information that helped them to manage their own uncertainty.

1. Introduction

Recent improvements in survival from childhood cancer mean that the context of communicating about childhood cancer has transformed over the last few decades. High quality, accurate and timely communication should be prioritised for all children with cancer (Knops et al., 2012). Communication and the transfer of information is known to be complex (Ringner et al., 2013). Healthcare professionals need to convey information about the child's disease, treatment and prognosis, as well as information that enables parents to care for their child while in hospital and at home, to create an environment of normality (Bjork et al., 2005). Nurses are well situated to share information and be a conduit for the translation of complex information (Citak et al., 2013, Hendricks-Ferguson et al., 2015). Parents must then choose when and how much of this information to share with their child (Mack et al., 2011). More complex, is prognostic disclosure with children, where 'never tell', 'always tell' and 'maybe tell', has been described more recently as a historical continuum, where the individual needs of children and parents have become more the priority (Sisk et al., 2016). There is evidence to suggest that children should be involved in decisions that affect them when they are able to do so and that children would like to be active participants in their health care, or at least have the choice to participate (Coyne et al., 2014, Hinds et al., 2001, Zwaanswijk et al., 2007). Children (primarily between the ages of 4 and 10) have shown a reliance on parents for information, therefore giving parents many important communication roles (reference removed for anonimity). Current perceptions surrounding communication patterns positions the parent and child in either background or foreground roles: being in the foreground or background depends on children's perspectives of their own communication skills surrounding their illness, and others' perceptions of the child's skills (Meleis, 2010). The study reported here describes a novel, and ongoing, communication programme to understand more about the roles parents play in the foreground and background, and how healthcare professionals prepare parents for these roles.

2. Literature review

2.1 Parents and children need information: why and how much

Though cure is not guaranteed, chances of survival have improved dramatically and questions about how to communicate effectively have focused on supporting children with a life-long chronic illness (Dixon-Woods et al., 2005). It is reported, "for virtually all parents, becoming a parent of a child with cancer marks a striking, biographical shift" (Young et al., 2002, p.1837). A major part of this shift involves parents taking on information-sharing roles during

their child's treatment, most predominantly executive-like roles, managing what and how their children are told about their cancer diagnosis (Young et al., 2003). Three factors described as contributing to restricted parents' communication with their child include: information overload and emotional turmoil, lack of knowledge and skills for disclosing the diagnosis, and assumptions about burdening the child when discussing cancer (Badarau et al., 2015). There is a clear dissonance between parents' desires to be informed, in order to make decisions about care and treatment and the steep learning curve and new language they face at diagnosis (Markward et al., 2013; McGrath 2002).

The desire to gain control has also been described by children, where they reported knowledge and understanding about their illness and treatment that allowed them to participate in their own care (Darcy et al., 2014). The sharing of information helps children better understand, prepare for, and cope with their illness, the procedures they may undergo, discharge from hospital, return to school, and in some cases, relapse or end-of-life care (Ranmal et al., 2008). Children who do not receive this kind of information early on are more prone than others to anxiety and depression during cancer treatment, and to long-term psychosocial adjustment problems following treatment (Skeen and Webster, 2004). Young children in particular are known to rely on their parents for all of their medical and non-medical information (Aldiss et al., 2009, reference removed for anonimity). Parents therefore have the onerous responsibility of understanding the information, assessing the appropriate amount of information that should be available to their child, and then disclosing it.

2.2. Parents and children's preferences for information

Many parents report a strong desire to take on information-giving roles within their families, and believe they are best positioned to discuss their child's illness with their child. Over 80% of parents in one study wanted to be viewed by hospital staff as their child's treatment coordinator (Mitchell et al., 2006). Parents recognise their own knowledge deficits at the outset, but often desire information even when the information is upsetting (Mack et al., 2006). Some parents choose to actively seek information as it helps reduce their uncertainty, and increases their sense of control (Kilicarslan-Toruner and Akgun-Citak, 2013). Knowledge early on has been shown to help parents gain confidence, feel secure and more able to become a 'member of the team', by being clear about their role and expectations (Kastel et al., 2011). Parents have reported greater satisfaction when information about the diagnosis is frank, and open, and where their privacy was respected, allowing sufficient time

to express emotions and have their questions answered (Beltrao et al., 2007): but less satisfaction with the amount and quality of information in the later phases of their child's illness (Ringner et al., 2011b). In instances where information was not provided adequately, parents sought other avenues for information such as the internet (Ringner et al., 2011b). Parents have reported being both over-informed and under-informed (McGrath et al., 2007) .

Despite clear evidence that children with cancer desire information about their illness and treatment (Ellis and Leventhal, 1993, Horstman and Bradding, 2002, Last and Van Veldhuizen, 1996, Zwaanswijk et al., 2007), previous research suggests that professionals might not always communicate complex information to children as effectively as they think they do. Children have reported lack of awareness of treatment plans, side-effects and recovery (Aldiss et al., 2009, reference removed for anonimity). Discordance between parents and children has also been noted (Zwaanswijk et al., 2011). Family communication is largely affected by parental preferences, and this executive parental role can cause some children to feel constrained in their understanding of their illness and decision-making, particularly adolescents (Young et al., 2003). Children's preferences, described as either information-seeking or information-avoiding, are often dependent on the situation (Coyne et al., 2016). Kazimierczak et al (2013) refer to 'navigating the knowledge landscape' (p360): information provision is not a benign intervention, it requires a responsive approach to patients' needs and preferences. What complicates this process is the different information needs and preferences of individual parents and children (Nightingale et al., 2015, Soanes et al., 2009, Young et al., 2013, Zwaanswijk et al., 2011).

2.3 Barriers to effective communication
The overwhelming nature of a diagnosis of a childhood cancer has been reported previously (Kessel et al., 2013, Landier et al., 2016, Mack and Grier, 2004). As a result of the associated shock and distress, parents have reported understanding less than half of what doctors say at the initial consultation (Kodish et al., 2004). They are most distressed at the time of diagnosis and early stages of treatment (Bjork et al., 2005, Kupst, 1992). Stress further hinders the processing of information as well as retention, making it extremely difficult for parents to relay and translate information to children following diagnosis (Aburn and Gott, 2014, Mack et al., 2006). Despite these inherent barriers, it is important that parents begin to share information with their child following diagnosis and build up complex information over time. The healthcare professional has a supporting role to reduce the burden on parents who feel

responsible for conveying information to their child and other family members (Ringner et al., 2011a, Ringner et al., 2013). Professionals may find it difficult to judge the amount of information that parents need in response to change as treatment and care progresses. Understanding needs and preferences of parents and children and tailoring information accordingly requires appreciation of these triadic encounters and the roles that each member takes, as well as how these roles change over time.

3. Aim

To examine parents' and healthcare professionals' perceptions of roles in receiving and communicating information when a child is diagnosed with and treated for acute lymphoblastic leukaemia (ALL): the most common type of childhood cancer, treated around the world by a short inpatient stay, followed by up to three years outpatient therapy.

4. Study design

We used the principles of grounded theory with the goal to elicit dominant categories and concepts within communication surrounding diagnosis and treatment (Corbin and Strauss, 2008).

4.1 The setting

This was a single site study, recruiting from a principal children's cancer treatment centre (PTC) in London, United Kingdom.

4.2 Sample and recruitment

Parents were recruited with the aid of two clinical nurse specialists on the outpatient unit. The sample included parents of children who were receiving and who had completed treatment for ALL (*n=28*), and healthcare professionals (*n=26*).

Parent group one (P1)

We purposively sampled families up to four months after an initial diagnosis of ALL. Six ethnically-diverse, two-parent families of children who were between the ages of 3.8 and nine years at diagnosis (four male, two female) were recruited (*n=12*). Two families declined to take part citing lack of time.

Healthcare Professional group one (HCP1)

Participants were invited by email by the research team within three days of being mentioned in an interview by parents in group P1, 11 agreed. The sample was composed of specialist nurses, social workers, play specialists, and medical doctors. We were unable to contact a number of healthcare professionals nominated, because they had left the hospital or worked

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elsewhere, such as local hospitals that shared care with the PTC.

Parent group two (P2)

Following early analysis, we theoretically sampled families who had completed therapy within the last five years to elaborate and refine emerging categories. Sixteen parents, from 12 families, participated, to reach theoretical sufficiency.

Healthcare Professional group two (HCP2)

Theoretical sampling also resulted in the recruitment of clinical nurses and healthcare professionals in shared care hospitals (SCH) as properties of the categories were emerging. To recruit a wider group of professionals an email invitation was sent to all 84 haematology/oncology clinical nurses. The final volunteer sample included 15 nurses from the outpatient ward (day care), inpatient ward, outreach into the community, and those in advanced practice roles. Eight healthcare professionals were recruited from the 11 shared care hospitals approached.

4.3 Data collection methods

Qualitative data collection methods included individual interviews (face-to-face and telephone, focus group, online forum): mode and location was guided by participant choice. All interviews were carried out by a single researcher (GB, FG, SK) and focus groups facilitated by two researchers (GB, SK). A summary of recruitment data, sample size in each group, and methods of participation are presented in Table 1. Individual interviews were held with parents and healthcare professionals nominated by parents to capture in-depth experiences of communicating with children, as well as to understand how parents and professionals interact to negotiate and build meaningful understandings. Interview schedules were semi-structured to allow for meanings and responses to be grounded in clinical encounters and jointly constructed (Mishler, 1996), and a visual guide was added in later interviews with parents in P1 to highlight key areas for discussion that were emerging through data analysis (Figure 1). All materials were piloted with parent and professional project advisors. All interviewees and focus groups were audio-recorded and transcribed and discussions from the online forum were saved online. Field notes were captured. Data were collected over a period of two years, with interim analysis informing further sampling of parents at different points in the treatment pathway (P2) and a wider range of healthcare professionals. The data collection team (GB, FG, SK) are trained researchers, at the time employed at a university affiliated with a hospital. FG has been employed and undertaken research on the wards in which the study took place and her research interests were familiar to long-standing staff members.

4.3.1 Interviews with parents

Interviews with parents in group P1 took place mainly in homes, and included three or four interviews over a period of 10 months: first and second interviews were between two and six months post-diagnosis, with interviews three and four between four and twelve months. Interviews were either with both parents together or independently. Interviews with parent group P1 were on average longer than those in P2, ranging from 11 and 105 minutes. Parents in group P2 took part in a one-off interview, at home or in hospital, enabling the interviews to focus specifically on emerging themes.

4.3.2 Interviews and focus groups with healthcare professionals

All interviews and focus groups with healthcare professionals in group HCP1 occurred face-to-face in private meeting rooms at the hospital. Professionals were asked questions on communicating with parents about a new diagnosis, as a distinct event from later treatment and tests as a series of events, and about their communication roles overall. A similar schedule was used for HCP2 interviews, focus groups and online forum. All SCH interviews were conducted via telephone.

4.4 Ethical approval

National Health Service ethical approval and local site approval were secured. The research team were particularly sensitive to the need in preparing the clinical site. All participants received written and verbal information about the study. Written informed consent was obtained and all participants were assured confidentiality. We stressed at the outset that professionals nominated by families would have the opportunity to discuss the study in detail with the research team, and have sufficient time to decide on their participation.

4.*5 Data analysis*

Data were uploaded into a computer software programme (NVivo 8). Data were added to NVivo as data collection continued, and analysis occurred iteratively. A prescriptive method of grounded theory advocated by Corbin and Strauss (2008) was used and we followed a synthesised approach, advocated by Chen and Boore (2009), presented in Figure 2. Codes were developed into categories, new data compared with existing codes and categories (Giles et al., 2016). Figure 3 presents a worked example of the process using part of the category for 'protocolisation'. Analysis was undertaken by SK with assistance by GB, checked by FG, and discussed regularly at team meetings where a sample of transcripts were analysed and visual maps were built around the coding procedure to broaden network analysis and draw upon all

data collected. Trustworthiness of the analysis was sought through these regular team meetings (GB, LF, FG, SK) and the final categories agreed.

5. Findings

Our focus in this publication is on parents' and healthcare professionals' perceptions of roles in information sharing from diagnosis through treatment. This explores parents' opinions and beliefs about their roles, as well as those of healthcare professionals as communicators. It follows a chronological narrative of key time points at which information is exchanged, starting at the SCH 'before a diagnosis', 'the diagnosis discussion', then over the 'period in hospital', when 'receiving out-patient care', and ends at 'life as an outpatient'. Parent and healthcare professional stories are woven together in order to best illuminate the different perspectives. Presenting our data in this way, our intention is to offer to the reader 'touch points' of dyadic communication, offering an explanation for what we think might be happening during such encounters at different time points. Quotes are indicated by participant group, for example, P1.01.I3 Parent Group 1, Participant 1, Interview session 3; SCH.01, healthcare professional working in a child's local shared care hospital. We discuss our findings, drawing on published work to begin to explain what might be occurring in these encounters.

5.1 Before diagnosis

Parents described the pre-diagnosis period, which most often took place at the child's local SCH, as full of unanswered questions; sometimes this was due to healthcare professionals' uncertainties about the possible diagnoses. One father said,

"information was overflowing left and right, and I think it was not the way to handle [the time waiting for a diagnosis]" (P1.05. I1).

Parents also discussed the difficulty in gaining information particularly about leukaemia before their child was diagnosed, with one parent stating,

"we couldn't quite understand why we were still waiting to get confirmation, not realising that it wasn't until they took a sample of bone marrow that they could confirm it was leukaemia and what type of leukaemia it was" (P1.02&04.I1).

Parents discussed how it would have been extremely useful before leaving their local hospital (SCH) and going to the PTC for the first time to have direct information on what to expect in discussions about their child's diagnosis or prognosis. They suggested that a conversation

about a possible diagnosis with a clinician at the local hospital or direction to a reliable website could have acted as a *"bridge"* that could have better prepared them for the news about their child's diagnosis *(P1.03&05.I4).* But without a definitive diagnosis, from the perspective of the professionals at the child's local hospital, *"we are unable to give them the exact diagnosis, which for them is really, really difficult" (SC.01)*; *"I can't give them the full treatment plan because we don't know what it is" (SC.07).* The notion of not being prepared for the next stage was a shared concern of parents and HCPs. Many of the parents we interviewed suggested they were given inadequate information from staff at their local hospital about a possible diagnosis of cancer until it could be confirmed at a specialist hospital. This resulted in a small number of parents being shocked to be taken to the haematology/oncology ward at the initial transfer to the specialist hospital. One parent described her situation,

"I asked them, 'Why are you transferring me to haematology and oncology, when oncology is cancer and haematology is blood? And that means that he has leukaemia.' 'Oh we can't tell you that just yet." (P2.17&18)

Parents talked about not understanding the meaning of leukaemia and seeking information via the internet or gaining information from family and friends. One mother stated,

"I just didn't know what it was. I knew it was something very worrying, but I didn't know it was a cancer" (P1.01.I1).

Parents who knew the words leukaemia and cancer immediately had "*perceptions of the worst*" (*P1.09.I1*). Families found themselves having to explain leukaemia to their extended family in different languages and methods to suit their level of understanding. They sometimes called it a type of cancer, a bone marrow illness or bone marrow cancer. Parents suggested that their lack of understanding about the illness and the challenges they encountered explaining it to family and friends might have been due to the fact that "*a lot of people don't know leukaemia in general, even adults*" (*P1.03&05.I2*).

Once at the PTC, one family described how they saw a child who was clearly a cancer patient. For a number of days while their child was being treated as an inpatient, they believed the appearance of their child would change as soon as treatment began. Communication was particularly central for parents prior to their arrival at a new specialist hospital. However, although all of the SCH professionals we interviewed reported they had tried to prepare families for the specialist hospital, clearly this information had not been

recalled by families sufficiently to prepare them walking onto a children's cancer ward.

5.2 Diagnosis talk

One mother had been given very little information before a PTC doctor revealed her child's diagnosis. She said a nurse approached her while in the waiting room to say that a consultant wanted to speak to her in a private room and that the room was being prepared. This moment reminded her of previous experiences with cancer and she became full of fear. She described her experience,

"I knew at that point that it was really serious because that's the same thing they'd done, the way they set the room up, when they were telling me that my dad was dying. So I knew then that it was really, really bad. So I think it had probably crossed my mind what it was."

(P1.09. I1)

Most parents reported being removed from their child's bed space to be told their child's diagnosis, but a few mentioned being given the information in front of their child, one mother said,

"And he told me in front of the kids and I broke down again, and started to cry and the girls had no idea what was going on". (P1.O3.I1)

Difficulties also arose where one parent was given the information and then had to communicate this to their partner, usually mother to father, as one father said,

"I was just googling what leukaemia was…….it was difficult for me as I was not there…….difficult for my wife but at least she had people around". (P1.05.I11)

Healthcare professionals, often consultants, who were present at diagnosis talks reported that they assumed that in-patient ward-based nurses would follow up with families to clarify complex issues and misunderstandings from the 'spiel' that was generally shared with families at diagnosis. The information discussed in the spiel covered the ALL treatment protocol and was described as a tacit understanding amongst all health professionals. A consultant said,

"we don't normally need to discuss what needs to be said to parents, because it's all pretty standard now…the information that gets given is exactly the same." (HCP1.06)

One nurse also said,

"I work really closely with the consultants, so I can predict what they're going to say in a given situation because I've sat there 90 times while they've done that talk. And it's always the same…so I know what they're going to say, or what I think they're going to say. And also

you know, that they've work with me long enough that they know that I know the process as well. So, we're quite lucky in terms of our relationships and how we negotiate and how we talk to families." (HCP2.01)

However, healthcare professionals described how the level of detail in which they provided the spiel was based on their perceptions of a family's knowledge and questions, and degree of a family's reception and acceptance of the disease-related information. Many doctors said they tried to individualise the information given, by suggesting, *"If a family wants numbers I give them numbers" (HCP1.10).* The issue with the spiel was that the agenda of the conversation was in the hands of doctors who had given the same speech numerous times. They saw it as normal to provide certain pieces of information, and made assumptions about what those were. Parents were given the opportunity to ask questions, but the spiel would continue, with consultants returning to the information they wanted to impart: *"before I want to talk about the stuff I want to talk about" (HCP1.05.I1).*

At diagnosis parents had very little knowledge about leukaemia and did not yet understand their communication role within the hospital system. They did not understand that the more they asked of the medical consultant, the more information they would receive. Nor did they know what information outside of the spiel they were missing out on. The burden of guiding conversation and seeking knowledge appeared to be unfairly shifted to parents in the period of time surrounding diagnosis. Despite these heavy criticisms of the spiel, there was also evidence in our data that some healthcare professionals intentionally built up information over time and would continue speaking in detail if parents confirmed that they were happy for them to continue, which contests the general assumptions that parents should guide the diagnosis discussion based on their questions: and may add to an 'increased sense of chaos' when trying to assimilate complex information.

After a medical consultant had revealed the diagnosis, another healthcare professional present, usually a nurse, clarified complex issues using four to five leaflets: leaving the leaflets with families to refer to later. However, detailed information sharing at this time was challenging for parents who reported feeling overwhelmed with information and having little capacity to retain information. While many families described the initial diagnosis talk as clearly explained, they also revealed that they forgot much of what had been discussed, and hence could not accurately pass the information onto others. One parent suggested that it would be helpful if a week or two after diagnosis one professional went back to the family

and asked,

"Now that you've had time to take this in, is there anything now that you want to ask that you didn't think to ask at the beginning" (P1.11.12).

There was no evidence in our interviews that formal discussions like this ever happened.

It appeared that healthcare professionals made assumptions about who was giving out particular types of information. For example, it was assumed that the social worker or play specialist would provide a certain book to a child or piece of advice to parents about translating information to their child. However, it did not appear that there were procedures in place to ensure that families who were referred to these professionals were followed up later to determine whether the book or piece of advice had been given and the family was satisfied. There was a clear communication hierarchy, where certain information was delegated to be given out by certain professionals, one nurse stating: *".....and blurt out a load of medical information........I wouldn't really feel that is my place" (HCP1.09.I1).* The absence of a comprehensive formal 'communication protocol' or follow up may have contributed to the deficiency of information shared during this period, as well as throughout treatment.

5.3 First week in hospital

Throughout the first week in hospital, parents had meetings with up to ten different healthcare professionals, each providing an introduction to their area of specialist knowledge. For example, social workers often described logistical issues of being in hospital, ward nurses talked about particular medicines, and specialist intravenous nurses visited to discuss the choice of central line (for administering chemotherapy) and procedure of surgical insertion. Most parents felt that visits from healthcare professionals were well coordinated,

"You wanted to know everything, but you didn't know how to deal with everything. You didn't know which bits you had to remember, and which bits you had to ignore – not ignore, but which bits you could forget perhaps" (P2.02).

One family commented that they would have felt better prepared if someone had told them, *"these are the people who will be coming to see you and this is why they're coming to see you" (P1.11&12.I2).*

Parents also described how they had to ask each healthcare professional who entered their child's room the same questions to build up a full picture of the diagnosis and treatment of ALL because no one professional could provide it all. As one parent noted,

"I guess the challenge back to the medical profession is that there's no single person with a complete picture and there is no single version or opinion. There's no finding that. So every doctor we speak to will give us, the whole picture is obviously 100% and everyone we speak to – they all know something like 60%, but they all know different percents. You've got to keep asking lots of different people to keep building it up and beyond that 60%." (P1.10.13).

When healthcare professionals were faced with questions from outside of their area of specialist knowledge they suggested to parents that another professional would address that concern. The focus on professionals' specialist knowledge was then prioritised over families' perceived information needs during communication encounters. For example, parents discussed difficulty in finding out the length of stay required in hospital or getting support to explain to their child the reason for the stay in hospital, and finding out about certain procedures that were 'being done on their child'. One family said,

"There were nurses coming in with medication all the time. And I must admit, sometimes I had to say, 'Well, what's this for, what's that for?' I don't feel that was particularly well explained what she was, you know the tablets she was having" (P1.11&12.I1).

Healthcare professionals speaking only about their areas of specialist information (and the lack of a communication protocol) was also problematic as there was no defined date by which each family should have been told about particular issues associated with treatment. Unless it was very clear that families had never received or had forgotten major information no one followed it up, and no one was held accountable for not sharing that information. We have evidence that very essential information was missed with some families in the first week, for example what to do when their child had a fever but was not neutropenic, which often lead to prolonged worries and a general sense of uncertainty. Despite these criticisms, many parents in our study commented on being very happy with how information was shared with them during this first week and subsequently revisited at clinic appointments. One parent said,

"I think the initial problem really was more the fact it was just that there was so much information to take on board. But I wouldn't say there was anything new, you know, sort of information that we have now that we would have sort of looked back and said, 'Wish we had that information at the beginning' to be quite honest" (P1.04.13).

5.4 Preparing to go home

In preparation to take their child home, parents were guided through their shared care booklet full of tick boxes addressing whether certain aspects of care had been discussed. The form was filled out often immediately before the child's discharge, generally after one week in hospital. Parents were sometimes rushed through all of the tick boxes in ten minutes, and healthcare professionals commented in interviews that the boxes did not address issues outside of medical aspects of care giving. One mother suggested the tick box process was far too rushed for her. She said,

"I obviously either hadn't taken it in or hadn't been prepared fully for what even those first eight weeks involved. I didn't appreciate that we would be going in every Friday and every Friday she'd be having a lumbar puncture and a bone marrow test." (P1.11&12.I2)

Nurses on the inpatient wards suggested the reason for inadequate communication was because medical tasks took priority and occupied much of their time, and patients with ALL are in the hospital for a short amount of time making it difficult to make a connection with families. This resulted in negative consequences for parents and families who created assumptions about the timing for treatment. Some parents were rushed through important concepts of medical care, including a number of mothers who suggested they felt uncomfortable with giving their child chemotherapy at home. They coped by asking further questions and telling themselves that it is just something they have to deal with.

It appeared that no real discussion or support was given to parents on how to help their child understand and cope with returning home and beginning outpatient treatment. As one mother stated,

"I think they never asked me whether do you want help in explaining or anything like that……..and remember at the same time the parents are dealing with it as well and finding it just as hard" (P1.01&0.8.I2).

There was evidence that parents in our study, particularly at the outset, found the language surrounding diagnosis, treatment and prognosis complex. Some parents in our study felt rushed to first learn about treatments and side effects, and then communicate this to their child.

5.5 Life as an outpatient family

Parents initially monitored and described their child's treatment progress using the phases outlined in the clinical trial treatment protocol. At the 'diagnosis talk', healthcare professionals described the treatment using this framework. Many families used the treatment protocol to track appointments and share information about the treatment with other family members, to do this one father had converted the protocol into a spreadsheet, many kept the flowchart on the fridge door. In our initial interviews, we heard parents discussing the week of treatment their child was on, and the types of medications and expected side effects for phases. It was perceived that parents used this medical-based language to demonstrate their competence in their child's treatment to healthcare professionals. As treatment continued, some families lost track of weeks and were used to the routine of attending clinic and no longer needed a visual reminder. Their language remained clinically focused in regard to procedures and tests, but appeared to lose the sense of urgency attached to learning a new language associated with treatment, one mother spoke about the *"penny dropping" (P2.02),* and a father stated *"we learned the detail"*. (P1.06&07.I1)

5.6 Parents' carer and communication roles

Parents coped with information differently, and this was often linked to the carer role in the PTC. Parents who did not attend hospital often suggested they were less in touch with the information, but trusted their partners' translations of information. One father suggested he preferred the *"KISS principle (i.e. keep it simple and stupid!)"*. Many parents described feeling more in control of their child's health due to their larger care giving roles. Despite significant feelings of uneasiness in knowing exactly how to care for their child, some parents said that they were much more comfortable with the information they were being provided one month after diagnosis. One father said,

> *"We know exactly what we can expect, and the expectations that we are likely to have are quite hopeful. So we are feeling much better than before." (P1.03.I1)*

However, his partner who primarily took their child to local hospital appointments described in a separate interview (that occurred within the same week) feeling very confused and anxious about waiting for minimal residual disease test results that would affect their child's treatment, and worried about the medications and side effects that would happen with their child starting a new block of treatment.

5.7 Parents' interactions with health professionals

As time on treatment continued, parents reported fewer interactions with healthcare professionals as clinic appointments were further apart and test results were not shared as frequently. One family said,

Mother: "We never get any results. We never know. We go every three months for a lumbar puncture, and they just say, 'Oh she's fine, if there's anything, we will let you know.' But even if it's fine, we want to know." Father: "We want to know, just tell us, 'Yes, it's fine, we looked at this, we looked at that. And everything looks fine to us. So we continue with this until the next lumbar puncture." (P1.3.05.I4)

"There's a feeling that you're an old hand at this now and you know the drill'.
(P1.11&12.I2)

Community nurses featured highly, *"they never rush you, they always have time for you."* *(P1.09.I4).* Similarly, nurse specialists, encouraged parents to write their lists of questions, *"they explain everything I want explaining." (P1.09.I4)* Consistency in who parents saw clearly influenced perceptions, seeing a different doctor each time was often commented upon, a relationship with professionals and ongoing trust featured consistently in the positive stories from parents.

6. Discussion

Triadic communication is described in children's cancer care (Coyne et al., 2016). Absent in our current study is the active voice of children. What we have offered however, are insights from the perspective of the two other roles in this communication liaison, namely parents and healthcare professionals.

Although many parents reported satisfaction with almost all of the information they had received, it appeared as if they only retrospectively realised that they were allowed to have preferences about what should be discussed and how information should be shared. They preferred face-to-face conversations over leaflets whilst at the hospital because they could gain information about their child specifically. Meetings with their child's medical consultant were very infrequent, yet parents valued these times and wanted more opportunities later on in treatment, not just at diagnosis and then again shortly afterwards: so that families can navigate the experience of care through education (Landier et al., 2016). They also wanted to

privately receive information at a time before their child so that they could deal with the emotional aspects. Parents saw themselves as being responsible for gathering, assimilating, and sharing information with their child and others: sometimes they felt inadequately prepared for the level of responsibility they were charged with and in the majority parents were not offered assistance on how they could communicate the diagnosis to their child. Transition from a parent of a healthy child to 'becoming a parent of a child with cancer' (Darcy et al., 2014, Young et al., 2002, p. 1837), conveys new responsibilities and roles, one of which is to understand about the disease and to know what to expect. The intensity and agony of this early period following a cancer diagnosis has been well documented (Clarke-Steffen, 1993), with parents describing 'losing their foothold' (Bjork et al., 2005, p.269), and others talking about 'a rollercoaster ride, ……accompanied by feelings of shock, fear, uncertainty, lack of knowledge about and experience with childhood cancer' (Bally et al., 2014, p. 366). Parents come new to this role, they are obliged to learn a completely new language when their child is diagnosed (McGrath et al., 2007), they become what has been described as 'lay experts' (Lozowski et al., 1994).

Professionals, particularly early on in a child's diagnosis, decide on the information to be exchanged, when, how, how much they share, or hide and save till later. There were assumptions made about which roles were providing particular kinds of information, for example, doctors primarily focussed on the disease and treatment, nurses focussed on care and side effects – both with parents - whilst health play specialists talked with children. Although these roles were understood by the various professionals, no obvious accountability left potential gaps in information provided to the parent and child. Information was protocolised, particularly in the 'diagnosis talk', and this established a pattern for all future conversations, thus parents learnt very quickly 'medical parlance' to aid exchange of information and to assist them in their carer role. Key ingredients for successful information exchange are thought to include health professionals being honest and sensitive, aware of parents' information overload, and understanding of the shock and denial that may come with a diagnosis (McGrath et al., 2007). Understanding family preferences is also key, where parental information sharing practice is not fixed, where facilitating and restricting information and preferences shift depending on the situation and health status of their child (Coyne et al., 2016). Tensions arise when healthcare professionals are unaware of these preferences, clearly shared goals are essential and need to be acknowledged across all parts of the cancer journey (Bluebond-Langner et al., 2017).

Uncertainty Management Theory (UMT) (Rains and Tukachinsky, 2015) offers one possible explanation for understanding the communication processes that we have described here (Figure 4). For most parents in our study they actively sought information that helped them to manage their own uncertainty. Information from healthcare professionals was crucial, if there was any perception about possible gaps and continuing uncertainty, then the internet was searched for additional information, and parents described not being satisfied with the information received. Information provided by healthcare professionals appeared to be 'protocolised', with very few allowances made for clarifying parents' information needs, resulting in a possible mismatch between parental uncertainty and the information provided by healthcare professionals. Considered in the context of Meleis's (2010) middle range transition theory, we might suggest that parental foreground (seeking information directly) and background (passive actors) roles are the result of differing levels of uncertainty, and depend on the situation and preferences, child and family need that may present differently over time in different contexts. Also, helpful in our explanation we refer to a new paradigm for clinical communication that makes its starting point the role that mortal illness gives patients' (in this case parents) and clinicians would emphasise patients' vulnerability and clinicians' goal directed expertise (Salmon and Young, 2017). Through continuing to research we might begin to examine more closely these two roles and describe better communication goals and outcomes.

6.1. Limitations

Our focus was on what is communicated, and when, as well as how and to what effect. However, our data were mainly retrospective reports. Future studies would benefit by including observational methods to capture fully the context and uncover the socialisation processes that parents, children and healthcare professionals encounter in the process of communicating. The mix of data collection methods with a range of participants was both a strength and limitation; strength in that it enabled participation, limitation in that we heard from multiple voices, some more dominant than others as accounted here. The online forum, introduced to facilitate data collection with those thought difficult to reach, such as fathers, was our least successful mode of data collection.

7. Conclusion and implications for practice

Our research team has a programme dedicated to improving communication in children's

cancer care, to improve timely access to high quality information for parents and their children. In this study we have examined the role of parents and healthcare professionals in clinical communication. Similar to others we have described the often 'mismatched' communication encounters where those seeking information and those providing information have different goals. One participant (HCP) in the encounter has expertise at the outset, the other (the parent) has no expertise, but this expertise grows over time and this can increase the perceptions of this 'mismatch' and create different challenges. We have described elsewhere the central role of parents in communicating complex information to their child (reference removed for anonimity), what we have described here are some of the challenges parents face in gathering this knowledge, and struggling with how best to prepare their child when they were often trying to manage their own anxieties and uncertainties. Our work contributes to the emerging consensus that communication is more than a core set of skills that a HCP just needs to learn (Salmon and Young, 2011): clear specifications of mutual roles, responsibilities and a shared understanding of goals are also essential elements of effective communication.

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Table 1: Summary of sample, sample size and data collection methods

Group	Sample	Number approached	n	Data collection method	Sample in each data collection method
P1	Parents	14	12	Interview at 3-4 time points	12 (who took part in 26 interviews)
P2	Parents	22	16	Online forum discussion	3
				Interview	13
HCP1	Health professionals	12	11	Individual interview	11
HCP2	Nurses	84	15	Online forum discussion	3
				Individual interview	5
				Focus group	7
SCH	Health professionals in shared care hospitals	11	8	Individual interview	8

P1: parent group 1
P2: parent group 2
HCP1: healthcare professional group 1
HCP2: healthcare professional group 2
SCH: shared care hospital healthcare professionals

Box 1: Interview questions with parent group one at first and second interview

1. Can you tell me the story about how your child was diagnosed with leukaemia?
2. When did you first start to think about how you would explain this to your child?
3. Who did you talk to about how you might do this?
4. Was there any person that was particularly helpful at this time?
5. What did (s)he do that was specifically helpful?
6. Who decided who would tell your child?
7. Did you think about who was the right person to do this?
8. Were there any books or leaflets that helped you?
9. What role did other parents in the ward play?
10. What was the hardest part about telling your child their diagnosis?

Figure 1: Interview guide at first and second interview with parent group one

What was the easiest to explain, and why?

What was the hardest to explain, and why?
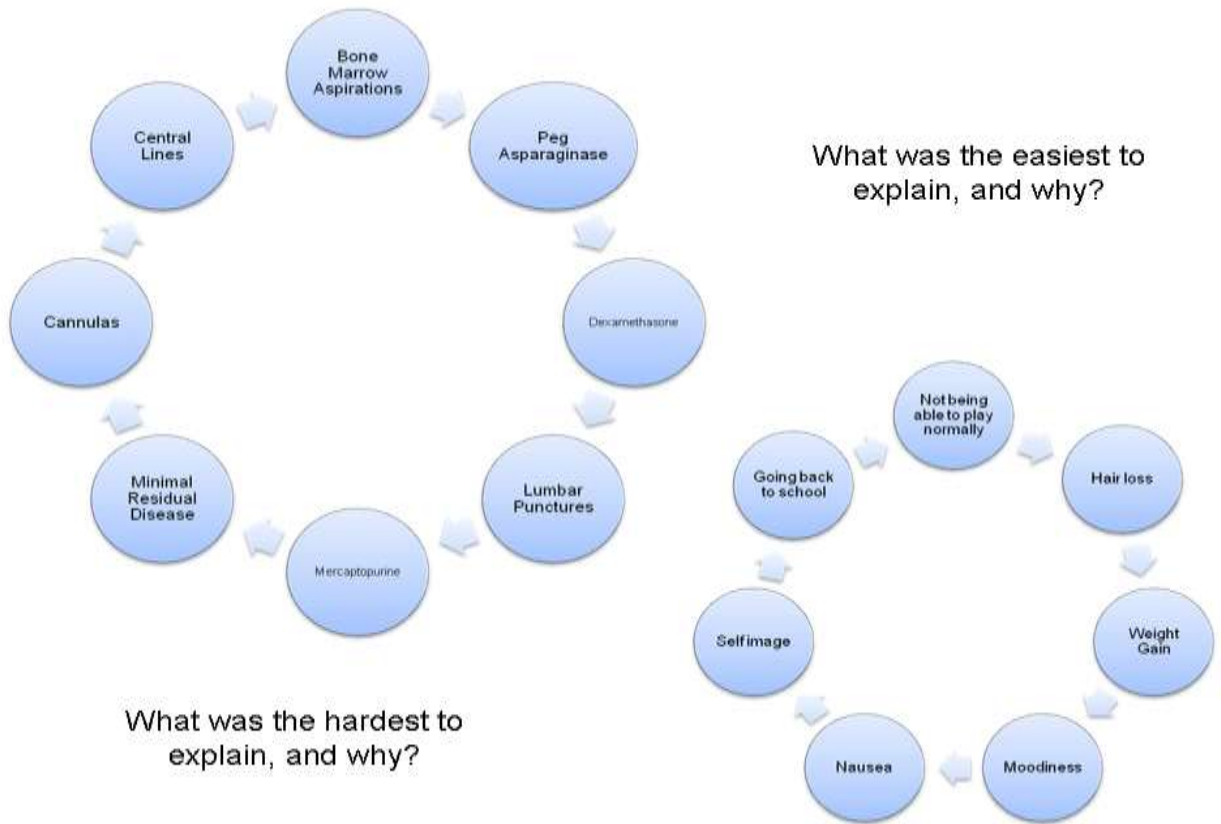
Box 2: Interview questions related to diagnosis with healthcare professional group one

1. Can you describe how you are involved in communicating diagnoses to parents (and children)?
2. How is "what is going to be said to parents" discussed among professionals before and after diagnosis has been told? How do you become involved in discussions?
3. How were you involved in discussions with Mum/dad?
4. What do you consider most important (in regard to communication) about relaying to parents about diagnosis? What do you say or do to be helpful to parents at this time? How do you decide what is "best" for each family?
5. What role do you play in helping parents tell their child about the diagnosis?
6. IF NO ROLE- Who may do this on the ward? What does this person do? How do you know? How does ethnicity influence your communication style?
7. In what ways do you facilitate a supportive network between families?
8. Which books or leaflets do you refer to most often *for your own information*? Which books or leaflets do you refer to most *in conversations with families*? Which books or leaflets do you *suggest to parents for themselves* most often? Which books or leaflets do you *suggest to parents for their children* most often?
9. What is the hardest part about being involved in communicating a diagnosis to a parent? Child?

Figure 2 Steps in data analysis

Stage 1

We examined relevant literature surrounding parents' and children's information preferences, theoretical understandings about the communication roles parents take on after their child is diagnosed with cancer, conceptual theory about children's roles in communication, and research in the communication roles of health professionals play in children's cancer care.
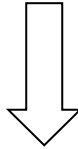
Stage 2

We asked ourselves 'sensitising questions' about the basic social psychological processes of parents, children, and extended families such as the worry and uncertainty caused by a diagnosis and individual prognosis of the child, and a lack of knowledge of ALL.

Stage 3

Two researchers (SK,GB) read each transcript line by line and discussed their initial impressions and the key themes that should be further explored (i.e. open coding).
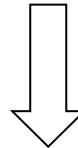
Stage 4

A group of four researchers from the team (FG,GB,SK,MH) then generated 'axial codes' from the open codes by moving our basic into high-level concepts and looked at their relationships with other concepts. In order to develop the codes, the researchers met several times for analysis meetings. The open and axial codes were shared with a further members of the research team (SA,LF) for their input on two occasions. New codes emerged as others were taken out as they appeared to not have sufficient evidence in the data.
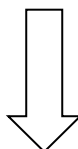
Stage 5

Three researchers from the team (FG,MH,SK) used analytical tools throughout the coding phases to create an understanding of the dimensions and properties of categories of each concept and recorded analysis via memos, visual maps, and diagrams of the coding developments. Visual maps and memos were drawn during analysis meetings, and then recreated using NVivo 8 and re-examined at following analysis meetings.

Figure 3 Process of analysis: 'protocolisation' as an example case

you can be fairly confident about what people have been told, you still need to play your way in and ask what information they've already been given about certain things and then take it from there

Erm, generally I don't go and speak to the parents until I know that one of the doctors has gone and talked to them and mentioned that they've having lines put in. Erm, and that's, everybody knows all of the ALLs unless they're high count, will have their line put around day 28. So it's just something that we have negotiated with the doctors, that they tell us when they've mentioned lines, and then, as I said, I normally go and see them around day four or day five once they know about the lines...

Because we see so many of it, we don't normally need to discuss what needs to be said to parents, because it's all pretty standard now. It's all, the information that gets given is exactly the same. The only slight difference is, I guess, we don't discuss what gets told because I mean, how we tend to operate is, we are completely honest with parents, we don't hold anything back.

I don't remember specifics because we've got so many children, like this week we had three. Erm, we have so many children, I won't remember specifics, but my approach is the same with all of them.

Some of the information becomes quite standard quite soon, because they are, they just erm, things we do very, very often. Some tests, especially some blood tests. So they become confident quite soon and they don't ask any more information.

Assumptions between HP's about roles

Individual info-giving best approach

No guidance on communication

Standardisation of communication linked to medical treatment

Parents as patients

No individualised information

Parent learning about treatment

Individualism as individual approach

Communication roles linked to treatment protocol

Lack of guidance re: communication = confusion

Communication is disease specific

Medical disease and treatment define communication

Lack of formal guidance leads to individual approaches

Protocolisation

Open coding

Axial coding

Original expressions | Empirical codes | Substantive codes | Subcategories | Categories
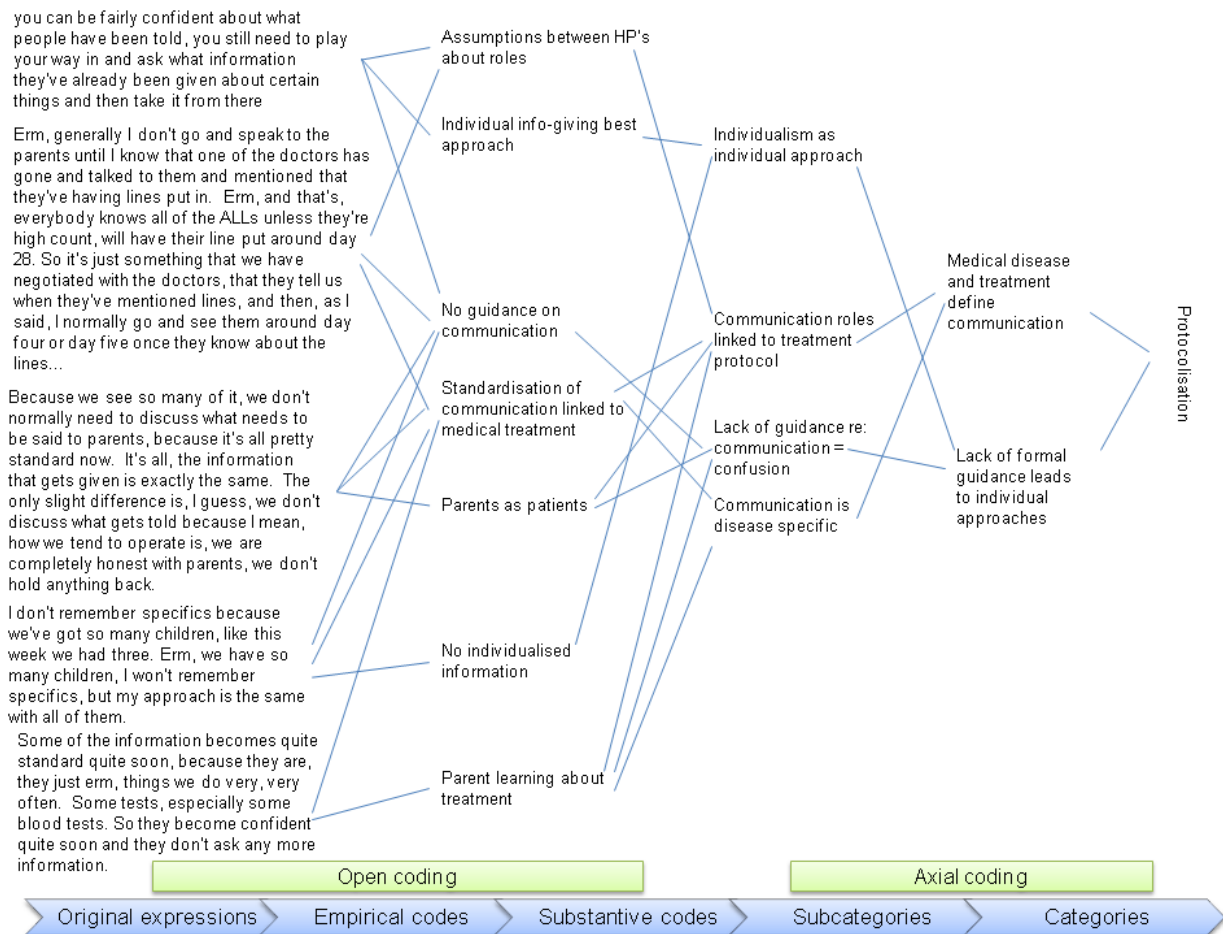
Figure 4 Best match for successful communication in children's cancer care

Mismatching occurs when:
- Information is routinized
- Complex information not revisited
- Impacts future communication
- Limits success of future relationships
- Leaflets are given too early
- Over-reliance on leaflets

Mismatching occurs

Matching occurs

Matching occurs when:
- Information is individualised
- Complex information is readdressed
- Informed consent is consistent
- Sets up future communication & successful relationships