ABSTRACT

This article presents the initial findings on informational issues from a recent longitudinal study that examined the psycho-social issues associated with the treatment of paediatric Acute Lymphoblastic Leukaemia (ALL). The treatment experience from the perspective of the child, their parents and well siblings was documented through qualitative research using open-ended interviews with the child patients, their parents and well siblings at key points in the treatment trajectory, including the first point (End of Induction Remission) which is presented here. Adequate information is vital in enabling parents to cope with the demands of treatment and to engage in the necessary planning for the maintenance of family life. However, parents differ greatly as regards the amount of information they require. The findings strongly indicate that the “language” of leukaemia treatment is complicated and challenging, even to those with a health professional background. Parents initially feel overwhelmed, especially as the learning will be taking place at a time when they are in shock and many are disorientated from the necessity of having to relocate for specialist treatment. Parents will be involved in a steep learning curve and will manage to comprehend significant concepts and information relating to diagnosis, treatment and prognosis. This understanding will develop from the written information provided by the hospital, conversations with health professionals during the daily care of their child, from other parents and, for some, the Internet. Some parents will cope by gathering a great deal of information to deepen their understanding and others will assimilate information gradually according to the immediate needs of the treatment situation. Parents in the study indicated that there were key therapeutic ingredients that assisted in the process of being informed, including: honesty; timing of information; sensitivity to the individual informational need to seek or limit material; an awareness of the possibility of information overload; and an understanding of the emotions of shock and denial.

INTRODUCTION

Accounting for around a third of all childhood cancer, leukaemia is the commonest form of cancer in children with Acute Lymphoblastic Leukaemia (ALL) being the most prevalent.1 With the ongoing development of effective...
chemotherapy, in recent decades there has been a dramatic improvement in the prognosis of children with leukaemia. Survival rate for children with ALL are now exceptionally high with 80 per cent of children surviving the first five years and those in the early age groups (from one to four years) with the most favourable prognosis. However, although the success rate is high, this benefit is achieved through an invasive and very arduous treatment process. Treatment protocols require ongoing chemotherapy (induction; first intensification; CNS-directed therapy; second intensification; third intensification; and continuing treatment). Extending over two years, these treatments necessitate that children spend lengthy times in hospital. This experience not only affects the child patient but the whole family. Therefore, it is important that the families coping with paediatric ALL receive as much support as possible in their efforts to cope with the demands of treatment. Receiving adequate information to plan family life, understand the disease and its treatments and adjust to the significance of the diagnosis is essential.

To date, there has been scant empirical data published on the informational concerns and needs of families coping with paediatric ALL. In the literature on adult haematological malignancies there is work suggesting that because of the serious, life-threatening nature of the diseases, patients do not perceive the possibility of choice in relation to informed consent to treatment. The situation with regards to information-giving and in relation to treatment for paediatric leukaemia has not been well documented. This article presents initial findings from a recent longitudinal study on families coping with childhood ALL. The findings focus on these important informational issues.

THE RESEARCH

The material in this article has been gathered from the first stage of a five year longitudinal study that examined the psycho-social issues associated with the treatment of paediatric ALL. This study explored the experience of paediatric ALL treatment from the perspective of the child, their parents and well siblings. This multi-disciplinary study was conducted by a psycho-social researcher in association with research clinicians from the collaborating hospitals. Parents were told of the study by the social worker on the hospital wards and were referred to the study’s research assistant for enrolment if interested. Participants were verbally informed of their research rights, and written consent was obtained for participation in the research. Parents provided consent for both the child patient and the siblings, unless the child was over the age of eight years, in which case the child’s consent was also sought.

Target Population

The research accrued consecutive patients, aged from birth to sixteen years, who had been diagnosed with ALL. Parents and siblings of these children were approached in regards to participation in the research during the initial stage of treatment. Overall, 62 families were involved in this study over five years. Of the initial 13 families approached, only one declined, giving a response rate of 92 per cent. The findings presented here cover interviews with parents of the first 12 ALL children who were enrolled during the first year of the study.

Demographics

The child patients in respect of whom the following findings refer ranged in age from nine months to ten years and males predominated (seven males to five female patients participated). All were diagnosed with ALL or a hybrid: eight ALL patients; two ALL/T Cell Lymphoma patients; one patient with Infant ALL and one patient with ALL/Philadelphia chromosome. Eleven of the patients were on the ANZCCSG study VII protocol (seven in the standard risk group; four in the high risk group) and one was on MRC UKALL Infant 1 Protocol.

All of the patients were from two parent families. All twelve of the patients’ mothers and four of the fathers participated. The age range of the parents was from 28 to 44 years. With the exception of three, all parents had other dependents that ranged in age from newborn to 20 years. Eighty percent of the families had one of the partners in full-time employment. Nine of the families had to relocate from their home town to the metropolitan area for treatment. Seven of the mothers ceased employment at the point of diagnosis because of the demands of relocation.

Methodology

The treatment experience was documented through qualitative research using open-ended interviews with the child patients, their parents and well siblings at key points in the treatment trajectory (T1: End of Induction Remission; T2: End of Reconsolidation; T3: Continuation Therapy; T4: End of Treatment Assessment; T5: Post Treatment).

The findings presented in this article of the first 12 interviews with the parents of the paediatric ALL patients are taken from T1: End of Induction Remission. The following discussion of methodology will outline the methodology specific to these interviews only. The interviews were conducted by a psycho-social researcher with a counselling background and many years experience...
working with families coping with a member with a haematological malignancy. The time and location of the interviews were chosen by the participants. The interviews were open-ended and focused on the experience of treatment as it impacted on all family members. Participants were encouraged to tell their story from the point of pre-diagnostic symptomatology up to the experience with treatment at the time of the interview.

Qualitative analysis is based on the principle of saturation of data, that is, common or reliable themes emerge when a number of participants say the same thing. By the time of the third or fourth interview it became obvious that parents were reporting very similar issues. However, as this was a longitudinal study the opportunity was afforded of following up with consecutive enrolments throughout the first year to affirm the original themes. Consequently, by the 12th interview a high level of confidence was achieved regarding the importance and relevance of the informational issues to the families involved.

The interviews were audio-recorded and transcribed verbatim. The language texts were then entered into the QSR NUD*IST (Non-numerical Unstructured Data Indexing Searching and Theorizing) computer program and analysed thematically. A phenomenological approach was taken to data collection and analysis. The aim of phenomenology is to describe particular phenomena, or the appearance of things, as lived experience. The process is inductive and descriptive and seeks to record experiences from the viewpoint of the individual who had them, without imposing a specific theoretical or conceptual framework on the study prior to collecting data. All of the participants' comments were coded into free nodes, which were then organised under thematic headings. Sixteen of the free nodes related directly to the parents' perspectives on informational issues, and the analysis of these are presented here.

**FINDINGS**

**Being told the diagnosis**

There were indications that parents first learnt of the diagnosis from situational clues rather than from the exact words used by the doctor. A pre-diagnosis example is when a parent guessed it was leukaemia because, "the doctor just cancelled the rest of his appointments and actually took us across [to the specialist]". An example of such a clue at the point of diagnosis was an approach from the doctor followed by the statement to the child: "I want to steal your mummy away for a moment". Body language was seen as important for clues, as one parent explained: "I subconsciously checked her body language and knew it wasn't going to be good". During testing at the hospital, it was noted that, as the child was "...in a ward with kids with bald heads", most had some idea of the seriousness of their condition even before the diagnosis was given.

Parents spoke appreciatively of the effort the doctors made in sensitively handling the information on the diagnosis. Important positive aspects of the experience included: the privacy of a consultation room; clear and honest information giving; the opportunity for the parent and doctor to jointly share in telling the child; being given space to regain composure after being told; and having the opportunity to immediately telephone a close family relative for support. Honesty was seen as very significant, with descriptions provided such as: "the doctors are very open; they don't hide anything from you".

This was noted to be an emotionally difficult time; for some, "...it hits you... and your heart just sort of sinks onto the floor". Others found it difficult to process, making statements such as: "[y]ou are not taking it in properly because you're not actually hearing... you sort of don't take a lot of it in". Detailed discussions on the diagnosis, using medical terms, were difficult to follow. Even with sensitive communication the parents indicated that they felt lost and on their own. Although parents were reassured by the success rate with ALL, most went into shock from the seriousness of the situation. Parents expressed attitudes about leukaemia that associated the disease with "frail" children and "cancer and death". There was a pervading sense of uncertainty associated with the prognosis, as one parent stated: "...in the end of it all they can't really guarantee that we are going to have the child forever". Only two parents made references to their child's reaction to the diagnosis. In both situations the parents noted calmness on the part of the child.

**Parents Understanding of Medical Information**

Treatment for leukaemia was described as a complex and challenging area to understand. The words used were described as a "new language". One parent explained that it was difficult; that it is not possible to simplify the knowledge, "...you have got to call it by the names that they call it so you know what everyone is talking about". There were descriptions of parents struggling with the "big words" and reading the booklets but not "remembering half of it". One parent stated: "[t]hey expect you to know too much". The parents' lack of familiarity with the medical jargon created a significant communication hurdle in their discussions with the experienced health professionals. There was a discrepancy in both the parents' understanding of the
treatment and their desire for detailed knowledge. However, it was at this stage that the parents noted that they were slowly beginning to understand.

There were statements indicating that many parents understood concepts such as cell classification, DNA and genetic screening and the importance of the Philadelphia chromosome. Some, however, did not, making statements such as: "I'm a novice as far as this sort of thing goes...".

Included in the sample were parents with a health care background, and even these parents noted difficulty with the area. One of the reasons for this was that paediatric oncology language was seen as quite specialised; another reason was the shock and emotional strain, as one participant with a health professional background indicated: "I've shut down for the moment...".

Parents used the information they were provided with to formulate a general understanding of the child's prognosis, with examples provided including: "[the child] is the right age, the right sex and everything is in our favour"; or: "[the child's] gender... is a bonus, so we believe she will be in the 70 per cent that survive". However, the fear of uncertainty usually accompanies statements about prognosis, such as: "...but then I'm sure every other parent does [hope for a good prognosis] too, and 30 per cent don't survive". The parents all had a sound understanding of the length of the treatment. There was an understanding of the notion of remission and an appropriate appreciation of the fact that children can relapse or "fall out of their remission".

In relation to the treatment protocol, some parents stated that difficulties in mastering an understanding were created because of constant changes to the exact treatment schedule. Even though the parent had a general outline, no specific dates were given, so the parent was unsure of when the treatment would occur. It was noted that appearing competent in the face of such complexity was important, as the parent wanted to appear to know what they were talking about. Even this proved difficult because, as one parent stated: "...when they say chemo, it doesn't mean [the parent] will know exactly which drug".

All parents understood and spoke at length about the child’s vulnerability to infection because of the low white blood cell counts. One parent explained: "If the child's levels are low, they can get an infection and it really can cause big problems, because they have no immune system. They can't fight any of that [infection]". This understanding created anxiety in parents, who spoke of: "doing what [the hospital] tell us to do, take [the child's] temperature, keep everything clean, keep away from measles and from kids who have colds".

Causal links were postulated throughout the discussion to explain the side effects the children were experiencing. Parents correctly explained that mouth ulcers, loss of hair and stomach upset, for example, were directly attributable to the toxic effects of the drugs. Some appropriately simplified medical knowledge, for example, with regards to cytotoxins: "...it's like poison in their system and at the beginning it's hard for them to adjust to that poison in their system so they get sick". Other explanations were more intuitive guesses, for example, a severe rash was seen to be caused by a child’s lack of previous experience with antibiotics; it was noted that blood transfusions make the child’s body “lazy” in blood cell production.

By the time of the interview parents had been exposed to an intense learning experience in haematology and many spoke with confidence about procedures such as the function and care of central lines and port-a-caths, and the “gas” used for anaesthesia in preparation for lumbar puncture. Parents also referred to the names of the drugs used in treatment.

Parents followed test results keenly and used them to interpret the child’s progress through the treatment. In particular, parents enthusiastically followed the results of cell counts from blood samples, making statements such as, "[the child's] red cells have stayed up, and [the child's] white cells have stayed up... [the child] is reacting very well to the treatment". Waiting for and gaining the information from test results were seen as anxiety provoking and stressful. Being told test results as quickly as possible was stated as very important to parents.

It was noted that parents used their understanding of the medical process to be vigilant about the child’s treatment and occasionally this meant acting to correct mistakes. In providing such examples, parents qualified their statements by noting that the observations were not a criticism of the hospital staff. It was noted that parents could easily feel “intimidated” in the hospital situation, but when parents did not speak up, when they observed something inappropriate happening, they had regrets, because the child suffered and the parent, "...ended up saying something in the end [that they] should have said at the time".

Special Issues for Parents with a Health Professional Background

There were participants in the study who had a background as a health professional. The details of the exact professional group have not been provided to ensure anonymity and
confidentiality. Specific issues were recorded for this subgroup of parents. In the early stages of diagnosis the parents with a health professional background made statements indicating that their knowledge base did help them recognise the signs of leukaemia early and have the confidence to pursue the diagnosis. One used professional contacts to accelerate the process of referral. It was stated that if a parent was a health professional, treating staff from the same profession “sort of picked up their act”. Although the positive side of this is that such parents are not “patronised”, there is also the problem of knowing that their presence can be challenging for the hospital staff. Such parents spoke about how: “[b]efore saying I’m concerned about anything I need to first of all think how the staff will take this and run with it and possibly over investigate”. There were additional challenges for these parents, such as that their knowledge made it harder to: “… stand back and not question”, and the possibility that their professional background could “rub people the wrong way”. This was a possibility; in spite of the fact that parents were taking all necessary precautions to ensure that they did not make anyone feel uncomfortable.

In the hospital setting it is possible for the parent to feel vulnerable to the power imbalance in the situation as the care of their child totally depends on the co-operation of the hospital staff. Mentioned was the fact that: “[u]ntil you actually have your own child go through it”, it might be difficult for staff to understand the experience from the parent’s perspective.

Information helps

There were considerable variations in the parents’ need for information. Eight of the parents made clear statements that the provision of detailed information is of assistance to them, such as: “[w]e very early on established with the staff that we were intelligent and capable of understanding what was going on and if we could have some literature”. These parents saw themselves as information seekers, with descriptions provided such as: “I’m a person that’s got to have the information and what’s happening... so I can make it right in my mind as to what is going to happen”. The provision of “significant information regularly” was considered important to these parents. The provision of information was seen as an important element in maintaining trust in the health professionals.

The written information on protocol was described as important for organising time and planning for the future. Particularly interesting to some parents was information on when they would be able to return home. As one parent stated: “… if we do get to go home... how long we go home for and when do we come back… and how long do we come back for this next one?”

The Going Home booklet (prepared by the hospital) which gives parents information on handling their child’s medical condition at home, was considered useful, but disappointingly named for parents who had relocated and could not actually return home. The fliers on specific drugs used were also considered of assistance.

There were indications that for some parents sufficient information was not available. Parents indicated that they had to be assertive with the doctors to obtain information. Some parents emphasised that they felt capable of absorbing the information. There were also indications that some parents would like more information on what the health professionals were looking for when they ran certain medical procedures and what are considered good outcomes for lumbar punctures and bone marrow aspirations. The suggestion was made that a liaison person, who the parents could turn to when they felt the need to discuss information, would be most helpful.

Parents appreciated the high demands on the health professionals within the busy hospital environment. Because of this “busy-ness” it was also noted that the hospital quickly communicated bad news, but “good news becomes a low priority because they are so busy doing other things”. Consequently, parents relied on situational clues for information, as can be seen in the comment: “[w]e assumed that because nobody had woken us up in the middle of the night for a treatment that everything is okay”. Another situational clue was the ordering of tests. As parents were not always familiar with the rationale for different tests, they made assumptions when the hospital started ordering more tests. As one parent explained: “[w]hen [the doctor] came back to the ward and said we have to run more tests you automatically think, ‘oh my god, that sounds worrying’”.

The need to limit information

Some parents found the written material too threatening, as one participant humorously noted about a partner’s refusal to read the protocol information: “[i]t was as if it was going to bite”. These participants spoke of their emotional difficulty in processing information: “I kept saying I want to know more, I must try to get a handle on this information, but I shut down the minute I try to look at it, I’m just not ready for it”. Much of the information on the child’s condition can be very challenging for the parent to cope with and can be a source of considerable anxiety, especially in regards to side effects of treatment. Relapse was noted as another emotionally difficult issue, as one parent stated:
You don't want to read that once in remission if you have recurrence our chances of complete recovery are significantly reduced... I wish I had never read that, you know, because now I am a little bit more uptight than I was.

The indications are that a desire to limit information is a situational, not personality-driven, dynamic, as some parents start out wanting a lot of information and then retreat. As one parent explained the process: “I had sufficient given to me from the start and then I wanted more. And the more I read the less I wanted”. It was considered better to deal with the information that was required for each situation. Appropriate timing of materials from health professionals was seen as important in assisting parents to cope. For example, in relation to learning information on relapse, one parent stated: “[i]f our child had gone through this and relapsed we would have asked anyway, but we just got the information earlier than we probably wanted it”.

A distinction was made between the information handed out at the hospital and the wider information available on the Internet. The information from the hospital was seen as easier to cope with, as the following statement demonstrates:

I guess there is a lot more emphasis on risk in the wider literature than there is in the information that they give the parents and that was just a little bit too hard to handle. It’s not that I’m denying risk; it’s just that I don’t want to hear about it all.

The information on protocols, although useful, was seen as challenging for some parents as it confronted them with “the long road ahead”.

Particular mention was made of the information overload in the first few weeks of treatment and the difficulties in processing all that information at once. It was stated that it was important to break the story up into understandable pieces of information, because as one parent stated: “I think if they started to tell you the whole story you would be going ‘ohhhhh! I can understand why they only told you a phase at a time”. The need for information changes over time and the giving of relevant information at the right time was considered to make it much easier to deal with.

There were indications that parents had information they didn’t need. When parents were experiencing information overload they either retreated from the information or coped by using strategies such as: “[j]ust taking each bit they give at a time and think about that bit, and then the next bit, and just don’t worry”. Some parents were ambivalent about the usefulness of written material on the side effects because of the uncertainty of how their individual child would react to the treatment, as one parent explained:

You read all the information about this could happen and that could happen, but like then [my child] was perfectly fine. Which was great, thank goodness, but you never know, like next time [the child] might have all [of the side effects].

Sources of information

Parents spoke of the different sources of information available, such as written material, discussions with health professionals and conversations with other parents. Many found it easier to assimilate the information at the point of actual experience. Nurses were seen to play a particularly important role in this process as they were around most of the time. Reference was made to particular nurses who “made it particularly easy to understand”. Some parents wouldn’t look at written material because they “listened” and learnt that way. Parents talked of intense situations where they had to learn very quickly, such as in Intensive Care Units, where in a short number of hours they could read all the machines.

Written material was seen as important for back-up references. Even where some parents preferred “verbal information”, they indicated a place for written material, especially in regards to complicated words where the sheet literature given to them could be used to “… slowly take it in and do summaries and go through it bits at a time”. Some parents did access the Internet, particularly in the early stages, but for some this produced information that was too threatening, too quickly.

Other parents were also an important source of information. As one participant stated: “[y]ou sort of pick up general knowledge in the outpatient clinic where mothers talk”. Parents were aware that in absorbing knowledge from these conversations, it was important to keep in mind that “[a]ll kids are different… it all depends on the individual child”. It was stated that parents can sometimes gain satisfaction from sharing information that helps other parents. The children also gather information from other families on the ward, as can be seen by the comment: “[the child] is always inquisitive so she always asks before I do, I always find out through her”.

Because a great deal of information is gained in the hospital context, the parent at the hospital is an important source of information for the stay-at-home partner or the family. It was noted that there are particular problems for the parent who has to stay at home and hence is away from the
information flow. As one parent stated:

There is a lack of information there [at home], even though [my partner] is only a phone call away there is a lack of information. I sit there staring at my ceiling at home saying I can’t do anything. What am I doing here?

This can also be a problem for other family members who do not have access to what is going on at the hospital, as one participant stated: “[t]hey [the family at home] need to know that [the child patient] is okay because they can’t see her and they know all about the nasty treatment and they need to know that physically she is okay”.

Because of the seriousness of the situation parents did have anxieties about coping medically and expressed appreciation for the fact that “the doctors are only a phone call away if you do query anything”.

Learning curve

It was clearly noted that parents were on a steep learning curve in relation to understanding the information related to ALL and its treatment. Parents indicated that: “[w]e get to know what they’re saying… now I know a lot along the lines of what sicknesses and what levels are”. The quick increase in knowledge was sometimes a surprise to those around them, as can be seen by the statement: “[b]y the time [relative] came back the next morning, [relative] was quite surprised at all this knowledge that I had. Like before this, Panadol was about the only thing in [my medical] vocabulary”.

DISCUSSION

Hearing the news that your child has the life-threatening condition of childhood ALL will be a substantial shock to parents and will need to be handled with considerable sensitivity. In fact, the stresses associated with the experience of treatment for childhood cancer are so severe that the concept of posttraumatic stress disorder is considered an effective conceptual model for studying that the concept of posttraumatic stress disorder is the experience of treatment for childhood cancer are so severe and denial.

Parents in the study indicated that there were key therapeutic ingredients that assisted in the process of being informed, including: honesty; timing of information; sensitivity to the individual informational need to seek or limit material; an awareness of the possibility of information overload; and an understanding of the emotions of shock and denial.

These findings strongly indicate that the “language” of leukaemia treatment is complicated and challenging, even to those who have a health professional background. Parents will initially feel overwhelmed, especially as the learning will be taking place at a time when they are in shock and many are disorientated from the necessity of having to relocate for specialist treatment.

The indications are that parents will be involved in a steep learning curve and will manage to comprehend significant concepts and information relating to diagnosis, treatment and prognosis. This understanding will develop from the written information provided by the hospital, conversations with health professionals during the daily care of their child, from other parents and, for some, the Internet. Some parents will cope by gathering a great deal of information to deepen their understanding and others will wish to assimilate information gradually according to the immediate needs of the treatment situation.

CONCLUSION

Adequate information is vital in enabling parents to cope with the demands of treatment and to engage in the necessary planning for the maintenance of family life. The insights provided by the parents in this study indicates that effective information-giving must be based on an understanding of the individual informational needs of parents, and sensitivity to the profoundly difficult life challenge that they face.

REFERENCES


