

‘Being in the same boat’: ethnographic insights into an adolescent cancer unit

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Abstract

Cancer may be considered a particularly challenging diagnosis for adolescents. Treatment for adolescents in the United Kingdom may be provided in paediatric or adult settings or, more rarely, in specialist adolescent cancer units. An ethnographic approach was adopted to gather ‘insiders’ views of one such unit using in-depth interviews with patients, parents and professionals, as well as non-participant observation of key events. Two data themes ‘cancer and the cancer unit’ and ‘changes over time’ are discussed in this paper. Benefits of the unit included shared understandings and the manner in which the privations of adolescent cancer were contained and managed by those involved.

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1. Introduction

The transition from childhood to adulthood is marked by a series of social and cultural rituals, such as experimenting with alcohol and sexual relationships, and testing the boundaries of parental and social authority. In embodied terms, adolescence is also characterised by an over-riding sense of ‘unfinishedness’; the young person is neither an adult nor a child, but is seeking to establish an identity in relation to their peer group and the wider social world (Lupton and Tulloch, 1998). Such factors require consideration in relation to the care needs of adolescents who face the disruption brought about by a diagnosis of cancer. Research into the adolescent cancer experience is needed to ensure that

appropriate services are provided for this unique patient group.

The complexity of the challenges facing adolescents with cancer should prompt health-care providers to question the adequacy of the services available. However, there is a lack of evidence, certainly in the UK context, concerning the needs of adolescents and the appropriateness of available services (Kelly et al., 2002; Hollis and Morgan, 2001).

For example, little attention has been paid to whether, or to what extent, specialist adolescent cancer units are more effective, or more acceptable, than general cancer care settings. Less than 10 specialist adolescent oncology units are currently established in the United Kingdom. They often rely on financial support being provided by dedicated adolescent cancer charities. Such developments have stemmed from a belief that it is inappropriate to provide care to adolescents in existing child or adult oncology settings. Those specialised care settings which do exist, whilst having the primary aim of improving standards of treatment, care and support,

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also offer the opportunity to examine the experience of adolescent cancer in more depth.

2. Adolescence and cancer

Cancer in adolescents is rare; it is estimated that there are about 600–800 new cases of teenage cancer diagnosed in the UK annually (Stiller, 1994; Souhami et al., 1996). Those cancers that do occur differ from those of younger children or adults making it also a specialist area of biomedical practice and research. For instance, there is a higher incidence of leukaemias, lymphomas, germ cell tumours, bone and soft tissue sarcomas, and brain and central nervous system tumours amongst adolescents. Although short-term prognosis is improving, and overall cure rates are now put at about 60% (Souhami et al., 1996). Cancer in adolescence has many of the characteristics of a chronic illness; long and sometimes aggressive periods of treatment are interspersed with remissions, cure or eventual decline as a result of the disease. Significant morbidity, as well as a number of longer-term side-effects, can occur as a result (Weekes and Kagan, 1994).

The emergence of adolescence as a recognised developmental stage between childhood and adulthood only emerged after the industrial revolution. It has since become embedded in cultural constructions of the lifecourse (Leonard et al., 1996). Adolescence is largely defined according to age. However, it is also characterised by embodied change, cognitive development and increasing social responsibility (Royal College of Nursing, 1994).

The accepted age range for adolescence varies widely in the literature. Lewis (1996) suggests that it can include individuals from 14 to 22 years. Even this, however, may vary by several years in either direction. Adolescence may be described as a complex developmental phase in the human lifespan which involved specific 'tasks', such as identity formation; the establishment of independence and autonomy; sexual, physical and emotional development, the building of self-esteem and an awareness of future opportunities through educational and vocational preparation (Lewis, 1996).

Adolescence is also perceived as a 'difficult time'; for the adolescent, their parents and other authority figures. Although a diagnosis of cancer can have devastating effects whenever it occurs, it may be acutely problematic during adolescence (Eiser, 1996). Maguire (1996) describes the extra burdens that may exist for the adolescent as a result of cancer, such as increased levels of uncertainty, lack of meaning, stigma, and social and emotional isolation. Adverse effects of treatment, such as the loss of body part or body function, are also common. Cancer disrupts social and emotional development, causing an increased dependence on parents,

and threatening future goals and alienation from healthy peers.

Although there is some literature on cancer and chronic illness in adolescents, it is only relatively recently that more wide ranging literature reviews (e.g. Ritchie, 1992; Whyte and Smith, 1997a, b) or empirical studies (e.g. Allen, 1997; Hinds and Martin, 1988) have been published. Interestingly, many psychological studies have focused on parents' perceptions in an attempt to explore the cancer experience in this age group (Maguire, 1996; Eiser, 1996).

Within the nursing literature, much of the research on adolescent cancer has concentrated on the concept of coping. Studies have focused on strategies to enhance adolescents' coping around the time of diagnosis (Allen, 1997; Neville, 1996). Others have investigated coping needs throughout the illness trajectory (Moore et al., 1969; Hinds and Martin, 1988). These studies suggest that adolescents may adopt a range of coping processes including adaptive denial. This emphasises 'normality' and a belief that everything will work out in the end (Neville, 1996). Following a large interview study, Hinds and Martin (1988) suggested four main coping stages: cognitive discomfort, distraction, cognitive comfort and personal competence. These appeared to assist the adolescent to remain hopeful in order to cope with their cancer. More recently, Hinds et al. (2000) evaluated a three-part educational intervention intended to facilitate coping using psychological and clinical outcome measures. Psychoanalytical explorations of adolescence are also available (Copley, 1993).

Survivorship has received more attention recently. The focus in this work includes the end of treatment phase (Weekes and Kagan, 1994); the impact of cancer on the developmental tasks of adolescents (Neville, 1999); and decision making in long-term cancer survivors (Hollen and Hobbie, 1993). Other work has focused on support and information as components of effective coping. This includes descriptions of support groups (Heiney et al 1990) and the examination of supportive care variables (Nichols, 1995). The importance of information giving for this patient group is also frequently highlighted. Tools have been developed to aid health professionals elicit the information and health needs of adolescents with cancer (Hooker, 1997; Whyte and Smith, 1997).

A limited body of work exists on the experiences and needs of parents and health care professionals in relation to adolescent cancer. Ball et al. (1996), for instance, explored the culture of childhood cancer care, and Hayout and Krulik (1999) have described the parental experiences of caring for a terminally ill adolescent.

The unmet needs of adolescents within hospital settings in the United Kingdom has been highlighted since the 1950s (Stuart-Clarke, 1953). Although there

has clearly been a focus on the development of appropriate children's services since the publication of the *Platt Report* (1959), few policy developments have been produced regarding the most appropriate care setting for adolescents. Short reports and guidelines include those by *The National Association for the Welfare of Children in Hospital* (1990) and the *Royal College of Nursing* (1994). However, *Viner and Keane* (1998) argue that the Department of Health's report on the *Welfare of Children and Young People* (Department of Health, 1991) was the first to consider seriously the need to develop specialist adolescent health services. This report stressed the impact that hospital admission can have on adolescents, and highlighted the need to provide adequate facilities with appropriately trained staff. After reviewing the evidence concerning the development of such services, *Viner and Keane* (1998) argue that, in reality, the commissioning rate remains low in the UK. They proceed to argue for the establishment of more generic adolescent inpatient units.

Against this background it was considered timely to conduct an empirical investigation into the adolescent cancer care experience by focusing on the first specialist unit to be established in the United Kingdom in the early 1990s. An in-depth ethnographic approach was adopted due to the exploratory nature of the work (*Kleinman, 1992*). The primary aim was to describe how this care setting itself was perceived from the perspective of those involved (*Mullhall et al., 2001*).

3. Methods

This project set out to provide insight into the experiences of adolescents, parents and professionals within the adolescent cancer unit of an inner London hospital. An ethnographic approach was employed to provide some description of the workings of this setting, whilst also allowing the issues that arose to be explored further during in-depth interviews (*Atkinson and Hammersley, 1994; Pawson and Tilley, 1997*). The researchers intended that adolescent cancer care would be better understood as well as providing information for those involved with the unit on which they could reflect (*Mullhall et al., 2001*).

Ethical approval for the study was first obtained from the Hospital Ethics committee. Data collection occurred over an 8-month period between June 1999 and January 2000. Interviews were conducted with 10 adolescents (six females, four males, age range 13–20 years), 10 parents (nine mothers, one father), and medical, nursing and 14 professional staff, including nurses, doctors, teachers, pharmacists and an activity coordinator. Each researcher assumed responsibility for interviewing all the

members of the same group of participants. Written and verbal consent was obtained prior to the interviews and observations. Parental agreement was sought for adolescents under the age of 16 who were then asked to provide assent.

Prior to periods of non-participant observation, notices explaining this aspect of the study were placed in prominent places throughout the unit. Discussions took place with the nurse in charge to ensure that we did not approach individuals to take part in interviews who might be feeling particularly unwell or whose condition was concerning. The same researcher assumed responsibility for non-participant observation to enhance consistency.

In addition, the researchers maintained a reflective diary throughout the study, which were later used to reflect on our personal responses to the study and the issues it had raised. Each data source was finally combined to enhance the authenticity of the findings through a process of triangulation (*Jick, 1983*).

The interviews lasted approximately 1 hour, were tape recorded (with the participant's permission) and then transcribed verbatim. Transcripts were returned to the professionals for any changes or deletions to be made. For practical reasons, this did not prove to be possible with all the patients or parents. Interviews were only loosely structured to allow participant to shape the topics covered (*Spradley, 1979*). Initial questions arose from initial observations of the unit, and were of the type:

Tell me how you came to be here? (Patients)

What's a typical day here like for you? (Parents)

What happens at the multidisciplinary team meeting—how do they go? (Staff).

Non-participant observation was initially used to capture a 'wide-angled' view of the unit and to reveal issues that the participants were asked to expand upon during the interviews (*Spradley, 1980*). Thereafter, observations focused on general activities on the unit over eight 3-h periods at different times of day—as well as from different vantagepoints on the unit. Finally, specific events were observed such as the multidisciplinary team meeting and medical rounds. Fieldnotes were either made at the time of observation or shortly afterwards.

4. Analysis

Data analysis involved each researcher first reading the transcripts of 'their' interviews to obtain an overall impression of the data. Significant statements were highlighted on a line-by-line basis, and clusters of these were grouped brought together as themes, and

over-riding these, data categories. For each group of participants (patients, parents and staff) data categories were mapped out to identify points of connection and overlap. These maps were then discussed and revisions made to the positioning of themes and data categories, such that a final map of data was obtained. As a further credibility check, the categories were presented to the staff of the unit for confirmation, revision and discussion. A detailed description of the methods and analysis was included in the research report to encourage readers to consider their authenticity (Kelly et al., 2000; Coffey and Atkinson, 1996)

Lastly, data from the observations and reflective diaries were combined with the emerging interview themes and categories. Six final data categories were produced which formed the basis of the ethnographic findings (Mullhall et al., 2001, 2004). A summary of these is included in Fig. 1. Two themes, *cancer and the cancer unit* and *changes over time*, are discussed in the remainder of this paper. Given the extensive nature of the data, the remaining themes will be presented elsewhere.

5. Cancer and the cancer unit

5.1. 'Cancer is not a label'

The fact that the unit was concerned solely with adolescent cancer emerged as highly significant. This theme incorporated the social image of cancer; how it felt to be the parent of a child with the disease; and the experiences of those who found themselves becoming part of a cancer unit.

Clearly, negative images of cancer had impacted on the adolescents and their families. However, the unit appeared to help people to cope with such attitudes. The benefits included the provision of a 'haven' from the rest of the world; essentially, cancer was the norm there. This allowed individuals to adapt, cope and find some meaning in their experiences. The various taboos and stigma that exist around cancer, as well as its vivid association with the body and medical treatments, also emerged as important concerns. Negative attitudes, such as the perception that everyone died from the disease, were compounded when parents first entered the unit

Data categories
Physical structure and facilities: although staff mentioned a lack of space, a physically small and quiet unit was perceived as beneficial by patients and families. Physical structures/facilities created an atmosphere that enhanced 'normality'.
The social context: the unit's relaxed nature and friendliness underpinned both parent's and patient's experiences. It felt 'Not like coming into hospital'. The unit's physical structure permitted rituals such as late wakening, open visiting and a non-uniform policy to enhance this atmosphere.
The family: the unit was described as being like a family itself. There was an emphasis on maintaining normal family routines, whilst managing the inevitable impact that cancer had on family relationships. Staff were viewed as being highly skilled in providing a supportive, therapeutic environment.
What it feels like over time: key points in the cancer experience (especially diagnosis, end of treatment and recurrence) were important. The challenges facing adolescents varied between coping with the cancer itself, managing the side effects of treatment and leaving the safety of the unit.
Cancer and the cancer unit: although the word cancer had negative connotations it was seen as a common bond; 'everyone was in the same boat'. There existed a shared sense of what cancer treatment involved and the expertise that was needed to deal with it.
Specialism and expertise: the availability of an expert team of professionals with an almost intuitive understanding of adolescent's needs was pivotal to creating a beneficial supportive environment. A relaxed and democratic style of working emerged from a shared understanding of adolescent cancer care and mutually respectful interprofessional working.

Fig. 1.

and realised what was to be found there. As one of the mothers said:

It's not something anyone wants...having to go there with your child.

Parents' preconceptions about cancer had both shaped their expectations and impacted on their initial impressions. Memories of the first visit were most vivid for those who had only recently encountered the unit for the first time. Fear was the emotion most frequently described by the parents. One mother dreaded this time as she had never before set foot in a hospital ward concerned with cancer. The following extract from the one of the researcher's diaries also reinforces the importance of initial impressions of the unit:

As a newcomer to the unit myself these first impressions were critical. Strange isn't it? I could hardly swallow my coffee, I had to take three deep breaths and I felt wobbly. And of course it was really easy. Very smiley friendly reception. I feel very welcomed. Reflection: If I am so scared of coming to the unit how do new patients and their families feel? Yet all it took was a friendly reception and a perception of a relaxed atmosphere to put me at my ease.

In addition, the level of activity on the unit fluctuated which meant that it could appear extremely busy to newcomers. As one member of staff said:

There are just so many people walking around I think even for a member of staff it gets overwhelming, so for people who come in new what on earth do they feel like?

One mother felt initially that she would have preferred the word cancer to be removed from the entrance sign. However, she also spoke of feeling safe and secure precisely because this was a specialist cancer unit. Having the word cancer in the title could also cause difficulties for professionals. This included answering the telephone to outside calls (for example, a relative or friend who might not have been told what the patient was being treated for), as well as for the adolescents themselves who may still be adjusting to their diagnosis. Otherwise, the word cancer was used freely by the majority of the parents when referring to the unit.

There was also consensus amongst the parents that it was important to acknowledge being on a cancer unit because:

The illness isn't a label.

It was normal practice for parents to share their experiences on the unit. Some found that it was a positive benefit as they could not do so in the outside world, even with their own family or friends. Disclosure

of experiences was also balanced by the need for parents to be aware of each others situation. For example, one of the mothers (whose daughter was dying) stated that her own story was too negative to share with other parents on the unit in any depth.

5.2. 'Being in the same boat'

All participants agreed that there were merits in caring for adolescents with cancer in one area. It was apparent that, in obvious and more subtle ways, adolescents and parents also supported each other. Some had experience of other hospitals prior to admission to the unit, whereas for others this was to be their first experience of ever being in hospital. A common perception of the unit was that it felt 'relaxed', and that a shared understanding existed from 'everyone being in the same boat'. The following statements from adolescents exemplify such sentiments:

You don't feel like an outcast, the only one with cancer and all the other people are, like normal. Yeah, it's good to see other people. I think if I had cancer and went to a private hospital I would be on my own all the time. I don't think that would be any good.

Since all the adolescents had cancer, those newly diagnosed met others who had already received a range of treatments. This seemed to be perceived positively:

When new people come in they like to see people further down the line, know what I mean?'

Staff also commented on this aspect of the unit's function:

They know what's going on with the others, so they must somehow interact. They know who they like and if there is a new person they all kind of quietly give their support.

Being together, however, could also create problems. These included being exposed to relapses and deaths on the unit. As one nurse said:

It is very difficult when patients don't do well, and other people ask and you have to say they have relapsed or died. They have got to get over their grief and think about how it is going to affect them if their disease is similar to the person who has died.

Similarly, another member of the nursing team suggested that the siting of single rooms at the entrance of the unit (where more seriously ill adolescents may be cared for) was less than satisfactory as they may be the first to be seen. Despite such reservations from the staff, this issue was not considered problematic by the patients themselves.

5.3. Treatment

The adolescents' discussions about cancer focused mainly on treatment experiences, especially, the problems faced during chemotherapy. Radiotherapy and surgery were discussed less frequently, perhaps because the side effects were less immediately disruptive.

Chemotherapy was referred to as a difficult experience that required considerable effort to endure. The majority spoke of it as 'arduous' or as a 'trial'. At best it was boring, at worst it led to sickness and debilitation. As one young man said:

Chemotherapy is a bit like having a hangover...some people find it easy and some don't...there is a lot of bile and the taste on your tongue is very metallic, and you smell because you generate sweat, ...retching, so sick, and then of course they say "Take your pills", you can't keep them down. They stick something in your line and you're out for the count.

Learning to cope with chemotherapy was explored with the patients further during the interviews. For some, sleep was the most beneficial option and being able to sleep late on the unit was welcomed:

Usually it depends' cos...err... usually it's not too bad but once you've had a whole day of chemo beforehand you tend not to get to sleep, you know with all those chemicals in you, it's quite a lot of liquid, so naturally you have to keep going to the loo. It's mainly a good sleep that you need when you are first put on it.

Suggestions were offered to improve the chemotherapy experience. These included having someone available to provide complimentary therapies such as aromatherapy or massage. A sense of privacy was also important. For those not in a single room, the advice from one patient was:

Just draw the curtains so no-one will bother you....

5.4. The body

From the observations of the unit it was clear that issues around the adolescent body with cancer—powerfully symbolised by baldness and amputated limbs—were also important. This was particularly striking on entering this clinical setting for the first time. As one mother said of her own first visit:

I didn't focus on anything except the children...it was all I could see.

Another told how she prepared her other children for their first visit by telling them:

There are a few sights here that are not pleasant.

Notes from one of the researchers' reflective diary underlined the importance of the adolescent body in shaping the first impressions of the cancer unit:

Two or three patients lying on their beds, their baldness is very striking. I know this is a common side effect, yet it still startled me—it seemed the 'centre' of how I saw them.

However, hair loss seemed to be something that both the adolescents and parents adapted to quickly. Eventually, baldness seemed to represent a mark of belonging. One mother described her sons' hair loss as a rite of passage:

He really loved his hair and I thought once he loses that it will really hit him but he has been brilliant...now he has got no hair he doesn't look any different from the rest of them.

Loss of limbs as a result of amputations also impacted powerfully on parents; one mother used the word 'scary' in connection with this. Amputation seemed to bring the serious nature of the cancer to the fore and made it immediately visible. It also limited the adolescent's physical function and mobility, yet even the most drastic of amputations could not guarantee freedom from cancer. As one nurse said:

That is one of the hardest things to face...they can go through all this and then still lose a limb and then still...

Other professionals on the unit also mentioned the difficulty of witnessing adolescents preparing for the amputation of limbs:

That's a strange situation (amputation)...that's the overwhelming thing I'm not comfortable about.

Loss of body parts seemed to symbolise the destruction that cancer brought to these young people's lives. Despite such disfiguring surgery, many looked generally well and most were positive and optimistic in their outlook. However, the loss of a leg or an arm was hard to ignore. Perhaps it served as a reminder of all that had been lost the luxury of good health and a carefree adolescence.

5.5. Shared understandings

A number of hurdles seemed to present when cancer had first been diagnosed. Not least was the importance placed on others' attitudes to the disease. Unlike parents, adolescents mentioned that the word 'cancer' was rarely used on the unit in their presence:

I mean you know what everyone else has got and you know it has the same name. There's not that much talk about, you know, cancer itself. Cancer, the word, is

very rarely actually used apart from 'the tumour has shrunk' or something like that...the word, cancer, they don't actually say it.

This may reflect the fact that cancers commonly treated on the unit, such as sarcomas, lymphomas and leukaemias do not require the use of the word cancer. Similarly, it may reflect general discomfort at using the word due to its negative connotations.

Some adolescents chose not to disclose their diagnosis to other people and avoided using the word cancer themselves. This suggested a possible coping strategy:

I don't tell everybody, just some people and then I don't want to talk about it. I don't like people saying cancer all the time. Some people say it all the time and I don't like that.

I've got a best friend I tell everything to, everyone else, I'm like, I'm fine don't worry, it's just too much to tell everybody. Best they think everything's going well.

Despite the fact that a small number appeared extremely ill, the general attitude to life with cancer, which now revolved around the unit, was generally positive. The relationships between patients, families and staff appeared central to the creation of an atmosphere of mutual support in reaction to what could either be optimistic or very pessimistic situations. As two of the adolescents said:

I think the nurses make you feel warm and caring...

The unit is small and compact...one of the nurses said the other day that they were thinking of mixing cancer patients with other patients but I don't think it is a good idea because you would feel like an outcast if you were the only one there and the others were, like, normal.

These data suggest that the culture of the unit evoked a powerful influence on those involved. An important factor was the way the professionals were perceived as being able to respond appropriately to the privations of adolescent cancer. As well as medical expertise, we interpreted the supportive role as indicative of a specific form of emotional labour, which Hochschild (1983) has described as:

'Requiring one to induce or suppress feelings in order to sustain the outward countenance that produces the proper state of mind in others - in this case being cared for in a convivial and safe place'.

The professionals clearly set the tone of this service, but were also required to manage the emotional demands resulting from their work. This required a balance to be struck between informality and professionalism. As one said:

This ward is very relaxed, but you have to have certain rules at some point. It is all advantageous when you have the team to support it and we are very supportive. We come over as very informal and very relaxed, but on the inside there is very much a structure. When people become unprofessional, that is when the wards' informality can become a problem.

The second data category to be discussed concerns how the adolescent cancer experience on the unit changed with time.

6. What it feels like over time

6.1. Diagnosis, recurrence and other 'difficult times'

The experience of a cancer diagnosis was the first step in a journey that the participants described vividly. For the majority of the adolescents, discovering that symptoms were actually indicative of cancer had resulted in feelings of shock, especially as many were just starting to establish some degree of independence in life:

When they said I had to go to Birmingham that was a bit of a shock...it was a shock because I was at University and it was unexpected...but you get vibes...waiting for the results was weird because they didn't think it was bad.

Once accustomed to the cancer unit, however, most of the young people talked about their illness in a more matter-of-fact fashion. This may have reflected the fact that they had grown more familiar to their situation. A recurring theme was the seemingly innocent nature of initial symptoms:

I was experiencing back pain in January and went to my GP several times about it and he eventually sent me for an X-ray of my back which revealed a tumour. They weren't sure if it was malignant or not so they operated on it and it turned out that it was.

Four of the adolescents had experienced a recurrence of their cancer. They were now receiving further treatment, and two had advanced disease that was now life-threatening. One young woman recounted the experience of learning that her cancer had recurred:

I was at the outpatients and they did an X-ray and they just said 'By the way, your cancer might be back', so I had treatment straight away basically...it was in my knee, I didn't take it that serious and I thought they would just cure it and they said something like 30 % chance it might come back. I think I was just unlucky when it came back. There is not a lot of people like me.

Discussions about the embodied impact of cancer, especially when recurrence was discussed, were particularly poignant. One incident, recounted in the words of one participant, described how she became aware of the extent to which her cancer had returned:

The last time I saw it was ages ago. When I saw the CT scan and they were just like little clouds, bits and bobs everywhere...it was quite a shock actually...when I saw it, it was a bit of a "Gosh, it's bigger than I thought".

This was despite a number of radical treatments already having been carried out:

I had a whole lot of chemo, had an operation to remove the tumour and they took a bit of bone out of my leg-fibula? They put that in the hole where the tumour was, more chemo, but found it didn't work so I had radiotherapy but still the tumour was growing in my arm and had also spread to my lungs.

This young woman died towards the end of the study and wrote to the researcher expressing her feelings about the situation. Other patients with more advanced disease also spoke of embarking on more aggressive treatment options to achieve cure:

Err, I had some more chemo but found it didn't work, so I had radiotherapy but still the tumour was growing in my arm and it spread to my lungs. So I decided after much thought to have an amputation and, err, I'm here now to start new high intense chemo which, hopefully, will sort out my lungs.

On the 15th January 1999 I was diagnosed with an osteosarcoma on my left ankle. I started chemo and surgery and was then re-diagnosed in February of this year. Whereas before I knew you could have surgery and then more chemo for this, now it's to see how I react because I've had so much.

Certain events, or particular times, were described as particularly challenging. For example, the importance of the 2-year milestone (during which time first-line treatments would normally be completed) was emphasised by the parents. Not knowing what to expect, either at the time of diagnosis or subsequently, was also described as a difficult issue to be faced:

It was terrible, if you had said to me a couple of months ago that I would cope with something like this I would have said no way, but you do.

With time, cancer seemed to be incorporated as an everyday part of families' 'new lives':

We don't give our old life a second chance... we just accept this is our way of life.

Witnessing other adolescents returning to the unit with cancer recurrence, or seeing them die, was also described as a particularly difficult aspect of parenting on the unit:

Seeing mums not taking their children home... emphasized the fact that you can never know what is round the corner.

Cancer recurrences, and the death of adolescents, were also particularly challenging for the professionals. As one nurse said:

The downside is they can't be protected when someone comes back with a relapse, somebody dies on the ward... they come in feeling well and you look around and everyone is suffering, you want to run out.

Parents attempted to make sense of such events in particular ways. For example, some chose to focus on the differences between diagnoses and the stage of their own child's disease, whereas others used what they witnessed as a form of preparation for their own possible loss:

Knowing these things may come along... children dying on the ward... a part looming for all of us.

However, one mother stressed that she would rather be part of such suffering, than be elsewhere and lose out on the supportive benefits that also came with being involved in the unit:

The intimacy and the security.

In contrast, another mother, whose son had been only recently diagnosed, had chosen not to become involved with other parents as it was:

Too frightening...if something goes wrong.

Despite the different ways that parents coped with their child's fluctuating condition, there appeared to be emotional costs that were common to all:

There are days when you feel like chucking it in. You have to be strong for them but underneath you are just breaking...it's your child, it's hard.

Particularly traumatic experiences for two of the mothers were described as 'mini-death' situations. One involved a mother watching her daughter being anaesthetised:

You watch them die for a moment.

For another, her child had been 'lost' to her, meaning that she had hardly moved or spoken for 3 days.

6.2. Looking to the future

The time leading up to the end of treatment was also highly significant for several of the parents. Importantly, other parents played an important role in helping to prepare individual families for this inevitability. For example, they would discuss with each other the challenges that would now face them in the outside world:

Adjusting to normal life...it will be a big gap in our lives when it is finished... a nice gap but a gap...it has been our life and then it won't be.

For professionals too, particular concerns existed about the end of treatment phase. They recognised the fear that patients and families faced when facing up to leaving the unit. Particular concerns existed about not having professionals immediately to hand to determine the significance of any problems that might arise. One nurse expressed insight into this issue in the following way:

Some patients...they don't look as happy as maybe you'd expect them to, they almost look quite fearful but you know that it's because we're going to give them their last chemotherapy. They are going to walk out the door and then we will leave them to get on with it.

Although all the adolescents would be followed up in an outpatient setting, other professionals also recognised the significance of leaving the security of the unit:

Physically they might be well again, but mentally they are no where near even going back to school or college.

This emphasised the need for rehabilitation services that addressed the challenges of adolescents returning to the world beyond the unit.

Parents also spoke of a desire to reciprocate in some way for the help they had received:

To give something back for what you have got out of it... say thank you for what they have done.

This often included raising money or offering to speak to other families new to the situation. Professionals also expressed a belief that, over the course of time, the experience of having cancer engendered an ambition in many adolescents to 'do something special' with their lives.

On a more day-to-day level, adolescents with cancer seemed to experience a tension between the desire to return to normality and the need for others to appreciate the nature of what they had been through. As one of the nurses said:

They cling on to the fact that they are just the normal self they were... 'Is that still me?'... They still want to

be me yet at the same time it does make them different and it does make them special.

The importance of a hospital/community liaison service was stressed by both the professionals and the parents as particularly important in helping to manage the transition between the various phases of treatment and care:

That role...the liaison nurse is something...it's difficult to imagine how we managed without it.

From the vantage point of professionals who had worked on this unit for some time, it seemed that the atmosphere of the unit was not static. It could, and did, change as a result of circumstances, management changes and the philosophies of the personnel involved. Whilst the contribution of individuals and specific professional perspectives were acknowledged, the importance of 'the person inside the professional' was also emphasised:

Oh the unit has changed over the years and it's very much the different personalities of the nurses in charge.

Anxieties were expressed about difficulties arising from former members of staff who did not seem to 'fit in' or about those who had become 'over involved'. There was also a fear of returning to an earlier situation where the team had become dysfunctional due to pressures of work, lack of management support and communication breakdown. The team approach to adolescent cancer care was emphasised by all the professional respondents as a key factor in enabling them to cope with this type of work. As one of the senior medical staff commented:

My job is made easier by a well-polished team because I know what to expect and I know that when I walk away, sand fills the holes, that there are people to carry on. I would regard myself as no more than a component in the process.

7. Limitations

Despite the richness of these data the study is limited by a number of factors. Only one unit was accessed due to resource constraints. It would now be worth comparing the culture and practices on this unit with others in the United Kingdom, as well as in other countries. The findings also reflect the views of those involved in the unit at this time and a longitudinal approach would help strengthen the findings further. Ethnographic approaches are also limited by factors such as observer bias, the limited number of people who can be observed and the reactive effects of the observer's presence (Bowling, 1999). We attempted to reduce these

effects by ensuring that a member of the research team who was not known to the unit carried out all the observations. Similarly, we extended an open invitation to all staff to take part and explained to them that we wanted to observe and interview them without disrupting their normal practice or behaviours. The patients and parents were also asked to 'tell it as it is' as far as possible.

There is a need to explore the issues that arose in this study in greater depth. The importance of end of life care and the impact of adolescent cancer care on staff are two findings that are now being addressed in further work.

8. Conclusions

This study provides insight into the experience of cancer in adolescence from the perspective of one specialist cancer unit. The culture of the unit emerged as a pivotal source of support and expertise. The benefits gained from the unit, however, were more than having particular facilities or professionals available. Equally important were the values, skills and personalities of those who were working there, as well the contribution made by the patients and families who entered and left the setting over time. This combination of factors resulted in the creation of what may be termed a 'therapeutic milieu'—a term that the researchers agreed captured the essence of this setting.

A relaxed, yet highly professional, atmosphere seemed to exist at the time this study. The culture was shaped by a mixture of effective management and strong leadership which helped to motivate staff and encouraged them to develop individual interests and skills. In turn, this seemed to encourage the creation of a more supportive atmosphere for patients and families. We suggest that this is a point worthy of more attention.

Capturing the therapeutic benefit of such a unit is challenging from a research point of view. There was evidence in these data that specialist units can, and do, benefit adolescents with cancer, as well as their families. However, one must guard against assuming that all adolescents' needs are similar to those described here or that any one facility could hope to meet such a complex range of needs all of the time. We do suggest, however, that the adolescents and parents who took part in this study appreciated the shared sense of support, understanding and expertise available to them. Such benefits outweighed any criticisms. As mentioned earlier, it is acknowledged the study is limited by focusing only on one area, and that larger-scale evaluative research is now needed (Kelly et al., 2002).

The experiences of the adolescents, families and professionals provide testimony of the challenges of cancer care in this patient group. Perhaps, the most

significant conclusion in this regard is the importance of effective care being provided within a supportive environment, which acknowledges the wider social and cultural needs of families. The shared understandings and sense of mutual support that the unit engendered was emphasised throughout these data and merits further attention.

We suggest that the setting of care may be highly significant for adolescents receiving treatment for cancer. This should be considered when health policy decisions are being made or when future adolescent cancer services are being planned. Particularly important is the need to discover whether adolescents with cancer benefit as much by being cared for in general adolescent care settings. Despite the need for further evidence to address such questions these data suggested that collective benefit arose out of adolescents with cancer '*being in the same boat*'.

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