

# CARE AND SUPPORT NEEDS OF CHILDREN AND YOUNG PEOPLE WITH CANCER AND THEIR PARENTS

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## SUMMARY

The importance of psychosocial support services for children with cancer and their families is recognised but evaluation of such services is less well developed with little information available about different patterns of provision. This paper provides an overview of psychosocial support children and their families in the UK receive during and after treatment. It reports the results of a postal survey of 303 families, within which parents and children identified their satisfaction with support services and also areas of unmet need. Satisfaction was identified in a range of areas, including medical information and support from nurses and social workers. However, areas of unmet need were also highlighted, especially age appropriate facilities, emotional support and information in different formats. Although British government policy currently seeks to develop standards and guidelines of care throughout the National Health Service, this paper demonstrates that there is still a need to develop psychosocial support services and work towards recently established guidelines in order to ensure that families receive flexible but equitable packages of care and support, wherever treatment is received. Copyright © 2005 John Wiley & Sons, Ltd.

**KEY WORDS:** childhood cancer; paediatric oncology; children and young people; psychosocial support; family support

## INTRODUCTION

There have been many medical advances in the treatment of childhood cancer and survival rates now exceed 70% (Cancer Research UK, 2003). Despite this, the diagnosis and treatment of childhood cancer remains a frequently traumatic experience for patients and their families. In addition, children and families can face difficulties in adjusting to living with uncertainty and the possibility of recurrence of the disease (McGrath, 2001; Eiser *et al.*, 2000; Woodgate, 2000; Van-Dongen Melman, 2000; Bearison, 1991; Koocher and O'Malley, 1981).

Efforts to understand the process of adjustment to serious illness have been informed by theories of stress and coping. Lazarus and Folkman (1984) maintain that people's efforts to deal with the

demands of stressful situations are dependent upon the availability and utilisation of resources. Important resources include social support, information that helps people understand the situation and the options open to them, and practical resources, such as finance. These resource areas can be broadly grouped under the label of psychosocial support.

Research on childhood cancer highlights needs for support with practical issues, relationships with family and friends, returning to school, information about the illness and treatment, and preparation and support for treatment procedures.

Families face many changes in their everyday lives. Practically, parents care for their sick child, whilst also trying to juggle everyday domestic and caring responsibilities (Soothill *et al.*, 2001; Sloper, 2000). This can have important financial implications in terms of employment patterns and incurring additional expenditure (Corden *et al.*, 2002; Yantzi *et al.*, 2001; Halliday, 1990). Practical and financial support and advice is therefore important.

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Family relationships, particularly amongst partners, parents and the ill child, and parents and siblings, can also change. For example, long periods of hospitalisation can separate family members and be emotionally stressful (Yantzi *et al.*, 2001; Van-Dongen Melman, 2000). For children and young people, the importance of ongoing family support, especially from mothers has been well documented (Ritchie, 2001; Woodgate, 1999). Friends, both home based and friends with cancer, are also valued, with the former providing important links to the child's 'non-cancer self', and cancer friends providing opportunities to talk to others who understand (Ritchie, 2001; Woodgate, 2000; Bearison, 1991). Helping children and young people with cancer to maintain family relationships, retain old friendships and forge new relationships are important elements of support provision.

Returning to school is a key consideration, one that requires well-planned and co-ordinated re-integration programmes between hospital, school and families (Bessell, 2001; Faulkner *et al.*, 1995; Larcombe, 1995).

Preparing and supporting parents and patients, discussing treatment procedures throughout the course of the illness and providing 'someone to talk to' has been demonstrated as beneficial (McGrath, 2001; Mastroyannopoulou *et al.*, 1997). Clear and accessible ongoing cancer information for parents and children/young people in a range of formats is also an important source of support (Jankovic *et al.*, 1999; Sloper, 1996; Eden *et al.*, 1994).

The value of psychosocial support and need for support services has been widely acknowledged. However, psychosocial support in paediatric oncology services in the UK has developed in a largely *ad hoc* manner, with both the public and voluntary sector providing support. Services have also developed over a number of years, and so do not always reflect current patterns of treatment and survival.

Past psychosocial support research has focused upon a few regional centres, with little information available about differing patterns of provision that patients and their families receive and their personal evaluations of this support. The research reported here sought to redress this balance, providing an overview of parents' and children's views of the psychosocial support they receive at different stages of the illness. The study was part of a wider project, the first phase of which consisted

of a postal survey exploring psychosocial services provided by all paediatric oncology treatment centres across the UK (Mitchell *et al.*, forthcoming).

## METHODS

Approval for the study was obtained from the Northern and Yorkshire Multi-Centre Research Ethics Committee.

### *Sample*

In order to safeguard patient privacy and comply with the Data Protection Act, questionnaires were distributed to families via their treatment centres. Eleven UK treatment centres were selected to provide a mix of northern and southern locations; metropolitan, urban and rural environments; ethnic diversity; centres sharing care with other hospitals and centres delivering care at a single site. However, four declined to take part due to staff shortages and tight project deadlines. Seven centres therefore provided the sample. These seven centres provided the desired demographic and service mix. With the aim of obtaining at least 300 responses, stratified by age of child and stage of treatment, and in order to facilitate stratification and minimise the burden on centres, each centre was asked to send questionnaires to 80 families, equally spread, as far as possible, across three age groups (0–5, 6–11 and 12–18 years) and three treatment stages (on treatment, off treatment and 5 years post-treatment-'survivors'). Questionnaires were sent to 560 families and returned by 303 parents and 112 children/young people. The parental response rate was 54%, the response rate for children/young people based on the number of parents ( $n = 127$ ) who responded with children aged 10 years plus (i.e. those eligible to complete a questionnaire) was 88%.

### *Questionnaire design*

The design of the questionnaire drew on existing literature on support for children with cancer and their families; results of the UK wide survey of paediatric oncology treatment centre provision

(Mitchell *et al.*, forthcoming); consultation with the project steering group, comprising professionals involved in care for children with cancer, representatives of key voluntary organisations concerned with childhood cancer and academics involved in the field; and qualitative research with children and parents. As part of the design process, individual and group interviews were held with 31 parents and 15 children and young people receiving or having received treatment from eight centres. Interviews highlighted key issues surrounding psychosocial support and service provision prioritised by children/young people and parents, and these informed the development of questionnaires.

Two postal questionnaires were then developed, one for children/young people (10 years and above) and one for parents. Nine parents and four young people piloted the questionnaires. In light of their comments and suggestions from the project steering group, minor amendments were made.

The questionnaires explored a similar range of services to the treatment centre survey. This included:

- Hospital facilities for inpatients, outpatients and those specifically for teenagers.
- Care received whilst in hospital.
- Social and emotional support.
- Support for other family members.
- Information and advice.
- Support surrounding the effects of treatment (such as future fertility).
- Transition support: hospital to home, returning to school and long-term survivorship.

Within the parents' questionnaire, respondents were asked to indicate if a particular facility or service was not needed, needed but not provided, or if provided, how satisfied they were with it on a scale of one to five. Children and young people were similarly asked if they had received a range of psychosocial services,<sup>1</sup> however, instead of using a satisfaction scale, the questionnaire asked children to evaluate their satisfaction in terms of happiness or unhappiness or 'it's not important to me'. In both questionnaires, most questions were closed questions, but an open section was provided for any additional comments about support services. Not all questions were fully completed by all respondents, but generally, the information provided was comprehensive.

### *Analysis*

Data were analysed using SPSS. Frequencies of response categories were analysed for all questions. The results reported here highlight key areas of satisfaction and unmet need identified by parents and children/young people. A key area of satisfaction was defined as over 70% of respondents reporting that they were satisfied or very satisfied (parents); happy or had found a service helpful (children/young people). Unmet need was defined as respondents reporting a service was needed but not provided or that provision was unsatisfactory (parents questionnaire) or in the case of children, they were not provided with a service needed or were unhappy with provision. Key areas of unmet need were defined as 40% or over of the sample reporting unmet need. The decision on the criteria of 70 and 40% was arrived at in consultation with the project Steering Group and influenced by general NHS guidelines indicating that services should be aiming to achieve satisfaction rates of around 80%. As some psychosocial support services are currently patchy and services are still being developed, it was decided that satisfaction rates of over 70% would identify areas where services were making good progress.

These data are reported across the whole sample. Differences between age groups, treatment groups and age by treatment groups were analysed using chi-square tests (as data were categorical). Areas showing a higher level of satisfaction or unmet need for a specific group, where differences between groups were significant at  $p < 0.05$ , are also reported.

## RESULTS OF THE FAMILY SURVEY

### *Family demographics*

There were no significant differences between the sample to whom questionnaires were sent and the achieved sample in terms of age, or whether on or off treatment (see Table 1). However, the number of questionnaires sent to families of children who had been off treatment for 5 or more years was lower than planned and varied considerably between centres. Overall, only 11% of questionnaires were sent to this group. In addition, only 5% ( $n = 16$ ) of returned questionnaires from

Table 1. Parents' responses compared with centres sample (broken down by age, whether on or off treatment, and treatment stage and age group)

	Centres sample % ( <i>n</i> = 560)	Achieved sample % ( <i>n</i> = 303)	Children's mean ages achieved sample years ( <i>n</i> = 303)
Treatment stage			
On treatment	44.5 (249)	43.9 (133)	
Off treatment	55.5 (311)	56.1 (170)	
Age group			
0–5 years	31.6 (177)	33.3 (101)	3.24 (101)
6–11 years	34.5 (193)	33.0 (100)	8.09 (100)
12–19 years	33.9 (190)	33.7 (102)	14.71 (102)
Treatment stage and age group			
0–5 years on treatment	17.3 (97)	16.8 (51)	
0–5 years off treatment	14.3 (80)	16.5 (50)	
6–11 years on treatment	16.1 (90)	15.8 (48)	
6–11 years off treatment	18.4 (103)	17.2 (52)	
12–19 years on treatment	11.1 (62)	11.2 (34)	
12–19 years off treatment	22.9 (128)	22.4 (68)	

Table 2. Children's responses compared to parents' responses

	Parents' response % ( <i>n</i> = 127)	Children's response % ( <i>n</i> = 112)	Children's mean age years ( <i>n</i> = 112)
Treatment stage			
On treatment	34.6 (44)	30.4 (34)	
Off treatment	65.4 (83)	69.6 (78) <sup>a</sup>	
Age groups			
10–12 years	35.4 (45)	33.0 (37)	10.95 (37)
13–19 years	64.6 (82)	67.0 (75)	15.49 (75)
Treatment stage and age group			
10–12 years on treatment	10.2 (13)	8.9 (10)	
10–12 years off treatment	25.2 (32)	24.1 (27)	
13–19 years on treatment	24.4 (31)	21.4 (24)	
13–19 years off treatment	40.2 (51)	45.5 (51)	

<sup>a</sup>13% of responding children were 'survivors'. A separate analysis of these children was not conducted due to the small sample size. Data for the off-treatment group thus includes children who had completed their treatment within the last 5 years and those who had completed treatment over 5 years ago.

parents and 13% of responses from children/young people (*n* = 14) were from this group. These numbers were too small for analysis, so off treatment and survivor groups were combined.

Table 2 compares the composition of responses from children and young people with responses from parents. Again very similar patterns were found.

Fifty-six per cent of responses were from parents of boys and 44% from parents of girls. This is consistent with the gender breakdown on incidence

of childhood cancer (55% boys and 45% girls, Cancer Research UK, 2003). Leukaemia was the most common cancer type (45), followed by brain tumours (12%). Other types of cancer reported each accounted for 7% or less of the sample. Most parents were married or living with partners (82%); 85% had more than one child and therefore had siblings to care for in addition to their sick child. Ninety-seven per cent of parents and 95% of children/young people were white British.

Table 3. Parents and children's satisfaction with basic leisure facilities for inpatients

Leisure facility	Parents	Children/young people
Television ( $n = 291$ )	82.5% (240/291)	90.9% (100/110)
Videos/DVDs ( $n = 290$ )	74.5% (216/290)	82% (91/111)

### *Hospital facilities and practical support*

The majority of parents and children were satisfied with basic leisure facilities for inpatients, as demonstrated by Table 3.

Provision of playroom facilities was an area of satisfaction for parents of younger children for whom playrooms are most relevant (inpatient facilities: 0–5 years, 80% and 6–11 years, 83%; outpatient facilities: 0–5 years, 71%).

Provision of age appropriate toys and activities was identified as an area of unmet need by children and young people (inpatients 47%, outpatients 60%). In particular, more activities for teenagers were wanted. Provision of teenage facilities was also noted as an area of unmet need, especially at treatment centres without separate teenage units, by parents of children on-treatment.<sup>2</sup> Parents' responses indicated that for inpatients, unmet need focused upon separate accommodation (64%), kitchen facilities (82%) and teenage activities (53%) and for outpatients, teenage lounges (42%), kitchen facilities (42%) and activity coordinators (50%). Young people did not indicate high levels of satisfaction with these facilities but unmet need did not reach 40%.

Two other key areas of unmet need were car parking provision and hospital catering. Seventy per cent of parents highlighted unsatisfactory car parking. In addition, families on treatment identified help with meeting parking costs as an unmet need (40%). Here, the proportion was significantly higher than for those off treatment (26%) ( $\chi^2 = 21.4$ ,  $df = 6$ ,  $p < 0.01$ ). Parents of children on treatment (41%), and children/young people on and off treatment (65%) were dissatisfied with unappetising hospital food.

### *Advice and information*

Parents, irrespective of their child's age, were satisfied with the medical information they received from doctors and nurses at diagnosis (80%)

and during treatment (81%). Similarly, children and young people of all ages were satisfied with the information they received about their illness at the time of diagnosis (75%). How information was provided was also important, as 88% of children/young people felt that staff had used easily understandable language and 78% valued staff talking directly to them.

In contrast, key areas of unmet need emerged with regard to accessing different types of information and for whom information was targeted. For example, children and young people (42%) and parents identified provision of video information about cancer and its treatment as an unmet need. Parents felt that this was an unmet need for all family members (58% for children, 50% for siblings and 44% for parents). Parents' responses indicated that this need was significantly higher for older children (6–11 and 12–19 years) and their siblings compared to the youngest children and their siblings ( $\chi^2 = 12.99$ ,  $df = 2$ ,  $p < 0.01$  and  $\chi^2 = 20.12$ ,  $df = 2$ ,  $p < 0.001$ ). Parents also identified a hospital library facility to borrow cancer related books as an unmet need for all the family (48%).

For the child with cancer, parents identified a need for more age appropriate hospital welcome packs (48%), and for older children (12–19), the provision of audio information was viewed as an unmet need (42%). With regard to their own unmet needs, parents highlighted summary sheets of outpatient clinic appointment discussions (59%) and of their child's case notes (62%). Parents wanted more advice on and assistance with accessing information via the internet. In particular, they wanted a list of recommended cancer websites (52%) and an internet search service for parents (41%). Although not a key area of unmet need for children/young people, 35% wanted more help finding information on the internet.

As noted above, the vast majority of respondents were white British, however, amongst families requiring the services of interpreters and translators ( $n = 10$ ), levels of unmet need were high at 50%. Similarly, 74% of parents requiring written information in different languages ( $n = 19$ ) felt this was inadequately provided.

### *Care and support needs*

Parents were generally satisfied with the continuity of care received by their child (79%), and

their own and their child's involvement in decision making with regard to treatment and care plans (85%). Eighty-two per cent of parents were satisfied with the extent to which staff relied on them to care for their child and to act as their child's treatment co-ordinator (84%).

Family support, socially, emotionally and practically, was also clearly valued by children and young people, irrespective of their age or stage of treatment. Over 90% felt it was important for close relatives, especially their parents, to be able to stay with them whilst in hospital (96%) and to help care for them (97%). Indeed, over 80% noted that this family support was 'very important' to them.

Preparation for treatment similarly emerged as an area of satisfaction amongst children and young people, with 86% of respondents indicating that doctors and nurses spent enough time explaining their treatment and possible side effects, and 80% feeling that staff provided helpful advice that sought to make treatment more bearable (80%).

#### *Social and emotional support*

Parents of children at all ages and stages of the illness were generally satisfied with the support provided by hospital staff, especially social workers and nurses (71%). This was also mirrored in the children's questionnaire. Here, children and young people valued the fact that hospital staff made time to talk to them (85%) and listened to their wishes and feelings (73%). Over half of the sample of children and young people (62%) had talked to a social worker and of these, 77% felt that they had been listened to. However, of those who had not seen a social worker, 88% did not wish to do so.

Talking to peers was also important for children and young people at all stages of the illness, in particular, talking to school peers (78%) and other children in hospital with cancer (71%). However, opportunities to meet and talk to other children with cancer were highlighted as an area of unmet need (42%), participants wanted hospital staff to provide more help facilitating this.

Less than a fifth of the sample (17%) had attended an organised support group for children/young people with cancer. Once again, this was not identified as an unmet need, as the vast majority (73%) did not wish to attend one.

Amongst those who had attended a group ( $n = 18$ ), all but one were happy with the support and there was a clear preference for activity based rather than more formally organised meetings.

Amongst parents, emotional support emerged as an area of poor provision. Parents of children at all ages and stages of the illness highlighted counselling services for parents as an unmet need (41%). In addition, couples counselling was identified as an unmet need by 44% of parents of older children, this was significantly higher than for parents of younger children ( $\chi^2 = 6.01$ ,  $df = 2$ ,  $p < 0.05$ ). 'Befrienders' (someone providing informal support via phone calls and hospital or home visits) and professional key workers (providing emotional support and a co-ordinating/liasing role) were also identified by parents (45 and 42%, respectively) as areas of unmet need. In contrast, children and young people did not identify the opportunity to talk to a counsellor or psychologist as an area of unmet need or an area of satisfaction.

Support for a child's emotional and behavioural problems was needed by a substantial number of parents ( $n = 201$ ) and, it is important to note that, of those who did require this support, 46% were dissatisfied with provision or had not received any provision.

#### *Support for other family members*

The children's questionnaire did not ask respondents to evaluate support provided for other family members, such as siblings and grandparents; results thus focus upon parents' perceptions. Satisfaction with support for siblings or grandparents was generally low. Information for grandparents about their grandchild's illness and treatment was highlighted as a key area of unmet need (48%). Parents of teenagers (12–18 years) identified unmet needs for siblings. These parents wanted more written age appropriate information about cancer and its treatment (60%) and also verbal information for siblings, in particular, someone to talk to brothers or sisters at home (53%), at hospital (48%) or to visit the sibling's school to explain the illness and answer questions (41%).

#### *Transition support*

*Returning home after treatment.* Survey data indicated that parents and children were generally

satisfied with the support received from hospital staff on return home. Parents were particularly satisfied with instructions received from hospital about who to contact and when, if concerned about their child (86%) and being able to phone hospital staff for advice (88%). Children and young people's satisfaction focused upon independence issues, such as staff helping them to become as independent as they wanted to be (75%), this also included staff explaining how to look after equipment, such as their 'line' (75%), and being shown how to take their medicine (71%). Provision of medical equipment at home was similarly an area of satisfaction amongst those parents requiring it ( $n = 235$ ), 81% were happy with provision and 79% of children and young people indicated that their parents had received support with regard to looking after equipment at home.

Returning home after treatment did not raise any key areas of unmet need for children and young people. In contrast, parents identified inadequate provision in two areas. Amongst parents as a whole, 43% felt that an end of treatment meeting with a group of parents and support staff (especially a nurse or social worker) would be helpful. Practically, among parents needing childcare and domestic help ( $n = 120$ ), 68% indicated that these needs were not met.

*Returning to school.* Children and young people were generally satisfied with both the educational and practical support they had received before and on return to school. Seventy-three per cent felt that school and college staff had helped them to catch up with their studies and 74% felt that staff had been understanding about changed appearance, such as wearing a cap or bandana in class. Although 94% of the sample of children and young people had experienced hair loss during the course of their treatment, discussion of hair loss with hospital staff did not emerge as a key area of satisfaction or unmet need.

For parents of both primary and secondary school children, key areas of unmet need were written and video information for their child about returning to school (54%), and for their child's classmates, information about cancer and its treatment (58%). An educational co-ordinator to oversee their child's return to school and liaise with service providers would also be welcomed (46%).

*Transition to adulthood and the future.* For parents with a child whose fertility may have been affected by cancer treatment ( $n = 252$ ), 72% had fertility matters discussed with them, and 85% felt that fertility issues had been dealt with sensitively. However, 45% of parents indicated that insufficient support had been provided for them around fertility issues and 44% felt support had been inadequate for their child. Parents of young people aged 12–19 years, in particular, identified information about fertility at diagnosis as a key unmet need (42%). Amongst children and young people themselves, only 41% indicated that staff had discussed fertility issues with them; half of those who had not talked about fertility issues ( $n = 36$ ) would have welcomed staff discussion.

The children's questionnaire invited 'survivors' (i.e. those who had finished treatment 5 years ago or more) to evaluate the provision of ongoing support. Although only a very small proportion of the overall sample ( $n = 14$ ) identified themselves as 'survivors' and completed this section of the questionnaire, results indicated that all 14 respondents received hospital checkups and for the vast majority ( $n = 13$ ) these were attended at least annually and were viewed as satisfactory.

## DISCUSSION AND CONCLUDING COMMENTS

Results of the family survey provide an evaluation of practical and psychosocial support for children and young people and their parents at different phases of the illness. However, certain study limitations are acknowledged. Whilst the response rate was reasonable for a postal survey and the achieved sample was generally representative of the total population surveyed in terms of age and whether on or off treatment, this was a self selecting sample and numbers were small for some important groups. The sample was predominately white and included few survivors, this prevented specific analysis of ethnicity and survivorship issues. The lower numbers of questionnaires sent to survivors may be a reflection of the variation between centres in arrangements for follow up. In addition, the low response rate from this group may reflect a desire of some parents and young people not to revisit their cancer experience.

In addition, asking participants to evaluate their level of satisfaction/happiness with existing

services and to specify if a service was needed or not is open to interpretation. It can be difficult for respondents, especially children, to envisage whether a service they have not received could have been helpful. Hence, unmet need may be underreported. An 'open' section for comments and the identification of needs not directly addressed was included in the questionnaire, however, few participants completed this. Irrespective of these limitations, the survey moves beyond previous research, as it presents the views of children, young people and parents and compares their experiences of support. Many of the results mirror findings from the earlier treatment centre survey (Mitchell *et al.*, forthcoming) and this is discussed below.

It is positive to note that there are a number of key areas of psychosocial support and service provision that parents and children/young people valued and regarded as satisfactory. This supports the general finding from the earlier treatment centre survey that psychosocial support has become an established part of centre service provision.

Areas of key satisfaction can be grouped into five broad themes: leisure and play, support from staff, medical information and preparation for treatment, involvement and independence opportunities, and support from family friends and peers.

Previous literature has noted the importance of how staff treat children (Woodgate, 1999; Faulkner *et al.*, 1995). Here, children and young people particularly valued staff making time for them and listening to their wishes, and staff support when faced with the transition back to school. For parents, staff support during transition was also valued, especially on returning home, when contacts and back up support were provided. Staff understanding, sensitivity and agreed procedures for contact with the hospital are clearly important aspects of psychosocial support.

How information is provided is also important (Jankovic *et al.*, 1999). It is thus heartening to see that children and young people felt that hospital staff, particularly doctors, provided easily understandable information and spoke directly to them. Although different children/young people want different degrees of information, children and young people in this study found it helpful when staff discussed and prepared them for invasive treatment.

The importance of involving families and respecting young people's independence is frequently noted (Diefer-Hicks and Lavender, 2001; Roberts *et al.*, 1998). Results from the parents survey indicate that many parents were satisfied with their own and their child's involvement in treatment and care planning. Amongst children and young people, it was opportunities to be as independent as they wished that came to the fore, especially during the transition from hospital to home. Clearly, not all young people can be as independent as they want to be at different phases of the illness; however, staff sensitivity to and prioritisation of independence opportunities are key components of support provision.

As in past literature (Ritchie, 2001), children of all ages valued the support of their parents during hospital stays. Peer support was also valued, however, children and young people would welcome staff providing more help to facilitate opportunities to meet and talk to other children with cancer. Support groups are often seen as a good way for children to meet others and support one another, however, the children's survey demonstrated that only a small number actually attended support groups and amongst those who had not attended any groups, there was not a desire to do so. This is important for centres and voluntary organisations to recognise when planning social support for patients, especially teenagers.

Despite these areas of good practice and provision, unmet need and poor support persisted; six broad areas can be identified.

#### *Practical support*

Car parking and hospital catering emerged as areas of poor provision in the family survey. This mirrors treatment centre survey results where staff at over half of the centres reported insufficient parking spaces and charges for parking. The additional expenditure incurred by car parking costs at a time when many families face changing financial circumstances (Sloper, 2000; Yantzi *et al.*, 2001) adds to the burden of trying to cope with childhood cancer. In addition, both parents and children/young people highlighted poor quality hospital catering. The importance of cancer patients maintaining a healthy diet and being encouraged to eat is recognised and information booklets (Henry, 2004) have been produced.



However, this advice still needs to be translated into practice by provision of food that is more appetising. These are two areas that clearly require further consideration. Centres may need to think innovatively, such as extending financial help and introducing parking priorities for some patients and providing more child friendly food or opportunities for families to prepare their own food.

#### *Age appropriate facilities and activities*

Provision of age appropriate facilities and activities, especially for teenagers, continues to be an area of unmet need. The treatment centre survey indicated that poorest provision was unsurprisingly at centres without separate teenage units and here the parents' survey reiterated this. Many positive inroads have recently been made by the Teenage Cancer Trust; however, this is an area that continues to require further development.

#### *Information: variety and scope*

Family survey results demonstrated that more information in a range of formats and specifically targeted for different groups was required. In particular, poor audiovisual provision was noted and more help was required to access information via the worldwide web. Targeting information for specific age and ethnicity groups was also highlighted as an area in need of consideration. More age appropriate information for children and young people was wanted and information provision for families whose first language is not English was poor. These findings reiterate previous results from the treatment centre survey where only a small minority of centres (6 out of 23) worked or had worked with children to produce age appropriate information and meeting the information needs of ethnic minority families was patchy and not always representative of the populations they served.

#### *Counselling support*

A key treatment centre survey finding was the shortage of psychologists and counselling support. Parents reiterated this, more counselling opportunities and options were wanted, including

informal and formal services, such as counselling, emotional support and service guidance, hence the suggestion for 'befrienders' and key workers. Both these concepts are not new, indeed, the value of key workers has been noted for many years (Greco and Sloper, 2004; Mukherjee *et al.*, 1999).

#### *Support for other family members*

Results from the treatment centre survey indicated that facilities and support focused largely upon patients and parents. This was reinforced by the parents' survey, as support for grandparents and siblings were noted as areas of unmet need. Parents of teenagers wanted more written and verbal information for, and someone to talk to, siblings. Parents of children of all ages wanted more information targeted specifically for grandparents. In light of these unmet needs, it is heartening to see that the UK Children's Cancer Study Group has recently published a series of information booklets for siblings and grandparents (Ablett and Ballard, 2005; Ballard and UKCCSG, 2004a,b). However, parents in this survey noted support needs beyond information; hence this is still an area that requires further development and consideration.

#### *Clear and co-ordinated transition procedures*

Clear and co-ordinated procedures lie at the heart of smooth transitions for patients returning home, back to school or moving towards adulthood. However, as the treatment centre survey indicated, there is little uniformity amongst centres in practices and procedures. Hence, it comes as no surprise that parents wanted more co-ordinated transition services, such as an educational co-ordinator to oversee their child's return to school. Transition issues are often complex, especially in areas such as fertility. Although fertility issues were handled with sensitivity, parents indicated a need for more support and both parents and children/young people would welcome more fertility information. Other research (Broome and Allegretti, 2001; Crawshaw *et al.*, 2004) has highlighted the difficulties in discussing information about fertility, both at diagnosis and later when treatment has finished, and the need for staff training.

The family survey has demonstrated that provision of psychosocial support is by no means clear-cut; families' experiences of support can be complex and multidimensional. Satisfaction with service provision and perceptions of unmet need can simultaneously exist in the same broad area of provision, for example, some aspects of information provision are satisfactorily provided but gaps remain. There are differences between children and young people and parents in their evaluations of support, perceptions of what support they want and when they want it. This emerged most clearly with regard to counselling and returning to school. Counselling was highlighted as an area of unmet need by parents of children all ages and stages of treatment and more counselling options would be welcomed. However, children and young people did not identify opportunities to speak to a counsellor as an area of need or satisfaction, but this may be because many had little knowledge of how counsellors could help. Children/young people were generally satisfied with the support received before and on return to school, whereas parents of both primary and secondary school children identified information and poor co-ordination as unmet needs.

A lack of co-ordination and uniformity amongst practices and procedures was noted in the treatment centre survey. English government policy recognises and is currently working towards establishing standards in all areas of health care (National Service Framework for Children, Young People and Maternity Services, Department of Health/Department for Education and Skills, 2004). There is clearly much good practice in paediatric oncology centres and psychosocial support is an established part of practice. However, there is still a need to develop more formal policies and standards across centres and the identification of key gaps by the family (and earlier centre) survey has informed the development of guidelines for childhood cancer published by the National Institute for Clinical Excellence—NICE (2005). NICE guidelines acknowledge gaps in psychosocial support provision and make recommendations for increased provision that would go a long way to fill the gaps identified by children and parents. These include recommendations that all children and families should have:

- access to the advice and support of a social worker;

- access to psychological services with expertise in children's cancer;
- structured psychosocial assessments at key points of the illness.

The family survey indicated that support should accommodate the needs of different family members, including siblings and grandparents, and different sectors of society. Support is further complicated as children's and families' needs change over the course of the illness and treatment. This need for an age appropriate and individualised yet holistic family approach is similarly recognised within the NICE guidelines. Such support packages draw on the knowledge and skills of different members of the multidisciplinary team and both psychological and social work services have key roles to play, along with nursing and medical staff. Appropriate training and support relevant to the needs of children and young people with cancer should be provided to enable staff to carry out these roles. The family survey illustrated the need for key workers and this has subsequently been prioritised by NICE. The development of clearer standards should help to provide a baseline from which centres can begin to work towards more comprehensive and comparable packages of care and support for families, irrespective of where treatment is provided.

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#### NOTES

1. The children/young people's questionnaire was shorter and the questions more direct compared to the parents' questionnaire. Thus it is not possible to directly compare parents and children's responses.

However, where consistency or inconsistency between parents and children was found, this is noted in the paper.

- Analysis of teenage facilities for inpatients was confined to responses from parents whose children were on treatment rather than those off treatment in order to reflect current inpatient facilities, as a number of teenage cancer units have recently opened.

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