

Psychosocial support services for children and young people with cancer and their families

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Advances in the medical treatment of childhood cancer mean that survival rates now exceed 70 per cent. With increasing survival, more attention has been given to the immediate and long-term psychosocial effects of the illness and treatment on children and families. However, there has been little research on children's or parents' views on the psychosocial support they need or receive. This study explored patterns of psychosocial service provision for children and young people with cancer and their families throughout the UK. Provision offered by NHS treatment centres was compared with parents' and children's own evaluations of the support and services they received. The main findings were:

- There was a lack of standard procedures and practices across treatment centres, especially in the type and frequency of psychosocial assessments, and support for transitions, such as hospital to home, returning to school and moving to adult services.
- There were variations in the type and number of staff who provided psychosocial support and in the ratio of such staff to patients.
- Parents and young people were satisfied with many areas of psychosocial support provision, including: support from nurses and social workers in hospital, preparation for invasive treatment, and medical information received across the illness.
- Key gaps in psychosocial support services, where treatment centre and family survey data concur, were: staff available to provide counselling and psychological support; emotional and practical support for other family members, such as siblings and grandparents; teenage facilities and activities; and age appropriate information for families in different formats, and, where needed, in different languages.

RESEARCH FINDINGS FROM THE
SOCIAL POLICY RESEARCH UNIT

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THE UNIVERSITY *of* York

JANUARY 2005
no.2005-01

Background

Previous research on the impact of childhood cancer has demonstrated that psychosocial support is an important part of service provision for patients and their families. Parents and children experience a wide range of emotions throughout the illness, uncertainty is a key cause of anxiety, and distress can persist for both parents and children long after treatment ends. Families also face many changes in their everyday lives, practically, socially and emotionally. In the UK, support is provided and funded by a number of different organisations, both statutory and voluntary. However, services have tended to develop in an ad hoc manner, and historically from a time when patterns of treatment for and survival from childhood cancer were different. There is little information about existing patterns of provision across the UK.

The charity CLIC (Cancer and Leukaemia in Childhood) recognised this need to investigate UK-wide patterns of psychosocial provision for children and their families, and commissioned this research to inform CLIC's future service development. A broad definition of psychosocial support was adopted, including help with social, emotional, psychological and practical needs.

Aims of the study

- ▶ To investigate the current pattern of provision of psychosocial support services throughout the UK for children with cancer and their families.
- ▶ To describe the needs of children with cancer and their parents throughout the illness and after treatment finishes.
- ▶ To compare patterns of support with parents' and children's views of their needs, and develop recommendations for the provision of services.

Findings

Results are reported from two postal surveys – the first to all paediatric oncology treatment centres and separate Teenage Cancer Trust units across the UK and the second to a sample of 303 families.

Centre survey results

The treatment centre survey was completed by all 21 UK paediatric oncology treatment centres and two of the three Teenage Cancer Trust units not based at these centres.

Results demonstrated a lack of standard practices and procedures across centres and considerable variability between centres in staffing and facilities for patients and their families.

The main gaps identified in the centre survey were in relation to:

Staffing Across centres there was variation in the number or type of staff providing psychosocial support and the ratio of staff to patients. In particular, many centres identified a shortage of psychologists and a lack of psychological and counselling support for patients and families. There was also variation in the support staff themselves received.

Facilities Provision of teenage facilities varied across centres, with poorest provision at centres without separate teenage units. Insufficient car parking facilities for families were also noted as an area of concern.

Social and emotional support Formal psychosocial assessments were not routine. Most assessments were informal and formal assessments were only carried out if a need had been identified. Family support focused upon patients and parents; staff recognised that other family members, such as siblings and grandparents, also needed support but often this was not available.

Information Centres varied in their provision of age appropriate information and information in different formats. There was widespread provision of computer facilities for patients but only half of the centres provided access to online information resources for patients or families.

Family survey results: satisfaction

A total of 303 parents of children aged 0–19 years, and 112 young people aged 10–19, took part in the family survey. The results demonstrated that parents and young people were satisfied with many areas of psychosocial service provision. Key areas of satisfaction, where 70 per cent or more were satisfied with provision are listed in Box 1.

Facilities Parents, especially parents of younger children, were satisfied with playroom facilities. Most young people were satisfied with the provision of basic leisure facilities, such as televisions, videos/DVDs and playstations, and with hospital visiting hours.

Staff support and care issues Most parents of children of all ages and stages of treatment were satisfied with the support hospital nurses and/or social workers provided. Parents were also satisfied with their involvement in the care and treatment of their child, and the degree to which they and their child were involved in decision making regarding treatment issues. Continuity of care was similarly noted as an area of parental satisfaction. Young people felt that doctors, nurses and social workers made time to talk to them and listened to their wishes. They were also satisfied with their preparation for treatment.

Information Medical information received from doctors and nurses before and during treatment was highlighted as a key area of parental satisfaction. Young people felt that staff used easily identifiable words and talked directly to them.

Transition Parents were particularly satisfied with support received during hospital to home transitions, especially opportunities to contact hospital staff on returning home and receiving information from staff. Young people were similarly satisfied with the support received from hospital staff on returning home. When returning to school, young people valued the support they received to catch up with their studies; and for those experiencing home tuition, home tutors were noted as supportive and understanding. Thinking about the future, parents were satisfied with staff sensitivity in handling issues about the impact of treatment on their child's fertility.

Family survey results: unmet need

The family survey also identified areas of unmet need (see Box 2). Key areas of unmet need were defined as areas where 40 per cent or more of respondents reported that a service was needed but not provided or that provision was unsatisfactory.

Facilities Both young people and parents, especially parents of patients on treatment, highlighted poor hospital catering. Parents also noted inadequate car parking facilities. Parents and young people wanted more specific facilities for teenagers, such as separate accommodation and lounges, especially in centres without separate teenage units. In addition, young people noted the poor provision of age appropriate activities, especially for teenagers.

Social and emotional support Parents of children at all ages and stages of treatment wanted more counselling options and support opportunities, including formal options, such as key workers, and more informal support provided by befrienders. Young people wanted staff to facilitate more opportunities to talk to other young people with cancer. Parents also felt that more support for other family members was needed, especially siblings of teenagers, for example someone to talk to siblings.

Information Parents generally wanted more age appropriate information in a variety of formats and information targeted at a range of family members, including siblings and grandparents. Young people noted a lack of video information, especially around cancer and its treatment. More specifically, parents wanted an internet search service and list of recommended internet sites.

Transition Before returning home, parents would welcome an end of treatment meeting with staff and other parents, and when their child returns to school, parents wanted more information and an education coordinator to oversee the transition. With regard to fertility issues, parents wanted more support for themselves and their child and more information on fertility for teenagers.

Box 1:

Areas of high satisfaction with provision

- Playroom facilities
- Basic leisure facilities
- Support from nurses and social workers
- Parental involvement in care and treatment
- Preparation for treatment
- Medical information
- Support when returning home and to school after hospitalisation
- Staff sensitivity in handling fertility issues

Box 2:

Areas of unmet need

- Hospital catering
- Inadequate car parking facilities
- Age appropriate facilities and activities for teenagers
- Counselling support and key workers
- Opportunities for children to meet other children with cancer
- Support for siblings
- Information in different formats and for different family members
- End of treatment meeting
- Information on return to school
- Support relating to fertility issues and information for teenagers

Implications for Service Development

The findings show that although there was widespread satisfaction with many areas of psychosocial support provision, further developments are needed in relation to:

Practices and procedures

The key message from the centre survey was the lack of standard practices across centres. There is a need to further standardise practices and procedures and to formally record them in writing. The government is currently developing standards and guidelines for care throughout the National Health Service, for example in the recently published *National Service Framework for Children, Young People and Maternity Services*, and the National Institute of Clinical Excellence is specifically working on childhood cancer guidelines. This study highlighted a number of areas where further development in services is needed and it is hoped that these results will inform the ongoing and future development of psychosocial support guidelines.

Recommendations for development in provision of psychosocial support services

The results of the study highlight the following as priority areas for development:

- ▼ Addressing the shortage of psychologists in many centres.
- ▼ Continuing to develop more separate facilities and age appropriate activities for teenagers.
- ▼ Providing more age appropriate information in a range of formats, including information for siblings and grandparents, as well as information in different languages, where appropriate.
- ▼ Providing more social and emotional support for other family members, especially siblings and grandparents.

Methods

The study had three stages:

Stage 1 was a UK-wide survey of paediatric oncology treatment centres (January to March 2003). Questionnaires were piloted by two centres, then sent to all 21 NHS treatment centres and three Teenage Cancer Trust units not based at these centres. Twenty-three out of 24 centres/units returned completed questionnaires, a response rate of 96 per cent.

Stage 2 employed a series of focus group and individual interviews with parents and young people aged 10 years or over. Thirty-one parents and 15 young people (of different age ranges and at different stages of treatment) from eight treatment centres participated. The themes and issues identified in these interviews were used to inform the development of the stage three family questionnaires.

Stage 3 was a family survey carried out in January and February 2004. Separate questionnaires exploring the support needs of families were developed for parents and for young people aged 10 years or over, and piloted by nine parents and seven young people. Seven centres each sent approximately 80 questionnaire packs to a total sample of 560 families. The sample was stratified by age and stage of treatment. Three hundred and three parents and 112 young people returned questionnaires: a response rate from parents of 54 per cent and from young people of 88 per cent (based on the number of parents who responded with children aged 10 years or over). There were equal numbers of parents with children in each of three age groups – 0–5, 6–11 and 12–19 years. One third of the young people who responded were aged 10–12 years and two thirds were aged 13–19 years.

Further information

The research was funded by CLIC. This publication should be cited as: Clarke, S., Mitchell, W. and Sloper, P. (2005) 'Psychosocial support services for children and young people with cancer and their families', *Research Works*, 2005-01, Social Policy Research Unit, University of York: York.

Copies of the full report, Clarke, S., Mitchell, W. and Sloper, P. (2004) 'Care and Support Needs of Children and Young People with Cancer and Leukaemia and Their Families' are available from SPRU Publications Office (price £15.50). Contact Ruth Dowling on **01904 321979** or email spruinfo@york.ac.uk.

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