

## Life threatening illness and hospice care

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**SUMMARY** A retrospective study was undertaken of 25 families and their 26 ill children attending the first children's hospice in the United Kingdom. The study examined the family's perceptions of the care offered and the impact of chronic and life threatening illness.

Eighteen (72%) of the families felt they had been well supported by the hospice and valued the family like atmosphere, perceiving the staff to be friendly, approachable, and helpful. The actual nature of hospice care, in an environment with other terminally ill children, was, however, considered a drawback for a few families. A number of families still had unmet needs, notably appropriate child minding when away from the hospice.

The impact of chronic life threatening illness on the families was substantial. The parents (particularly the mothers), the index children, and their siblings all experienced much higher levels of psychological symptomatology than would have been expected from normal samples. While families felt greatly helped over symptom control, a proportion remained very worried about certain symptoms, particularly breathlessness, seizures, and pain. A high proportion of families were experiencing financial and employment difficulties as a result of their children's illnesses.

Since the early 1970s the adult hospice movement has gradually increased in size as a result of a growing awareness of the needs of terminally ill people and their families.<sup>1</sup> In the United States a comprehensive review of the work of the hospice movement (National Hospice Study) has been carried out,<sup>2</sup> while in Britain there have been reports of the work of individual hospices. The British studies have suggested that the quality of care offered by certain hospices is good. For example, Parkes compared the report of spouses of patients who died in a hospice with those of patients dying in a hospital ward.<sup>3,4</sup> The hospice group spouses spent more time at the bedside and reported less anxiety, and fewer felt that their spouses had suffered pain. The spouses of hospice patients also perceived the hospice ethos as 'family-like' and 'helpful'. None the less, despite the continued expansion of the adult hospice movement much of the care offered in hospices in Britain has not yet been evaluated.

In 1981 the first children's hospice in Britain, Helen House, was built in Oxford<sup>5</sup>; since then Martin House in Yorkshire has opened and others are planned. It seems essential at this stage in the development of children's hospices that the needs and problems of the families of children with life

threatening illnesses are assessed and hospice care evaluated in a systematic manner.

This paper reports a retrospective study of Helen House which is the first phase of our evaluation of this hospice for children. The aims of this study were twofold: to assess the impact of chronic life threatening illness on the family and to examine the family's perception of the care offered by the hospice.

Helen House was opened in 1982 as a purpose built eight bedded unit and was funded by charitable subscription. It provides respite and terminal care on a 'home-away-from-home' basis for children suffering from chronic life threatening and terminal illnesses. It has space to accommodate families of children. Most children and families stay for up to two weeks at any one time but may return on a number of occasions, up to six or seven times per year depending on the need. The hospice attempts to provide a 'family-like' atmosphere. Half the staff have formal nursing qualifications. A full description of the hospice has been published elsewhere.<sup>5</sup>

### Subjects and methods

We aimed to study a series of families referred consecutively to Helen House, whose homes were

within 50 miles of Oxford (a pragmatic decision taken before the study was commenced to facilitate home visits to the families). Twenty seven of the first 29 referrals were included in the study. Two families were excluded because the hospice staff felt it inappropriate for us to contact them at that time. Another two families were unable to take part: in one family the mother was terminally ill herself and the other family consisted of a single mother who was abusing illicit drugs, and whose child was in the final days of her illness. This left a study population of 25 families, 20 with surviving children ('surviving group'), and five whose children had already died ('bereaved group').

Written informed consent was obtained from all the families who were then seen at home for a single session of between two and three hours. We requested to see both parents, although our primary informant was normally the mother. The interview consisted of a semistructured questionnaire followed by a number of self report questionnaires that we asked the parents to complete in their own time and post back to us.

The semistructured questionnaire dealt with a number of issues: (1) background details and demographic data—including information about the family constellation—the family's medical history, and details of the child's illness. (2) Other services the family were receiving—including medical, educational, and social—in addition to the help they were receiving from Helen House. (3) The nature and extent of the child's symptoms. The parents were also asked to rate how worried they were about each symptom (scored according to Parkes<sup>4</sup>). (4) Family health, finances, employment difficulties, and coping strategies. (5) The extent to which the child's illness had limited the parents' social activities and the lives of siblings. (6) Perception of Helen House care—the extent to which the families felt they were supported and their needs catered for, especially those of the siblings. (7) Needs which they felt had not been catered for by any of the services, including Helen House.

Both parents were asked to complete self report questionnaires concerning: (a) their psychological health by the general health questionnaire,<sup>6</sup> (b) their marital adjustment by the dyadic adjustment scale,<sup>7</sup> and (c) their social adjustment by the social adjustment scale.<sup>8</sup> The mothers were asked to complete questionnaires (Rutter A2 scale<sup>9</sup>) concerning the emotional and behavioural state of the school aged 'intellectually intact' index children and their siblings. The mothers' return rate of the self report questionnaires was 100%. Two fathers did not return their general health and marital adjustment questionnaires.

#### THE FAMILIES (TABLE 1)

There were 20 families with surviving children and five in which the index child had died. One of the families in the surviving group had two affected children. The mean age of the surviving children was 10.6 years, while the mean age at time of death of children in the bereaved group was 4.7 years. The mean length of illness of the surviving children was 7.6 years, and of the bereaved group was 2.7 years. Thus many of the children had suffered from their illnesses for most of their lives, the surviving group being older and having suffered longer from their illnesses.

The time scale of referrals to Helen House and our subsequent interviews varied substantially. The surviving group were referred to Helen House between six and 30 months before our interview and the bereaved group from between 12 and 30 months before our interview. The deaths within the bereaved group occurred between 11 and 23 months before the interview; no family was interviewed sooner than 11 months from the time of the child's death.

#### DIAGNOSES (TABLE 2)

As can be seen from the table the children were suffering from a wide range of conditions with

Table 1 Demographic data concerning the families, index children, and siblings

	Families with surviving children	Bereaved families
No of families	20	5
No of children	21	5
Mean (range) age of index children	10.6 years (4-17 years)	4.7 years (4 months-14 years)
Mean (range) length of illness	7.6 years (1½-15 years)	2.7 years (17 days-7 years)
Siblings:		
Alive	29	12
Deceased	4	1

Table 2 The children's diagnoses

Diagnosis	No of children
Neurodegenerative disorder:	
With specified diagnosis	5*
No specified diagnosis	5
Muscular dystrophy	6*
Mucopolysaccharidosis	3
Cerebral neoplasm	2**
Other	5*

\*Denotes a child who has died.

neurodegenerative disorders and muscular dystrophy forming the largest groups.

#### SOURCE OF REFERRALS

Nine (36%) of the families referred themselves to Helen House (having heard about the hospice usually through the media and self help groups), six (24%) were referred by a paediatrician, and five (20%) by a social worker. The remainder originated from a variety of sources. None of the families were referred by a general practitioner. In subsequent years the source of referrals has changed and now includes children referred by general practitioners.

The amount of time spent by the children and their families at Helen House varied greatly. The surviving group had spent from between eight days to seven weeks over the previous 12 months (mean 24 days) at Helen House. The bereaved group spent from between three days to three months (mean 31 days) over the year before the child's death. Contact was maintained by letter or telephone between visits.

#### Results

Statistical comparisons between the surviving group and the bereaved group were not considered appropriate. Not only were the bereaved group children significantly younger and suffering from illnesses of shorter duration, but the two groups were facing very different situations. The surviving group were coping with the ongoing illness of the child while the bereaved group were at various stages of dealing with the loss of the child.

#### FAMILY NEEDS, EXPECTATIONS, AND PERCEPTIONS OF HELEN HOUSE CARE

Each family had specific and individual reasons for seeking Helen House care, but a number of common themes emerged. Most common was the desire for care in a non-hospital environment with an emphasis on emotional support and time to talk in a relaxed and homely atmosphere. The second theme was the wish for medical care with emphasis on the relief of symptoms rather than on active intervention. Third was the need for respite care. One family, for example, had not had a day's break from their daughter since her birth 13 years previously (except for emergency admissions to hospital) until they came to Helen House. This family's plight was compounded by the fact that their daughter had manifested severe behavioural problems for many years.

#### HOSPICE HELP AND SUPPORT

Eighteen families (72%) felt very well supported by Helen House, the remaining seven only moderately

so. The latter group's main reservations were about their own children seeing other ill and dying children. Many of the families commented on the opportunity to meet and receive support from other families at Helen House, and felt relieved to know that there was a place where their children could go when they as parents were ill, or a family crisis arose.

Many of the parents commended the fact that the entire family, including the siblings, were made to feel welcome at Helen House. They felt this contrasted with general hospital wards on which the family were often not readily received. The parents said the children often looked forward to the Helen House visits, and enjoyed being made to feel special as did the siblings.

The bereaved group felt particularly supported at the time of the child's death, especially those whose children died at Helen House. A variety of rituals surrounding the death were reported as being especially helpful—for example, bathing and laying out of the child after the death; the opportunity for the whole family to be with the child, and to spend time with the body in an unhurried manner. They also appreciated the flexibility of the ongoing support.

Many families felt reassured by the staff's evident experience with the children's illnesses, particularly the rare ones—for example, Batten's disease and the mucopolysaccharidoses. This gave them confidence in the staff's management of the complex combination of symptoms and deteriorating abilities that characterise many of these illnesses.

The parents were asked to rate on a scale of 1 to 5 (1, does not apply at all; 5, applies very much) their views of Helen House staff on a number of dimensions. Twenty three (92%) of the families saw the staff as very 'friendly', 'approachable', and 'helpful'; 12 (48%) rated the staff as very 'efficient'; and only five (20%) rated the staff as very 'busy'.

#### ADVERSITY FACTORS AND THE IMPACT OF ILLNESS ON THE FAMILY

It is important to note that there were five families who had already experienced the death of another previously ill child, as well as the one family who currently had more than one affected child.

##### (1) Marital

Among the surviving group three out of 20 were single parent families. Of the two parent families, five (30%) were experiencing substantial marital problems (using a score of less than 80, a conservative cut off on the dyadic adjustment scale). Of the five bereaved families, two had such marital problems.

*(2) Psychosocial functioning (parents)*

In the surviving group 45% of mothers and 27% of fathers had psychological difficulties (as indicated by scores of 12 or above on the general health questionnaire). These rates are both over 70% greater than those found in random community samples.<sup>10</sup> Notably 35% of the mothers and 17% of the fathers scored *very* highly (above 20) on the general health questionnaire. Furthermore 45% of mothers and 17% of fathers had been prescribed and had taken a course of tranquillisers over the preceding 12 months. These rates of tranquilliser use are approximately double those found in a community sample.<sup>11</sup> The parents were asked how they coped with stress and the extent to which they used alcohol and smoked cigarettes to cope with the child's illness (over and above their 'normal' intake). Of the mothers, 25% said they used alcohol to a moderate or great degree to help them cope, and 35% of fathers smoked moderately or heavily to help them cope.

Among the bereaved group, two mothers and one father were rated as having psychological difficulties on the general health questionnaire with one mother and one father scoring *very* highly. The general health questionnaire scores were generally lower in the bereaved group than in the survivor group.

*(3) Symptom worry*

Almost half the families (45%) of surviving children were very worried about at least one of their child's symptoms, particularly breathlessness and seizures (table 3). However, the extent of the worry did not necessarily relate to the severity of the child's symptoms. For example a mother of a child who was having up to 50 seizures a day, and was occasionally in status epilepticus, did not rate herself as being specially worried about the child's symptoms as she felt everything had been done to control them, and the child was not suffering any pain. Of the bereaved families three out of five recalled being very worried about at least one symptom. Most families spontaneously mentioned the care and

attention that staff paid to symptom control and appreciated the experience of the staff and the very high priority placed on symptom relief.

*(4) Psychosocial functioning of children and siblings*  
Of the 10 'intellectually intact' children, four (40%) were rated as having psychological difficulties on the Rutter A2 scale. These rates were approximately 75% greater than those found in normal children in primary care settings.<sup>12</sup> All of these problems were of an emotional nature, such as anxiety and unhappiness. Two fifths of all the school age siblings (n=20) were rated as having psychological difficulties: these children had either emotional, behavioural, or mixed emotional and behavioural problems.

Of the bereaved families, one set of parents felt so distressed about the sibling's problems that they felt unable to complete the questionnaire but they did report substantial problems in two siblings. Among the remaining four families there was a total of three school age siblings only; two of these had significant problems one of which had the highest score on the Rutter scales of any child in any group. His problems were both of a behavioural and emotional nature.

*(5) Financial*

A third of the surviving families felt they had made a substantial 'financial sacrifice' as a result of the child's illness; and one bereaved family reported likewise. Many of the families, however, pointed out that they did not see the term 'sacrifice' as appropriate but did acknowledge that having an ill child was very expensive. The sorts of expenses incurred were the cost of travelling and heating bills for keeping the house warm throughout at least nine months of the year. (Individual heating bills often exceeded £1000 per annum.)

*(6) Employment*

Many of the parents had experienced employment problems. Only a quarter of the surviving group mothers had any sort of employment; none worked full time and most worked only a few hours a week. Sixteen (64%) of the mothers had given up their jobs once the diagnosis had been made in order to look after the child. Among the bereaved group, three mothers worked part time and one had given up a job to look after the child. One father's business had gone bankrupt; he attributed this to the time he had spent looking after his child as well as the financial input needed to help care for the child.

## UNMET NEEDS

The most frequently mentioned concern was that of child minding facilities. Many parents (60%) said

Table 3 Families' current worry over surviving child's symptoms

Symptom	% Parents very worried*
Seizures	25
Breathlessness	25
Pain	20
Swallowing	5

A total of 45% of families were *very* worried about at least one symptom.



that the difficulties in obtaining child minders limited their lives to a substantial degree. It proved very difficult to secure a child minder for a child with a very serious illness particularly if a child suffered from epilepsy. A few families mentioned the need for local respite care. None felt the need for additional specialist medical care or intervention. A high proportion of families said they were concerned as to what would happen to their children if the parents themselves became ill or died before their children.

## Discussion

This study forms the initial phase of our evaluation of the first children's hospice in Britain and of the effect on the family of chronic life threatening and terminal illness in childhood. Until our prospective controlled study is completed in 1989 it will not be possible to assess the efficacy of Helen House compared with regular health service provisions in mitigating the impact on the family of life threatening and terminal illness in childhood. None the less certain noteworthy points arise from the present study. The findings suggest that the impact of these illnesses on the families studied is substantial. This manifested itself in a number of areas of psychosocial functioning. The parents experienced high levels of psychological difficulties with a number of families facing a great deal of marital stress. The index children had emotional difficulties and their siblings were experiencing emotional and behavioural problems at substantially higher levels than would be expected in a normal population. Furthermore a substantial proportion of families reported financial and employment problems that seemed to be significantly affecting their lives. Overall it seems that the mothers were carrying much of the burden of the emotional and employment problems. These problems, which are largely unremitting, are especially worrying in view of the length of the children's illnesses. While it is not possible to say whether this group of families is representative of all families who have children with life threatening illnesses, our findings are in keeping with other studies indicating that high levels of individual and family difficulties are very common in this situation.<sup>13-16</sup>

Most families felt that they were greatly helped by Helen House. The families were particularly reassured by the staff's experience and help with the symptoms and the disabilities inherent in these illnesses. Many pointed to the individualised approach to each child and family. Most valued the 'family-like' atmosphere with the option of 'whole family' involvement. This seemed to be especially

important for the siblings who are so easily and perhaps inadvertently excluded by conventional hospitals. The actual nature of hospice care, however, in an environment with other terminally ill children, was a significant drawback for a few families.

These findings suggest that children's hospices offer a special style of care to families of children with life threatening illnesses. The hospice provides a warm friendly unhurried environment, unburdened by the rapid turnover and daily medical emergencies of the acute paediatric ward. This seems particularly appropriate for families suffering great strain, with children with degenerative conditions for which curative treatment is not appropriate. The hospice allows the whole family to be together instead of divided while focusing attention on symptom relief and helping the family cope with their worry over the symptoms. In some cases the hospice may have a special role around the time of death, providing the whole family with privacy, continuity of support, and ample time in situations when dying at home is not desired nor possible. Furthermore families facing the isolating long uphill struggle of many degenerative conditions are able to draw support from other families while attending the hospice.

While there might be certain special features of care which are offered by the hospice, certain aspects of the style and nature of care could be further enhanced in paediatric wards. For example, ward staff could focus their care not only on the child but on the entire family particularly the siblings. Simply making them all feel welcome and encouraging them to visit regularly is greatly appreciated. In addition, attention to symptom relief needs to be directed not only to reducing the severity of the symptoms, but to recognising and allaying the parent's anxieties and helping them to cope with the specific symptomatology. Furthermore, providing families with the opportunity to meet and draw support from each other may be helpful and while this may not always be possible on the ward, families may appreciate being put in touch with self help groups, for example the Muscular Dystrophy Society or the Mucopolysaccharidosis Society. Families may also be appreciative of short episodes of respite care. It should be emphasised that many of these children face years of a deteriorating illness and that hospice and hospital care are not mutually exclusive.

In conclusion this study points to certain issues that children's hospices should be able to address including: the provision of flexible care and support for the whole family (especially involving well siblings); continuity of support after the death of the

child; help with anxiety over symptoms and their relief, and help with the physical problems of daily living. However, our findings also indicate that a number of the problems, particularly the financial and employment ones, go well beyond the remit of a hospice: these problems are not easily resolved but at least warrant recognition.<sup>17</sup>

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