

## Parental involvement in the lives of children in hospital

J CLEARY, O P GRAY, D J HALL, P H ROWLANDSON, C P Q SAINSBURY,  
AND M M DAVIES

*Institute of Health Care Studies, University College Swansea, Department of Child Health, University of Wales College of Medicine, Cardiff, and Department of Sociology, University of Liverpool*

**SUMMARY** A care by parent scheme was established in the children's department of a university hospital. It was seen as the natural extension of the increased involvement of parents in the care of their children in hospital. A structured observational study was carried out to monitor its effect on the lives of child patients. Children in the scheme spent far less time awake alone, cried less, and slept less than those nursed unaccompanied. They had far more social interaction with a smaller number of adults, most of their contacts being with family members rather than hospital staff. Children with a resident parent but outside the scheme were generally in an intermediate position on these factors.

In Britain the daily and daylong presence of parents in children's wards is essentially a postwar phenomenon, despite Spence's earlier pioneering work in Newcastle upon Tyne.<sup>1</sup> The war itself provided ample evidence of the effects of the separation of young children from their parents. During the same period the advent of powerful anti-infective agents meant that isolation and the exclusion of 'outsiders' were no longer prerequisites for the treatment of many conditions.

The publication of the Platt report<sup>2</sup> in 1959 was the turning point in the importance of visiting children in hospital being accepted, and the report urged the provision of beds for mothers to stay with the youngest children. The Platt committee advocated this to avoid the damage caused by the separation of young children from their mothers and, also, to provide stimulation, occupation, and education appropriate to the age range. The extension of hospital education and improved play facilities, with specialised staff, followed. These aspects of Platt's recommendations were more acceptable to ward staff than the unrestricted presence of mothers. It was feared that sheer numbers would interfere with the running of the ward, that crossinfection would increase, and that, in their ignorance, mothers would frustrate the aims of nursing care for both their own and other children, while expecting hotel service for themselves. A paper written in 1965 by McCarthy and MacKeith was recently reprinted.<sup>3</sup> It included one

mother's account of severely restricted access to her child, who died after routine surgery. The emotional needs of children in hospital were discussed in relation to the requirements of their medical care.

Mothers, on the other hand, had been assured for years that their presence was upsetting (if not actually dangerous) for their children, who were in 'the best place' and would settle down better without them. They were, not unnaturally, puzzled by the change of policy. When they did make extended visits or stay they thought that they were getting in the way of the nurses and the real work.<sup>4</sup> Deprived of the resources of their own homes, and without any of their normal occupations, they often found living in extremely boring as well as inconvenient and uncomfortable. Being only half convinced that their presence was beneficial to the sick child, they worried constantly about the needs of the rest of their families, particularly their husbands, who were still expected to be helpless around the house. Meadow has described this state in 'The captive mother.'<sup>5</sup> Mothers were seldom included in the care of their children and suffered the frustration of watching others feed and bath them.

In the last 15 years the atmosphere of most children's wards has changed and mothers (and other family members) are welcomed and expected to carry out the kind of caring tasks they would normally do at home. In the United States the provision of specialised staff to care for children's psychological and social needs has been a major

postwar development. Wide ranging educational schemes and 'Child life programs' were established using playleaders, play therapists, and child psychiatrists and psychologists as part of the normal care team.<sup>6,7</sup> The effect of this trend was to make this aspect of child care more professional, substituting expertise for familiarity.

In the late 1960s and early 1970s a different approach emerged—the care by parent movement. It was inspired partly by the feeling that families were the proper people to look after their own sick children and partly by the need to cut the crippling cost of American hospital bills. The first unit was set up in Lexington, Kentucky, in 1966, followed by one in Indianapolis a few years later.<sup>8,9</sup> Since then others have appeared in many parts of North America, including Canada.<sup>10,11</sup>

In these care by parent units, which are generally purpose built, all nursing tasks are carried out and recorded by parents. Nurses teach the parents, do 'rounds', and are available for consultation, but they are not routinely present on the units: the parents are responsible for the nursing. The care by parent units have brought economic advantages, and the benefits to health have been striking.<sup>12,13</sup> In many cases the duration of stay has been cut and the child's health prospects have improved because the parents have become more confident and competent at dealing with the present and subsequent illness episodes and long term conditions. The children have suffered less psychological disturbance and parents have had ample opportunity to learn necessary procedures and, if need be, come to terms with an altered or curtailed future for the chronically or terminally ill child.

Not all child patients are suitable for this kind of care and guidelines are necessary for selecting them. The work of the North American units (and previous experience in Cardiff of both child patients and their parents) suggests that these will be based on consideration of the child's condition and the desirability of improving the family's nursing skills and health education. They may be formulated in the following way:

- (1) Cases where, although medical supervision is necessary, the nursing care required is minimal or of the kind that any mother would normally expect to carry out.
- (2) Cases where the condition is long term and specific techniques, of observation or treatment, must be learnt and carried out at home if the child is to live at home and the effects of the condition be minimised.
- (3) Cases where improvement in the family's general health education—for example, in diet, hygiene, or childrearing practices—will

lessen the likelihood of deterioration in the child's condition or recurring episodes of illness.

Parents have been able to resume care shortly after cardiac and neurosurgery and have learnt to manage complex procedures like parenteral nutrition and tracheostomy care, which made return home possible.

In Lexington it was considered that above all these the most important criterion was the willingness of the parent to participate fully.<sup>8</sup>

### Care by parent in Cardiff

In the Department of Child Health at the University Hospital of Wales in Cardiff parents have always been welcome to stay with their children since the Paediatric Unit opened in 1972, and many do. It was decided that the care by parent system would be the next step logically in involving parents in the care of their children in hospital. There was no possibility of providing a purpose built facility in the near future, so it was decided, with the concurrence of the nursing administration, to introduce it as an option for patients on the two wards that had access to an existing parents' lounge, kitchen, and bathroom, albeit rather small. The wards are all or largely divided into cubicles.

No extra finance or staff were available, but it was considered that the innovation could be absorbed within the current budget and staffing levels. The care by parent scheme began in May 1984. A child may join the scheme immediately upon admission or at any subsequent time. The operational application of the guidelines requires that:

- (1) A parent (or another relative such as a grandmother) must be willing and able to be resident.
- (2) The resident parent must be willing to and capable of learning the nursing techniques involved (which implies use of the English language adequate for the task in almost all circumstances) and conscientious about carrying them out.

The techniques that parents may need to learn will vary from recording vital signs and giving oral medication to much more complex procedures like tracheostomy care or parenteral administration of fluids and drugs. This diversity, the parents' understanding, and its importance for the child's future must all be taken into account when child and parent are considered for care by parent schemes. If a family seems to satisfy the criteria the care by parent scheme is explained to them by a senior registrar or a nurse. They are given a leaflet about it and time to consider before being asked for their decision about

entry. Few have ever refused and only one child has been returned to conventional care because the mother did not seem capable. Those selected by the staff have included very young parents, single women, and immigrant mothers with adequate English, as well as the more mature, well educated, and professional women.

All mothers or fathers who spend time in the ward have long been expected to carry out their child's normal personal care and give oral medication. Those whose children have chronic conditions have often learnt to carry out nursing procedures or physiotherapy—for example, with cerebral palsy, diabetes, or cystic fibrosis. Participation in the care by parent scheme differs from normal practice in most wards in three ways:

- (1) Children with common acute conditions can be included.
- (2) The parents learn and become responsible for carrying out and recording those aspects of care that they have taken on during the child's stay.
- (3) At any one time there is at least one nurse whose specific task is to teach, support, and counsel the parents in the scheme. This is part and parcel of modern paediatric nursing,<sup>14 15</sup> but the exigencies of the workload often mean that they must give way to carrying out physical care.

During the case study period (see below), when one child developed an unrelated infection the carer—in this particular case a grandmother—asked the staff to take over the nursing care again during this episode. The establishment of the scheme within the ward means that this kind of transfer can be effected without difficulty: there is no shifting of beds or removal to a different area and, on recovery, the child can as easily return to the care by parent scheme.

It is important that the effects of innovations in clinical practice should be evaluated. Funding was obtained from the Leverhulme Trust for an observational study. Its primary aims were to test the hypothesis that the change in style of nursing would be associated with measurable differences in the pattern and nature of the patients' contacts and interactions and with observed distress.

## **Methods**

Two types of non-participant observations were made, activity sampling and case studies, supplemented by diary records. Interviews and questionnaires were used with parents and nurses to investigate their reactions to the scheme. A child's inclusion in the scheme was dictated by clinical and

parental decisions rather than the random allocation appropriate to an experimental study.

This paper reports the effects of the degrees of parental involvement in their children's care on the lives of the children in the Infants' Ward (North Ward), using one group of data drawn from activity sampling.<sup>16</sup> In this technique the presence and activities of the children and those in contact with them were systematically sampled at fixed intervals, but with the starting time varied daily to introduce a random element. The observer made a circuit of the wards and recorded everyone who was present in the cubicles and corridors, using a precoded schedule (see Box). Observations were made every

### **Activity sampling**

- (1) The observers were all originally experienced teachers or health care professionals and were trained by the medical sociologist in the use of the precoded record sheets.
- (2) At 20 minute intervals from roughly 0615h until 2330h (the precise times were varied daily) the observer made a circuit of the ward, beginning at the entrance near the parents' lounge, and checked off the activities of or around every visible patient at the moment when they were first sighted and the presence of anyone else in the cubicles or corridors. Offices, bathrooms, the parents' lounge, etc, were treated as private and not entered.
- (3) The activity sampling record sheets were a diagrammatic representation of the relevant areas of the ward with codes to check off for each patient, covering the following factors: emotional state—happy, crying, angry, neutral; position—lying down, sitting up, near the bed or away from it, being held or carried by someone else, moving; place—in bed, in pram/pushchair, on chair or equivalent, on the floor or another person; level of activity—asleep, awake but inactive, observant, active alone, alongside or with someone; interaction—being fed, other personal care, nursing or medical attention, play, conversation or being physically soothed in some way. Other people who were present and any interactions they might have that did not include the child were also recorded. There were codes for various categories of medical, nursing, ancillary, and other hospital staff as well as family members and other visitors.

20 minutes from 0615h at the earliest, 0630h at the latest, to 2315–2330h (the extended day) by a team of seven observers under the direction of the medical sociologist (JC). They provided a serial cross-sectional account of what was going on, and the figures presented here refer to this series of occasions. Activity sampling was carried out for seven days, which, at 52 sets of observations a day, provided a total of 364 circuits of the ward. This was followed by four weeks of case studies of individual children in the care by parent scheme.

The kind of information recorded at each round of observations began with the presence or absence of the child and whether he or she was awake—for example, it transpired that on only one of the 364 occasions were all the children in the ward awake, and that at 2230h, and on only two were they all asleep, both of which were in the middle of the day. It showed the child's position—for example, lying down or being carried—and whether they were alone or 'in company'—that is, when someone was in the cubicle or obviously with the child outside it, perhaps carrying him or her, or outside but paying attention to the child within. A mother hoping that her child would go to sleep might stand in the corridor, gazing in but unseen.

### Subjects

North Ward has 14 individual cubicles and during the week under review the numbers admitted to the ward on any day ranged from 11 to 14 and those present at any one observation from nine to 14, an average occupancy of 88%. Patients fell into three groups: those who spent most of the observation period in the care by parent scheme, those who had a resident parent but were not in the scheme, and those without a resident parent. The composition of the population for the week is given in Tables 1 and 2. All three groups were recorded whenever they were in the ward and visible but not if they were out temporarily with their parents, had gone to another department for treatment or investigation, or had simply disappeared from view behind blinds.

In all there were 4225 observations of patients, missing observations accounting for 4% of the possible total. Any bias produced is likely to be an underestimation of the time the child spent with adults, whether staff or parents, but will be small compared with the 96% of observations actually made.

The biggest difference between the three groups was obviously in duration of stay. Three patients in the group without a resident parent had much longer than average stays—60, 70, and 119 days (the mean for the other seven in the group was 7.1 days). All

Table 1 *Composition of the population in North Ward for the week during activity sampling*

Group	No	Age (weeks)*		Duration of stay (days)	
		Range	Mean	Range	Mean
Without a resident parent	10†	3–107	30	4–119	30
Resident parent but not in scheme	7‡	0.3–48	25	1–9	4
Care by parent scheme	9	3–89	37	2–7	4

\*As at 1 May 1984.

†One child in this group had a parent resident for one night.

‡One child in this group was transferred to the scheme but was discharged within two hours. One other did not have a parent staying one night.

Table 2 *Social class and family size of subjects*

Children in family*	Care group								
	Without a resident parent			Resident parent but not in scheme			Care by parent scheme		
	1	2	3	1	2	3	1	2	3
Social class:†									
I and II		1		1			1	2	1
III Non-manual	1			1					
III manual	2								1
IV and V	1	2			1	1			1
Unemployed			1		1	1			2
Single									
mothers‡	1				1			1	
Not known	1								

\*No family had more than three living children, but in one family in the group without a resident parent a fourth child had died.

†Social class is based on the father's occupation (Office of Population Censuses and Surveys, Classification of Occupations, 1980).

‡Single mothers means those who were not living with the baby's father.

suffered from congenital abnormalities and the longest staying child was the subject of legal proceedings. An admission of this duration is not necessarily a barrier to the residence of a parent, or both alternating, and children who have stayed as long have spent most or some of their time in the care by parent scheme. Recently, a mother who had lived in with her son for more than four months (the early part of which had been spent in another hospital) was able to take him home after learning how to manage parenteral feeding.

The diagnoses for the three groups of subjects show that some conditions appear in all of them. The diagnoses in the group without a resident parent were two cases each of multiple congenital malformations, hydrocephalus (one complicated by chickenpox), and investigation of irritability, and one case each of urinary tract infection, upper respiratory tract infection, diarrhoea, and head injury. The diagnoses in the group with a resident

parent but not in the scheme were one case each of hydrocephalus, pneumonia, mastoiditis, diarrhoea, and investigation of failure to thrive, and two cases of breath holding attacks. The diagnoses in the group taking part in the care by parent scheme were one case each of bronchitis, diarrhoea, and umbilical infection, and two cases each of upper respiratory tract infection, congenital heart disease, and investigation of failure to thrive. In the following four weeks three babies with hydrocephalus were nursed in the care by parent scheme.

**Results**

**Alone or in company/awake or asleep.** The difference between the proportions of sleeping and waking was not great, but children without a resident parent did sleep more than the others. The other factor, 'alone' or 'in company', showed a much more dramatic difference (Fig. 1): children in the group without a resident parent were alone two and a half times as much as either of the other groups. The situation when they were awake and alone was even more striking (Table 3). That the children in the group without a resident parent should be awake and alone nearly three times as often as the children in the group with a resident parent but not in the scheme is not as surprising as the fact that the children in this latter group were awake and alone nearly three times as often as the children in the care by parent group.

The children without a resident parent were alone more when they were asleep, which in itself may be unimportant, but probably meant that they were alone when they went to sleep and woke up.

**Crying.** The patients in North Ward are nearly all

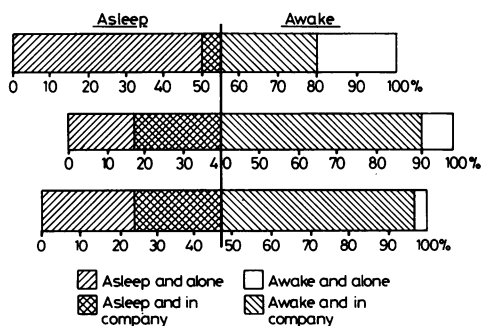


Fig. 1 Proportions for sleeping and waking and being alone or in company in children in the three groups without a resident parent (top), with a resident parent but not in the scheme (middle), and in the care by parent scheme (bottom).

Table 3 Crying alone or in company as % of observed awake

Awake	Care group		
	Without a resident parent	Resident parent but not in scheme	Care by parent scheme
Crying alone	11	4	2
Crying in company	11	13	11
Total alone	44	16	6
Total in company	56	84	94
n*	1211	338	518
Total observations	2684	563	978

\*n=No of occasions when children were 'observed awake' during one week of activity sampling. As a percentage of total observations this was 45% for the group without a resident parent, 60% for the group with a resident parent but not in the scheme, and 53% for the group in the care by parent scheme.

infants, therefore their crying was one of the items recorded. The baby who cries in company may be reacting to something that is being done to him or her or, seeking attention, has found someone to respond to the cry. Crying alone may be regarded as an indicator of some unmet need. The crude figures for crying alone as a percentage of total observations of the ward were 5%, 3%, and 1% for the groups without a resident parent, with a resident parent but not in the scheme, and in the care by parent scheme, respectively.

Children in the scheme cried less in total than the others, perhaps because their care was being carried out by familiar hands or their mothers or fathers were more confident than others about what to do in most circumstances, so that their needs were met quicker. There was little difference between the total crying of the two groups not in the scheme, though the children without a resident parent cried more alone.

**The child's company.** Recordings were made of who was present with the child and any interaction. Figure 2 gives the analysis of 'observed in company' (contacts) by the broad categories of family (parents, grandparents, and other adult or child visitors) and staff (medical, nursing, \* and ancillary), as well as 'alone', as percentages of total observations.

Nursing staff spent less time with the care by parent group than with the others, despite the demands of teaching and providing support. Children in the group without a resident parent, on the

\*Nurses were recorded as sister, staff nurse, state enrolled nurse, student or pupil nurse, nursing student, nursery nurse, and auxiliary. The first three were sometimes grouped under the heading 'qualified'.

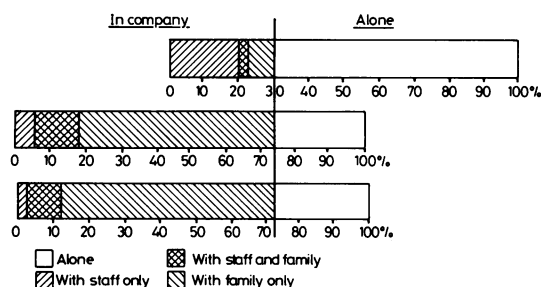


Fig. 2 Proportions of contacts with family or staff, or both, by children in the three groups without a resident parent (*top*), with a resident parent but not in the scheme (*middle*), and in the care by parent scheme (*bottom*).

other hand, experienced a greater degree of separation from their families and had most of their contacts with members of staff. This is unsatisfactory, as this study shows, because inevitably many different people are involved in their care.

It is one of the aims of paediatric nursing to reduce the number of nurses who handle any one child. Case assignment, the normal practice in the Child Health Department in Cardiff, has brought considerable improvement over task assignment. Nevertheless, the number of nurses involved with one child may still be large. Nurses were recorded by category—for example, sister or pupil nurse—unless they were known to the observers and could be named. The record shows that on a single day one baby received attention from at least three student nurses, two pupil nurses, a staff nurse, two sisters, and a nursery nurse. An older child was recorded with two staff nurses, a state enrolled nurse, a sister, two student nurses, and one pupil nurse. The more senior a nurse the more likely it was that she could be called away from hands on patient care to some other duty and it could happen (though rarely) that a change had to be made in the middle of a feed.

**Pattern of contacts.** Given the classification of people in contact with the child patients, as described above, there was obviously a large number of possible combinations, even when the categories were not divided by number—for example, two student nurses are not distinguished from one, although contact with doctors did include a separate code for a 'round' of more than four. Limited in this way, there were 96 different combinations of family, family and staff, or staff recorded, although nearly half of them only occurred once.

The mother was the most important family contact in all groups, almost to the exclusion of all

other family members in the group with a resident parent but not in the scheme. In the care by parent group mothers were present at 69% of contacts and fathers at 31% (not mutually exclusive), while the figures for the group with a resident parent but not in the scheme were 73% for mothers but only 9% for fathers. The care by parent group children saw much more of other members of their families, as did the resident parent who was in the scheme, while the resident mother not in the scheme seemed to be almost marooned with the patient, the father and other children seldom appearing. In the group without a resident parent the mother had the third largest number of contacts (27%) behind two categories of nurse, each of which had many members. The lives of these children were totally different from what was assumed to be normal for them. Instead of care from a few familiar people there was a bewildering series of strangers. Contacts that included qualified nurses (with or without family or other staff) formed 37% of the contacts of the group without a resident parent but only 15% of contacts of the group with a resident parent but not in the scheme and 7% of contacts of the care by parent group. For other nurses the figures were 31%, 7%, and 6%, respectively. The figures for all contacts with parents were strikingly different. Overall, mothers or fathers, or both, appeared alone or in combination with staff and other family members in the following proportions of total contacts: group without a resident parent 32%, group with a resident parent but not in the scheme 86%, and care by parent group 94%.

Doctors' attention was more evenly spread, as would be expected as the organisation of medical care was unaffected by the innovation. Contacts with them were: group without a resident parent 2%, group with a resident parent but not in the scheme 3%, and care by parent group 3% of total observations. The figure for the group without a resident parent was smaller because of the number of long stay children, who had been admitted before observations began: doctors' attention was generally concentrated in the early stages of an admission.

Occasions when both staff and family members were present were particularly important for the opportunities they gave for the mutual exchange of information and for the staff to teach parents how the condition should be handled or possibly avoided. As the nursing care of the group with a resident parent but not in the scheme was being carried out by the nursing staff they had the greatest number of this category of contacts, followed by the care by parent group who were being taught nursing techniques and also needed support in their additional responsibilities. Parents of children in the

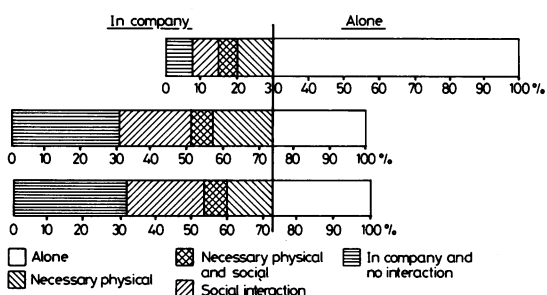
group without a resident parent had much less opportunity for this kind of helpful discussion or to develop their understanding of their children's needs.

**Interactions.** The people observed as contacts with children were not necessarily interacting with them. They were available for interaction and might indeed be preparing to give a feed or clearing up after a nappy change. Overall, interactions formed between 80 and 90% of the category 'observed awake and in company'.

Interactions are of two broad kinds, which may be described as 'necessary physical' and 'social'. Necessary physical interactions include nursing and medical attention as well as feeding and ordinary personal

care. Social interactions include talking, playing, and activities designed to soothe and may be combined with necessary physical interactions. Nursing and professional attention were a much smaller part of the necessary physical interactions than personal care and feeding, the figures being 20% and 80% for the group without a resident parent, 26% and 74% for the group with a resident parent but not in the scheme, and 16% and 84% for the care by parent group. This was one of the few instances when the group with a resident parent but not in the scheme were not intermediate, including, as it did, children who were more seriously ill, some of whom entered the care by parent scheme when their condition improved. The overall distribution of social and necessary physical interactions is shown in Figure 3 and the figures as a proportion of awake in company are given in Table 4.

Children in the care by parent group received the most social attention, 68% of all interactions, and only 14% was incidental to necessary physical care. For the group with a resident parent but not in the scheme the proportions were 63% and 15%, but for the group without a resident parent they were 58% and 24%, a higher proportion of incidental social interaction. Necessary physical interaction without any social component formed a larger proportion of interactions (44%) among this group than the others (37% for the group with a resident parent but not in the scheme and 32% for the care by parent group).



**Fig. 3** Distribution of social and necessary physical interactions in children in the three groups without a resident parent (top), with a resident parent but not in the scheme (middle), and in the care by parent scheme (bottom).

Necessary physical interaction includes medical and nursing attention as well as normal personal care.

**Table 4** Necessary physical\* and social interactions of the children as percentage of time awake in company

Interaction	Care group		
	Without a resident parent	Resident parent but not in scheme	Care by parent scheme
Necessary physical	39.1	32.6	27.4
Necessary physical and social	20.6	11.9	12.0
All necessary physical	59.7	44.6	39.4
Social	28.1	40.0	45.4
Social and necessary physical	20.6	11.9	12.0
All social	48.7	51.9	57.3
All interactions	87.8	84.6	84.7
All contacts	100	100	100
Total contacts	680	285	485

\*Necessary physical interactions include normal personal care as well as medical and nursing attention. They can be combined with social interaction.

### Discussion

The analysis of the observational data on the three groups of children shows that, while there is no doubt that all of them receive adequate nursing attention and physical care, those without a resident parent lack the warm social atmosphere that a family can provide. Children who are being nursed in the care by parent scheme and others with resident parents who awaken requiring attention will probably find someone there to respond. There will be more opportunity for social interaction—play, soothing, and simply nursing the baby—as well as carrying out the necessary physical care. The baby in the group without a resident parent is more likely to wake alone and cry for attention, which will be given by one of a series of nurses. Case assigned nurses inevitably have more than one child to care for and other work to do besides. When not otherwise occupied they are to be found playing with the patients, and babies seldom cry for more than a few minutes without receiving some attention, but inevitably pressure of work means that they cannot spend as much time as they would wish with each child.

Children in the care by parent scheme spend less time alone, particularly when they are awake, and cry less. Most of their contacts, and nearly 90% of their interactions, are with family members, particularly mothers. They, and their mothers, see more of the rest of the family than either of the other groups. The mothers or fathers who are caring for them can give all their attention to the one patient, and all the attention comes from a small number of people. There is time for discussion with the nursing staff, which is helpful to both parties, while mothers and fathers are more likely to see the doctor together.

Children without a resident parent, on the other hand, are cared for by an everchanging series of nurses, as the hospital as a workplace must provide acceptable hours for its staff. These children sleep more than the other groups, which suggests that their environment is unstimulating, and when they wake they are generally alone. In most instances the position of the child with a resident parent who is not taking part in the care by parent scheme is intermediate between the other two.

In the study of the care by parent scheme by Sainsbury *et al* nurses were asked to assess the parents' performance of their nursing tasks.<sup>17</sup> They rated it as satisfactory or better in 30 of a series of 32. The senior ward sister, writing in another context, said being in the scheme 'would assure the child of individual and committed care' and that 'the majority of parents were absolutely capable, with a little direction...'. These conclusions bear out the American experience that parents provide an acceptable level of nursing care. The success of this kind of scheme will then depend on two further factors—namely, the willingness of the nursing staff to operate it and the enthusiasm of the parents.

Systematic interviews were not conducted with parents observed during activity sampling, although they were with those of the case study children. Nineteen (or 21) said that if they had a child in hospital in the future they would like to be in the care by parent scheme again. A few who had been both resident with a child in hospital and in the scheme said how much they preferred the latter. They felt really useful rather than that they were getting in the nurses' way. The conviction that they were contributing usefully to the child's recovery by the tasks they were undertaking may have encouraged parents in the scheme to interact with their child more than other resident parents, as well as alleviating their boredom and, more importantly, their anxiety.

Ten of these mothers had one other child and one had two, including the twin of the child in hospital. Other children could visit the ward and one spent a good deal of the day with his mother there, but

generally they were looked after by grandmothers or fathers, several of whom took time off work for this purpose. Mothers were very much aware of the needs of the other children and made great efforts to prevent them feeling left out.

It was assumed from the start that the parent in the scheme would need breaks from the ward for meals and fresh air, at least, and visits home if the admission lasted more than a few days. In the latter case, or for longer trips, with the agreement of the care by parent nurse, care might be taken over by the other parent or a grandmother for a few hours or by the nurse herself. Confusion could arise if the mother could not find the care by parent nurse. In practice mothers seldom went far from the bedside, using the parents' lounge or the smoking area for their recreation.

Two mothers, one father, and one grandmother said that the added responsibility worried them, but only one mother gave it as a reason for avoiding the scheme in future. Another two agreed that being tied to the ward could 'sometimes' be irksome. Meals could be taken in the staff canteen in a distant part of the hospital, generally when the child was asleep or another relative was there; seven of the 21 preferred not to leave the child for so long and relied mainly on food brought in by relatives.

The longer term benefits for children with recurrent illnesses may include being nursed entirely at home in future episodes, because with greater knowledge and skill the parents will feel able to cope. For chronically sick or handicapped children the benefits are even more obvious in terms of fewer and shorter hospital admissions. Data from other aspects of the study suggest that a care by parent option is acceptable to nursing and medical staff, and it seems from this evidence that where a care by parent option can be introduced into a paediatric unit it has distinct social and psychological advantages for the children in hospital as well as longer term benefits.

This work was supported by the Leverhulme Trust and could not have been carried out without the help of the observers: Christine Bennett, Joan Edwards, Maureen Hedley-Clarke, Sheila Jennings, Christine Pavelin, Wendy Paxton, Linda Snell, Greta Thomas, and Shelagh Williams. We thank Mrs Marion Ferguson, Mr Meurig Morgan, Mrs Margaret Puddifer, Professor Margaret Stacey, Mrs Annette Watkin, and Dr Corinna Weaver, members of the steering committee. We are grateful for the cooperation and patience of the nursing staff of North Ward and the children and their parents.

#### References

- <sup>1</sup> Spence JC. The care of children in hospital. *Br Med J* 1947;i:125-30.
- <sup>2</sup> Committee on the Welfare of Children in Hospital. *Report of the committee on the welfare of children in hospital.* (The Platt report.) London: Mott, 1959.



- <sup>3</sup> MacCarthy D, MacKeith R. A parent's voice. *Arch Dis Child* 1985;**60**:179-81.
- <sup>4</sup> Pill R. The sociological aspects of the case study sample. In: Stacey M, Dearden R, Pill R, Robinson D. *Hospitals, children and their families*. London: Routledge Kegan Paul, 1970.
- <sup>5</sup> Meadow SR. The captive mother. *Arch Dis Child* 1969;**44**:362-7.
- <sup>6</sup> Plank E. *Working with children in hospital*. London: Tavistock, 1964.
- <sup>7</sup> Petrillo M, Sanger S. *Emotional care of hospitalized children: an environmental approach*. Philadelphia: Lippincott, 1972.
- <sup>8</sup> Lerner MJ, Haley JV, Hall DS, McVarish D. Hospital care-by-parent: an evaluative look. *Med Care* 1972;**10**:430-6.
- <sup>9</sup> Green M, Green J. The parent-care pavilion. *Children Today* 1977;**6**:5-8.
- <sup>10</sup> Robinson GC, Clarke HF. *The hospital care of children*. New York: Oxford University Press, 1980.
- <sup>11</sup> Evans RG, Robinson GC. An economic study of cost savings on a care-by-parent ward. *Med Care* 1983;**21**:768-82.
- <sup>12</sup> Caldwell BS, Lockhart LH. A care-by-parent unit: it's planning, implementation and patient satisfaction. *Children's Health Care*, 1981;**10**:4-7.
- <sup>13</sup> Vermilion BD, Ballantine TVN, Grosfeld JL. The effective use of the parent care unit for infants on the surgical service. *J Pediatr Surg* 1979;**14**:321-4.
- <sup>14</sup> Brunner LS, Suddarth DS. *The Lippincott manual of paediatric nursing*. (Adapted for United Kingdom by Weller BF.) London: Harper and Row, 1981.
- <sup>15</sup> Jolly J. *The other side of paediatrics*. London: MacMillan, 1981.
- <sup>16</sup> Currie RM. *Work study*, London: Pitman, 1972.
- <sup>17</sup> Sainsbury CPQ, Gray OP, Cleary J, et al. Care by parents of their children in hospital. *Arch Dis Child* 1986;**61**:612-6.

Correspondence to Professor O P Gray, Department of Child Health, University of Wales College of Medicine, Heath Park, Cardiff CF4 4XN, Wales.

Received 8 May 1986