Hospital Topics

Respite care on a children's ward

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Abstract

In March 1984 a short term respite care facility for handicapped children was opened in a children's ward catering primarily for acute medical and surgical problems. The facility was based on a four bedded room designed so that if beds became short in the main ward it could revert immediately to the care of acutely sick children. Three nurses were appointed specifically to staff the facility, the nursing budget for the rest of the ward being reduced proportionately. Conversions were funded by charities and some of the conversion work done by volunteers.

The main users were totally dependent children aged under 5 with severe mental and physical handicaps. Parents found the service invaluable, and in addition to planned admissions it was usually possible to accept a child at short notice—for example, when some domestic crisis occurred. Only very rarely was admission impossible because of the needs of acutely ill children.

A short term respite care facility not only helps parents cope and may provide beneficial experience for a handicapped child but is also a useful training ground for medical students and junior staff.

Introduction

With the continued decline of serious acute illness in childhood the care of handicapped children is an increasingly important aspect of paediatric practice. The incidence of handicap determined prenatally has not changed substantially (except for the decline in neural tube defects) and there appears to be some increase in the number of children with handicapping disorders acquired in the perinatal and postnatal periods. Children of extremely low birth weight or those who have suffered perinatal asphyxia, meningitis, or other devastating neurological illness are now more likely to survive because of skilled intensive care, but inevitably some of the survivors may be seriously handicapped.

The already heavy burden on the parents of caring for these children is increased when accommodation or income is inadequate, when the parents are separated, or there is no support from the extended family. All of these problems are common, particularly in inner city areas. In addition, a severely handicapped child in the family causes considerable stresses on the parents' marriage and health and on the normal siblings.

Not surprisingly, therefore, short term respite care is highly

valued by parents for their handicapped children. Short term respite care may be provided by relatives or foster families, but this is often difficult or impossible to arrange. Many social service departments provide some form of hostel accommodation for short term respite care but they have no statutory obligation to do so, nor do they have any special resources. Furthermore, the more profoundly handicapped children are often very difficult to feed and handle, and some have frequent convulsions. Many parents of young multiply handicapped children have been reluctant to use social services facilities for short term respite care, even when these are available, because the provision offered is often perceived as not suitable for the special needs of the child.

Our paediatric wards (like many others) have often accommodated several handicapped children at any one time, either for purely social reasons or because of some minor ailment. These admissions often entail some degree of collusion among parent, general practitioner, and admitting doctor to find a valid medical reason for what was primarily a respite admission. The parents often express feelings of guilt for using hospital facilities, and sometimes the nursing and house staff have been quietly resentful of the extra work, which they see as not being part of the acute service they provide. After suggestions from several sources, notably our local school for severely mentally handicapped children, we decided to rationalise and improve the services for short term respite care in our paediatric wards, and this paper describes our experiences.

Preliminary survey of parents' and staff views

After a pilot trial a questionnaire was administered to 25 parents of children who attended our child development centre. The aim was to determine parents' views on short term respite care, their use of currently available facilities, the circumstances under which they thought they would use the paediatric ward for short term respite care, and the improvements they thought would be desirable. The feasibility of achieving the parents' needs and the aims of an improved service were discussed with the staff and nurses of the child development centre and the hospital administrator and an action list prepared. The appendix summarises the outcome.

Planning, design, and execution of project

Since our wards often had two or three handicapped children at any one time, it seemed reasonable to allocate one four bedded room for the project. It was agreed that whatever changes were to be made the room must be able to revert immediately to the care of sick children when pressure on beds was excessive.

A local architect volunteered his services free of charge. He advised on room layout, furnishings and floor coverings, decor, and lighting. Drawings were prepared and quotations obtained. Protracted discussions were held with the fire prevention officer on the flammability of curtains and materials. Minor structural changes were made by the hospital works department and painting undertaken by ward staff and volunteers. The total cost of the project was around £2500, which was donated by several local and national charities. The facility was named the Ursula James Room (Dr James was paediatrician at the hospital until 1976).

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ADMISSIONS POLICY

Parents considered that successful short term respite care was dependent on familiar and permanent staff as much as on the physical environment. Three nursery nurses were therefore employed to work specifically in the unit, and as a result parents are now usually greeted by at least one person whom they know well. The funding for these posts was taken from the nursing budget and the nursing establishment for the rest of the ward reduced proportionately.

Admission for short term respite care is usually planned in advance, either on a rota basis or to help parents by caring for the handicapped child during an important family occasion, such as a holiday or wedding. In addition to these planned admissions, it is usually possible to accept a child at short notice when some social crisis occurs or the handicapped child is being exceptionally difficult at home.

The facility is available to any handicapped child who lives in our health district or is under the care of a consultant at our hospital. In practice, however, the main users are totally dependent children with severe physical or multiple handicap, and most are under 5; the local social services can often provide short term respite care for older children.

Because of limitations of space and staff and the lack of a readily accessible play area outside we are reluctant to admit ambulant hyperactive mentally handicapped older children except as a very short term emergency measure. Such children are the ones for whom families most often seek help but in our district (as in many others) provision for these is virtually non-existent.

INFORMING PARENTS ABOUT THE SERVICE

A leaflet about the short term respite care facilities was circulated widely to parents, doctors, and other professionals via, for example, outpatient clinics, the child development centre, special schools, nurseries, and social services. As well as describing the service and admissions policy, the leaflet is intended to make parents feel comfortable about using the service and to minimise the guilt that often accompanies admissions.

Review of the first two years

The short term respite care facility opened in March 1984 and has proved very popular with parents. Some parents who previously attended paediatric departments at other nearby hospitals and in other respects were well satisfied with the medical care have tried to arrange transfer to our hospital clinic in order to qualify for the service. Perhaps this indicates how parents rate the various services offered by paediatricians and their colleagues.

Inevitably the bed occupancy fluctuates considerably; the greatest demand is at weekends and holiday times, which causes difficulties with staff rotas. Furthermore, caring only for children with severe handicaps may depress even the most dedicated nursery nurse. A regular multidisciplinary meeting is held to discuss new referrals and management problems, and this helps to maintain morale. It is desirable to allocate some time for the staff to develop other interests and contacts—for example, helping the physiotherapist with treatment sessions or making regular visits to special nurseries to extend their knowledge of handicapped children. This is particularly important, as most admissions are too brief for the nursery nurse to establish any kind of teaching or training programme, and she may come to regard her job as nothing more than basic nursing care.

The number of admissions for short term respite care has increased since the service began. This is partly because of the increase in the number of handicapped children attending our child development centre, but there is undoubtedly an increase in demand as well.

Some parents have needed considerable support from paediatricians, therapists, or social workers before they can overcome their anxieties and leave their handicapped child in the care of strangers, often for the first time in his life. We emphasise that, handled carefully, this can be a positive and beneficial experience for the child.

We have been able to maintain this service despite the district's financial problems, and only rarely has it been necessary to refuse admission for short term respite care because of the needs of acutely ill children.

Conclusion

We recognise that a paediatric ward is not the ideal place for providing short term respite care. The most attractive solution is to provide small community hostels, equipped and staffed to deal with even the most severely handicapped child. Short term fostering arrangements (the "foster granny") and baby sitting schemes are invaluable, but because they are expensive to organise and maintain they are unlikely to cope with the number of children needing short term respite care. All forms of short term respite care are expensive, and given the present financial restrictions few social service departments can afford to launch new schemes. Providing three or four respite care beds in a children's ward is in our view a legitimate answer to a difficult problem, certainly for the next few years. Nevertheless, because of the conflicting priorities of children with acute illness, unless generally acceptable arrangements over admission policy, staffing, and facilities can be made along the lines suggested standards of care are likely to be suboptimal.

The care of handicapped children occupies an increasing proportion of the paediatrician's time and energy. In providing short term respite care facilities we have not only helped our patients and their families but also provided a useful learning opportunity for medical students and junior staff.

We thank the many people who contributed to the success of this project; the architect, Martin Lipson; several local and national charities; and the staff of the ward and child development centre.

Appendix

ACTION LIST BASED ON SURVEY OF PARENTS' AND STAFF VIEWS

<i>Suggestions made in preliminary survey</i>	<i>Action taken</i>
Continuity of care staff needed	Appointment of nursery nurses (see text)
Comfortable homely environment	Careful choice of decor, soft furnishings, etc by architect
Non-institutional furniture	Selection of suitable furniture by architect, with some items custom built
Easy admission procedure—avoid repetition of detailed history and examination on every admission	Patients not clerked unless inquiry from nursing staff elicits (a) acute problem, (b) change from previous medical condition, (c) altered medication
Physiotherapy and occupational therapy supervision of seating etc in ward	Simple instruction chart devised by therapists to instruct nursery nurses on daily care
Option of direct transport to day nursery from hospital	Transport arranged with social services
Space for child to have own possessions	Under bed storage lockers
Avoid risk of regression by continuation of daily routine	Continue treatment, nursery attendance, etc.
<i>Constraints</i>	
No extra staff or capital costs	Nursery nurses appointed from existing budget; capital conversion costs funded by charity
Non-standard materials must meet fire safety regulations	Treatment of materials approved by Department of Health and Social Security and fire officer
Instant reversion to acute nursing needs	All pipes, services etc, left in situ
Carpet easy to clean	Industrial quality carpet tiles used