

**BRI INQUIRY PAPER ON SUPPORT AND COUNSELLING FOR
PARENTS OF CHILDREN IN ACUTE HEALTH CARE SETTINGS**

BRI Inquiry Secretariat

December 1999

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EXECUTIVE SUMMARY

The purpose of this paper is to use the research, professional and policy literature to clarify the care needs of parents of children in acute health care settings, to look at policy recommendations on the provision of counselling and support to meet those needs and consider how well, in practice, the needs of parents in such settings are being addressed. The paper draws primarily on research studies published in nursing journals, as the majority of relevant studies identified relate specifically to nursing practice. The paper focuses predominantly on studies undertaken in the UK context and reported in British journals, although some relevant studies undertaken in Australia and the USA are also referred to. The paper does not cover support or counselling of parents in other settings, such as prenatal testing or genetic screening.

Section 1 outlines and distinguishes between the concepts of support and counselling and looks at who is likely to be involved in the provision of such help.

Para 1.1 defines “support” for parents as including all activities or arrangements within the health care environment which help meet the psychological or social needs of parents whose children are receiving care, whether or not they are specifically intended to fulfil this purpose. It points out that support covers a wide range of issues from practical arrangements for accommodation to the provision of advice and sympathy. Thus anyone involved at an individual or institutional level in the provision of care may have a part to play in providing for parental support.

Para 1.2 defines “counselling” as a specific activity aimed at providing support through face to face interaction with parents and discussion of their feelings and concerns. Four different levels of counselling are identified including: information giving, implications counselling, supportive counselling and psychotherapeutic counselling. The first two levels (and in some circumstances the third) are seen as a routine part of care for all patients, while the last is more likely to be provided to selected patients through referral to specialist counsellors. All health professionals are likely to have need of generic counselling skills; formally defined counsellors tend to have more theoretically informed approaches to the counselling process.

Section 2 outlines what is known about the problems and difficulties experienced by parents whose children are receiving care in hospital, summarises any strategies that have been suggested to diminish their impact and discusses parents’ perceptions of their needs for support and/or counselling.

Para 2.1 explores a range of problems for parents including: those that are caused simply by being with their children in an unfamiliar institutional setting; those that derive from the way in which hospitals are organised and the role that parents are expected to play in their child’s care; and those that reflect the inherent anxieties associated with serious illness and vary according to the circumstances of the individual child. Specific consideration is given to difficulties for parents when their child suddenly becomes seriously ill, is damaged through treatment or dies, and also when someone else’s child dies.

Para 2.2 looks at the specific needs that parents of children in acute care settings have themselves identified.

Section 3 summarises recommendations and guidance from government, professional and voluntary organisations in relation to the provision of support and counselling for parents of children in acute health care settings

Para 3.1 outlines the main government recommendations and guidelines concerning support for parents which have been published in the last ten years. The majority of these reflect the contemporary philosophy of family-centred care and are concerned with supporting parents to be actively involved with their children in hospital. There is relatively little detailed advice or recommendations specifically about the provision of psychosocial support or counselling for parents except in the context of life-threatening illness and bereavement.

Para 3.2 summarises relevant recommendations and guidance produced by professional and voluntary bodies over the same period (including the British Paediatric Association, Action for Sick Children, the National Association of Health Authorities and the King's Fund). Most of these are quite similar to those of the Department of Health though some go into more detail about how services should be managed and make additional recommendations.

Section 4 briefly outlines some evidence on the extent to which parents' needs for support and counselling are being met in practice, looks at some of the reasons why parents may find it hard to ask for support when they need it and why providers may fail to offer appropriate support

Para 4.1 presents data from a 1993 Audit Commission report which shows that parents' needs are still not always being met. The report identifies lack of written policies and management focus and poor communication between staff and families as important symptoms of and reasons for inadequate services. This is followed by a summary of some of the research evidence on parents' inhibitions about asking for help and on factors at ward level which may prevent nurses from practising family-centred care or finding the time to give support to parents in other ways. The paper concludes with a summary of the main points raised.

1. THE ACTIVITIES OF SUPPORT AND COUNSELLING

This section:

outlines and distinguishes between the concepts of support and counselling
looks at who is involved in the provision of such help

1.1 Psychological and social support for parents

1.1.1 What is support?

i. For the purposes of this paper, “support” is defined as including all activities or arrangements within the health care environment which help meet the psychological and social needs of parents whose children are receiving care, whether or not they are specifically intended to fulfil this purpose. Support thus covers a wide range of issues from practical arrangements for parents to stay in the hospital and help in their children’s care to the giving of information, encouragement, advice and sympathy.

ii. Who provides support?

i. Given this broad definition of support, it follows that anyone involved in the provision or organisation of care at an individual or institutional level may have a part to play in ensuring that parents’ needs are provided for and taken into account. Support may also be provided from sources outside the health care setting including self-help groups or facilitator-led support groups.

1.2 Counselling in health care settings

1.2.1 What is counselling?

i. Within the broader framework of psychological and social support, counselling is the activity which occurs when a person (either regularly or temporarily in the role of counsellor) offers time, attention and respect to another person or persons to explore their feelings and concerns.

Counselling has been defined by Bor et al¹ as:

“An interaction in a therapeutic setting, focussing primarily on a conversation about relationships, beliefs and behaviour (including feelings), through which the patient’s perceived problem is elucidated and framed or reframed in a fitting or useful way, and in which new solutions are generated and the problem takes on a new meaning.”

- ii. The same authors distinguish four different levels of counselling in health care settings:
 - i **Information-giving:** the provision of factual information and advice about medical conditions, laboratory tests, treatments etc.
 - ii. **Implications counselling:** a discussion with the patient and/or others which addresses the implications of the information for the individual or family and their personal circumstances.
 - iii **Supportive counselling:** in which the emotional consequences of the information and its implications can be identified and addressed in a supportive and caring environment.
 - iv **Psychotherapeutic counselling:** focuses on healing, psychological adjustment, coping and problem resolution.

The first two levels are likely to be regarded as a routine part of care for all patients, which will usually be provided by the health professionals responsible for their medical and nursing care. In certain situations (such as bereavement and diagnostic testing for genetic disorders or HIV) where psychological issues are recognised as particularly significant, supportive counselling may also be offered to all patients. Formal psychotherapeutic counselling will not be needed by all patients and is more likely to be provided through referral to a specialist counsellor.

1.2.2 *Who does counselling?*

- i. Counselling skills, such as listening, reflecting and conveying empathy, are not exclusive to the counsellor. Almost all health care professionals need such skills in the course of their interactions with patients, for example in giving information, clarifying treatment options and helping people adjust to new and sometimes unwelcome circumstances. The difference between these generic skills and those of a formally defined counsellor (or psychologist or psychotherapist) is that the latter is expected to have advanced training and qualifications in their field and is likely to approach the counselling process within a specific theoretical framework (such as humanistic counselling, psychodynamic counselling or cognitive behaviour counselling²).

1.2.3 *What sort of counselling?*

Families may present a number of times for therapy, each time with different needs and dilemmas with only minimal contact in between. Formal counselling interventions for families of children who are sick vary according to the task faced by the family. Examples include crisis counselling to help facilitate and contain emotional expression following diagnosis or relapse; insight-orientated psychotherapy for considering future uncertainty over illness; and family therapy when unacknowledged conflict, or differing opinion on appropriate coping strategies and

communication, is resulting in problems such as non-compliance with therapies or refusing to eat.³

2. PARENTS' NEEDS FOR SUPPORT AND COUNSELLING

This section:

- outlines what is known about the problems and difficulties experienced by parents whose children are receiving care in hospital and summarises any strategies that have been suggested to diminish their impact
- discusses parents' perceptions of their needs for support and/or counselling

2.1 Problems and difficulties experienced by parents

Some of the problems experienced by parents are caused simply by being with their children in an unfamiliar institutional setting and are not specific to the hospital context or the child's illness or treatment. Other difficulties derive from the way in which hospitals in particular are organised and the role that parents are expected to play in their child's care. Others again reflect the inherent anxieties associated with serious illness and vary according to the circumstances of the individual child. Each of these different types of problem is outlined below.

2.1.1 Being in a strange environment

i. Problems of being in a strange environment include:

- lack of familiarity: not knowing the way around, who is who, who does what, where and when to ask for information, how and when things happen, what to expect or what is expected of oneself
- isolation: from usual resources, social networks and one's own usual social roles

i. One unit's approach to help address some of these problems includes an education package for parents whose child is booked for surgery which includes a tour of the paediatric intensive care unit, explaining the use of equipment and how their child will look, by means of verbal, pictorial and printed material.⁴

2.1.2 Losing the parental role

i. The ordinary care of any child involves meeting his or her physical, psychological, social and spiritual needs. These are normally met primarily by the family. Illness affects the nature of some or all of these needs, and also the ability of the family to meet them. Hospitalisation of a child forces changes in the parents' view of themselves as protectors and nurturers. They may have to relinquish much of their

parenting role to the nurses, being anxious about performing even normal every day care on a sick child in an unfamiliar environment and not knowing what they are expected or permitted to do.

- ii. Parent's views about the amount of involvement they would like to have in their child's care vary and the same parents' views may change over time as their own and their child's circumstances alter. It is suggested that the best way of achieving an appropriate balance of care is through negotiation between nursing staff and individual families to reach agreement based on the parents' wishes rather than by imposing the expectations of the professional staff.⁵

2.1.3 *Costs of Participation*

- i. Since the 1959 Platt report⁶ recommended that mothers should be welcomed into hospital with their children it has become widely accepted in the UK that parents, usually mothers, should participate in their children's hospital care.⁷ Participation is desired by parents and children and is also consistent with current discourse about empowerment and involvement of users in health care.⁸ Nevertheless, such involvement may exacerbate some of the financial, social and personal costs experienced by parents:⁹
- ii. **Financial costs** may include: costs of travelling to hospital, especially where children are being treated in regional centres; extra costs of staying away from home (buying meals, telephones, paying for alternative care for siblings); loss of income (especially for those who are self-employed).
- iii. **Social costs** may include: using up holiday entitlement; depleting reserves of goodwill from employers, friends or neighbours who may be co-opted in to help
- iv. **Personal costs** Participation in unpleasant experiences (such as accompanying a child to the anaesthetic room, staying with them during a painful procedure or refusing to let them have a drink) has been identified as difficult because it challenges parents' ideas of themselves and their usual roles in providing for or protecting their children.⁹ This may be seen by parents and staff as something to be coped with, rather than avoided, because of the benefits to both child and parent of having the parent present and involved.
- v. Suggested strategies for limiting some of the costs of parental involvement include:
 - ensuring that parental costs are taken into account in the design of services (eg by ensuring parents are not expected to pay more than hospital workers for food and drink).
 -
 - enabling parents to choose whether or not to participate in their child's care and not to be required to be involved simply because of lack of nursing staff

2.1.4 *The child's condition*

For all parents of children with serious illness, one of the most important sources of stress will be anxiety about the child itself and its condition. A number of studies have been undertaken to explore these problems at particularly critical junctures:

i. When a child suddenly becomes seriously ill

In a study of mothers whose children had been admitted unexpectedly to a paediatric intensive care unit, respondents described the sudden transition from having a healthy child to having a child who was critically ill as causing catastrophic feelings of shock, guilt, helplessness and confusion.¹⁰ Key issues identified included:

- the tension experienced while getting to and waiting for their partners to reach the hospital
- waiting in acute stress without nursing assessment or therapeutic support through a period of enforced separation during the medical stabilisation of the child
- being re-united with a child whose appearance had changed (being nursed naked, intubated, ventilated and attached to a variety of monitors and infusion devices)

ii. When a child is damaged through treatment

A study of the experiences of parents whose children suffered neurological damage after cardiac surgery¹¹ identified the following:

- shock, loss and grief, combined for some parents with a profound sense of “aloneness”
- guilt, blame and anger - almost all the parents identified a specific focus of blame for their child's brain damage. These included “medicine”, “the driver”, “the child” and “themselves”
- fear for their own sanity linked to emotional and physical exhaustion
- fear of injuring the disabled child and thoughts of euthanasia

iii. When a child is dying

The death of a child has been repeatedly identified as the most traumatic experience a family will endure. The grief process has been described as falling into three phases: a period of numbness, shock, disbelief and unreality; a period of intense grief; and a period of reorganisation and recovery. Additional feelings that may arise include anger, helplessness, rage, frustration and guilt. Behavioural reactions to these feelings can include hysteria, crying, wailing, hitting and physical acting out.¹²

Aspects of emotional support that have been found to be helpful to families after the death of a child in hospital include: listening, talking openly and honestly, providing words of comfort, showing feelings, providing privacy and choosing words carefully.

iv. **When someone else's child dies**

In a paediatric intensive care unit, families may be exposed to deaths of children other than their own. On such units, families often form their own support network and become important parts of each other's "family" while their children are ill. Witnessing the death of someone else's child in the unit will intensify fears of death and feelings of uncertainty about one's own child's outcome. Watching a child die, especially if witnessed more than once, may also cast doubts on the belief that one's own child is receiving the best care possible.

For all these reasons it is suggested that parents present during and after the death of a child other than their own have significant needs and their normal coping behaviours may be compromised if they feel their needs are insignificant compared with those of the bereaved family.¹³

2.1.5 Waiting

- i. Waiting has been identified as one of the most stressful parts of the experience for parents of hospitalised children.¹⁴ Remaining inactive and unable to leave an area for fear of missing an important report denies an individual the mobility often used to deal with stress and can lead to feelings of powerlessness. Families who wait often feel neglected and forgotten. The expected event - a test result, a date for surgery or an improvement in the child's condition - is often unpredictable and uncertain. All of these characteristics may affect the parent's ability to cope with the stress of waiting. Manifestations of waiting when the outcome is not known include fear, fatigue, anxiety, lack of ability to concentrate, restlessness, inability to eat or drink, anger and frustration. Stressful periods of waiting occur at various different stages in the child's care. These include waiting:
- for admission, for surgery and for discharge (all of which may be unexpectedly brought forward or postponed for a variety of reasons not always directly connected with the child involved)
 - for the results of diagnostic tests (to know what is wrong and what the prognosis and required treatment may be)
 - during surgery and medical treatment (waiting to know whether the child has come through alright and whether the treatment has been successful)
- ii. Some waiting is unavoidable (i.e. that related to the time it takes to perform tests, procedures and surgery and for a child's condition to improve) Other types of waiting could potentially be reduced or eliminated (that relating to admissions procedures, pain alleviation, delay in conveying medical reports and messages and arrival in a treatment area long before the procedure can be done).

- iii. Suggested strategies to help parents cope with waiting include¹⁴:
- - acknowledge to parents that it is difficult to wait
 - provide a comfortable setting in which to wait
 - assist parents to find a support person to share the waiting
 - be aware of parents' physical needs (for food etc) while they wait
 - keep parents regularly informed of progress
 - ensure a system for prompt delivery of messages
 - assist parents to use coping strategies that have helped them before
 - use hospital volunteers to maintain waiting areas and help meet parents' needs
 - develop strategies for care delivery that minimise avoidable waiting

2.1.6 *General findings about parental stress*

- i. A review of general findings about stress among parents of children admitted to paediatric intensive care units¹⁵ found that:
- parents experiencing unexpected admission of their child had higher stress scores on all dimensions than planned admission parents
 - parents' overall stress levels are highest early on in the experience of hospitalisation and diminish over time (except where things go wrong)
 - factors concerning the child (diagnosis, prognosis, experience of pain) and the parents' relationship with their child were major sources of stress and were more important to parents than factors affecting their own comfort, self-care or spiritual needs

2.2 Parents' perceptions of their needs

- i. Several studies^{16,17} have been undertaken to identify parents' own perceptions of their needs for support while their children are in hospital. Identified needs include:
- to receive accurate information about their child's condition that is honest, exact, understandable, ongoing, freely offered, consistent, well-timed and comprehensive
 - to have ready access to their child, continue in the parental role, have meaningful participation in their care and be recognised as important to their recovery
 - to trust in the staff and feel that they care about (as well as for) the child
 - to be assured that the child is receiving the best care possible
 - to receive support from their own social networks (including relatives, friends and workplace colleagues) and opportunities for the direct involvement of grandparents and siblings (include somewhere for the latter to play)
- ii. Needs identified by parents whose children who had suffered brain damage after surgery¹¹ included:

- contact with other families in similar situations
- an individual with whom they could build a trusting one-to-one relationship (both at the time of the injury and afterwards) with the skills and detachment to discuss the tragedy openly and to listen to their doubts, anxieties or anger as parents. It was frequently suggested that this person should be detached from the child's care, available on a regular basis and easy to reach as required
- the provision of written summaries about their child's brain damage, to ease the burden of having to retell the story to every new contact
- information about local support services, within the first few weeks, repeated as required and in writing
- for the fate and future of children like their own to be openly discussed by society and by the medical profession

3. RECOMMENDATIONS AND GUIDANCE

This section:

- summarises recommendations and guidance from government, professional and voluntary organisations in relation to the provision of support and counselling for parents of children in acute health care setting

3.1. Government recommendations

The 1959 Platt Report⁶ on the welfare of children in hospital led to radical changes in, among other things, access and provision for parents. These original government recommendations were based on a psychological viewpoint, but research carried out subsequently added a sociological dimension based on the relationship between the child and family and the discontinuity in family life caused by hospital admission.¹⁸

Over the past few years there has been an increasing consensus between government, professional and voluntary organisations on the benefits of parental participation in “family-centred” care. More recent government guidelines in this area published in 1984¹⁹, 1991⁷ and most recently the 1996 “Children’s Charter”²¹ reflect this philosophy, giving considerable attention to enabling parents to be with their children in hospital and ensuring access to information and improved contact with hospital staff to facilitate this involvement. Many of the national recommendations are in tune with the research evidence outlined earlier on parents’ needs in these respects. In contrast, there appears to be relatively little detailed advice or recommendations specifically about the provision of psychosocial support or counselling for parents of children in hospital except in the context of life-threatening illness (which is not precisely defined) and bereavement.

The 1991 report⁷ on the welfare of children and young people in hospital represents the first comprehensive set of recommendations from the Department of Health in this area since the Platt Report. Its key points are therefore described here in some detail, along with those of some of the key voluntary agencies that have made relevant proposals, including Action for Sick Children and the British Paediatric Association.

3.1.1 *Accommodation and facilities*

- i. 1991 Department of Health guidance⁷ specifies that “Every children’s hospital or children’s division of a district general hospital must provide facilities to enable the mother and other members of the family to sustain the normal relationship to which the child is accustomed at home”. It recommends that parents should have:
 - appropriate sleeping accommodation at no cost
 - access to washing facilities, toilets and telephones
 - the use of a sitting room and kitchen
 - access to any available subsidised canteen meals
 - in specialist hospitals which may be distant from the family home, accommodation should be provided for siblings as well as parents
- ii. Since 1984 there have been detailed guidelines¹⁹ about accommodation for parents on childrens’ wards, but the 1991 guidance acknowledged that more accommodation was likely to be required than these guidelines suggest. It recommended hospitals to collaborate with voluntary organisations helping families with children suffering from serious or chronic illness, which might also be able to provide accommodation for families near regional centres in some specialities.

3.1.2 *Escorting and visiting children in hospital*

- i. The 1991 guidance⁷ advises hospitals to ensure that the Hospital Travel Costs Scheme is publicised within the children’s department and that a named member of staff is designated to help advise families on benefits which may be available to help with travel costs. Where a family’s financial situation is particularly difficult, parents should be made aware of any assistance the hospital social worker can provide.
- ii. In the case of emergency transfers where parents are unable to accompany their child in the ambulance, the 1994 Ashworth Inquiry²⁰ recommended that parents be equipped with a map of the hospital and the name of the unit their child is being transferred to.

3.1.2 *Participation in child care*

- i. The 1991 guidance⁷ advises the agreement of service specifications which:
 - recognise that parents and members of the immediate family are not visitors, encourage and assist them to be with their child at all times (especially those that are most stressful i.e. during anaesthesia, treatments, investigations and during post-operative recovery) and enable them to give continuous love, care, comfort and support to their child
 - help parents to undertake many familiar tasks helpful to the care of their child and provide help and advice to continue the care following the child’s discharge

- ii. It also recommends that hospital routines should be sufficiently flexible to adapt to families' different cultural practices and that parents be encouraged to express their preferences for the care of their children in relation to diet and feeding, clothing, washing and bathing, and beliefs or traditions in respect of healing, treatment and care while dying

3.1.4 *Life-threatening illness*

- i. The 1991 guidance⁷ encourages health authorities and hospitals to establish links with voluntary organisations active in their areas to achieve maximum co-operation in the planning and organisation of services like social work support. It also recommends that those involved in agreeing contracts should ensure that:

- all staff are sensitive to the needs of children and their families with life-threatening conditions and are able to draw upon staff specifically trained in care and counselling
- parents are informed in an appropriate manner, as soon as possible of their child's condition and given every opportunity to talk through their feelings
- care is taken not to "avoid" parents whose child is dying, while at the same time recognising the need for privacy
- where children are taken home, advice is available to parents on the help available from statutory or voluntary agencies to ensure ongoing support and counselling for as long as necessary
- parents have the opportunity to return to the hospital to find out anything further they wish to know about any aspect of their child's illness, care or treatment

3.1.5 *Death of a child*

- i. When a child dies, the 1991 guidance⁷ states that it is essential that parents/carers are helped to cope with the sense of loss and grief and also given practical assistance to help them make necessary decisions. Health authorities and hospitals are advised to ensure that:

- a member of staff trained in care and counselling is designated to give families, including siblings, all the necessary support including help with the arrangement of bereavement counselling and practical issues like burial arrangements
- the results of any post mortem investigation are conveyed in a sympathetic manner to the family in order that the therapeutic value of the discussion of the pathologist's findings is fully realised

- the family's GP is informed as soon as possible so that, as necessary, the GP can help them cope with the medical effects of bereavement

3.1.6 *The Children's Charter*

- i. The 1996 Children's Charter²¹ contains a number of statements about the rights and expectations of parents whose children are sick. These include rights:
 - to take part in any discussions and decisions about the child's treatment and care and to be kept up to date with their progress
 - for the child to have a named consultant paediatrician or surgeon and named qualified nurse to look after them and provide quality of care
 - to stay in hospital with the child, participate in their care, accompany them to the anaesthetic room and be informed about pain relief

3.2 *Guidance and recommendations from non-governmental sources*

- i. In addition to the Department of Health guidance, a number of professional and voluntary bodies have made recommendations in recent years concerning the care of children in hospital^{22,23,24,25}. Most of these endorse or reiterate the standards contained in the DoH guidance in relation to parental involvement and support. Some go into more detail about how services should be managed in this respect or make additional recommendations. These additional points are summarised below:

3.2.1 *The British Paediatric Association*

- i. A 1995 report by the BPA²³ points up the "vital role" of the specialist social worker. It observes that the combination of social work skills and knowledge of rare and life threatening conditions give them an advantage in dealing with the problems that arise in families when a child has a serious disease or organ failure. It observes that in some regions, specialist social worker posts have been reduced or discontinued because of new funding arrangements.

3.2.2 *Action for Sick Children*

- i. Detailed recommendations on standards for children undergoing surgery were made in 1994 by the voluntary agency Action for Sick Children.²⁴ Guidance relating to parent's needs included recommendations for:

information:

- about wards and hospital facilities on admission
- about the reasons for starvation before operations and on what the child can eat and drink and when
- about the illness and the operation, preparation for the operation, operating procedures and routines, how to help the child, aftercare, where and how to obtain further information and advice

- about where parents can wait during the operation, how long the child is likely to be and about what is happening if delays occur
- about what to expect in the recovery room and their role
- about the likely condition of their child after the operation
- about the outcome of the operation or procedure at the earliest opportunity by a member of the surgical team and reinforced by the recovery room and ward nurses
- on how to care for the child after discharge and an emergency number to contact
- an agreed policy on the information to be given to parents on the ward and a checklist to avoid duplication or conflicting information
- a policy and procedure for interpreting services for families who do not speak English

involvement:

- in discussion on how anaesthesia will be given and assistance to parents to make an informed choice about going into the anaesthetic room
- in assessing and managing pain and information about whom to contact if parents are not happy with their child's pain control

support:

- link workers to help prepare families from minority communities and help them to express their wishes and anxieties and to ask questions
- for parents who may become distressed and anxious once the child is unconscious

- ii. The same document contains checklists for purchasers and providers covering these standards and suggests that where these are not met, contracts should be reviewed and managers should review the services they provide to see if any changes can be made. It also contains a number of examples of good practice.

3.2.3 Guidelines on the care of dying children and their families

- i. In 1988, a working party involving the British Paediatric Association, the King's Fund and the National Association of Health Authorities produced guidelines on the care of dying children and their families.²⁵ These go into considerable detail into the support needs of parents at all stages from diagnosis to bereavement including, for example, the need to:

- ensure that parents are centrally involved and treated with respect as partners in the care
- ensure good communication between parents and professionals
- ensure that parents have adequate finance
- ensure that parents are aware of the range of people (and self-help groups), both in hospital and in the community, who might help by listening and talking
- give parents the opportunity to talk to other parents in a similar situation
- offer continuity, friendship and sensitive support, responding to individual

needs

- ii. The guidelines also suggest mechanisms for ensuring that these principles are translated into practice through, for example, education and support of staff involved. They also contain a summary list of recommendations to health authorities.

4. PROBLEMS IN MEETING PARENTS' NEEDS

This section:

- briefly outlines some evidence on the extent to which parents' needs for support and counselling are being met in practice
- looks at some of the reasons why parents may find it hard to ask for support when they need it and why providers may fail to offer support appropriately

4.1 Problems in meeting parent's needs

Despite the plethora of research evidence and extensive recommendations concerning the needs of parents of children in hospital, there is some evidence that these needs are still not always being met.

4.1.1 Audit Commission report

- i. A 1993 investigation by the Audit Commission²⁶ identified the root problem as being that "clinicians, managers and other staff do not give sufficient attention to the needs of children and their families" and argued that this is manifest in a lack of written policies, management focus and poor communication between staff and parents.

- ii. **Lack of written policies and management focus**

The report observed that written policies for family-centred care often do not exist, and those that do seldom state clearly the standards to be adopted or who should be responsible for co-ordinating and carrying them out. This is because the practices have been developed in an ad hoc way by enthusiastic staff, primarily paediatricians and nurses, with little or no input from senior management. Consequently, there is no consistency from one ward or department to another and parents and children find the differences confusing and unjustifiable.

- iii. **Poor communication between staff and families**

The investigation found that:

- information leaflets rarely make it clear that parents are encouraged to stay and many parents felt their role on the ward was unclear and their experience in caring for their child was sometimes ignored
- in a sample of 47 wards admitting children (including adult wards), none had a policy of allocating a named nurse for the duration of stay of all children,

though most allocated such a nurse to a child for the duration of a shift

iv. **Lack of provision for parents**

The Audit Commission found that despite the increased demand, there remain serious deficiencies in the provision of accommodation for parents in terms of distance from the ward, lack of facilities and lack of arrangements to monitor parents' satisfaction with the facilities.

These findings are backed up by another study of provision for parents undertaken in 1995²⁷ which suggests that, at least in the region studied, a large number of paediatric wards were providing poor and inadequate facilities (expensive and inaccessible food; lack of storage or laundry facilities; no concessions on car parking costs) and accommodation for parents, and were not meeting Department of Health requirements.

4.1.2 *Problems in asking for care*

i. The research literature identifies a number of factors which may inhibit parents from asking for help and support:

- Parents who feel themselves to be unequal and relative powerless partners in the provision of care may be hesitant about pressing their requests for information^{16,28}
- Parents may be hesitant to cast themselves as needing support if they feel it would divert attention away from their child. Others may simply regard it as inappropriate for mothers or fathers to be considered as "patients" when it is their child who is ill.²⁹ Thus parents tend to turn to their own families first and request support from professional staff only as a last resort, when their personal support systems are insufficient to prevent distress spilling over and becoming a matter of overt concern to nurses.

4.1.3 *Problems in providing support*

i. The research literature also shows up some further reasons why appropriate support may not always be provided:

- Nurses do not always recognise parents' needs³⁰ and may not share their views about what issues are important.³¹
- The concept of "family-centred" care is now widely accepted in paediatrics and most staff view themselves as "family-friendly" but in practice some nurses remain concerned that through sharing their knowledge and skills with parents they may be compromising their own professional roles.³² At ward level, in most cases the practical implications of family-centred care are not clearly defined and its interpretation varies between individual staff members.

Consequently, parents experience conflicting and changing rules governing their involvement with their child.⁴ In particular, it has been found that when the going gets tough” families still tend to be regarded as “visitors”.³³ Places where there are systematic arrangements to ensure that the role of parents in caring for their children are individually negotiated with each family (such as the *Care by Parent* scheme³⁴) tend to be more successful.⁵

- The care of parents is regarded by nurses on paediatric wards as a part of their everyday work, although perceptions of the importance of this function vary.

Nurses’ perceived responsibilities include:

- explaining comments made by doctors
- teaching parents skills needed in the care of their children
- offering health education
- encouraging parents to leave the ward for a break
- counselling distressed parents

However, work of this sort tends to be ad hoc and unpredictable, undertaken in response to demand, rather than as part of a planned intervention. Time spent with parents is not seen as a legitimate nursing activity (nor is it recorded as such), and therefore such work does not have a space of its own but has to be fitted in while other things are going on. While this is the case, parents’ needs pose a potential threat to nurses control over their own work load. A systematic assessment of parents needs would have significant consequences for staffing levels and skill mix on wards.²⁹

- The research literature on parental needs and stresses is limited by the fact that studies have tended to exclude non-English speaking parents and those whose children are sickest. There is little information about the specific needs and coping mechanisms of different ethnic and cultural groups or of family members apart from parents, such as siblings and grandparents.¹⁵
- There is evidence of unequal treatment of mothers and fathers.³⁵ For example, in a study of parents of newborn infants hospitalised for gastro-intestinal surgery it was found that fathers often had different questions to ask but were inhibited from doing so because they felt ignored. Those who did ask questions invariably found that the reply was directed to the mother.¹⁶

4.1.4 Conclusion

- i. Parents’ potential needs for support and counselling when their children are in hospital are varied and extensive. They range from practical and financial assistance to psychological support in situations of acute stress. The range of people potentially involved in meeting such needs includes health service staff from ward level to management as well as friends, relatives, voluntary agencies and social services.

- ii. There is a considerable body of research on parents' needs. Many of the findings have been taken into account in policy and guidance aimed at improving the hospital experience for both children and their parents, primarily through promotion of the philosophy of family-centred care. Attention has also been given to parents' needs for more formal counselling, but this has focused mainly on specific crisis situations.
- iii. Despite the efforts to ensure that parents' needs are met, this is still not always the case. Key problems identified relate to lack of explicit and consistent policies at local level and insufficient management involvement to ensure that the resource and training implications of the policies are adequately provided for.

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