

4. The psychology of chronic childhood illnesses

E. P. Sein E. J. Eastham I. Kolvin

'It has been said to understand an individual, you must see him in love, in cards, and in drink. Better still to see him in the stress of battle or of domestic hardship. Doctors and nurses are privileged to come near to those occasions'.

Professor Sir James Spence, 1949
Newcastle-upon-Tyne

SOME CURRENT THEMES

There is an increasing awareness amongst paediatricians, child psychiatrists and their colleagues of the necessity for a better appreciation of the psychological aspects of chronic medical illness in childhood. This is allied to the recent advances in the medical management of many diseases which, previously, were often fatal. Such advances, while leading to reductions in both morbidity and mortality, e.g. in acute lymphoblastic leukaemia, may also lead to prolonged duration of care and management—as in children with cystic fibrosis and infants of very low birth weight—and a subsequent increase in the number of children in the population with chronic illness. The emphasis is therefore extending from saving lives to managing disorders on a long term basis; from cure to long term care in conditions in which there may be unremitting stress and distress for children and their families. These circumstances are bound to reflect on the families, care-givers and society and, in turn, must raise issues of treatment, of hospitalisation, of management and rehabilitation, school and education, public awareness and perceptions, and social policies.

Policies and decisions need to be based on an accurate picture. Unfortunately the technical advances have not yet been paralleled by a similar increase in knowledge and understanding of the emotional, psychosocial and educational impact of the chronic illness. Until recently, much of the current knowledge was based on anecdotal material from single case studies or from small cohorts.

Definitions

Chronic illness has been defined as 'a health condition that lasts for more than three months in a year or that leads to continuous hospitalisation for at least one month in a year' (Hobbs et al 1985). In this chapter, greater emphasis will be placed on chronic medical illness and less on mental handicaps. *Severity* is more difficult to define but it has been suggested that it should be measured on four dimensions (Hobbs et al 1985). The first is physical/physiological severity. It is relatively easy to measure severity in conditions such as haemophilia based on the Factor VIII level, but it is impossible to do so in a young child with cystic fibrosis on the basis merely of the sweat sodium level. The second dimension is the severity of psychological disturbance

of the child; the third is an economic factor, represented by the financial burden of the illness on the family, together with disruption of parental occupation. Finally, there is the extent of the disturbance of intra-familial relationships and the social functioning of the family.

Epidemiology

The rate of chronic illness in the community depends on whether one is studying point or period prevalence. Thus 5.5% of the children, aged 9–11 years, in the Isle of Wight study were found to be suffering chronic physical disease, the commonest being asthma (2.3%) followed by epilepsy (0.9%) (Rutter et al 1976). On the other hand most studies suggest that up to 10% of all children have, for a period of their childhood, a moderately to severe handicapping long term illness or disability (Perrin & Gerrity 1984, Pless & Roghmann 1971). There is also evidence of a steady increase, over the years, in the percentage of children with chronic illness in the Western industrialised countries (Gortmaker 1985).

Psychological factors and chronic illness

The relationships between chronic physical illness and psychological factors are complex, varied and often controversial. Nevertheless, clinical experience suggests that there is an interaction between illness factors and child personality on the one hand, and environmental and family factors on the other (Perrin & Gerrity 1984). In addition, there is evidence that there is a closer relationship between psychological disturbance and the maturational factors than with the severity of the illness itself (Rutter 1970, Pless & Roghmann 1971, Rae-Grant 1985).

Illness has a different meaning to young children as compared with adolescents (Orr et al 1984). A child with onset of illness in infancy or early childhood may feel abandoned on admission to hospital which may be combined with fears of intrusive treatment; these may be reflected in separation anxiety with long lasting consequences of attachment and bonding. In adolescence there will be concerns about prognosis, peer relationships, family life, education and the future; all of these are represented by associated psychological disturbance.

Psychological stresses or personality factors are no longer perceived as being of primary causative influence in most physical diseases but, nevertheless, they do contribute to the total clinical picture. Such influences are more widely recognised in conditions such as asthma, where psychological factors, though not primary, may also precipitate an attack. Furthermore, while psychological factors are unlikely to play an important part in the aetiology of malignancies, they are often integral components of reactions and attitudes of both the child and the family. For instance, an increase of non-specific psychiatric morbidity may be noted both in malignancy and epilepsy. In diabetes, such associations are less consistent.

For the purpose of prevention and management, we should endeavour to understand the underlying operative mechanisms; those postulated appear to vary according to the condition itself. For instance, in diabetes the mechanism is more likely to be an increase in the demands placed upon the child and the family, whereas in epilepsy there may be an additional direct influence by a dysfunctional nervous system.

As there are a multitude of chronic illnesses, each with their own aetiology, management and prognosis, it is unlikely that their psychological effects could be the same.

Furthermore, different families may react in different ways to the same condition; on the other hand it is helpful to seek those factors which are common to most. In addition, the picture may vary at different stages of the same illness: for example, in the early stages of a malignant illness, the child and the family have to cope with the shock, distress and anger associated with the realisation that the child's life is in serious jeopardy; if the child survives for several years, and the prognosis improves, the entire family will have to readjust to the situation. Finally further medical progress will inevitably be paralleled by changes not only in the professionals' but also in the families' perceptions, attitudes and reactions.

Some direct effects of the illness

By their very nature, some illnesses impose *limitations* which may impede development (Rae-Grant 1985). Some may entail reduction in environmental stimulation, such as immune deficiency disorders; others (e.g. spina-bifida, profound sensory disorders) may decrease mobility and thus give rise to reduced opportunities for exploration of the environment or even play; others again, such as spina bifida, congenital malformations and amputations after bone cancers, which have obvious physical signs, may lead to some degree of stigmatisation. The Ontario Child Health Study has reported that children with chronic illness associated with limitations of physical function have a threefold increase in psychiatric disorders and a significant excess of social adjustment problems. However, those with chronic illness alone have only a twofold increase in psychiatric disorders and little in the way of excess social adjustment problems in contrast to peers free of such health problems (Cadman et al 1987).

Of all chronic illness, cancer is viewed with a particular sense of dread by parents, children and society; this is especially true in adolescence where it is viewed as being more serious than all other illnesses (except heart diseases). There also exists a perception that it may be contagious and, further, that it is likely to be least responsive to treatment compared with heart diseases, diabetes and mental illness (Micheilutte & Diseker 1982).

Again, other conditions, which could lead to stunted growth and delay in secondary sexual development, may interfere with self-esteem, self-confidence and sexual identity. Examples include chronic renal failure, cystic fibrosis and diabetes mellitus. Inevitably, with further development, the child becomes increasingly aware that he/she is different, which could give rise to preoccupations with body image. Thus socialisation may become a major focus of concern or even a serious problem in adolescence. How the youth copes is dependent on an interaction between the type of the illness, the reactions of the care-takers and peers, and their own perceptions of themselves. In all these circumstances the care-taker is an important figure, having to consider ways of helping children to cope with their handicaps and their distress and having to understand each individual child's sense of frustration, distress, resentment and anger.

Pain merits special consideration. Infants who have good and firm attachments to parents have probably learned to tolerate discomfort with the expectation of its attenuation by the parents. But when this does not occur and when the illusion of the powerful influence of the parents is shattered, the child may become distressed, bewildered and fearfully anticipate further discomfort (Nover 1973). The possibility of surgery may compound such distress and fearful reactions (Głuk 1977).

MODIFYING FACTORS

Age as a factor

The age of the child at diagnosis is an important factor and seems to determine the effects of a chronic physical illness. A child born with a deformity or serious illness, irrespective of whether noted at birth or diagnosed in the first few days, may be placed in a special care unit with all the attendant medical paraphernalia. These may constitute a hinderance to attachment and bonding processes and, further, the mother may be deterred from attempting to form any deep attachment to the child because of the possibility of the child dying.

At the pre-school age, hospitalisation may well give rise to fears of abandonment by the child. Further, the child may think that the illness is a consequence of misbehaviour. At school age, the child may have to cope with the sense of being 'different' and this can be aggravated by hurtful remarks and teasing by peers.

Adolescence is the time of individuation and identity formation, and these may be affected by a chronic illness. Peer acceptance may also become a problem at this stage, for example, temptations and group pressure on a diabetic teenager on a restricted carbohydrate intake to ignore the dietary regimen when attending a party.

Hospitalisation and its effects

Up to the 1950s it was common practice in paediatric wards to pay greater attention to sterile conditions than to the needs of the child. Most of the earlier reports of the traumatic immediate effects and longer term consequences of hospitalisation were based on a small number of cases or clinical impressions; many reflected on the inhumane and insensitive approaches to policies rather than the impact of hospitalisation itself (Robertson 1958, Platt Committee 1959). With the more humane modern approaches, a single brief hospital admission is known to have little impact on most children. However, multiple or prolonged hospitalisations, such as occur in chronic illness, are another matter. Douglas (1975), on the basis of his national study, reported that one admission to hospital of more than a week's duration or repeated admissions before the age of five years were associated with both behavioural and reading problems in adolescents. These findings have been replicated, albeit on a different population (Quinton & Rutter 1976).

One important study, using post-hospitalisation questionnaires, identified six dimensions of children's responses (Vernon et al 1966): (1) general anxiety and regression; (2) separation anxiety; (3) anxiety about sleep; (4) eating disturbance; (5) aggression to authority; and (6) apathy-withdrawal. Although these do not necessarily reflect disturbance, they suggests that children between the ages of 6 months and 4 years are most likely to be vulnerable to the effects of hospitalisation with the pattern of response having a basis in separation anxiety. These responses were more evident in younger children with longer lengths of stay. This is dated research and it is doubtful that this still holds true for those paediatric wards/units where there have been substantial changes in the philosophy of care. For decades, mothers have been admitted with young children; nowadays rules about visiting are almost non-existent with open and frequent visiting being encouraged, and children are allowed to bring their own clothes and toys. While some have imaginatively pioneered ward programmes wherein

children are cared for by parents (Goldbloom 1987), some retain rather rigid traditional philosophies which may give rise to a stressful experience for the child with chronic illness. It is now widely accepted that hospital admissions should be kept to a minimum, both in duration and frequency. Preparations for admissions can reduce anticipatory anxiety and other stressful responses (Wolfer & Visintainer 1979).

Treatment effects

Some treatments may be both burdensome to the family and restrict the child's lifestyle, e.g. the need for regular dialysis in chronic renal failure, and injections of insulin in diabetes. Children may view these as symbolic of their lack of independence and opportunities for individuation and they also may become a focus of resentment, if not rebellion (De-Nour 1979, Burton 1984).

Although the prognosis of some forms of childhood cancer has improved dramatically, the treatment involved may be intensive and painful. Howarth (1972) found that amongst a group of children suffering from leukaemia, distress seemed to be related as much to medical procedures (venepunctures, sternal marrow punctures, transfusions) as to the nature of the illness. Similarly, powerful drugs may have physical side effects (such as alopecia with cytotoxic drugs and changes in physical appearance and immunity with steroids) and all these bring in their wake various degrees of psychological distress. Cosmetic remedies are now readily available, such as wigs for alopecia, which may help to alleviate distress but for others there are no remedies; for instance, cranial irradiation can give rise to progressive and permanent intellectual deterioration (Twaddle et al 1983).

Family factors

Chronic illness does not impinge on the affected child alone but potentially involves the whole family. Although some family reactions are more or less common to all chronic illness, others are more specific to a particular type. Common problems and reactions include a reorganisation of the way the family functions, economic hardships, parental adjustment reactions and even psychological disturbance and marital stress (Rae-Grant 1985). Thus family systems may become dysfunctional, often with mother accepting the main responsibility for the ill child or with the parents becoming over-involved or overprotective (Ounsted 1955), to the detriment of other family members (Minuchin et al 1978). Some parents may undergo 'anticipatory' mourning reactions; intellectualisation, irritability, depression, somatisation of their distress, denial and frenzied activity (Binger et al 1969). In the case of parents of children born with congenital malformations Drotar et al (1975) describe a distinctive or specific pattern of five stages of reactions, consisting of shock, denial, sadness and anger, adaptation and reorganisation.

In malignant illness, Marky (1982) has added definition to the picture by summarising its effects on Swedish children and their families. Most parents reported themselves as being healthy prior to the diagnosis and yet one-half developed sleeping disturbances during the *initial period* of hospital admission. Further, over the next two years about one-half of the mothers and one-third of the fathers reported not feeling well, which probably reflected their increased anxiety, sadness, fatigue and constant awareness of the disease. Subsequently, one-third of the mothers still did not view themselves as being healthy.

There are a number of reports of fathers tending to 'withdraw' from the child's illness (Binger et al 1969, Heffron et al 1973) and this probably represents their way of coping with stress; it is understandable that their wives may resent this attitude and feel they have been left to cope with the burden. The evidence concerning marital breakdowns is conflicting: some studies deny an increase in marital breakdowns (Droner 1975, Martin 1975); others have reported that in specific illness, such as Down's syndrome (Gath 1977), higher rates of marital disruption are demonstrable; others may even assert that chronic illness may draw couples closer together (Marky 1982, Koocher & O'Malley 1981). It is tempting to speculate that relationships which were satisfactory prior to the diagnosis of the illness may survive, whereas those of poorer quality may be less resilient.

On theoretical grounds it is to be expected that the siblings will be adversely affected. Their parents will be devoting an inordinate amount of time, care and affection to the ill child, and thus there will be less time and attention for the brothers and sisters, which they may resent and this resentment will express itself in a variety of ways. Anecdotal case studies and clinical research provide evidence that siblings may resent what they perceive as special affection and preferential treatment being given to the affected child. Although family dynamics may prevent the emergence of any overt hostility or jealousy, repressed hostility may reveal itself in a number of different ways, including deterioration in school work (Vance et al 1980), and the emergence of behavioural and social problems. Some siblings may develop concern and fears regarding their own health. Others may have fantasies of the affected child disappearing, and if there is deterioration or death, the attendant guilt feelings could be severe. The crisis of actual death may lead to a range of pathological psychological reactions (Cain et al 1964). On the other hand there are reports of families and especially siblings drawing more closely together (Marky 1982, Koocher & O'Malley 1981). Other clinical research suggests that the effects are directly related to the number of ill probands and the type of illness. Where an illness has a genetic basis, the presence of healthy siblings may have a positive effect in that it can reduce parental feelings of guilt and inadequacy (Rae-Grant 1985); however, the sense of guilt of parents is likely to be heightened if there are a number of afflicted children within the family. Some patterns are emerging from studies of groups of children with particular types of chronic illness: increased disturbance of older siblings of Down's syndrome sufferers (Gath 1973); all siblings of chronic epileptics (Hoare 1984a); neurotic behaviour in siblings of nephrotic children (Vance 1980).

All the above findings from clinical research appear to bear witness to the notion that siblings of probands with chronic illness are at risk of psychological disturbance and interpersonal problems. More recent epidemiological research does not appear to support these conclusions (Cadman 1987). This latter work asserts that siblings of the chronically ill enjoy good mental health and social well-being. They found only modest trends to increased emotional problems and attempt to explain the previously reported patterns in clinical literature as expectation bias by clinicians. It may well be that the notion of widespread disturbance in siblings of the chronically ill has been exaggerated and epidemiological research puts this in perspective. However, there is also the possibility that the measures used in the Ontario Child Health Study by Cadman and colleagues were not sufficiently sensitive, or that the population surveyed was too small to yield sufficiently large samples of children with special

categories of disorders such as Down's syndrome, leukaemia or nephrosis, and this may have hindered the emergence of differences. However, on balance, we must continue to accept that the siblings of chronically ill children are at risk and that risk is likely to increase with deterioration in the index child.

Other factors

Other factors have been highlighted which appear to modify the psychological adjustment of children with chronic sickness. For instance, in survivors of childhood malignancies, the following factors appear to predict adjustment (Koocher & O'Malley 1981). First, different categories of illness are associated with different outcomes: survivors of childhood cancer are more likely to have poor adjustment after diagnosis and treatment than a matched group of children with other chronic but not life-threatening illnesses (e.g. nephrotic syndrome, chronic urinary tract infection, congenital cardiac defects). This pattern of differences has been replicated in comparisons of other disorders. Hoare (1984b) confirms previous findings that children with chronic epilepsy have a higher rate of psychiatric disorder when compared with children with chronic diabetes. Second, an age of onset during infancy or early childhood appears to be associated with better adjustment. Other workers have reported that psychological impact diminishes with increasing age (Illingworth & Holt 1955). Finally, those patients who lack confidence in the outcome of their illness, or who are frequently reminded about the threats to their health, are at greater risk of adjustment problems.

However, in many ways, the above constitutes an oversimplification as there may well be complex interactions amongst factors. For example, some childhood cancers such as Wilms' tumours have an earlier mean age of onset compared with acute lymphatic leukaemia. However, the better eventual adjustment of children suffering from the former may well be attributable to its 'known to be better' prognosis, which in turn is likely to engender a greater sense of confidence in outcome.

The school and the community

The adjustment of a child with chronic medical illness to his/her school has been relatively poorly studied in comparison with mental and physical handicap. There has been less public awareness and debate about the educational needs of these children. They are being placed in 'mainstream' education with the expectation that the staff would understand their problems and cope with their needs. However, these high hopes and expectations are, in practice, unlikely to be achieved. This is well demonstrated in the study of asthma by Hill et al (1987). First, schools appeared to have underestimated the prevalence of recurrent wheeze in children. Second, some 40% of the schools said that teachers were concerned about their lack of preparation to cope with an attack of asthma. Finally, in some instances there were reports about the lack of suitable facilities for such an event. This lack of reasonable understanding of the illness and its management is bound to be amplified in less common disorders, such as epilepsy and malignant illness.

Fortunately society is becoming more aware of chronic medical illness and the stresses imposed thereby upon children and families and there has been an increase in the number and scope of voluntary and self-help organisations. However, the stigma attached to these children has not been totally eradicated.

PREVENTION AND MANAGEMENT

Counselling the family

A crucial matter is the communication of the diagnosis to the child and the family. It has often been claimed that this has been done insensitively or brusquely on the one hand and hesitantly or diffidently on the other. In this respect Graham (1986) has outlined a series of principles. First, the imparting of information should be undertaken by the most senior and experienced member of the team as soon as possible and in as open and honest a manner as possible. Second, the shocked parents are unlikely to be able to take in all the relevant information on the first occasion and so there is a need for someone such as a nurse or social workers to follow this up with further discussion. The parents would also need advice on the best way to explain to the child the diagnosis and its implications.

Another crucial issue which needs to be borne in mind is the effect of treatment itself. Possible psychological effects of some powerful drugs and the pain and psychological impact associated with some forms of interventions such as surgery and intravenous injections should be recognised and dealt with. Finally, parents and children often find simply worded and well presented leaflets containing information about the illness, its effects and approaches to management most invaluable but there are simply too few of these currently available.

Liaison with the community

This does not merely entail referring children and families who are distressed or with problems: there is a need for close and regular collaboration between members of paediatric teams and other caring professions, including social workers, child psychiatrists and psychologists. This will help to foster cross-fertilisation of ideas and understanding of the needs of chronically ill children and their families. Liaison schemes as represented by regular joint clinics have been established but so far not on a widespread basis. Some authorities argue for a core of experts who are well trained in the care of chronically ill and disabled children and who have, in addition, special skills in the assessment of psychological adjustment. They will be in strategic position to identify problems, to undertake prevention or initiate intervention.

Teachers often express the need to increase their understanding of physical conditions, but as yet there is no unanimity among educationists as to how this could be achieved. It is sensible to keep school staff informed, preferably with parental consent, and advice on management of individual children is always welcomed. Consultant community paediatricians and their colleagues are in a strategic position to facilitate such developments.

Improved public education could counter some of the myths and stigmas attached to physical conditions and in turn may help to alleviate a child's distress or disturbance. Government policies, as in the Platt report (1959), could also be of great benefit to the child and his family.

COMMENTARY

It is evident that the optimum management of children with chronic illness cannot be achieved solely by looking at their physical or physiological needs. Professionals

must not only be aware of the possible concomitant psychosocial effects in the children with chronic illness, and their families, but also must help to prevent and alleviate such effects and their sequelae. Furthermore, in view of the knowledge that the vast majority of these children are coping well, there is an urgent need to understand the coping mechanisms employed by them and their families. Indubitably, more systematic research is necessary in our endeavours to understand the interactions between chronic illnesses and their psychosocial effects. Closer liaison between various professionals is essential to ensure the provision of comprehensive and effective management programmes. Public policies aimed at improving the educational environment of affected children and increasing public understanding of the concept and impact of chronic illness are also crucial to the welfare of such children and their families alike.

REFERENCES

- Binger C M, Ablin A. R, Feuerstein R C, Kushner J H, Zoger S, Mikkelsen C 1969 Childhood leukemia: emotional impact on patient and family. *New England Journal of Medicine* 280: 414-418
- Burton L 1984 *The Family Coping with a Heavy Treatment Regime: Care of the Child Facing Death*. Routledge and Kegan Paul, London
- Cadman D 1987 Siblings — similarities and differences. Findings of the Ontario Child Health Study. Lecture — Contemporary Issues in Child Psychiatry and Developmental Pediatrics. 20th Anniversary Conference, Chedoke-McMaster Hospitals
- Cadman D, Boyle M, Szatmari P, Offord D R 1987 Chronic illness, disability, and mental and social well-being: findings of the Ontario Child Health Study. *Pediatrics* 79: 805-813
- Cain A C, Fast I, Ericson M E 1964 Children's disturbed reactions to the death of a sibling. *American Journal of Orthopsychiatry* 34: 741-752
- De-Nour A K 1979 Adolescents' adjustment to chronic hemodialysis. *American Journal of Psychiatry* 136: 430-433
- Douglas J W B 1975 Early hospital admissions and later disturbances of behaviour and learning. *Developmental Medicine and Child Neurology* 17: 456-480
- Droner S 1975 The relationship of physical handicap to stress in the family with an adolescent with spina bifida. *Developmental Medicine and Child Neurology* 17: 765-776
- Drotar D, Baskiewicz A, Irvin N, Kennell J, Klaus M 1975 The birth of an infant with a congenital malformation: a hypothetical model. *Pediatrics* 56: 710-717
- Gath A 1973 The school age siblings of Mongol children. *British Journal of Psychiatry* 123: 161-168
- Gath A 1977 The impact of an abnormal child upon the parents. *British Journal of Psychiatry* 130: 405-410
- Gluk M R 1977 Psychological intervention with preschool age plastic surgery patients and their families. *Journal of Pediatric Psychology* 2: 23-25
- Goldbloom R 1987 The care by parent unit. Lecture — Contemporary Issues in Child Psychiatry and Developmental Pediatrics. 20th Anniversary Conference, Chedoke-McMaster Hospitals
- Gortmaker S L 1985 Demography of chronic childhood diseases. In: Hobbs N, Perkins J M (eds) *Issues in the Care of Children with Chronic Illness: A Sourcebook on Problems, Services, and Policies*. Jossey-Bass, San Francisco
- Graham P 1986 *Child Psychiatry: A Developmental Approach*. Oxford Medical Publications, Oxford
- Heffron W A, Bommelaere K, Masters R 1973 Group discussion with parents of leukemic children. *Pediatrics* 52: 831-840
- Hill R A, Britton J R, Tattersfield A E 1987 Management of asthma in schools. *Archives of Disease in Childhood* 62: 414-415
- Hoare P 1984(a) Psychiatric disturbance in the family of epileptic children. *Developmental Medicine and Child Neurology* 26: 14-19
- Hoare P 1984(b) The development of psychiatric disorder among schoolchildren with epilepsy. *Developmental Medicine and Child Neurology* 26: 3-13
- Hobbs N, Perrin J M, Ireys H 1985 *Chronically Ill Children and their Families*. Jossey-Bass, San Francisco
- Howarth R 1972 The psychiatry of terminal illness in children. *Proceedings of the Royal Society of Medicine* 65: 1039-1040
- Illingworth R S, Holt K S 1955 Children in hospital: some observations on their reactions with special reference to daily visiting. *Lancet* ii: 1257-1262
- Koocher G P, O'Malley J E 1981 *The Damocles Syndrome*. McGraw-Hill, New York.

- Marky I 1982 Children with malignant disorders and their families. *Acta Paediatrica Scandinavica* (Suppl) 303: 1-82
- Martin P 1975 Marital breakdowns in families of patients with spina bifida cystica. *Developmental Medicine and Child Neurology* 17: 757-764
- Michielutte R, Diseker R A, 1982 Children's perceptions of cancer in comparison to other chronic illnesses. *Journal of Chronic Diseases* 35: 843-852
- Minuchin S, Rosman B, Baker L 1978 *Psychosomatic families*. Harvard University Press
- Nover R A 1973 Pain and the burned child. *Journal of the American Academy of Child Psychiatry* 12: 499-505
- Orr D P, Weller S C, Sattershite B et al 1984 Psychosocial implications of chronic illness in adolescence. *Journal of Paediatrics* 104: 152-157
- Ounsted C 1955 The hyperkinetic syndrome in epileptic children. *Lancet* ii: 269-303
- Perrin E C, Gerrity P S 1984 Development of children with chronic illness. *Pediatric Clinics of North America* 31: 19-31
- Platt Committee 1959 *The Welfare of Children in Hospitals*. HMSO, London
- Pless I B, Roghmann K J 1971 Chronic illness and its consequences: some observations based on three epidemiological surveys. *Journal of Paediatrics* 79: 351-359
- Quinton D, Rutter M 1976 Early hospital admissions and later disturbances of behaviour; an attempted replication of Douglas' findings. *Developmental Medicine and Child Neurology* 18: 447-459
- Rae-Grant Q 1985 Psychological problems in the medically ill child. *Psychiatric Clinics of North America* 8: 4653-663
- Robertson J 1958 *Young Children in Hospital*. Tavistock, London
- Rutter M 1970 Psychological development predictions from infancy. *Journal of Child Psychology and Psychiatry* 2: 49-62
- Rutter M, Tizard J, Yule W, Graham P, Whitmore K 1976 Research report: Isle of Wight studies (1964-1974). *Psychological Medicine* 6: 313-332
- Twaddle V, Britton P G, Craft A C, Noble T C, Kernahan J 1983 Intellectual function after treatment for leukaemia or solid tumors. *Archives of Disease in Childhood* 58: 949-952
- Vance J C, Fazan L E, Satterwhite B, Pless I B 1980 Effects of nephrotic syndrome on the family: a controlled study. *Pediatrics* 65: 948-955
- Vernon D T A, Schulman J L, Foley J M 1966 Changes in children's behavior after hospitalization: some dimensions of response and their correlates. *American Journal of Diseases of Children* 111: 581-593
- Wolfer J A, Visintainer M A 1979 Prehospital psychological preparation for tonsilectomy patients: effects on children's and parents' adjustment. *Pediatrics* 64: 646-655