



# FAMILIES, PARENTS AND CHRONIC CHILDHOOD ILLNESS



The common childhood illnesses are a regular feature of family life. Coughs, colds and a variety of other acute illnesses have to be managed by parents of all young children, with decisions to be made about the use of medications, whether to keep sick children home from school and whether to seek help from the family doctor. In two-parent families, decisions have to be made about which parent will get up at night to care for sick children and which parent will stay home from work to provide care for children during the day. Single parents have to balance the needs of sick children against those of their other children. Fortunately, for most families, these minor crises quickly pass.

However, for a minority of families childhood illness is not a transitory event. Children with cerebral palsy, cystic fibrosis, diabetes or chronic asthma do not quickly recover from their illness and return to normal functioning. The disruption to family routine caused by the need to attend medical appointments, periods of hospital admission or the requirements of special treatments is ongoing. Children with these disorders and their families experience continuing demands as the children progress through childhood and adolescence.

For families in which there is a child with a chronic illness, it is hard to escape the intimate connection between family life and the child's illness. Children rarely make their own appointments in order to obtain help, they rarely come to appointments unaccompanied and they are not legally allowed to give informed consent for their treatment. For many years, children must rely on their parents for the implementation of their treatment regimens. However, parents must accept that as children move towards adolescence they need to be given greater autonomy to manage their illness. In some cases, adolescents will reject the approaches employed by their parents and this can lead to family conflict.

cessfully with the demands of chronic childhood illness (Kupst et al. 1988; Kazak and Nachman 1991).

Several issues have acted to draw attention to the close relationship between parental adjustment, family functioning and the psychological, social and biological outcomes of children with chronic illness. First, several large scale epidemiological studies reported that children with chronic illness in the community experience more mental health problems than children who are free of such illness (Rutter, Tizard and Whitmore 1981; Cadman et al. 1987). For example, the results from the Ontario Child Health Study suggest that compared with their healthy peers, children with a disabling chronic illness have three times the risk of psychiatric disorder and a markedly increased risk for social adjustment problems (Cadman et al. 1987). These findings highlighted the potential adverse impact of chronic illness on the psychological and social development of children. They also encouraged further studies to identify why children with chronic illness are at greater risk for mental health problems. Inevitably, these studies have focused on issues such as family functioning and parental psychopathology which are known to influence the mental health of children in the general community.

A second factor which has focused attention on the family life of children with chronic illness has been the enormous growth in family systems theory over the last two decades (Barker 1986). For children with chronic illness, the early work of Minuchin et al. was particularly influential (Minuchin 1974; Minuchin et al. 1975; Minuchin, Rosman and Baker 1978). In a series of publications this group suggested that certain types of family organisation were closely related to the development and maintenance of 'psychosomatic' symptoms in children. Minuchin et al. identified several characteristics which were felt to be typical of families containing children with psychosomatic disorders and suggested that in these families the children's psychosomatic symptoms played a major role in stabilising the pattern of family organisation. Unfortunately, the lack of a comparison group leaves it unclear whether these characteristics are unique to families of children with psychosomatic symptoms or whether they are patterns which are present in many families.

Rapid expansion of family systems theory was accompanied by a considerable expansion in the use of 'family therapy' in clinical practice to help children with emotional and behavioural problems. This approach to therapy involves several members of a child's family attending therapeutic interviews which focus on exploring patterns of family relationships and trying to understand how these patterns might contribute to a child's problems. Expansion of family systems theory was also associated with an increasing emphasis on the practice of 'family medicine' in which medical practitioners place greater emphasis on viewing the family as a discrete entity (Turk and Kerns 1985). This approach encourages practitioners to make the family unit the focus of treatment and prevention rather than just focusing on

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## Interview of Past Research

Over the last two decades, research focusing on the relationship between parental adjustment, family functioning and chronic childhood illness has examined a diverse range of issues. These have included, for example, the relationship between childhood chronic illness and parental psychological adjustment (Johnson 1985; Bonner and Finney 1996), the relationship between chronic childhood illness and family functioning (Johnson 1985; Kupst and Schulman 1988; Campbell 1993; Kazak et al. 1995), and the financial impact of chronic illness on children's families (Jacobs and McDermott 1989). Other studies have focused on parental and family factors affecting treatment compliance (Baranowski and Nader 1985), parental factors influencing children's ability to independently manage their illness (Drotar and Ievers 1994), and approaches that enable families to cope suc-

individual members. Not surprisingly, the increasing use of these approaches has drawn greater attention to the reciprocal influences of chronic childhood illness and family functioning.

## **C**hanges in Health Care and Patterns of Illness

The use of shorter hospitalisations and increased home-care for even severely disabled children has also highlighted the key role played by families in caring for children with chronic illness (Korpela et al. 1992). Partly these trends have been driven by a view that better quality care is provided for children in their own homes than in hospitals or other institutions.

However, the changes have also been driven by a reduction in health services during a time of economic restraint. As these changes have occurred, the substantial economic burden of caring for children with chronic illness has passed from publicly funded health services to the individual families containing a child with a chronic illness. The financial burden for these families can be substantial, involving, for example, the cost of transportation, the cost of equipment or home renovations, and possible loss of earnings due to the need to provide ongoing home care for a chronically ill child (Jacobs and McDermott 1989). Parents and guardians of children with chronic illness have increasingly demanded greater recognition of the considerable emotional and financial burden being carried by the families of children with chronic illness.

Over the last several decades there has also been a steady change in the pattern of paediatric illness with a marked increase in the number of children with chronic illness living in families in the community. Results from the Ontario Child Health Study suggest that approximately 14 per cent of children in the community have a chronic medical condition without limitation of function, and 4 per cent have a chronic illness which limits their functioning (Cadman et al. 1986).

There are a number of reasons for the increasing number of children with chronic illness in the community including the availability of new treatments for disorders which were previously fatal at a relatively early age. These include cystic fibrosis, thalassaemia major, haemophilia, chronic renal failure, congenital cardiac malformations and a variety of cancers. For example, prior to 1973 only 40 per cent of children with cystic fibrosis survived to 14 years, while currently over 90 per cent of children with this disorder will live to this age (Hill 1985). New technologies have also led to enhanced survival rates of preterm infants. For example, currently more than 50 per cent of infants weighing less than 1000 gm at birth will survive. However, approximately 30 per cent of these very small infants will experience ongoing problems including cerebral palsy, mental retardation, hearing and visual problems and chronic lung disease (R. Haslam, personal communication, May 1996).

While the physical sequelae of chronic illnesses can be minimised, medical treatment can rarely cure these illnesses. As a result, parents and children must take substantial

responsibility for the management of these illnesses over long periods of time (Johnson 1985). This management can be very demanding for both parents and children. Take for example cystic fibrosis. This is an inherited condition affecting the lungs and gastrointestinal system. Children with this disorder suffer from recurrent chest infections, chronic sinus infections, poor growth and liver problems. If these children are to survive into adulthood, parents must carry out a complicated management program at home. This typically includes twice daily patting of the chest to encourage clearing of sputum, something which may be vigorously opposed by a young child. Each day children must take a large number of medications including antibiotics, vitamins, mineral supplements and a variety of inhaled medications. To ensure that food is adequately absorbed, children must take eight to ten pancreas tablets with each meal. Some children must endure prolonged periods of supplemental feeding using a tube passed through their nostril to their stomach. Others are chronically dependent on cylinders of oxygen which must be carried everywhere by the child or other family members. Finally, children with cystic fibrosis often require repeated long periods of hospitalisation when they experience respiratory difficulties.

## **N**ew Approaches to Chronic Illness

Recently a change in the approach to the way chronic childhood illnesses are conceptualised has encouraged new research examining the relationship between family functioning and chronic childhood illness (Stein and Jessop 1982). The proponents of this approach argue that chronic childhood illnesses are best viewed in a generic or non-categorical fashion. This reflects a view that the similarities between the problems of children with different chronic illnesses greatly outweigh the differences which arise because of the specific nature or treatment needs of individual disorders.

It is also argued that diagnoses do not adequately describe the full extent of morbidity experienced by children with chronic illness and that diagnoses may be employed inconsistently across different settings (Stein et al. 1993). The use of diagnostic labels may also lead to greater emphasis on some disorders (for example, childhood cancers) at the expense of others such as childhood mental health disorders, despite the fact that the two groups of disorders may have similar levels of morbidity and mortality.

The use of a non-categorical approach has also encouraged research to move away from the study of individual disorders or comparisons of children with and without various illnesses. Rather, the impact of common elements of the illnesses have increasingly become the focus of study. These may include, for example, the duration of the illness, the treatment intensity demanded by the illness, financial costs of treatment, or the pattern of the illness over time. The latter can vary greatly. Some disorders such as cerebral palsy are associated with relatively permanent problems, others such as muscular dystrophy

are associated with a deteriorating course over several decades, while others such as epilepsy or asthma are associated with episodic problems.

## **F**amilies and Chronic Childhood Illness

A large number of theoretical models have been employed to study the relationship between family functioning, health and illness (Turk and Kerns 1985). Most commonly however, studies of family functioning involving chronically ill children focus on the pattern of interpersonal relationships exhibited by family members. The importance of these studies has been highlighted by Kazak, Segal-Andrews and Johnson (1995) who point out that 'children live within the context of their families which have rules, organising principles and beliefs systems about health, development and illness'.

For families, Stein and Jessop (1982) suggest that chronic illness poses two forms of stress. First, they suggest that there are stresses which arise from the specific biomedical components of each condition. These may include, for example, the need to adhere to a specific diet with diabetes, or the physical vulnerability which can accompany haemophilia. Second, there are stresses common to all severe chronic illnesses such as the disruption to family routines caused by the need to attend medical appointments or the care required for a sick child at home.

Gonzales et al. (1989) suggest that it is the latter group of stresses which have more profound consequences for family life. In addition, Gonzales et al. draw a distinction between the stresses which can arise during the acute phase of an illness and stresses which emerge only after an illness has reached the chronic phase. They suggest that during the latter phase of an illness families must achieve the ability to balance the requirements to provide support for the chronically ill child and the support required for the family's own life and development.

Initially, it was assumed that stresses associated with managing a chronically ill child would lead inevitably to family problems. However, it appears that many families cope well in this situation, and only a minority of children with chronic illness develop psychiatric disorders (Cadman et al. 1987; Kupst and Schulman 1988). As a result, it has been suggested that families with a chronically ill child are much better conceptualised as a normal group of people who are reacting to an abnormal situation rather than a group of people with psychological problems (Kazak and Nachman 1991).

This has led to a change in research direction. Less emphasis is placed on trying to identify differences between families with and without a child with a chronic illness, with the expectation that the former will exhibit some form of psychopathology. Instead, there is an increasing emphasis on trying to identify the differences between families in which chronically ill children are coping well versus those in which children are not coping adequately.

Several studies have attempted to identify the family characteristics associated with the

best outcome for children and families. For example, in a ten-year follow-up of children with cystic fibrosis, Patterson et al. (1993) reported that achieving an appropriate balance between time devoted to the child's treatment and time devoted to other family activities, and a family emphasis on personal growth, were associated with a better health outcome for the chronically ill child. In a six-year prospective study of children with cancer, Kupst and Schulman (1988) reported that open communication, marital satisfaction and better family support were associated with better coping by families.

Several methodological problems have hindered research examining the relationship between chronic childhood illness and family functioning. These have included the valid and reliable assessment of family functioning. The majority of research examining the functioning of families with a chronically ill child has used one of two broad approaches to evaluate family functioning.

One approach employs self-reports obtained from individual family members who describe their families' pattern of functioning in a range of areas. The use of self-reports is inexpensive and enables collection of data from several family members which describe family functioning over set periods of time. However, the reports only represent the view of individual members and it is unclear how differences between reports should be reconciled (Sawyer et al. 1988). The highly structured nature of self-report questionnaires also tends to limit their scope, and their focus on the entire family may obscure important differences in relationships between specific dyads within families (Wade et al. 1995).

The alternative approach generally employs some form of direct observation. This can include observation in family homes or observation in clinics while families complete a specific task assigned by researchers. Direct observation is potentially a rich source of information but also has a number of disadvantages. For example, it is very time consuming to conduct studies involving direct observation of families and data collection may require considerable training of observers. Also the extent to which short periods of direct observation accurately reflect family functioning over longer periods is unclear. The greater difficulty of direct observation is reflected in a review of articles published from 1980 to 1989 which reported that 80 per cent of studies relied on a single family member to describe family functioning while only 15 per cent of studies included observation by an outside observer (Patterson 1990).

Another problem hindering family research is the difficulty in clearly defining concepts such as 'family functioning' and 'good family coping' or 'poor family coping' (Johnson 1985). Most studies have also employed cross-sectional designs and assessed family functioning across only brief intervals of time. It is unclear whether these assessments are an accurate reflection of what happens within families over much longer periods of time. This is important because the influence of family life on children's development may accrue over many years.

Many studies have also tended to include children and adolescents of widely varying age; however self-report questionnaires take little account of the developmental stage of participating children or families. This hinders the interpretation of results from these studies as it is plausible that different elements of family functioning assume greater or lesser importance for children with chronic illness at different ages. For example, approaches to behaviour management or the appropriate level of affective involvement of parents are very different for children and adolescents.

A further problem for research in the area of family functioning has been the difficulty in keeping the unit of analysis conceptually and operationally clear (Patterson 1990). In particular, there has been a tendency to confuse variables describing the functioning of individuals such as parents or siblings and variables which describe the functioning of families as a whole. Family members participating in such research may also have difficulty with this issue. While the terms 'family' and 'family functioning' are widely used in the social sciences, participants who are asked to complete self-report questionnaires can have difficulty responding to questions which ask them to rate their family as a single unit. This is a particular problem when respondents believe there are marked differences in the quality of relationships between different members of their family. In these circumstances, how they weight these differences may have a significant impact on the overall rating they assign to their family's functioning. This can make it difficult to interpret the meaning of scores on questionnaires which are designed to rate the functioning of families as a single unit.

## **P**arents and Chronic Childhood Illness

There is a vast literature examining the relationship between parental characteristics and the psychological, physical and social adjustment of children with chronic illness (Johnson 1985; Bonner and Finney 1996). This includes studies investigating: (i) the relationship between parent and child health beliefs and behaviours; (ii) the relationship between parental psychological problems and physical or psychological problems experienced by their children; and (iii) the relationship between parental patterns of health service utilisation and patterns shown by the children.

Parental factors which influence the health status of children have recently been reviewed by Bonner and Finney (1996). These authors highlight the key role that parents play in aiding children to interpret the meaning of somatic sensations such as abdominal pain, particularly when the meaning and cause of the symptoms may be uncertain. For example, somatic sensations associated with chronic illness such as abdominal distress, tremors or palpitations can also occur as a result of emotional distress. As a result, parents' views about the likely cause of their children's symptoms and the actions that parents take when their children complain of these symptoms can have

a significant influence on children's interpretation of their symptoms. Parental views also have a significant influence on the treatment regimens chosen to manage the children's problems. For example, a parent who believes that his or her child's abdominal pain is a sign of significant physical illness is likely to adopt a quite different treatment approach than a parent who believes the pain is a reflection of anxiety about school attendance.

Most studies of the psychological adjustment of parents of children with chronic illness have focused on mothers (Eiser 1990). In part this may reflect the greater ease with which data can be collected from mothers but it may also reflect a greater burden of care carried by mothers of chronically ill children. While many of these studies have been criticised because of their methodological limitations, there is evidence that mothers of children with a chronic illness are at increased risk for psychological problems, particularly depression. The impact of children's illness on fathers is less clear.

Clarification of these issues is important because of the potential influence of parental psychopathology on parents' perceptions of their children's health status. As noted by Bonner and Finney (1996), parents' appraisal, interpretation and subsequent labelling of their children's symptoms may be influenced by the parents' psychological distress. If so, this may influence the management of children's illness independent of the specific illness being experienced by the children.

Finally, there is considerable evidence that the pattern of health service utilisation shown by children is influenced by factors independent of the children's illness. These factors include high parental health care use, poor parental mental health, high maternal distress, and overall family distress (Riley et al. 1993). In their own studies Riley et al. found that predictors of child health care use included family conflict, the mother's assessment of the child's vulnerability to illness, and the mother's own pattern of use of health services. This suggests that a full understanding of parental patterns of health service utilisation will be an essential prerequisite to understanding patterns of utilisation by chronically ill children.

## **F**uture Research Directions

Despite its potential importance, Campbell (1993) has noted the paucity of research investigating the relationship between family variables and children's health. Campbell identifies two reasons for this paucity. First, he suggests that few paediatric residency programs provide training in family systems theory. As a result, it appears that paediatricians are poorly prepared both at a clinical and a research level to investigate the relationship between family variables and chronic childhood illness. Second, he suggests that there has been a tendency by clinicians to interpret earlier research, such as that conducted by Minuchin et al. (1975, 1978), as blaming families for the problems experienced by their children. This may have

deterred researchers from undertaking studies which focus on the family life of children with chronic illness.

Patterson (1990) has highlighted several areas in which future research is warranted. These include research looking at the family's role in the aetiology and maintenance of the illness, research examining the effects of illness and its treatment on the family, research investigating the relationship between families and health services, and research investigating the potential role of the family as a health promoting agency.

Patterson also drew attention to the limitations of recent studies, pointing out that very few studies have investigated the full range of potentially relevant biological, psychological and social variables in a single study. Most studies are limited to variables at only one of these levels. Patterson has also highlighted several of the methodological issues which need to be addressed in future studies. In particular, studies must include larger sample sizes to ensure that meaningful differences between groups of families can be detected. They must also ensure that representative groups of families are included so that results are relevant to a wide range of families in which there is a child with chronic illness. Finally, there is a great need for longitudinal studies which can identify coping patterns and family characteristics which are associated with the best outcome for children experiencing chronic illness.

More research which focuses specifically on the role of parents and guardians is also needed. For example, Eiser (1990:76) notes: 'We know very little about how parents modify discipline practices, or the demands or expectations of their children. There is an assumption in much clinical literature that parents over-indulge and protect sick children, but there is no substantial empirical evidence for this'. Eiser also noted that most research is based on the traditional two-parent family unit and we know little about the impact of chronic childhood illness on single parent families or newly constituted families containing siblings of different biological origin. There is considerable scope for studies which identify the impact of these family characteristics on the social, psychological and physical health for children with chronic illness.

Finally, Gonzales (1989) notes that there have been few interventions which have focused specifically on family issues, needs and stresses during the chronic phase of childhood illness. Typically, interventions occur when patients are dying or at the initial diagnosis when health education is provided for children and for the parents accompanying the children to hospital, usually the children's mother. Few attempts have been made to engage families as a whole.

## Conclusion

In summary, the study of children with chronic illness, their parents and families is at an early stage of development. Information in many areas is based on only one or two studies and in many cases the limitations of these studies are well known. There is a

need for a new wave of more refined research. This research should draw on existing knowledge but should incorporate better approaches to the measurement of key variables and employ more adequate sample sizes to ensure that hypotheses can be properly tested. Finally, there is a great need for longitudinal studies which can evaluate over time the relationship between the quality of life of children with chronic illness, parental adjustment and family functioning.

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