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.

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 Whatmore 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 Kerrs 1985). The approach encourages practitioners to make the family unit the focus of treatment and prevention rather than just focusing on...
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.

**New 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 unique medical components of each condition.

Instead, there is an increasing emphasis on the ability to balance the care required for a sick child at home. 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 more 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 how 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 coping adequately. Several studies have attempted to identify the family characteristics associated with
best outcome for children and families. For example, in a ten-year follow-up of children with cystic fibrosis, Patterson et al. (1995) 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 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. The first 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 where 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 1990 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). Many studies have 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 may 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, they may 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.

Parents 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 been recently 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. 1995). 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.

Future 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 etiology and maintenance of the illness, identifying 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 representation of groups of families is 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 (1990:70) 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 child to hospital, usually the child’s mother. Few attempts have been made to engage families as a whole.

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 the inter-time the relationship between the quality of life of children with chronic illness, parental adjustment and family functioning.

References


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