

Factors in the Long Term Adjustment of Children and Adolescents with Sickle Cell Disease: Conceptualizations and Review of the Literature

By: Joseph Telfair

Telfair, J., (1994). Factors in the Long-Term Adjustment of Children and Adolescent with Sickle Cell Disease. *Journal of Health and Social Policy*, Vol. 5, Nos 3/4, p 69-96. DOI: 10.1300/J045v05n03_06

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Summary:

This paper focuses on the psychological and social factors that influence the adjustment process of children and adolescents with chronic conditions, primarily sickle cell disease. A review of the literature will reveal that psychological variables, such as anxiety and depression affecting adjustment, are the most studied. However, it will be pointed out that social variables such as family, school, and peers, also play a major role in this process. Furthermore, in keeping with the approach of this special collection, these psychological issues will be discussed within a developmental context. Clinical teams and practitioners are encouraged to take a longitudinal-biopsychosocial approach in addressing the needs of these children and their families. By doing so, they will be able to meet the present and long term psychological, social, educational, as well as medical needs of children and adolescents with sickle cell disease and other chronic conditions, and their families. This approach will also allow professionals to recognize and utilize the strengths of this population in the promotion of their overall well-being.

INTRODUCTION

Sickle cell disease demonstrates significant variation in symptomology and overall functioning across individuals with various hemoglobin types. Often, this variation occurs independent of disease severity (Vichinsky, Hurst, and Lubin, 1983; Williams, Earles, and Pac, 1983; Powars, 1975; Vichinsky and Lubin, 1980). Specifically, it has been noted that both children and families vary in their reactions to the unpredictability and seriousness of this disorder's complications and the various treatment issues associated with the disease (Kumar, Powars, Allen, and Haywood, 1976; Lemanek, Moore, Gresham, Williamson, and Kelley, 1986; Hurtig and White, 1986; Dilworth-Anderson and Slaughter, 1986; Evans, Burlew, and Oler, 1989). Health care providers who treat individuals with sickle cell disease and other chronic conditions point to the influence of bioclinical as well as psychosocial issues as the primary factors influencing these reactions (Vichinsky et al., 1983; Williams et al., 1983; Powars, 1975; Charache, Lubin, and Reid, 1984). Of the two, psychosocial issues have been the least studied.

The focus of this paper will be on psychosocial issues within a developmental context, specifically, child/adolescent (from here forth referred to as child or children) and family variables. The variables to be discussed include indicators of children's relationship with their parents and families, their families' overall functioning, psychological functioning (i.e., anxiety and depression), and social functioning (i.e., peer relations, school environment issues, and social adaptation/adjustment).

OVERVIEW OF THE LITERATURE

Studies examining the relationship between chronic conditions and psychosocial outcomes of children generally are of two types. The first examines the relationship between the presence of the condition and the child's psychological and social adjustment. The second type looks at the impact/burden that the presence of a child with a chronic condition has on the dynamics of the family and the importance of the family to the child's adjustment. For the purposes of this paper, both kinds of studies will be discussed within the context of the child's adjustment to sickle cell disease.

CONCEPT OF ADJUSTMENT

The adjustment processes of the child with a chronic condition are usually divided into two categories—psychological and social. These categories include indicators that are commonly felt to be predictive of various levels of adjustment outcomes (Pless and Pinkerton, 1975).

Psychological Functioning

In the literature on children with chronic conditions, psychological functioning is the most studied measure of their overall adjustment to their illness (Pless and Pinkerton, 1975; Hobbs, Perrin, and Treys, 1985). Researchers look for the presence or absence of indicators of psychopathology attributed to the child's coping with a chronic medical condition (Ness, 1975; Leventhal, 1984; Coupey and Cohen, 1984). Researchers point out that the primary reason for studying the processes involved in the child's psychological functioning is that these processes hinder or enhance cognitive coping strategies needed to overcome the burden of the illness as well as the crises of normal development (see especially Pless and Pinkerton, 1975; Moise, 1986; McAmarnay, 1985; Mattsson, 1972). As pointed out by Mattsson (1972), LePontois (1986), and Fischhoff and Jenkins (1987), positive psychological functioning is essential if the child is to develop a sense of mastery over his or her condition. For example, Mattsson (1972) studied the adaptation process of children with chronic conditions to the long term stressors associated with their condition. He identified several "psychologic threats" influencing illness mastery and coping (pg. 802). These include: uncertainty as to why pain and suffering occur, developmental regression, physical restriction, social stigma, fear of death, and other threats specific to certain conditions (pgs. 803-805). He goes on to warn that if these threats are not effectively addressed, they could lead to emotional difficulties (e.g., depression, anxiety, social isolation, etc.) and poor "long-term psychosocial adaptation" (pg. 806).

The proper care of children with sickle cell disease requires that they are supported in their attempts to adjust to their condition and become functioning members of their own environments (Garbarino, 1985; Bronfenbrenner, 1979; Garbarino, 1982). If they are more depressed or anxious than expected (given the natural history of their disease), their psychological state will affect their ability to participate in their own care, creating a dependency that can last throughout childhood and into their adult lives. Therefore, it becomes important to understand the extent to which psychological factors may truly affect the adjustment of these children. This information will allow practitioners to plan and carry out effective intervention strategies aimed at improving the quality of care for these children. As part of this planning two problem areas specific to practice and research must be considered.

Cultural and Measurement Considerations

In the study of the psychological variables influencing the adjustment process of the child, it is important to have an understanding of the empirical processes involved and the criticisms related to their interpretation and measurement (Nobles, 1978).

The common practice of using psychometric instruments standardized on majority population samples with children of color presents many problems for those seeking empirical models to study individuals with sickle cell disease, as well as those attempting to interpret existing studies. Nobles (1978), Akbar (1985), Comer (1985), McCloyd and Randolph (1981), and Staples (1971) all argue that the current "interpretive framework" of Western research is, more often than not, based on an understanding and perception that reflects a "non-reality" of children of color and their families (specifically, African Americans) (Nobles, 1978, pg. 679). This, they feel, has only a limited capacity to aid in the analyses of African-American life, and has led to a "misdirecting" of these analyses and the "acceptance of erroneous assumptions and 'meanings' which define the phenomena under investigation" (Nobles, 1978, pg. 680). They point out that this framework assumes Americans are all the same (assumed cultural homogeneity) (Nobles, 1978, pg. 680), thereby failing to take into account the unique stressful social factors (like racism, discrimination, and economic isolation (McAddo, 1982)) that people of color face on a daily basis (Akbar, 1985, pg. 26; 31).

Staples (1971) argues that the analytical end result of this perspective is that the person of color is often found to be "deviant" from the "white middle class normative model." He and other researchers argue that people of color deal with life issues in diversified ways within the context of their unique social environments, and that many of these coping strategies should be seen as adaptive (Corner, 1985; Staples, 1971; Russo, 1981; Crain, Sussman, and Weil, 1971). Any model of psychosocial functioning should take into account the child's or family's adequate use of these strategies, particularly those related to the treatment or study of sickle cell disease (Battle, 1984).

Disease Considerations

In the study of sickle cell disease and other chronic conditions, it is important to examine the assumption of adverse psychological outcomes secondary to disease exacerbation. It has been noted that severe disease is not always synonymous with significant psychosocial problems of the child or family (Tavormina, Kastner, Slater, and Watt, 1976; Wallander, Varni, Babani, and Wilcox, 1989; Battle, 1984), particularly if the family is studied longitudinally (Cowen, 1985). Debate in the literature centers on the question of whether children with severe chronic conditions actually have, in general, more psychosocial morbidity than their healthy peers (Mattsson, 1972; Tavormina et al., 1976; Moise, 1986; Pless and Roghmann, 1971), or are they simply psychosocially more vulnerable than their healthy peers due to the unique stressors of their condition (Tavormina et al., 1976; Pless and Roghmann, 1971; Stein and Jessop, 1984)? That is, are there particular psychological differences between children with and without chronic conditions that predispose the first group to psychopathology, or are children with chronic conditions displaying psychological responses appropriate to the presence of a significant life stressor? Although much of the early literature (and some current) found children with severe exacerbations to have the most psychological difficulties (Mattsson, 1972; Tavormina et al., 1976; Travis, 1976; Sperling, 1976), recent reports suggest that this is not always the case and add that treatment and research should investigate and reinforce personal and social mechanisms that promote and enhance adjustment of these children throughout their developmental years and into adulthood (Hurtig and White, 1986; Moise, 1986; Tavormina et al., 1976; Battle, 1984; Cowen et al., 1985; Holaday, 1984; Collins, 1986).

For example, Murphy (1982) points out that much of the earlier research on children with chronic conditions focused on the "problems and deficits" of its subjects (pg. 81) and not on their strengths (i.e., those who assume pathology versus those who examine resilience; for example, Boyle et al, 1976 vs. Tavormina et al., 1976 (35)). Drotar (1981) states:

Investigators who study group differences sometimes assume that what is adaptive behavior for a healthy child is also adaptive for a chronically ill child who faces very different life circumstances. As a consequence, adjustment patterns that are functionally related to the unique stresses posed by a chronic illness may be prematurely judged as indicative of psychopathology . . . Since measures of psychological adjustment have been standardized on physically healthy rather than chronically ill children, inferences concerning the meaning of obtained differences between physically healthy versus chronically ill populations must be made cautiously. (pg. 218)

Moise (1986) labels this approach the "comparative deficit model" (pg. 10). She points out that although it is a popular investigative approach in the study of psychological adjustment of children with sickle cell disease, it yields very little benefit for the patients or their families and results in an overemphasis on emotional problems that sometimes accompany children with chronic conditions (pg. 10). As an improvement on this model, she suggests a *within* group analytical model (pg. 11)—one that seeks distinctions between children with sickle cell disease using a broad-based comprehensive assessment as perceived by the child and parent, and one that has direct application to comprehensive clinical practice (a biopsychosocial model). This approach allows one to look at "clusters" or patterns of psychological adjustment within groups of children to target for intervention. This model also allows treatment teams to take a preventive approach to dealing with psychological issues that are more specific to their patient population, and in the long run, can prove more effective.

Therefore, any model assessing the psychological functioning of children with sickle cell disease, particularly those models related to the treatment or research, should take into account the adequate use of unique coping strategies by the child and by the family and determine the extent of psychological distress experienced within the context of their biopsychosocial environment. This will enable practitioners to focus on the strengths of these children and their families. Suggested steps for this type of assessment are as follows:

1. Focus on the psychological characteristics of children with sickle cell disease and their families that are either adaptive or maladaptive;
2. Examine patterns of association between these characteristics and the psychological functioning of these children within their biopsychosocial milieu;
3. Design and implement interventions aimed at enhancing the optimal psychological functioning of these children; and
4. Provide, through support and education, parents and families with the practical skills to continually reinforce coping throughout the children's formative, adolescent, and adult development.

Social Functioning

Unlike issues involved in the psychological functioning of children with chronic conditions, their social level of adjustment has not been as extensively studied (Mattsson, 1972; Tavormina et al., 1976; Travis, 1976). Some of the psychosocial literature, however, has examined social functioning as related to the psychological and physical health of the child (Leventhal, 1984; Coupey, 1984; McArnarney, 1985; Starfield, 1984; Issacs and McElroy, 1980; Schlieper, 1985; Salk, 1972).

This literature suggests that social functioning not only plays a role in affecting children's (and their family's) illness adjustment, but is itself an indicator of children's illness adjustment. McArnarney (1985) discusses the important role that age appropriate *peer interactions* play in the overall psychosocial adjustment of the adolescent with a chronic condition. On the other hand, Leventhal (1984) points to the need for clinicians to focus on and to encourage patients and their families to carry out their *normal family roles* as part of the family's adjustment to the child's illness. Similarly, Stein and Jessop (1984) state that in terms of treatment and management issues, chronic childhood illness "has biologic, behavioral and *social* manifestations" causing strains in a variety of areas— "economic, emotional, marital and social" (pg. 190).

The following sections will briefly review how the social functioning of children with chronic conditions is understood in the literature and will also examine three areas of social functioning influential in children's adjustment: family socialization, peer relations, and school relations.

Social Functioning/Competence

Social functioning is generally linked to children being able to carry out prescribed developmental "roles" in light of their chronic condition (McArnarney, 1985). For example, the adolescent with sickle cell disease who has not yet reached puberty, is nevertheless expected by his or her peers and others to be involved in dating and other teen social rituals. How well they do this determines their level of social functioning (Diamond, 1983). Because biomedical technology has allowed these children to live longer lives, social competence (ability to carry out these roles) is emerging as an important issue (Hurtig and White, 1986; Coupey and Cohen, 1984; LePontois, 1986; Earles, 1986; Pearlin and Aneshensel, 1986).

Longer, potentially more active lives, means that these children are faced with the need to develop socialization skills that will allow them to adequately function in childhood, adolescence and through adulthood (Coupey and Cohen, 1984, pg. 211). For the practitioner, learning to enhance a child's ability to psychologically cope with his or her illness is no longer adequate. As children begin to broaden the sphere of their interactive environments, they will be faced with new external demands and challenges and will need a broader repertoire of coping skills.

Thus, in understanding what influences patients' disease course variation, from a psychosocial perspective, it becomes important to look not only at individual psychological processes, but also at their interactive processes with the social environment. Research addressing these social processes for children and adolescents has primarily focused on several indicators. They are (1) school activities (e.g., school performance); (2) relationships with family and peers; and (3) general social isolation or withdrawal (see Dilworth-Anderson and Slaughter, 1986; Pless, 1976; Moise, 1986; Hymovich, 1976; Garbarino, 1982; Schlieper, 1985; Connor, 1975; Walker, 1984; Weitzman, 1984; Bierman, 1987; Orr et al., 1984; Bordman et al., 1975; Evans, Burlew and Oler, 1988).

It is true that these children may face social developmental challenges that are the same as their "normal" peers, but *how* they experience them is determined by the course of their physiological and psychosocial illness experience. For example, McArnerney (1985) argues that enhancing adequate social functioning is particularly important for adolescents with a chronic condition because,

Their social experience may differ from their normal peers by (1) their exclusion from school activities secondary to school absences; (2) their inability to keep up playing with peers, as well as exclusion from peer activities because of feeling ill or different; and (3) the lack of opportunity for normal, informal interaction with peers in or out of school. (pg. 90)

Thus, understanding how these children experience their social environments is important, particularly the experiences they have with family and peers.

Role of Family: Socialization and Medical Care

The primary socialization unit of children is the family (Dilworth-Anderson and Slaughter, 1986; Pless and Pinkerton, 1975; McArnerney, 1985; Fischhoff and Jenkins, 1987; Battle, 1984; Bronfrenbrenner, 1973; Alleyne et al., 1976; Chess et al., 1980; Prendergrast, 1975; Mechanic, 1964; Burr, 1985; McCollum and Gibson, 1970; Werthhiem, 1975) and as such, it can play a major role in their social adjustment (McArnerney, 1985; Fischhoff and Jenkins, 1987). Children also contribute to this relationship (Chess et al., 1980). In fact, a reciprocal relationship exists between the family as it influences the unique sociocultural development of the children, and the contribution of children to the family's development (Dilworth-Anderson and Slaughter, 1986; Mattsson, 1972; LePontois, 1986; Garbarino, 1982; Staples, 1971; McAddo, 1982; Russo, 1981; Crain, Sussman, and Weil, 1971).

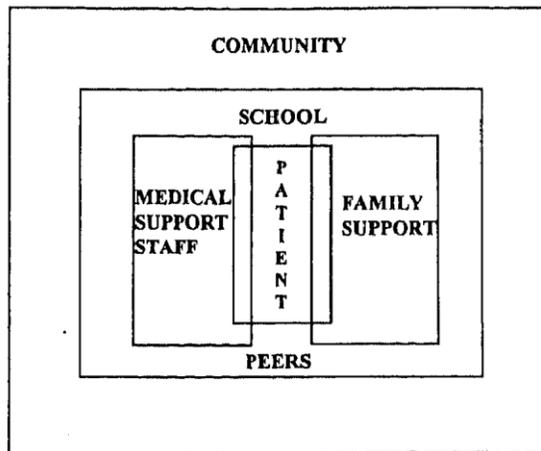
Positive functioning in the family social environment occurs when there is a "goodness-of-fit" (Chess et al., 1987; Schalock and Jensen, 1986) between the demands and characteristics of the family and the demands and characteristics of the children (both individual and disease related). This implies that a balance between the dynamics of children and the dynamics of their family must exist for optimum promotion of both children and family illness adjustment.

The understanding of social factors that influence children's development of coping strategies would be incomplete without some understanding of the context of their family environment (Pless and Pinkerton, 1975, pg. 128; Hobbs, Perrin, and Ireys, 1985; Burr, 1985; McCollum and Gibson, 1970; Pless and Satter-White, 1975), and the role played by the parent(s). Moreover, the social unit or "field" (Kellam and Ensminger, 1980; Kellam et al., 1983) of the family is seen as the foundation for the child's early development of needed social skills to cope with the outside world (McAddo, 1982; Battle, 1984).

Within the overall personal support system of children, family forms the most vital link and is important to their treatment milieu along with the other vital link—the medical staff (Lemanek, 1986; Pless and Pinkerton, 1975; Leventhal, 1984; Mattsson, 1972; Burr, 1985; Perrin et al., 1972). If one considers the child's support system as consisting of several layers, parents and medical staff would be the inner layer (school-peers and the community comprising the other layers). This is illustrated by the Venn diagram in Figure 1.

This model is based on the writings of Battle (1984), Pless and Pinkerton (1975), and Vavasseur (1977). They discuss the importance of the inner connected roles of the health care provider and the parent in affecting the health outcome of children with a chronic condition, in this case children with sickle cell disease. Although the roles of the family and medical staff are defined by the separate context within which they function (Boykin and Toms, 1985; Parson, 1958; Hobbs, 1975; Evans, Burlew and Oler, 1988), they become interdependent via their link of mutual concern for the health and well-being of these children. As the model illustrates, they are physically separate, but their influence overlaps within the inner sphere of the social system of these children.

**FIGURE 1
STRUCTURE OF THE SICKLE CELL CHILD'S SOCIAL SYSTEM**



Because children with sickle cell disease create a dynamic of reliance on the family and medical staff (Lemanek, 1986; Hurtig and White, 1986; LePontois, 1986; Battle, 1984; Conyard et al., 1980; Vavasseur, 1977), this interdependence (of family and staff) is felt to be functioning on two levels: (a) their mutual influence and relationship with these children, and (b) their interrelationship with each other. These functional roles move them into the place of primary social agents that significantly influence children's adjustment to their condition. For example, Mattsson (1972) states that from his experiences,

The successful psychological management of a child with a long-term physical illness and his family depends on two *interrelated* factors—continuous support of the medical staff and parents' acceptance of the disease. (pg. 806)

Others have also emphasized the importance of family and medical staff support (Williams, Earles, and Pack, 1983; McArnamey, 1985; Peters and Massey, 1981; Battle, 1984; Holaday, 1984; Stein and Jessop, 1984; Burr, 1985; Offer, Ostrow, and Howard, 1984; Hurtig, Koepke, and Park, 1989). Just how this influence of the family may be manifested is discussed below.

Role of Family: Caregivers

Research and clinical practice have principally focused on the influence that changes of the individual member, the child, have had on the overall functioning of the family, either at a single point in time or longitudinally (Burlew, Evans, and Oler, 1989; Burr, 1985; Pless and Satter-White, 1975; Morgan, 1988). Research by Burlew, Evans, and Oler (1989) on families of children with sickle cell disease suggests that children's illness can alter the dynamics of the parent-child relationship, increase the amount of emotional strain on the primary care taker and the family, and cause financial hardship (pg. 161).

The family's responsibility in caring for their children, and the consequences of this on the family system is labeled the "impact on" or "burden of" the family (Stein and Reissman, 1980). The interactive relationship between the family's level of burden and their ability to fulfill certain tasks of adaptation is seen as a

determinant of their coping status (Battle, 1984; Holaday, 1984; Spinetta, 1984). For example, Stein and Riessman (1980) in discussing the development of their scale to measure family burden, point out that illness related events (such as acute exacerbations) cause changes in the family that force "adaptations in the family environment" (pg. 466). This approach is consistent with a family systems perspective. Each system functions as a whole and the parts are functionally interdependent, so changes in one part necessarily cause changes in the whole system. Thus, exacerbations of illness in the child (intrinsic changes) can theoretically alter the functioning of the family system (Wallander et al., 1989; Collins, 1986; McCollum and Gibson, 1970; Bordman et al., 1975; Fordor, 1979; Campbell, 1975; Liem and Liem, 1978; Berkman and Breslow, 1983; Berkman, 1984; Hopper, 1983; Thoits, 1986; Venters, 1981; Litman and Venters, 1979; Dembo et al., 1956).

What has not been systematically studied in the sickle cell disease literature is the functional relationship or role the dynamics of the family system has with the illness adjustment process of children. In other words, the reverse should also be true; changes in the family should influence changes in children, and in turn effect their ability to deal with their own intrinsic processes and interactions with other microsystems (like school and peers). Although not as well examined in chronic disease, this assumption has been implied by many writers (Pless and Pinkerton, 1975; Leventhal, 1984; Moise, 1986; Collins, 1986; Chess et al., 1980; Bordman et al., 1975; Edelman, 1985).

Child-family relationships (with siblings, parents, and other relatives) have been noted as vital to understanding the normal functional development of children (Boykin and Toms, 1985; Spinetta, 1984; Johnson, 1982; Hunt and Winokur, 1961), as well as their adjustment to their condition (Dilworth-Anderson and Slaughter, 1986; Moise, 1986). Clinicians working with children with sickle cell disease have observed that the child's family is intimately involved in the child's overall well-being (Charache, Lubin, and Reid, 1984). Children and families vary in their reactions to complications and treatment issues. Some children and families cope well with the "ups and downs" of the disease, while others have a difficult time regardless of illness complications or prescribed treatment. There are many possible reasons for these differences.

Stress research has shown that individuals and families living under adverse social conditions or experiencing a significant stressor (i.e., illness of a family member), are at higher risk both to be functioning poorly and to have more negative health outcomes than those individuals and families experiencing better conditions (McArnarney, 1985; Russo, 1981; Crain, Sussman, and Weil, 1971; Wallander, 1989; Murphy, 1982). Further, the quality of the family environment, children's integration or isolation from their families, and the quality of the family's social networks and sources of social support, all influence children's adjustment to their illness (Dilworth-Anderson and Slaughter, 1986; Stein and Jessop, 1984; Collins, 1986; McCollum and Gibson, 1970; Egbuonu and Starfield, 1982; Berkman, 1984; Thoits, 1986).

Lastly, others (Battle, 1984; Stein and Jessop, 1984; Mechanic, 1964; Burr, 1985; Kovacs et al., 1986; Phillips, 1973) have found two major family characteristics particularly valuable in ensuring the child's successful or unsuccessful illness adjustment. These characteristics are of particular interest to clinical teams working with children with sickle cell disease because they allow them to focus on areas where family intervention would be most effective. These are child-family relations and family functioning.

Child-Family Relations. Studies suggest that children's relationships with siblings, parents and other relatives are vital to understanding their psychosocial development (Spinetta, 1984; Boykin and Toms, 1985; Johnson, 1982; Hunt and Winokur, 1961), as well as the child's adjustment to the adversities of life, especially illness (Hurtig and White, 1986; Moise, 1986; Murphy, 1982; Bordman et al., 1975; Russo, 1981; Cowen et al., 1985; Wallander et al., 1989; Holaday, 1984; Pless and Satter-White, 1975; Kazak, 1986; Venters, 1981). McAmamey (1985) observes, "disabled (chronically ill) young people who have supportive families, do better psychosocially than those with few family supports" (pg. 98). Children's ability to articulate their fears, anxieties, and frustrations associated with their condition to supportive and understanding parents is essential in their developmental process (Burr, 1985).

Further, in children's development of mastery over psychosocial barriers resulting from adversities associated with their chronic condition, the consistency of parental management plays a vital role. Winterbottom (1955) hypothesizes that "children who are more intensely and frequently rewarded for accomplishments are more highly motivated and that children who are more frequently and intensely punished for failure are more highly motivated" (pg. 455). She argues that consistency of demands on the child reflects the parent's opinion of the child's ability to achieve in life (pg. 454). Thus, congruity in parenting style (rewarding or punishing) is seen as communicating to children with chronic conditions parental confidence in their ability to perform social tasks and to carry out certain sick role expectations, such as learning pain management strategies. This confidence is viewed as positively effecting the ability of children to adjust to their chronic condition.

In the child's development of particular health beliefs and behaviors, parents play a major role (Mechanic, 1964; Campbell, 1975). In the literature on children with chronic conditions, Pless (1976, pg. 169) and others (Garbarino, 1982; Murphy, 1982; 46) have noted that the health attitudes, beliefs and behaviors of these children during their formative years (6-12) are strongly influenced by their parents. Mechanic (1964) and Campbell (1975) hypothesize that in the case of children without a chronic condition, a "teaching" and role "learning" process occurs (Mechanic, 1964, pg. 445). In this process the mother is "teaching the child to respond to symptoms of illness . . . also teach him how to respond to these signs" (Mechanic, 1964, pg. 445). Thus, "illness behavior" is seen not only as influenced by characteristics of the child's illness, but is also socially influenced (in this case by the parent). As part of their intervention strategy, clinical teams must seek to continually assess and support good relations between children with sickle cell disease and their parent(s). If poor relations are found, clinicians must decipher their source and provide assistance as is appropriate for that family. Note that not all attempts to aid families are successful or even desired, but nonetheless attempts should be made and the effort noted. Continuity and availability are the keys, for if children and/or families know that assistance in dealing with their interactional difficulties is available, (through sources known to them), they are much more likely to seek help when they need it.

Family Functioning. Pless and Satter-White (1975) suggest that a primary determinant of children with a chronic condition's relationship with their family is the level of "family functioning" (pg. 41). It is not just the internal workings of the family that influence family functioning, but external social demands or supports such as economic, job, and other day-to-day realities (Moise, 1986; LePontois, 1986; Morgan and Jackson, 1986; Edelman, 1985; Linheim and Syme, 1983; Hopper, 1983).

The task of the family to cope with the presence of the child with a chronic condition is assumed by many to be very difficult and should be of primary concern to those who treat these children (Williams, Earles, and Pack, 1983; Hobbs, Perrin, and Keys, 1985; Battle, 1984; Holaday, 1984; Sabbeth, 1984; Whitten and Nishiura, 1985). As several authors have pointed out (Murphy, 1982; McCollum and Gibson, 1970; Morgan, 1988; Kazak, Reber, and Carter, 1988; Sabbeth and Leventhal, 1984), the introduction of chronic illness into the family system is a test of the family's resources. It could bring family members closer together or cause major disruption of familial subsystems, i.e., parenting roles, marital relations, relations with siblings. Others studying children with a variety of chronic conditions (Dilworth-Anderson and Slaughter, 1986; Hymovich, 1976; Battle, 1984; Stein and Jessop, 1984; Chess et al., 1980; McCollum and Gibson, 1970; Kazak, Reber, and Carter, 1988) have pointed to these same findings and add marital disruption, divorce and distress, and psychopathology in both parents and children to the list of negative outcomes.

Therefore, functioning can be adequate or inadequate depending on a number of familial characteristics and psychosocial circumstances such as: (1) the parents' level of understanding and beliefs about the child's illness; (2) the quality of the child's family environment; (3) the children's level of integration or isolation from their family; (4) family structure; and (5) the quality of the family's social networks or sources of financial and social support (Bronfenbrenner, 1979; Issacs and McElroy, 1980; Connor, 1975; Kellam and Ensminger, 1980; McGrath, 1978; Bordman, 1975; Linheim and Syme, 1983; Liem and Liem, 1978; Litman and Venters, 1981; Dembo et al., 1956).

Thus, the ability of the family to adequately cope with and adjust to the child's chronic condition is a long and complex process involving a host of social, behavioral, and psychological variables. Further, not only can the relationship of children with their parents and family have a direct influence on their illness adjustment, this relationship is also determined in large part by the family's own level of adjustment.

For all children, the workings of their family are related to their overall well-being. Therefore, it is especially important for children with sickle cell disease to have adequate family resources to deal with the hassles of day-to-day life (as well as the added burden of a long term illness). As part of their intervention strategy, it is essential that clinical teams continually assess the functioning of the sickle cell child's family and support actions (by team and family) aimed at enhancing long term disease adjustment (Steidl, 1980).

Peer and School Relations

Peer Relations. Like the family, peer relationships are an essential influence on children's development (McArnamey, 1985; Battle, 1984; Bronfrenbrenner, 1973; Gath et al., 1980; Connor, 1975; Walker, 1984; Bierman, 1987). As children attempt to be independent of their parents, interactions with and acceptance by peers become very important (Erikson, 1968). Literature on children and adolescents with a chronic condition indicates that poor peer relationships are related to poor illness adjustment (Leventhal, 1984; McAmamey, 1985; Mattsson, 1972; Issacs and McElroy, 1980; Orr et al., 1984). McArnamey (1985) and Weitzman (1984), point out that adolescents with chronic conditions who have poor overall psychosocial functioning have very little or no peer contact, or are overly adherent to peer norms without necessarily seeing their peer group as supportive.

Peer contact is particularly important during adolescence. It is a time when body image and autonomy are significant issues. McArnamey (1985) and others (Williams, Earles and Pack, 1983; Hurtig and White, 1986; Drotar, 1981; Orr et al., 1984; Morgan and Jackson, 1986) suggest that peer contact is influenced by children's ability to deal with bodily changes, other physical restrictions secondary to their condition, and the given of a prolonged dependence on their parents for care.

Orr et al. (1984), for example, suggest that poor peer functioning is correlated with moderate and severe illness (pg. 156). In 1976, he and his colleagues followed up on a sub-sample of children 6 to 14 years (first sampled in 1968) from the Rochester Child Health Study in order to assess psychosocial functioning of those with chronic medical conditions. Using the California Psychological Inventory (CPI) as their primary assessment tool, one hundred and six (106) young adults and adolescents were examined. They compared this group to a "healthy" peer group matched on age, sex, socioeconomic status and race. They found those with "persistent" medical problems demonstrated a larger number of psychosocial problems centering around school, peers and family life than the "healthy" controls and those with less severe illness (pgs. 155-156). (These investigators pointed out that their findings of differences were "small but measurable" (pg. 152).)

In her discussion of children with sickle cell disease, LePontois (1986) points out that the quality of their relationships with their peers interacts with their psychological adjustment to influence their overall psychosocial well-being (pgs. 78-79). That is, what these children bring to the peer group is reflected in the way they are accepted and treated. The literature on children without chronic conditions has also found this relationship to be true (see Crain, Sussman, and Weil, 1971; Kellam and Ensminger, 1980; Kellam et al., 1983; Boykin and Toms, 1985). Therefore, LePontois (1986), Orr et al. (1984), and others (Leventhal, 1984; McArnamey, 1985; Issacs and McElroy, 1980; Sabbeth, 1984), advise practitioners and parents to encourage these children "to develop characteristics, skills, and talents that add to their sense of accomplishment and that make a positive contribution to" their peer group (Weitzman, 1984, pg. 68).

School Issues. For children with a chronic condition, success in school is often perceived as indicative of good social adaptation to their illness (Kumar et al., 1976; Pless and Pinkerton, 1975; Crain, Sussman and Weil, 1971; Schlieper, 1985; Klienberg, 1982). Children with chronic conditions are often at risk for having problems in school, most commonly academic performance. Frequently cited reasons include disruptions of attendance

and inability to participate successfully due to disease exacerbation (Morgan and Jackson, 1986; Serjeant, 1985; Conyard et al., 1980). Further difficulties have included emotional-behavioral problems (Weitzman, 1986, pg. 800), relation problems with peers and teacher (Issacs and McElroy, 1980), and dissatisfaction with the school placement (Weitzman, 1986). In addition, some of the literature on children with and without chronic conditions, suggests that children's success in school is also affected by their home environment (Oath et al., 1980; Connor, 1975), their self-esteem/self-image (Coupey and Cohen, 1984; Weitzman, 1986), their parental/family resources (Pless and Pinkerton, 1975), their sociodevelopmental age (Issacs and McElroy, 1980), and their school social life (Williams, Earles and Pack, 1983; McAmamey, 1985; Walker, 1984; Weitzman, 1986; McGrath, 1978).

Schlieper (1985) points out that when these children do attend school, they do quite well, but due to the nature of their conditions they are at risk for academic failure (pg. 75). She and others (Walker, 1984; Weitzman, 1984; Gutstadt et al., 1989) have argued further that it is the dynamics between children's problems and their family's ability to cope with the effects of their disease (and the resulting school disruptions), more than disease exacerbation, that is the primary risk factor for failure. Thus, school success is closely related to the psychosocial functioning of children and those factors that impact on them, such as the familial environmental factors of child-parent relations and overall family functioning.

Therefore, children should be encouraged to take advantage of special opportunities that may be available to them, i.e., after school tutoring, work with peers, etc. Parents should be encouraged to work with the teachers of their children in an effort to keep up with their progress and to discover ways in which they can help children succeed academically. Practitioners can work with parents and teachers by keeping track of the progress of children in school and by assisting them in identification of the etiology of problems, i.e., neurological or behavioral, etc. By developing a pattern of working together, all involved can assist children in acquiring skills they will use for the rest of their lives.

In summary, school and peer interactions are the work and social life of children. For children with sickle cell disease, the importance of their ability to adapt well to a peer group and to the demands of school cannot be overstated, particularly since school absence is a common problem among these children. Weitzman (1984) points out that "although the family remains very important to the child throughout this period, experiences within the school and peer group exert major influences on the development of school-aged children" (pg. 59). He goes on to state that the influence of school and peers becomes instrumental in addressing major developmental tasks of childhood (pg. 59). These include the following:

1. Separation from the family and the development of a sense of belonging and identification with values, rules, and standards of the peer group and larger society.
2. Acquisition of social skills and values that are necessary for comfortable and effective interactions with others.
3. Development of a sense of accomplishment.
4. Learning how to effectively cope with stress, anxiety, impulses, and frustrations, and discharge emotions in a socially acceptable fashion.
5. Adjusting to a work setting and acquiring the skills and attitudes that will eventually result in self-sufficiency.

Thus, the concern of clinical teams and practitioners should be children's success in school and with peers as they may be indicators of overall social functioning and of the children's ability to fulfill key developmental tasks.

DISCUSSION

The focus of this paper has been on psychological and social factors that influence the adjustment of children with chronic conditions, particularly those with sickle cell disease. A review of the literature revealed that psychological variables affecting adjustment (i.e., anxiety and depression), are the most studied. However, it

was argued that social variables such as family, school environment, and peers, also play a major role in this process. This paper supports the perspective that parents and families play a major role in the illness adjustment process of children and adolescents with sickle cell disease. Integrating mechanisms that could assist them in reducing the burden they may have in caring for these children should be a part of any practice committed to their treatment.

Multi-disciplined ongoing assessments from the birth of the child on would prove the most effective because they would provide for the early identification and amelioration of psychosocial problems that in the long run could prove difficult for the child and family. Clinical teams and practitioners are encouraged to take a longitudinal-biopsychosocial approach that provides quality, comprehensive continuity of care that addresses the needs of children with sickle cell disease and their families. By doing so, four specific psychosocial outcomes relevant to these individuals can be achieved. These are:

- a. Effective treatment strategies that meet the needs of the children and their parents,
- b. Effective dissemination of psychosocial information to parents and children that is relevant to their needs and particular situations,
- c. Understanding the variations in coping of the child and of the parent with the child's disease, and
- d. Understanding how children and parents cope when the child is not ill (asymptomatic); that is, outside of the medical setting.

Addressing these outcomes has direct implications for clinical practice and future research.

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Notes:

Funding for this research was provided by the Heart, Lung, and Blood Institute of the National Institutes of Health (Grant# 5P60 HL28391-10).

Special thanks to Margaret Ensminger, George Dover, Barbara Curbow, and Jeffrey Johnson for their review of early drafts of this paper. Major thanks to Ann Earles and Elliott Vichinsky for their time and support. Thanks to Michelle Hughes for her editorial revisions of the final draft. Thanks to Kermit Nash for support during post-doctoral time to finish work on this paper.