# CHRONIC ILLNESS AND ITS EFFECTS ON THE FAMILY SYSTEM
## A Literature Review

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The diagnosis of a chronic physical illness in a family creates a crisis which results in the family's change in order to accommodate for the illness. Change can be described in three ways:

1) Structural changes, i.e., in terms of alliances, coalitions, generational boundaries and hierarchical structure;

2) Developmental changes, i.e., family organizes around the disease and focus shifts from developmental tasks of the life cycle to stages of disease and recovery of its ill member and

3) Communicational changes, i.e., pre-existing patterns of communication affect family's ability to communicate about, and cope with, the disease. In turn, ability to cope effectively with the illness influences style of communication and expression of affect. How a family changes as a result of the illness depends, not only upon the unique combination of its current members, but also from the way past generations have resolved and/or adapted to similar situations, and from the way the medical system and the larger social context will react to, and interact with, the family.

The current literature review will focus on how chronic physical illness affects the family's structural, developmental and communicational functioning. Suggestions for intervention will also be discussed.

## STRUCTURAL CHANGES

Peggy Penn (1983) and Gillian Walker (1983) describe the primary coalition that develops between ill-child and caretaker parent as the most important shift in alliances within the family. These coalitions cross generational boundaries but are not kept secret or denied in the usual sense. They look adaptational, i.e., dictated by the demands of the illness. Mother, who is usually the primary caretaker also develops coalition with treating persons (Penn, 1983) leaving father even further outside the relationship.

Peggy Penn (1983), Gillian Walker (1983), and Michael Glenn (1982) emphasize the importance of understanding how the past influences the present, i.e., how past generations handled patterns of coalition formation, illness and dysfunction. Patterns that develop in response to the illness, and are powered by irresolution’s from the past, are resistant to change. When change is anticipated, in these families, it is usually negative change, death, or further deterioration. To introduce the possibility of another change, of any sort, especially a structural one like the dissolution of a coalition, increases the family's resistance and serves to reinforce the present structure. These coalitions were termed "binding" by Peggy Penn (1983) "because they are rigidly committed to one course and one outcome; it is as though the characters in the sequence are literally bound together." (p.22) Velasco de Parra, et.al. (1983) defines a common diagnostic pattern around which a family with a leukemic child reorganizes its structure. Family displays tendency to isolate from the rest of the surrounding world and the family boundaries are diffused in regard to the family of origin. Generational boundaries break; maternal grandmother or oldest daughter ("parental child") enter the parental subsystem. The ill child is also included in the parental subsystem and along with mother acquires authority and a central position through his/her disease. The ill child invades the couple's relations even in the intimate area.

According to Walker (1983) the relationship most vulnerable to disruption is the parental marriage which may lose its primacy to the caretaker-parent/ ill-child coalition and to a secondary coalition which the caretaker-parent forms with the medical professionals treating the child. Bruhn (1977), Velasco de Parra, et.a1. (1983), and Walker (1983) write that father and siblings are forced in a peripheral and lower hierarchical position. Interestingly enough, however, overt counterbalancing coalition between one of the well children and the non-caretaking parent seldom occurs (Walker, 1983).

Friedrich (1977), Lavinge (1979), and Cassady (1982) report that siblings may in fact bring family for therapy because of behavioral problems. Problems ascribed to an individual are relational and can be seen as attempts to resolve coalition shifts in the family (Sheinberg, 1983), although the family is unaware that problems stem (or are related) to the illness.

Velasco de Parra, et.a1. (1983) report that in 8 out of 10 families, with a leukemic child, feelings of increased togetherness was obvious in response to the diagnosis. However, in two families there was a complete breakdown in the family structure. Bruhn (1977) writes that family breakdown often results because family members cannot or will not change roles and reallocate tasks.

Soon after the diagnosis all previous family rules and norms change dramatically in response to patient's needs. Despite the increased feelings of togetherness, Velasco de Parra, et.al.(1983) observed that individual limits become closed and rigid. Everyone is locked up in thoughts of guilt, sadness, and fear, being absolutely unable to externalize their feelings.

Mc Collum and Gibson (1970), Bruhn (1977), Friedrich (1977), Tsiantis, et.al. (1982), and Eisenberg, et.al. (1984) report that families who have a member with a chronic illness invariably go through a phase of grieving of the loss of the healthy child they were hoping for. Furthermore, in hereditary illnesses feelings of guilt, shame and self-blame are high. Anxiety about the illness and about death, depression, and denial of the problem and the feelings it creates, are commonly found among parents of children with a chronic illness and affect the well being of all members of the family with particular repercussions for the child's psychological adjustment to his/her disease.

## DEVELOPMENTAL CHANGES

Not much has been written about the effect chronic illness has on the life cycle of the family. Peggy Penn (1983), however, writes that "… when a family's evolutionary time seems to stop, the system becomes dominated by the recovery time of the patient. This means other events that would normally unfold in the course of time have less priority than the illness, for the system is making sense of itself only around the recovery of its ill member ... It is as though no other event may exist simultaneously with the illness ... " (p. 23). However, the recovery time of the individual depends on recovery time of the family. Family and individual are interdependent and so is their emotional and physical well being. Marcia Collins-Moore (1984) describes the crisis which the birth and diagnosis of a chronically ill infant provokes for the family. Parents and other family members are confronted with a traumatic and unexpected situation which shatters their dreams and upsets their equilibrium. After the initial shock and denial subside, family goes through a period of intense mourning and grieving which is accompanied by feelings of guilt, inadequacy, anger, and depression. Adequate resolution at this stage is important in order for the family to be able to move beyond the losses and focus on normal developmental tasks.

Herz (1980) writes that "... the degree of emotional fusion between a parent and child is a good predictor of the degree of family disruption at the death or illness of the child. That is, the more the child is viewed as an emotional extension of self, the more disruptive his/her serious illness or death will be to the family" (p. 227). She also describes how the effect of diagnosis of a serious illness varies depending on the stage at which both individual and family are. In those instances in which the adolescent is chronically or seriously ill the adolescent and the family are often engaged in a prolonged weaning process. The family fearful and concerned about their child's health, often act to protect the child by keeping the adolescent within the family fold. The family's ability to attend to, and adequately resolve, age appropriate developmental tasks is important for adequate coping and adjustment of ill child.

## COMMUNICATIONAL CHANGES

Adequate communication among family members is affected by the presence of the disease. Tsiantis, et.al. (1982) report that although everybody in the family knew and experienced the burden of the illness nobody talked openly about it. Thoughts and feelings were not shared and parents could not or would not answer questions the child had regarding his/her disease. This "conspiracy of silence" intensified feelings of alienation and isolation of both the family and the child from the larger social context. Reduction in interfamilial communication, feelings of social isolation and disturbances of sexual relationship among parents are also reported by Mc Collum and Gibson (1970).

In a study by Caldwell and Pichert (1985) the communication patterns of 30 families with insulin-dependent diabetes were explored. "Functional communication patterns", i.e., where members provide clear messages in context with the situation, correlated significantly with lower levels of felt stress for both diabetic child and his/her siblings, as well as for parents. Furthermore, total family stress correlated with siblings' and diabetic children's self-concept. High self-concepts were related to low levels of stress. Families with "dysfunctional communication patterns", i.e., members gave vague, indirect messages or messages that seemed out of context, had higher levels of felt stress and lower self concepts. However, 87% of "functional families" included a parent with more than high school education.

Weinstock and Paquay (1979) report family's response to the diagnosis of hemophilia depends on the family's level of functioning before the diagnosis. They found that in families that had a strong identity in which functioning was based on *"open communication"* before the appearance of the disease hemophilia provoked a shock that led to depression. After the initial shock subsided, however, these families restructured and consolidated their bonds and became more open towards the outside world. In families characterized by *"blurred communication",* phase of depression and isolation was also important. However, it was not openly recognized and communicated to others and finally led to an impoverishment of the bonds both inside and outside the family, the withdrawal of each member in himself, the appearance of alliances and a displacement of the conflicts. In the very *"conflictual"* families, in which dysfunctioning was evident before the appearance of the disease, Weinstock and Paquay noticed either a dislocation of the couple or the appearance of psychiatric problems in one of the parents.

## SUGGESTIONS FOR INTERVENTION

In recent years the push for family therapy has increased. Many authors suggest (Walker, 1983; Drotar, et.al., 1984; and Leahey, et.al., 1985) that family attitudes and actions are crucial in determining the course of the illness and contribute to remission or exacerbation of symptoms. The family system influences the course of illness and thus interventions should be targeted at whole system.

However, life threatening illness acts to increase the rigidity of the family organization and often families attend family therapy but may secretly resent the referral (like the illness) as an invasion which seems to threaten the organization they have established. Walker (1983) suggests that the most effective interventions with these families may be: "... (a) paradoxical injunctions which capitalize on the internal conflicts in the family systems, or (b) systemic prescriptions which include the prescription of the presenting problem. The family, by resisting the intervention, changes." (pp. 11-12). Leahey and Wright (1985) stress the importance of understanding the reciprocal influences between family and health care professionals. In cases of chronic illness there is a long term relationship that develops between the two systems. It is important that both professionals and family do not get attached and dependent on one another. Health care professionals often get depressed when working with these families and it is important that they ask the family to teach them about the disease.

Finally, Leahey and Wright (1983) suggest that direct interventions need to focus on three levels of functioning in families:

(1) Cognitive level: new information and/or ideas about a particular problem are provided. Information (medical, educational, financial, etc.) need to be given in a supportive context which has often proven more important than information per se.

(2) Affective level: designed to modify intense emotions that may be blocking a family's problem-solving efforts. Validation of family's emotional responses alleviates sense of aloneness. Health care professional should acknowledge the fact that something sad, bad, or awful has happened, and that the family is entering a life-long process of coping.

(3) Behavioral level: designed to help family members interact differently. Encourage family not to make severe adjustments in their daily life and encourage them to take time off from their caretaking duties.

## BIBLIOGRAPHY

- Bruhn, J.G. Effects of Chronic Illness on the Family. Journal of Family Practice, 1977, 4,6, 1057-1060.
- Caldwell, S.M. and Pichert, J.W. Systems theory applied to families with a diabetic child. Family Systems Medicine, 1985, Jill, 34-44.
- Cassady, L. The forgotten children: A study of the interpersonal perceptions of healthy siblings of children with a life-threatening or chronic illness. Dissertation Abstracts International, 1982, 181pp.
- Collins-Moore, M.S. Birth and Diagnosis: A Family Crisis. In Chronic Illness and Disability through the life span: Effects on Self and Family. Eisenperg, M.G., Sutkin, L.C., & Jansen, M.A. (Eds.), New York: Springer Publishing Company, 1984.
- Drotar, D., Crawford, P., anq Bush, M. The family context of childhood chronic illness: Implications for psychosocial intervention. In Chronic Illness and Disability through the Life Span: Effects on Self and Family. Eisenberg, M.G., Sutkin, L.C., and Jansen, M.A. (Eds.), New York: Springer Publishing Company, 1984.
- Eisenberg, M.G., Sutkin, L.C., and Jansen, M.A. (Eds.) Chronic Illness and Disability through the Life Span: Effects on Self and Family. New York: Springer Publishing Company, 1984.
- Friedrich, W.N. Ameliorating the psychological impact of chronic physical disease on the child and family. Journal of Pediatric Psychology, 1977, 1i1l, 26-31.
- Glenn, M.L. Family illness rituals. Journal of Family Practice, 1982, 14(5), 950-954.
- Herz, F. The impact of death and serious illness on the family life cycle. In The Family Life Cycle: A Framework for Family Therapy, Carter, E.A. and McGoldrick, M. (Eds.) New York: Gardner Press, Inc., 1980.
- Lavinge, J.V. Psychologic Adjustment of Siblings of children with chronic illness. Pediatrics 1979, 63, 4, 6, 616-627.
- Leahey, M. and Wright, L.M. Intervening with families with Chronic Ililiness. Family Systems Medicine, 1985, 3(1), 60-70.

- McCollum, A.T. and Gibson, L.E. Family Adaptation to the Child with Cystic Fibrosis. Journal of Pediatrics, 1970, 77(4), 571-578.
- Penn, P. Coalitions and Binding Interactions in Families with Chronic Illness. Family Systems Medicine, 1983, 16-25.
- Sheinberg, M. The Family and Chronic Illness: A Treatment Diary. Family Systems Medicine, 1983, 1111, 26-36.
- Tsiantis, J., Xypolita-Tsantili, D., and Papadakou-Lagoyianni, S. Family Reactions and their Management in a Parents' Group with Beta-Thalassemia. Archives of Disease in Childhood, 1982, 57(11), 860-863·
- Velasco de Parra, M.L., Davila de Cortazar, S., and Covarrubias-Espinoza, G. The Adaptive Pattern of Families with a Leukemic Child. Family Systems Medicine, 1983, 1(4) 30-35.
- Walker, G. The Pact: The Caretaker-Parenti Ill-Child Coalition in Families with Chronic Illness. Family Systems Medicine, 1983, 1(4), 6-29·
- Weinstock, M. and Paquay, L. Influence of a Chronic Disease on the Evolution of the Family Dynamics: Study of 25 families of Hemophilic Children, Acta Paedopsychiatrica, 1979, 44, 3-4, 219-228.