CHRONIC ILLNESS AND EMOTIONAL DIFFICULTIES.

A review of the literature

Eugenia T. Georganda, May 1984.

When an individual is born with a chronic physical illness she brings with her* in the world a number of problems that are quite distinct from the problems that all individuals are faced with. She carries with her an obvious physical ailment which needs to be addressed, dealt with and incorporated into her identity and everyday living. This later need forces us to look at another aspect of the physical being, the psychological one.

A human being is a biological entity but equally so a psychological -mental, emotional, spiritual- entity. When the biological entity is struck by a misfortune the whole being is affected. Until very recently the body-mind dichotomy prevented people -theorists, scientists- to see the whole and address the issues that the system, as a system and not discrete parts, has to be dealt with.

The chronically ill individual is a being who lives, moves and exists in a given environment. The environment is equally affected by the individual who is sick as is the individual affected by the illness. In addition, the response of the environment to the individual equally affects the individual and her response to her illness. Thus, the circle is repeated since the individual's response affects the environment and so on and so forth.

The environment is composed of a number of subsystems, such as the immediate family, the extended family, the school, the neighborhood, the culture, the society, etc. The bigger the subsystem the greater its impact on the whole. Also, the bigger the subsystem the less it is influenced by the smaller subsystems. The opposite is also true.

In this paper I will try to review some of the major research that has been done on the effects of chronic illness on the family system as a whole and also on different subsystems within the family unit.

---

* In this paper her will be used for referring to both male and female individuals.

Bruhn (1977) reports that the rate of breakdown in families with severe chronic disease is high. It has been shown that the combined effects of poor health and unfavorable family situations are cumulative over time (Pless, et.al., 1972). Diabetes mellitus, hemophilia, and epilepsy are examples of chronic illnesses with high rates of family breakdown. Family breakdown in these instances often results because family members would not or could not change roles and reallocate tasks.

The presence of a diabetic child is associated with lower marital integration and greater conflict among parents. Although a new equilibrium can be established in the family, it is often less stable and integrative than before the chronic illness (Crain et. al., 1966). The families of diabetic children show a variety of psychological structures. Childhood diabetes presents numerous difficulties because of the susceptibility to other diseases, changing requirements of growth, unpredictable outbursts of physical energy, and emotional disturbances. The effects of the disease continue throughout adulthood influencing the diabetic person's educational, marital, and occupational plans. Thus, as the diabetic person grows older, .problems expand into other systems outside the immediate family.

The presence of a hemophiliac son can draw parents together. In the majority of families, however, hemophilia contributes to the withdrawal of the husband from family relationships and to the breakup of the marriage (Salk et.al., 1972). Hemophilia limits family mobility, creates financial strain, generates feelings of guilt and resentment among the parents, and often strains the relationships between healthy sibs and the hemophiliac child.

The idea that epilepsy is a shameful disease is often foremost in the minds of the parents of an epileptic child. Many parents feel that epilepsy has a hopeless prognosis, especially if a cause cannot be discovered for their child's convulsions. Parents may become protective of the child with respect to emotional excitement and physical activity. Young children sense any type of restraint and soon learn that others, even family members, do not see them as normal. The actions of others help to mold the epileptic's self image which, in turn, influences her educational, mental and occupational plans (Livingston, 1957).

Chronic disease in a child or adolescent is perhaps more difficult for the physician to manage clinically for several reasons.

1. Parents often protect the chronically ill child or adolescent from learning adult roles and responsibilities.
2. The chronically ill child or adolescent may learn to use her illness as with, for example, control over diet and insulin in diabetes to "get her way", learning, possibly, that manipulation of others is a successful way to solve problems of living.
3. The chronically ill child or adolescent usually lives with one or both of his parents or relatives who impose their perception of the type of life style or routine that the ill person

should follow. Therefore, the young chronically ill person may not be able to adjust to his illness as she wants to.

4. The chronically ill child may be the "lightning rod" for marital and family problems, so her and her family's adjustment to the illness is further complicated.

These issues, which must be discussed with the parents, present problems for the physician in the clinical management of chronic illness. Parents often think they are being thoughtful and helpful in removing tasks and responsibilities from a sick child completely, especially from a child with a chronic illness. Indeed, such action may foster feelings of hopelessness and helplessness and work against good clinical management of the illness. Chronically ill persons, irrespective of age, must retain their integrity as human beings and be given the opportunity to participate in their families and society as their social and clinical circumstances permit.

Tsiantis, et. al.(1982) report that there were four clusters of feelings and behavioral patterns that were noted in the parents of children with beta-thalassemia.

(1) Depression,
(2) Death anxiety,
(3) Denial of the problem and feelings, and
(4) Conspiracy of silence.

The parent’s depression was accompanied by feelings of guilt and self-blame. Self-blame was associated with the hereditary nature of the illness and the fact that the parents transmitted the illness to the child. Anxiety about death is common in parents with a chronically ill child and usually it is linked with issues around the life expectancy of the child. The denial was in some cases an attempt to cover unconscious hostility towards and rejection of the child. Social factors were also concerned in the mechanisms of denial. These parents felt that a sick child was a demonstration of their failure, so that they were ashamed and tried even more vigorously to deny that there was anything wrong with the child.

The "conspiracy of silence" describes the situation whereby nearly everybody in the family, even the sick child, knew about the illness, they all experienced the burden of it, but nobody talked openly about it within the family. Often the children wanted to ask questions about the illness and to discuss their feelings and worries about it, but attempts were blocked "by the half-truths and evasive answers they received!” Sometimes children themselves preferred not to ask, as a defensive mechanism.

In the same vein Burton (1975) and Gayton (1977) report that healthy children rarely ask questions related to the disease or its treatment. Burton interpreted this to be a reflection of the children's need to protect their parents. Children fear that the parents may lack the capacity to tolerate the illness and that their questions may precipitate a breakdown or a rejection of themselves. Thus, siblings avoid loss of contact and maintain the approval of significant adults by keeping thoughts and feelings to themselves.

Children suffering from a chronic or life-threatening illness may enjoy a special status within their family. This status may deprive the healthy siblings from necessary parental support, thus, impairing normal psychological development.

Bank and Kahn (1975) cited two major reasons why siblings have rarely been studied systematically by health researchers. They claimed that, in this culture, dominant value is placed on the romantic relationship between parents rather than on fraternal ties between children. Secondly they noted that family size has diminished and the health care delivery system is structured such that siblings are considerably less visible than they were a few decades ago. These authors highlighted the importance of the sibling relationship by asserting that siblings spend much more time together than any other family subsystem and that they are strikingly empathetic with one another.

Given that all siblings significantly influence one another, it seems clear that one child's chronic illness or disability will affect healthy siblings to a greater or lesser extent. Due to spectacular medical progress, the major difficulties in the management of many chronic diseases are often related to the patient's and family's social and psychological adjustment to the disease (Allan, et.al. 1974). Unfortunately, existing research findings that attempt to illuminate the effects of a child's chronic illness on her siblings are frequently undermined by methodological shortcomings. Examples of such limitations include small samples, less than rigorous designs, and the use of cross-sectional sampling techniques. Perhaps of most significance is the fact that siblings have rarely spoken for themselves. Descriptions of siblings in families with a chronically ill child have been based largely on the observations and interpretations of parents or health professionals. Despite these weaknesses, when taken together the available research strongly suggests that siblings of chronically ill children are a population at risk (Falkman, 1977 & Klein, 1976). Coddington (1972), in a survey of life events as etiological factors in childhood disease, found that sibling illness ranked among the most stressful.

Crain, Sussman and Weil (1966) concluded that, of all family members, the siblings of childhood diabetics bear the greatest burden of stress. They noted that, due to the demands of the illness siblings are handicapped in the race for parental attention and affection.

The literature related to the incidence of behavior problems among the siblings of handicapped children is somewhat contradictory. However, most studies report that the siblings of children with chronic health problems are more likely to experience adjustment or behavior problems than are their peers (Allan, et.al., 1974, Binger, et.al., 1969, Farber, 1972 and Gath, 1973). Negative self-image and high-anxiety levels have also been noted among. siblings of the handicapped (Galdwell & Guze, 1960).

Litman (1974) observes that the family's response to the sick individual may influence both the course of the patient's illness and the family's health and happiness. Bentovim (1972) categorically states that " ... satisfactory emotional development of the handicapped child depends more on the way in which the parents and family relate to the child than to the extent of the handicap itself” (p.581). Handicapped children have been found to have emotional problems concomitant with their physical illness. At times these secondary psychological problems become the true handicap.

Battle (1975) writes that children with chronic physical disease are invariably depressed, and exhibit obvious or subtle signs of sadness. The chronic disease undermines children's self concept, and rarely allows them to reach equilibrium with their disease. The chronically ill child has to cope not only with the demands of maturation and development, but also with the disease itself.

Mattsson (1972) writes that ill children who adjust poorly to their condition generally fall into one of three behavioral patterns: the first is the fearful, inactive, isolated and dependent child; the second is the overactive, overly independent child who defies her illness by engaging in numerous risk-taking activities, and the third group contains children who harbor resentment towards normal individuals, who they regard as owing them payment for their afflictions.

It is often assumed that the more severe the disability, and the more apparent it is to others, the higher the probability that emotional difficulties will be present. However, illness which is not apparent to others, may leave the child, or adolescent, with little understanding or sympathy for them. Recognizing this, Barker, Wright, and Gornick (1953) introduced the concept of "marginality", referring to those with chronic illness not visible to others. The term marginality connotes that the patient is neither normal nor perceived as handicapped. Thus, he or she does not enjoy the benefits of being "normal", nor evokes support from the environment. Individuals with epilepsy tend to fall into this marginal group as their illness is not visible, except in instances where their seizures are actually witnessed by others.

In a study of epilepsy in adolescents, Hodgman, McAnarney, Myers, Iker, McKinney, Parmelee, Schuster, and Tutihasi (1979) postulated that the less visible the handicap, the more normal the patients are expected to be, placing upon them an emotional burden which is greater than that of a child or adolescent whose problem is clearly visible.

McAnarney, Pless, Satterwhite, and Friedman (1974) studied this question by comparing the school adjustment of 42 children with chronic arthritis to each other and to healthy children. They found that the children with arthritis had more psychological problems than the control group. However, children with arthritis, but with little or no physical disability, had more emotional problems than the more visibly disabled children with arthritis. It was suggested that the more severely disabled are forced to accept reality earlier in life and more completely and are more likely to develop successful compensatory mechanisms, such as gratification based on school performance. Individuals in the child or adolescent's environment set their expectations in accordance with the perceived illness. If the disease is visible, certain allowances will be made. The implication of marginality is not that it is "better" to be visibly (more severely) handicapped, but rather, that emotional difficulties may be more of a problem in patients coping with a disease that does not evoke support from the environment. Thus, psychological and social services should not focus solely on those with the most severe physical disabilities.

Adolescence poses special problems. All adolescents are struggling with tasks of becoming independent, realizing sexuality, and establishing identity. The individual with a chronic illness, due to their illness, have, by necessity, been more dependent on parents and other adults and may be afraid to strive for independence. On the other hand, they may completely deny their need for dependence on others and begin to refuse to follow through with the necessary medical regiment.

Developing concepts of sexuality may be affected by the adolescent's feelings of being different from peers. Leichtman and Friedman (1975) in their discussion of the effect of chronic illness on the formation of identity in the adolescent, emphasize the importance for the adolescent of incorporating the illness into her self-image. Recognition of such limitations is important in the definition of "self”.

But assigning emotional problems to all handicapped children would be as inappropriate as thinking that all families with an ill child suffer from marital discord and maladaptive siblings. Tavormina, et.al., (1976), in a study of 132 children with either asthma, diabetes, cystic fibrosis, or hearing disabilities, administered five standardized personality inventories to these children which, upon examination, demonstrated normalcy rather than deviance in this particular sample. Overall, the children's functional strengths and coping abilities outweighed their weaknesses. Possibly the measures tapped only limited areas of functioning, but nevertheless, in this case, the typicaly ill child performed much like a "normal" child.

From personal experience I would say that one of the major reasons why I decided to study psychology was because I was aware of, not only, the burden that a child with a chronic illness carries but also of the great fluctuations in the ways kids cope with the illness. As an adolescent, and-even as a child, I was aware that the way I coped with my chronic illness was very different from the way other kids dealt with it. I became increasingly aware of the difficulties they were facing that I did not have to cope with because my parents and my immediate environment responded to my illness in a very different, and much more helpful way, than their parents.

Looking back at my childhood and adolescence I can recall the struggles I was faced with and the invaluable help and support that I received from my high school professors, who often served the role of a therapist. I remember deciding not to go to medical school because finding the "magic cure" for my illness became less important than talking with people about their emotional problems.

Some of the conflicts I was, and still am, faced with revolved around my looking, and oftentimes feeling, healthy and my awareness of the special care I have to pay to my body. I always had to be cautious about how much activity and stress I get involved in, how much I rest, when I need to go to the hospital, etc. However, I always had encouragement about being active, which I believe has been valuable for giving me a sense of competence and independence. In addition, I always struggled with whether I talk and share with other people my experience of my illness or whether I keep it to myself. Support from classmates and professors was, and still is, valuable and I often wonder how difficult it must be for children who learn that they should not talk about their illness to other people because having a chronic (hereditary) illness is shameful.

During my visits at the hospital I had the opportunity to observe the interaction between children and their parents and I am convinced that the way the parents dealt with their feelings about the child's illness and the social implications of having a "sick" child had a direct impact on, not only, how children cooperated with doctors for the management of their illness but also on their physical well-being.

One of the last, but not least, things that I want to mention is the tremendous impact that social values and prejudices have on the lives of children with chronic illness. I have seen a lot of young men and women waste their lives because society considers them invalids. The social stigma that the family carries is often heavy to bear not only for the family as a unit but also for the individual who is afflicted by the illness. Many children never go to school because the parents do not want the teachers to know that they have a child with a chronic disease. Many parents do not talk even to their own family (siblings, etc.) about the child's disease. The parental subsystem becomes isolated and carries the total burden because sharing it is considered inappropriate and shameful.

Finally, I must say that although it was hard for me to read all of the above research findings I found them congruent with my personal experience of being a child with a chronic illness, of growing up in a family that had such a child as well as a healthy sibling and with my observations of other children with the same disease and their families.

BIBLIOGRAPHY

- Allan, J., Townley, R. and Phelen, P. Family response to cystic fibrosis. Australian Pediatric Journal. 10: 136-146, 1974.
- Bank, S. and Kahn, M. Sisterhood-brotherhood is powerful: sibling-subsystems in family therapy. Family Process. 14(3): 311-339, 1975·
- Barker, R.G., Wright, B.A., & Gonick, M.A. Adjustment to physical handicap and illness: A survey of the social psychology of physique and disability (Rev.). New York: Social Science' Research Council, 1953.
- Battle, C.D. Chronic physical disease: behavioral aspects. Pediatric Clinics of North America. 22, 525-531, 1975.
- Bentovim, A. Emotional disturbances of handicapped pre-school children and their families: attitudes to the child. British Medical Journal, 3, 579-581, 1972.
- Binger, C.M., Ablin, A., Feuerstein, R., Kushner, J., Zoger, S., and Mikkelsen, C. Childhood leukemia: emotional impact on patient and family. New England Journal of

Medicine. 280, 414-418, 1969.

- Bruhn, J.G. Effects of chronic illness on the family. The journal of Family Practice. Vol. 4(6), 1057-1060, 1977.
- Burton, L. The family life of sick children. Routledge and Kegan Paul, London: 1975.
- Coddington, R. The significance of life events as etiologic factors in the disease of children, I and II. Journal of Psychosomatic Res. 16: 205-215, 1972.
- Crain, A., Sussman, M. and Weil, W. Family interaction, diabetes, and sibling relationships. International Journal of Social Psychiatry.121 35-43, 1966.
- Falkman, C. Cystic fibrosis: a psychological study of 52 children and their families. Act. Pediatrica Scand. (Supp. 269), 1977.
- Farber, B. Effects of severely retarded child on the family. In Readings on the Exceptional Child, E. Trapp and P. Himelstein, Eds. Appleton-Century-Crofts, New York, 1972.
- Gath, A. The school aged siblings of mongol children. British Journal of Psychiatry. 132: 161-167, 1973.
- Gayton, W. Chi:dren with cystic fibrosis: psychological test findings of patients; siblings and parents. Pediatrics, 59(6), 888-894, 1977
- Hodgman, C.H., McAnarney, .E.R., Myers, G.J., Iker, H., McKinney, R., Parmelee, D., Schuster, B., & Tutihasi, M. Emotional complications of adolescent grand mal epilepsy~ Journal of Pediatrics. 95, 309-312, 1979·
- Klein, R.F., Dean, A., Bogdonoff, M.D. The impact of illness upo~ the spouse. Journal of Chronic Disease. 20: 241-248, 1967.
- Leichtman, S.R.: & Friedman, S.B. Social and psychologieal development of adolescents and their relationship to chronic illness. Medical Clinics of North America, 59:1319-1328, 1975.
- Litman, T.J. The family as a basic unit in haalth and medical care: a social behavioral overview. Social Science and Medicine. 8, 495-519, 1974.
- Livingstone, S. Psychosocial aspects of epilepsy. Journal of Clinical Child Psychology. 6, 6-10, 1977.
- Mattsson, A. Long-term physical illnesses in childhood: a challenge to psychosocial adaptation. Pediatrics, 50, 801-811, 1972.
- McAnarney, E.R., Pless, I.B., Satterwhite, B., & Friedman, S.B. Psychological problems of children with chronic juvenile arthritis. Pediatrics. 53, 523-528, 1974.
- Pless, I.B., Roghmann, K.J., & Haggerty, R.J. Chronic illness, family functioning and psychological adjustment: A model for the allocation of preventive mental health services. International Journal of Epidemiology, 1: 271-277, 1972.
- Salk, L., Hilgartner, M., & Granich, B. The psychosocial impact of hemophilia on the patient and his family. Social Science Medicine. 6: 491-505, 1972.
- Tavormina, J.B, Kastner, L.S., Slater, P.M., & Watt, S.L. Chronically ill children: a psychologically and emotionally deviant population? Journal of Abnormal Child Psychology, 4:99-110,1976.
- Tsiantis, J., Xypolita-Tsantili, D., & Papadakou-Lagoyianni, S. Family reactions and their management in a parents group with beta-thalassaemia. Archives of Disease in Childhood. 57: 860-863, 1982.