

THE EFFECTS OF ILLNESS AND HOSPITALIZATION OF CHILDREN ON THEIR FAMILIES

This article attempts to highlight the difficulties of families with sick children in the hope that personnel involved with them could be more aware and assist where possible.

INTRODUCTION

There has been a plethora of articles on hospitalization and its effects on children. In a hospital where the primary function is geared towards medical diagnoses and treatment of patients, the emotional needs of families can be easily overlooked. This paper discusses some of the psycho-social implications of a family with a sick child, who may or may not require hospitalization. By highlighting these areas it is hoped that those personnel involved with such a family could help to alleviate stress where appropriate.

Illness in a family, particularly chronic illness, frequently impairs the family's effectiveness as a functioning unit. Adverse effects on the family may arise from several sources but these tend to be chiefly social, economic and emotional.

EMOTIONAL

When a child becomes ill and is hospitalized, it usually creates a stressful situation for the family. The level of stress depends very much on the seriousness of the illness and the coping mechanisms of the family. To a resource-

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ful family with a supportive network, the illness and consequential hospitalization of a child might not present much of a crisis. However, many families, for example, from an isolated background, are already functioning to the best of their ability. Illness in a child can easily disrupt the family equilibrium. It might mean a single mother on her own having to nurse a sick child amongst other tasks in a family of growing children.

Illness in an adult, especially the breadwinner, can cause extreme financial hardship. In the case of the carer, it means alternative caring has to be provided for a family with young children. Although illness in a child does not pose such inconveniences it still disrupts the family's lifestyle. It means parents having to spend more time with the ailing child at the expense of other children in the family. A child who is chronically ill needs continual care and this can pose a problem. All young children need their parents' care and attention and a parent may be less than effective to other children at home if she is pre-

occupied with caring for the sick child by the hospital bed. In this dilemma, parents need to be gently and tactfully reminded that their other children need reassurance too and sibling rivalry and jealousy need to be anticipated and dealt with before this becomes too much of a problem.

ECONOMIC

Treatment and hospitalization can prove very expensive to a family where special devices may have to be purchased, e.g. in asthma or diabetes. Travel expenses from home to treatment centre further compound financial stress. A family threatened by financial problems is unable to deal adequately with adaptation and is inaccessible to guidance efforts until their economic condition is improved. Where appropriate, the afflicted family could be linked with Social Security entitlements. This may not be much but it would alleviate their impoverishment somewhat.

Incidental expenses can stretch family funds and deprive the siblings of opportunities that may otherwise have been possible. It might be the difference in the family having a holiday or not at all. The expenses incurred by an ailing child may mean an estrangement of the family from socio-economic groups they were accustomed to because of a lowered lifestyle. In addition to this the family might be more isolated than pre-

viously because of a reluctance to leave the sick child on his own. The emotional disorganization in a family and the fact that energy is channelled into caring for the chronically ill child may have implications for the parents' occupational productivity and job prospects.

The reluctance to move away from the treatment centre with familiar staff members restricts the parents' mobility in seeking transfer or accepting promotion elsewhere. Therefore, we see that illness of a chronic nature particularly, can pose economic burden, thus limiting the family's level of housing, education of siblings, and the social and economic status which may have been attained under other circumstances.

All these factors can at times foster resentment and chronic anger towards the child. Parents should be allowed to talk about this in a non-judgemental, non-threatening atmosphere to prevent further guilt feelings. To alleviate some of the stress mentioned the social worker could provide the family with adequate social and emotional supports. She could enlist the help of family members of liaison with community-support services such as Home Help or Family Day Care in providing emergency child-care. This could then free the parents to attend to the sick child without feeling too guilty and harassed having to attend to numerous other tasks.

Illness in the family can affect marital relationship. With the additional stress and strain on family finances and coping ability, the family with pre-existing marital discord could give way under these circumstances. It would be the last straw which breaks the camel's back. In other cases, where there are positive aspects present in the relationship the mutual parental concern can actually reinforce the marital relationship. The sensitive social worker should use this situation to involve both parents. It may require dissipating the tension and conflict prevailing and encouraging more open and honest communication between parents. We know that a lack of communication between parents concerning the child's condition often indicates a non-supportive relationship. This may also suggest withdrawal by one or both parents. Hence it is important to encourage parents to be more open and to encourage parents to be more open and communicative with each other.

FAMILY ROLE

When dealing with these families we need to be aware of the sociological concept of roles that exist within a family. When a child is hospitalized, the

family as a system, undergoes changes. The fact that the patient would not be participating in family activities would mean a re-definition of roles for the remaining members at home. Readjustment would need to occur when the patient re-enters the family system, particularly when hospitalization has been protracted.

This is worth remembering because changing roles require overt behavioural changes as well as changes in family-interactions. A simple example might illustrate this point. If a child takes over the role of being the baby of the family that has been vacated by the sibling who has been admitted to hospital, he would need to readjust on the patient's return to the family system.

Any dysfunctional adaptation can lead to disruptions in the smooth flow of family life. The degree of disruption depends on how flexible and adaptable the family is. This depends to a degree on preparation of the family for the child's homecoming. A sick child gets much more attention in hospital than he would in a large family or a family with a deprived background. An informed family unit prepared for this is more able to contribute to the patient's readjustment when discharged. This is important in that a parent from an isolated background, having little support, may not be very tolerant of a demanding sick child. The harassed parent with other children to attend to and an irritable child create an at risk situation which can lead to abuse. Hence the need to prepare the family for this possible difficult adjustment phase.

ANXIETY

Anxiety is another common experience of families with a sick child. When a child is admitted to hospital it is inevitable that parents are anxious about this and it is beneficial for both the child and the family to have a chance to express these fears and anxiety, i.e. to ventilate their feelings. The social worker can help allay some of these fears; to clarify their expectations of the situation, and to help them adjust to realities. It may be that the family has to be guided in their anticipation of the outcome rather than live in false hopes. This can be unfair and deleterious to the child and family. We know that high levels of anxiety often prevent the parents from hearing and incorporating what has been said. They would need to have diagnosis and treatment explained simply in lay terms so that they can understand. This would ensure less likelihood of imagination filling in gaps in knowledge thus leading to unfounded fears and misinterpretation.

We need to remember that the equipment used in the hospital is taken for

granted by the staff. It may often be strange and intimidating to the family. It is helpful if the staff involved in the care is alert to such reactions and explain this to the family where appropriate.

DISCIPLINE

Another area of difficulty for parents with a sick child is that of child-discipline. Parents of chronically ill or handicapped children frequently are frustrated and angered by their fate. There is a component of guilt too as many parents tend to assume personal responsibility for the child's illness. Their object of anger may be the child who has been responsible for their burden and discomfort. When they become aware of these negative feelings, they are overcome by a sense of guilt, so in many instances we see parents vacillating between anger towards their child and subsequent guilt. This creates problems in discipline as parents are not able to set consistent limits. They may be over-indulgent or overly-punitive under essentially identical circumstances. Therefore parents need help to work out a more consistent approach to child-discipline.

Sometimes parental guilt feelings may have a reality basis as in genetically transmitted diseases. In these cases parents should have access to information in decisions regarding additional children. They should also be helped in adapting to the reality of genetic transmission through themselves.

Some parents of children with a condition such as bleeding disorders are inclined to be overprotective to the point of stifling the child's need for some autonomy. These parents need assistance and guidance to gain perspective, and objectivity in relation to the child's needs to develop autonomous skills, compatible with his capabilities. The helping professions need to allay anxiety and stress where possible. This is one area where we can prevent chronic anger and frustration from developing between the child and his parents, i.e. to allow the child to gain some independence. The process of adaptation by the family can be helped along not only through regular contact with hospital staff but also through enlisting the help of community support services providing material and emotional supports. It might include a reorganization of the home environment appropriate to the sick member and the family.

FAILURE TO THRIVE AND FEEDING PROBLEMS

Another group of parents needing help are those with babies admitted for feeding problems or failure to thrive

that have no apparent organic causes. These mothers often tend to come from deprived backgrounds themselves. They are inclined to feel diffident and threatened caring for the child in the presence of ward staff. Also associated with this are feelings of guilt and anxiety and naturally a reluctance to appear on the ward to be reminded of their inadequacy as parents. Trying to communicate to such a mother the concept of parental care in hospital is a difficult task. Such a mother would benefit from encouragement and reassurance from ward staff and all concerned in helping her establish a routine of feeding and baby-care within an accepting and non-blaming environment.

At times parental anxiety may be expressed in other forms not easily defined. This may be manifested in the form of withdrawal, irritability or hostility directed at medical and nursing staff. The social worker in this situation could help by acting as the parent's advocate, re-interpreting the negative symptoms in a more constructive manner to others involved with the family. In this way the staff is going to be more understanding and tolerant of parents' apparent hostility and not react likewise which would only aggravate the situation.

NON-COMPLIANCE

Medical non-compliance seems to be quite an issue with a few families. Patients and families do not comply for many reasons. This could be denial on the part of the patient and the family especially when the child is in remission thus allowing the parents to believe that everything is alright with the child. Sometimes it may just mean a lack of knowledge about the treatment regime. The hospital staff has an important role to play in educating the patient and family on the need to adhere to medications as instructed.

We would have a problem when an asthmatic child does not adhere to his therapy. This refusal may be seen as a passive resistance to a situation where he has little control. It may simply mean a rejection of anything associated with authority if this non-compliance is seen in a child of pre-pubescent age who is testing out the limits of his autonomy. Sometimes non-compliance may indicate sheer indifference because a growing child has other more interesting things to attend to than the tedium of adhering to medications, for example, four times per day. Overt expressions of a child's anger or frustration are normally not tolerated by the family or staff alike, and the child's chief recourse may be in passive resistance to procedures and other aspects of management.

Thus finding the underlying reasons

for medical non-compliance is necessary if this is to be rectified. Genuine concern, reinforcement from the family, the social worker and other significant people in the child's life may alter this situation. It is important to note that often-times it is easier to achieve compliance through enlisting the co-operation of the child than getting into a conflict situation when everyone ends up feeling exasperated. It certainly would improve the quality of care if parents could learn through modelling, by observing the nurses and having instructions explicitly given. By having clear explanation the older child and parents could be helped a long way towards understanding the diagnosis, and co-operating in the treatment.

Another major factor in medical non-compliance lies in the cultural norms and values inherent in many migrant families. When hospital staff try to introduce ideas alien to the family culture one can understand why a parent may object to a child having a particular treatment regime. Certain ethnic groups have firm ideas about dietary needs of a sick patient and this can cause friction with medical and nursing staff when relations may insist on bringing in home-cooked food against dietary prescription.

The social worker or other personnel who are aware of such cultural differences could help bridge this gap between traditional beliefs of the family on one side and those of hospital staff on the other. Better communication and understanding could obviate many of these conflicts in values, beliefs and cultural myths.

BEREAVEMENT AND LOSS

In a hospital milieu, it is inevitable that we encounter the death of a child. Death of a loved one mobilises deep human anxieties concerning separation. It is after all the ultimate separation. Death of a child is premature in a sense because it is attended by the shattering of many hopes and aspirations held by the family. This is a critical event which tests the integration of parents and the family, in their capacity for meeting and handling stress. Death may be of a sudden onset such as from an accident, in which case it is most traumatic as the parents and family have been unprepared for it. In illness where death is inevitable, the family needs to know the truth as early as possible. Reality, however painful, does promote adjustment. In this instance, the facts must be conveyed to the family, in a sensitive and caring manner by someone who knows the family and whom they trust.

This would allow the family to prepare themselves and the child for the

imminent separation and loss that would occur. Anticipatory grieving is important for both the patient and the family, so that the members can gradually move on to some resolution and acceptance of what is ahead of them. The parents need guidance to differentiate the needs of the dying child, and that of the living, and to recognise in the family's ongoing existence. Participation at this stage should not be encouraged to the neglect of others in the family. At the same time, it is important that the family does not disengage too early from a dying child. Feelings of fear and inadequacy can prevent parents from participating in child-care and the child can misinterpret this as an inability to care for him. Anxiety impairs the parent's ability to relate to the dying child too. Denial and distancing, i.e. disengagement, need to be understood as defences expressed partly, as an attempt to avoid the pain and sadness of losing someone dear to them. There is much apprehension about the uncertainties of what to expect, the prospect of final separation and unpredictability of what each day will bring. All these and the stress of making decisions about such matters as treatment and care compound the anxiety experienced by family members.

Yet, during these difficult times, the family must be encouraged and helped to participate fully in caring for the dying child – providing life-promoting opportunities to the child for as long as possible. The family needs opportunities to express their various affects of grief. The social worker here can help by providing a generally supportive role; helping the family make practical arrangements and providing opportunities to recollect events which lead to the terminal phase as a means of helping them master the shock in small doses. There may be guilt feelings which the parents need to talk about.

Parents need assistance in dealing with this issue of death with the dying child. To the very young children, death anxiety is actually felt as separation anxiety, as they do not perceive death as a concept of permanence. Therefore, parents can reassure the child that they will stay with him.

Parents also need to discuss their feelings and the response of their surviving children. For example, a much mourned son can hang like a shadow over the life of a later child. Unless the parents are helped to overcome their grief, the child may feel that he can never match up to his dead brother. Many parents derive temporary support from the opportunity to experience a dependent relationship with the physician at periods of greatest stress. It would help if they were given this opportunity. It is important that the

social worker or whoever is following this case through, help in the bereavement phase and facilitate healthy grieving.

CONCLUSION

This paper has attempted to highlight the implications of illness on a family. We see that illness and hospitalization of a child affect the family in various ways which call for adaptation emotionally, socially and economically. The degree of family disorganization depends on the severity and nature of illness and the family resources. Their healthy adaptation to the problem depends on internal and external resources of the family and the supportiveness of all those hospital staff who are involved with the family. For this reason, we need to be aware of their needs and assist where we can.

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