

## DEVELOPING A SUPPORT PROGRAMME FOR FAMILIES WITH SERIOUSLY

### ILL OR DYING CHILDREN: THE FIRST SIX MONTHS

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Death of children in our days has changed its character according to the development in society at large and within modern medicine. The most frequent causes of death among children today are accidents. In most cases this means a sudden death. Next to accidents, cancer is the most frequent cause of death among children in the western world. According to the development in modern medicine one has coined the concept "prolonged death" (in many of the cases prolonged life would have been a more positive and better expression). The concept covers the fact that children with malignancies, for example solid tumor, may be kept alive for weeks and months and years because of modern treatment with cytostatica and radiation. Children with leukemia receive blood transfusions and medical treatment curing the illness in circa 50% of the children and prolonging life from one to five years among the rest of the children.

This development means new hope for lots of families, but it also means tremendous stress during the treatment phase at hospital, fear of infection at home, always looking for signs of relapse signalling that their child is among the unfortunate group with a fatal illness.

Several authors have described the effects of fatal or chronic illness on the siblings, on the parents and on the whole family system. (Birman 1956, Cobb, 1956, Green 1958, Tisza 1960, Murstein 1960, Knutson et al. 1960, Friedman et al. 1963, Morrissey 1963, Chodoff, 1963, Gordon 1965, Howell 1966, Green 1967, Friedman 1967, Findlay 1969, Binger 1969, Ablin et al. 1971, Pless et al. 1972, Share 1972, Commerford 1974, Willis 1974, Malley et Coucher 1975,

In Pines, M., & Rafaelsen, L.<sup>163</sup> (Eds.): The individual and the group. Boundaries and interrelations. Volume 2 Practice, New York; Plenum Press, 1982.

Lascari 1976, Geist 1977, Sourkes 1977, Tiets 1977, Churven 1977, Ross 1978, Helmrath 1978, Bahnson 1978, Bahnson 1979, Coocher et al. 1979, Krell 1979, Nir 1980, Schulman et Kupst 1980).

Most of the authors emphasize the need for a family support programme in connection to the pediatric unit or division of oncology. The main purpose of a programme for the family should be to give support therapy in the initial phases of shock and stress, finding new structure and solutions to problems during remission and treatment or loss of the child.

A second purpose is also mentioned among a few of the authors looking upon cancer as a psychosomatic solution to inner conflicts and disturbances in the family system: A restructuring of the system through family therapy may directly interact with the symptom force and thus help the child getting well again. This way of thinking is still at a pioneer stage, but it is widely recognized in the hospital that there exists a connection between the well being of the child and his general condition of health. Thus some hospital has as a routine to treat patients reacting to hospitalization in a negative way as out-patients as much of the time as possible.

We can conclude that there exists two psychosomatic theories concerning life situation and cancer: an optimistic one which held that one can alter the state of cancer directly with psychotherapy, one which held that the illness may partly be defeated by a good general condition.

Our programme started 6 months ago and was during the planning period supervised by Claus Bahnson and very much inspired by his programme in Philadelphia, U.S.A. and Germany (Bahnson 1978).

Our main task was to meet the needs of parents and children from the point of diagnosis, through the first treatment sequences at the hospital and all critical stages to come during remission or during the terminal phase. From the hospital it was also expressed a need for counseling parents with children who had for shorter or longer periods stayed in remission, children who had got their diagnosis before we started our programme. These two services call for different approaches. Meeting new families the arena was the pediatric unit and from the beginning there existed a suspicion in the direction of a serious illness (eg tumor, leukemia, cystic fibrosis and others). In the second service, given to families already staying in a certain treatment programme, the responsible pediatrician referred to our programme as a new service from the hospital given to all families with serious illnesses. Seeking psychological help or consultation is still not part of the daily life of Norwegian families but still subject to prejudices that you

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have to be on the point of breakdown or "crazy in your head". Of course the attitude is rapidly changing, but still there. Therefore it was of most importance that the pediatrician had a positive attitude to the programme, motivating the parents to see the psychologist although they did not think they had significant problems. The motivation was done when the patients were in for routine controls. At the very beginning of the programme the pediatrician announced it to the parents as a new service, but after a few weeks it was well known among several of the parents and they started themselves to call for consultation. In many cases we therefore met together with the parents and presented the programme for the parents. One strongly motivating factor was undoubtedly that the parents needed very much to talk about what to tell the child when ailing, what to tell relatives and siblings, how to interpret the medical language, and what to do with anxiety-making symptoms in child or siblings of the ill child.

Before we started we had three basic guidelines for the way we wanted to run the project. First of all we wanted the service to be presented for all the clients to avoid a common referral system where only the most sick or troublesome person should see the psychologist. We strongly chose the outreach model and it should include all children with serious or terminal illnesses.

Second our programme was a family-oriented one realising the widely held view that a serious illness affects the whole family system and even vital parts of the social network in some cases (Tisza 1960, Knudson et al. 1960, Morrissey 1963, Chodoff 1963, Gordon 1965, Howell 1966, Bahnson 1978, Koocher et al. 1979 among others). There exists also several reports on the effects of siblings (Bender 1954, Cobb 1956, Cain et al. 1964, Binger et al. 1969, Wold and Townes 1973) but most of them focus on the death of a child and the reports are seldom controlled in the sense that they are compared to the effect of other illnesses or to problems in the general population. We now have the first studies indicating that siblings of children with leukemia have more frequently psychological symptoms than siblings of children with other chronic illnesses (Binger 1969, Lavigne 1979, 1980).

Third we aimed at the ideal of availability; to be part of the wards daily life and being there when the parents needed support, not the day after. Achieving this made it necessary to have two psychologists (one on half-time basis) and to find a balance between time used on appointments (therapy hours) and time scheduled for being on the ward, being available at weekends, at nights and holiday seasons.

Classification of causes of intervention  
in total number and percentage of total  
number of causes (38 families)

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	number	%
State of crisis, breakdown	17	9.3
Family system disorders	13	17.3
After effects disease hospitalization	20	26.7
Direct intervention on problems presented at the hospital/anxiety other states of stress	25	33.3
<u>Total</u>	<u>75</u>	<u>100.0</u>

This is a rough classification to elucidate the causes of intervention among our 38 families. The high percentage therapy on after effects reflects that there has not existed a support programme for the parents earlier.

Types of intervention  
39 families, 59 types

Play therapy, support children	22	37.3
Family Therapy	7	11.9
Home visits	7	11.9
Support parents both or alone	16	27.2
Direct change, work economy, kindergarden, hospital routines, etc.	7	11.9
<u>Total</u>	<u>59</u>	<u>100.0</u>

Time used in hours and in percentage of the total amount of hours used

	hours	%
Family oriented therapy	72	21.5
Individual therapy - child	91	27.2
Individual support - mother	64	19.1
Individual support - father	22	6.6
Mother and child	43	12.8
Father and child	10	3.0
Parents counseling	21	6.3
Institution's changes counseling	12	3.6
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Total	335	100.0
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These figures do not reflect the philosophy of the intervention programme, but the way one more or less had to work taking into consideration long travelling distances for a large sample of the population excluding the possibility to treat the whole family system. However, in many of the families we tried very hard to motivate them although it would cost time and money to come all together. In most cases where they really did, they continued to come on their own motivation.

Until now we have done no systematic analysis of the therapy hours with children and families but we will here briefly comment on some of the recurring topics and problems observed. First we can mention that we are struck by the occurrence of social stress in the families with leukemia. Our impression here is in accordance with Murstein's findings (1960) that emotional adjustment were poorer for leukemic parents than for other parents with a fatal illness in the family. We think that parents with leukemic children very often seem to be in a state unable to support each other. The father is occupied building a new home, engaged out of town in further education, travelling or being a seaman. In this "centrifugal family" as described by Bahnson (1978) we see an abnormal communication between mother and child. The deviating communication consists mainly in the mothers domination of the child in

almost always talking for him or her. They are not only answering the questions for the child, but they very often also put the questions ready to be answered by themselves. At the same time the mothers complain having very dependent children, being locked up with the children the child tries to creep into her body again! We want to underline that these observations are impressions not systematic ones controlled for with comparisons with groups of patients and families with other chronic illnesses. We will also mention the possibility that these patterns might have been formed in the pre-diagnostic phase. It is well known that children may have distinct signs of abnormality for some time before parents take any overt action to discover their causes or seek doctoral advice. Many deny such symptoms for weeks and are overtly fearful of confirmation of their fears.

Most of our families seek help. They very much want to find new strategies and in many ways we feel that it is easy to support those families and that the main strategy ought to be family oriented therapy whenever possible.

The families are presenting a multitude of problems and we can only mention a few here:

First of all they need help in communicating with their children about what is going on. In many cases they have chosen to say nothing at all and the child is left alone with their worries - depending on their ages.

Parents often express the need for meaning with the illness and if they have a religious background they often wonder if this could be punishment from God. Many parents are often preoccupied with thoughts about what they have done wrong in their physical care for the child. So guilt in some fashion plays an important part in the problems parents have. Other areas of problems is the relationship between mother and father and their sharing of the care at the hospital and their conception of the child's prospects of being well again. If one of the parents, mostly the father, do not share the events at the hospital, for several reasons, a polarization between the parents may occur with mutual accusations that the other does not care for their problems and stress.

Many other areas could be mentioned, e.g. impact on relationship to grandparents and other family members of the child, impact on social network and friends, on death and dying, on new orientation and new values, anxiety and pathological grief. All the therapy sessions are taped, and systematic analysis on those topics mentioned and others will be made.

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