

Original Papers

Polish Psychological Bulletin
 2008, vol. 39 (4), 192-201
 DOI - 10.2478/v10059-008-0023-6

Maria J. Siemińska*
 Elżbieta Greszta**

The family of a child with cancer - changes within the family system

This study aimed to describe the functioning of families of children with cancer. A semistructured questionnaire was used to interview 116 parents from 58 such families. Changes occurring within the family system from the parents' perspective have been determined and recorded. Most of the changes turned out to be directed at internal relationships within families. Families with much self-orientation have been shown to be prone to transforming into hermetic systems. Polish version of FACES-III was applied to map families as balanced (20%), mid-range (52%) or unbalanced (28%). Results of the study underline the importance of illness duration for functioning of the family. Cancer persisted for the shortest time in balanced families (4.3 years), slightly longer in mid-range (4.5) and the longest in unbalanced families (6.9). The difference between balanced and unbalanced families was significant ($u=1.9615$, $p<0.05$).

Keywords: childhood cancer, family functioning, family system, Olson's Circumplex Model

Introduction

A family facing childhood cancer

Childhood cancer constitutes one of the most stressful experiences for a family. When child is diagnosed with cancer the family system faces many new stressors as well as special challenges and demands associated with frequent hospitalizations, difficult and often painful therapies, uncertainty as to the course of the illness (e.g. McCubbin, et al, 2002), potential loss of life and loss of hope for the future. Family life as it was before is often lost. Childhood cancer reverses the cycle of family life, forcing parents to redefine their personal philosophy of life and death, their goals, expectations, hopes, and dreams for their child and family (Grootenhuis & Last, 1997; Stuber, et al., 1996).

It has been shown that childhood cancer is the second leading cause of mortality among children (Ward, 2000). Child's chronic illness is synonymous with long-standing disorders, not necessarily progressing or worsening, but always interfering with family life. Of all serious illnesses, cancer poses the greatest threat to functioning of a family (Zahr, 1994) by threatening its security and integrity. "The illness integrates with the process of life. A family is a unity in illness as it is a unity in life" (Ranson & Vonderroot, 1973, p. 1110). In contrast, acute illnesses that are not life-

threatening merely induce an imbalance in the physical and psychic functioning of the child and its family. Such imbalance does not last long and therefore does not transform into a general principle governing the life of the child and its family.

Both the structure as well as relationships within a family are negatively influenced by chronic illness, such as cancer – families experience greater financial burden, family members spend less time with one another, personal and social life is disturbed, the level of subjective distress or strain increases and marital disorders appear (Barbarin, et al., 1985; Sabbeth, 1984; Dahlquist, et al., 1993). Other studies show, however, that the experience of childhood cancer exerts a positively impact on some families by strengthening marital relationship, unifying the family, and assigning a role to each family member. Moreover, this difficult experience creates a platform of a shared experience for the family unit to interact around (Hoekstra-Weebers, et al., 1999; Ross, 1989).

Childhood cancer and parents' stress

Childhood cancer impacts all family members. Parents have been shown to experience the greatest degree of stress and trauma. In families of children surviving leukaemia, the impact of the disease on psychic health was the strongest in

* Pomeranian Academy of Medicine, Rybacka 1, PL-70-204 Szczecin, Poland; sieminska@stud.pam.szczecin.pl

** Warsaw School of Social Psychology, Chodakowska 19/31, PL-03-815 Warsaw, Poland; egreszta@swps.edu.pl

parents, irrespective of illness duration (Kazak, et al., 1997). A study of 64 child leukaemia survivors, their 63 mothers and 42 fathers revealed that 12.5% of children, 39.7% of mothers and 33% of fathers exhibited symptoms of painful post-traumatic stress (Stuber, et al., 1996). While children suffering from a disease may disregard it, for the parents it often becomes a major factor disturbing the family life. Diagnosis of cancer in their child is difficult to accept for many parents, who experience a number of unanticipated and powerful stresses: medical (related to the diagnosis); intellectual (inability to comprehend new medical information); instrumental (related to hospitalization and treatment of the child and redesigning family life); interpersonal (related to child's adjustment to the disease and treatment as well as related to parental relations with the familial and social environments); emotional; and existential (associated with parental need to answer the questions 'Why me?' and 'Why now?') (Clarke-Steffen 1993).

Parents of children diagnosed with cancer experience intense emotions. They usually feel an acute sense of loss upon learning of their child's predicament, reporting overwhelming sadness. Parents often grieve for their child, even when the prognosis is good. They grieve the loss of normalcy realizing that life will never be the same and they are forced to modify their dreams and aspirations for their child. Even if parents overcome this feeling of helplessness when a sense of reality returns, fear, panic and anxiety periodically erupt. After the initial shock, parents usually react with to their child's illness with denial, disbelief, anxiety, bitterness, anger and helplessness (e.g. Brown, et al., 1993; Dahlquist, et al., 1993). Sometimes they blame themselves for illness of their child. Comaroff and McGuire (1981) suggested that guilt reactions represent parents' efforts to control the uncontrollable. As shown by Clubb (1991), chronic parental sorrow should not always be regarded as completely detrimental as there are times when it helps families benefit and grow. However, it has been pointed out in literature that some parents never overcome the initial sadness and grief (e.g. Frailey, 1986). And unchecked emotions of parents may turn against their child. For coping to become effective, family members need to discover ways of controlling these emotions (Brown, et al., 1993).

Kazak and colleagues (1994) concluded that families of children with a chronic health problem will be more prone to psychopathology than similar families without an ill child. Families of sick children have been shown to possess strengths as well as vulnerabilities. Studies have been conducted on the prevalence of posttraumatic stress disorder (PTSD) or posttraumatic stress symptoms (PTSS) in the parents of children diagnosed with cancer. The percentage of mothers of survivors, currently exhibiting PTSD has ranged from 6.2% (Manne, et al., 1998) to 54% for lifetime PTSD. Interview data in this study supported

the assumption that higher level of stress resulted from the childhood cancer experience (Pelcovitz, et al., 1996). Stuber and colleagues (1996) discovered a severe level of posttraumatic stress in 39.7% of mothers. Barakat and colleagues (2000) connected traumatic stress symptoms in mothers with long-term adjustment difficulties. Fewer studies have been devoted to PTSD/PTSS in fathers, but it has been found that 7.1% and 28.3% of fathers suffered from severe and moderate PTSD symptoms respectively (Barakat, et al., 1997). Stuber and colleagues (1996) reports the overall PTSS rates for fathers at 33.3%.

These findings imply significant differences in how mothers and fathers react to their child's illness. The research of McCubbin and colleagues (2002) has been a breakthrough in this field by directing attention to differences in strategies adopted by each parent. According to this author, mothers focus on family life and the ability to express emotions, while fathers tend to minimize conflicts, suppress anger, concentrate on organization and control through strict principles and rules. Shapiro (1986) challenged this view by declaring that parents adopting similar strategies have a greater chance of coping with their child's illness.

Changes and coping strategies in families with ill children

"Apart from individual reactions to stress, the family in a unique manner mediates its members. (...) Acting through its adults the family is the first to facilitate or hinder the individual coping efforts" (Kaplan, et al., 1973, pp. 60, 62). Parents overwhelmed by fear or depressions are so self-absorbed that they become incapable of dealing with their child's illness. Internal balance is a prerequisite for a parent to cope with frustration. Of all serious illnesses, cancer poses the greatest threat to the functioning of a family system (Stuber, 1995). Confronted with such challenge, the life of the sick child, its siblings, parents and the family as a whole undergoes change. Some studies have indicated that parents experience definite and long-lasting changes in their life style due to their child's cancer (Stuber, 1997; Kazak, et al., 1997).

The family as a whole, guided by the parents, starts to deal with the illness. Faced with extraordinary threat, family cohesion drifts either to togetherness or separateness depending on its internal norms and family rituals (Morval, 1993; McCubbin et al, 2002). More effective coping by the family requires exploitation of family's resources. Koch-Hattem (1987) described four categories of potential resources at the disposal of the family to cope with a serious illness of the child. During the child's illness the family remains in an unbalanced state and attempts with all known and available means and skills to regain balance. To cope with illness as effectively as possible, the parent must show self-respect, sanguinity and faith in the dominance of man over fate (Koch-Hattem 1987). Family returns to

balance by reorganizing itself, changing behaviours and modifying relations with the external world (McCubbin, et al., 2002). Koch-Hattem (1987), one of the few researchers studying family adaptation to child's serious illness, has distinguished three types of families: (1) Flexibly adapting to the stressor, successfully balancing between affiliation and differentiation of its members, possessing financial, personal, social and psychic resources, aiming at a realistic, controlled understanding of the stressor; (2) Reacting with dysfunction, rigid, not adapting to the stressor, chaotic or disengaged, without resources, tending to question the stressor's existence thereby incapable of effective adaptation; (3) Dysfunctional, prone to be "hurt" by the weakest of stressors, totally incapable of adaptation, already dysfunctional prior to the stressor, likely to have a history of ineffective adaptation to stress.

Reports published on familial reactions to child's cancer identified two principal stresses for the parents to cope with: (1) understanding the nature of cancer by the family; (2) redefining hopes and expectations of parents towards their child (e.g., Kazak 1995). Inspiration for further research has come from studies of Kazak and Fife (Kazak, et al., 1997; Fife, et al., 1987). The first study found that functioning of a family and the level of parental distress remains essentially constant during the illness. The second study demonstrated that coping of the family and its members remains relatively unchanged during the illness. A family with stable and structured relations, good communication and supportive members is capable of maintaining previous quality of life. These observations suggest the existence of a fixed model of family reaction to illness, corroborating the opinion of Bateson (1988) that the choice of reaction is limited by the "familial world map" which determines the rules governing selective inflow of information to the family.

Purpose of the study

The main purpose of this study was to describe functioning of families of children ill with cancer from the parental perspective. We focused on leukaemia, which is the most common type of childhood cancer (app. 90% cases). According to Eiser (1998) childhood leukaemia survival rates approach 70 to 80%. Long-term effects of leukaemia, effects of improved survival rates and potentially toxic and intense treatment as well as the physical, psychosocial, and familial effects on children and their families are still under study. Although much research focused on the parents and the family outcomes of childhood cancer, relatively little has been related to the family as a system. A relative lack of comparative research with respect to parental responses, combined with conflicting research findings, calls for identification of similarities and differences across parental couples in how they view their child's illness and what implications of illness upon their family life they are aware of. The study protocol was based on theories of Prigogine (1978), Wertheim (1973, 1975) and Walsh (1982) and

Olson's Circumplex Model (Olson, Sprenkle and Russel, 1979; Olson, 2000). The following assumptions were made: (1) The illness appears at random and due to its nature forces the family to adopt changes affecting several levels: parents, the family as a whole, relations with the external world (Wertheim 1973, 1975); (2) Changes take place continuously, slowly and irreversibly, i.e. the return to former model of family functioning is impossible (Prigogine, 1978); (3) Family functioning is determined by the propensity of the family system to maintain its balance. This requires achieving optimal and adequate balance within social and cultural constraints between stability and change forced by the illness (Walsh, 1982).

Methods

Participants

One hundred and sixteen parents from 58 families from the north-western part of Poland participated in this study. In 81% of all those families a child was diagnosed with acute lymphoblastic leukaemia (ALL). Volunteers for the study were granted anonymity and confidentiality. The children were treated at the Department of Paediatrics, Pomeranian Academy of Medicine, which is a regional ALL cancer facility. Management of leukaemia consists of three stages: (1) intensive treatment, chemotherapy; (2) maintenance of remission; (3) follow-up. Children, whose families volunteered for the study were in the second or third stage of the disease. The majority of parents were 30 to 50 years of age and most of them obtained vocational level of education (secondary education). Parents usually originated from families with at least two children, the number of siblings being higher for fathers. When arranged by age, 50% of mothers and 34% of fathers were neither the oldest nor the youngest among their siblings. The percentage of mothers being the oldest child was higher than fathers, while the percentage of fathers being the youngest child was much higher than mothers. The demographic characteristics of the parents and children with leukaemia are displayed in Table 1. Data regarding children were collected only when parents agreed to participate in the study. This was the case for 58 children, 64% of them boys and 52% of school age. Leukaemia lasted from 1 to 14 years. When arranged by age, boys being the youngest child predominated (41%), while girls predominated as the oldest child (48%). Demographic data of the children are presented in Table 2. Data collected for this study seems valuable for two reasons. Firstly, all children were diagnosed with the same disease; therefore all families were exposed to the same stressor. Secondly, the children were treated at the same medical centre.

A control group was not used in this study. Kazak and her colleagues (1994) questioned the use of control groups in such projects. A growing body of literature has shown no differences between families with and without

Table 1
Demographic data of the parents.

Demographic feature	Mothers (%)	Fathers (%)
1. Age (years):		
up to 30	7	4
31-40	57	43
41-50	24	51
2. Education:		
primary	16	6
vocational	27	45
secondary	16	18
3. Number of children in parent's family:		
one	2	12
two	31	6
three	12	27
four and more	36	55
4. Place among siblings:		
single	2	12
oldest	38	25
youngest	10	29
other	50	34

Table 2
Demographic data of the children.

Demographic feature		
1. Age (years)		
3-7	24	
7-15	52	
16-20	24	
Duration of leukaemia (years)		
< 3	38	
4-8	43	
9-14	18	
Place among siblings		
	Boys	Girls
Oldest	27	43
Single	11	5
Youngest	41	29
Other	21	23

ill children. The null hypothesis should have therefore been rejected. Adaptive functioning within families despite chronic strains of childhood illness should be examined, but at the same time there is a need to further understand and determine the impact of these strains on ill children and their families. Recorded differences are most likely not psychopathological in nature, but are related to more subtle aspects of adjustment and coping. The use of comparison or control groups may therefore be altogether inappropriate since they fail to control (or contain) the critical elements in coping with childhood chronic illness (Kazak & Nachman, 1991).

Measure

This study consisted of collecting and processing qualitative data. Lazarsfeld, one of the leading methodologists in this field of research, stressed the need for qualitative methods and noticed the importance of

qualitative analysis, particularly valuable in explaining problems and finding research topics that lack scientific clarification (cf. Merton, 1979). The value of qualitative methods in research of childhood cancer has been well recognized. McCubbin and colleagues (2002) carried out a study based on a semistructured interview conducted with parents of a child suffering from cancer. The study of Patistea and colleagues (2000), consisted of open-ended interviews with parents of children with leukaemia.

Semistructured questionnaire offers parents freedom and control in answering questions and is an efficient way to investigate this topic. It allows parents to explain their beliefs accurately and in their own words. We have used standard semistructured interview questions. Having considered both qualitative and quantitative data from studies of family response to childhood chronic illness (Knafl, et al., 1996), our questionnaire addressed the following questions: What is the reported perceived impact of illness on the family? What intracouple and familial differences and/or similarities have been reported in perceptions of impact of child's leukaemia? Do mothers and fathers agree on the impact of illness on the functioning of individuals and the family as a whole? Our questionnaire consisted of open-ended and close-ended questions. Open-ended questions referred to changes experienced (and reported) by parents upon learning of their child's cancer (for example: „How have you changed because of your child's illness?"). Close-ended questions referred to changes within the family (for example: “Which of the following changes have you noticed in your family: 1. greater care of sick child; 2. mother abandons job; 3. mother changes job; 4. more time devoted to children; 5. stronger ties between spouses; 6. family more coherent; 7. parents more responsible; 8. change of career plans; 9. greater fear; 10. closer ties with relatives; 11. pauperization; 12. severed ties with friends; 13. increased religiousness"). Answers were analyzed for their content. First emerging themes have been identified and coded (as needed). Codes had to be carefully designed to capture respondent's thoughts. All answered questionnaires were compared to one another to create broader categories cross-linking the codes. Again care was applied not to distort the content.

The Family Adaptation and Cohesion Evaluation Scales (FACES) are based on Circumplex Model of Marital and Family Systems. This model was developed by Olson, Russell and Sprenkle (1979) in an attempt to create conceptual model for the assessment of family functioning. It also aims to bridge the gap between research, theory and practice. This model stresses cohesiveness and adaptability as two dimensions central to the functioning of the family. Authors of the Circumplex Model have designed an instrument called FACES to measure cohesion and adaptability. Cohesion has been defined as the extent to which family members bond to one another. It is similar to what Minuchin (1974) described as running between the

extremes of disengagement and enmeshment and to the scale Bowen (1960) identified as running from emotional divorce to emotional fusion. Adaptability indicates the ability of the family system to respond to situational and developmental stress by changing its power structure, role relationships, and relationship rules (cf. Olson, 2000). In the Circumplex Model, Olson and colleagues distinguished between four levels of family cohesion, from extremely low cohesion to extremely high cohesion - disengaged, separated, connected, and enmeshed. Similarly they determined four levels of family adaptability, ranging from extremely low adaptability to extremely high adaptability - rigid, structured, flexible, and chaotic. The cross-categorization of these two dimensions yielded a 16-category classification with three different family systems: the balanced family system, characterized by four categories in the middle range of both cohesion and adaptability, the mid-range, characterized by eight categories, which had a medium score on one scale and the extreme score on the other; and the extreme, characterized by four categories with extreme scores on both scales (cf. Olson, 2000). Major hypothesis of the Circumplex Model was that balanced couples and family systems tended to be more functional compared to unbalanced systems. Strong support has been found for this hypothesis in over 250 studies using FACES (cf. Olson, 2000).

In this study FACES - Version III was applied to map families as balanced, mid-range or unbalanced. FACES-III is a self-report scale, containing 20 statements in Likert-scale format ranging from 1 ("Almost Never") to 5 ("Almost Always"). Family cohesion and adaptability scales each contain 10 items. Alpha reliabilities reported in the FACES-III manual range from 0.58 to 0.77 (Olson 1986; Olson 2000). The scales are useful in differentiating between functional and dysfunctional families. FACES has been specifically designed for planning research, clinical assessment and treatment of families (cf. Olson, 2000). This study uses a Polish version of FACES-III adapted by Radochoński' (1987, pp. 121-123).

Results

Impact of child's illness on the parents

Mothers reported the following changes associated with their child's illness: nervousness and distress (38%), anxiety and fear (16%), ignorance of minor problems (9%). Fathers reported nervousness (19%) and marked fear (16%). Parents were asked whether the illness had any impact on their values. The intention of this question was to find if the illness was accompanied by positive revaluations and whether these were implemented by the parents. Although it was uncertain whether the parents would find this question relevant, the outcome was better than expected - 66% of fathers and 52% of mothers responded. The illness helped

parents appreciate the value of life (18% of mothers and 21% of fathers), notice the importance of the family (15% of mothers and 17% of fathers), understand the nature of the disease and efforts of the doctors (11% of mothers and 13% of fathers). One of the mothers wrote: "I became aware how little is needed for our world to fall apart. Human life is no more than dust blowing in the wind."

Changes within the family as perceived by parents

The object of this analysis was to detect changes in the family system as seen from the parents' perspective. Essentially, the aim was to discover differences between mothers and fathers in their perceptions of changes taking place in the family under the pressure of illness. The majority of mothers (79%) and fathers (74%) reported greater attention being devoted to the child since the illness began. This seemed a natural parental reaction to such dreadful disease. Positive emotions - kindness, concern and tolerance, were mobilized and focused on the child. Both parents reported more fear in the family (72% of mothers and 60% of fathers). Fear and threat to the family was independent of the duration of disease. Fear of relapse became a permanent factor of family life. Some changes reported by mothers were different from those reported by fathers. Mothers noticed that more time was devoted to children and the family became more responsible as a whole (57%). Fathers reported tightening of marital ties (62%), a change reported only by 48% of mothers. Deeper emotional ties with partner were more important to fathers. The family became more coherent according to 57% of fathers and 50% of mothers. Dwindling of finances was equally often acknowledged (43% of mothers and 45% of fathers). Fear of the future, feeling of danger, lack of support from the society brought families closer to religion according to 33% of mothers and 32% of fathers. Ties with relatives have improved albeit slightly (17% of mothers and 11% of fathers). Contacts with friends have diminished according to 32% of mothers and 35% of fathers or severed (7% of mothers and 9% of fathers). A mother of a seven-year-old wrote: "I understood that only a few are concerned with my family's tragedy. Friends and relatives have left us. They do not want to look at our suffering".

Coping of the family with child's illness

The process of change in the family is a reaction to the child's illness as the family tries to cope with it. Thus, only changes reported jointly by both parents were subjected to further analysis. More attention was paid to the sick child in almost all families (84%) and the majority of them (60%) experienced uncertainty and fear. In view of the child's illness many families (48%) became more coherent and marital ties became tighter (44%). Care of children increased (44%), as did parental responsibility (42%). As religious faith grew stronger (24%), relationships with the external world improved slightly and only in the form of

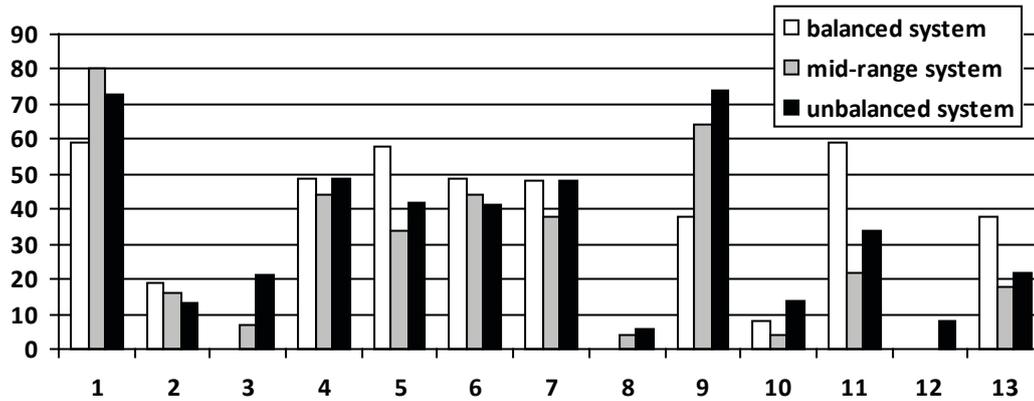


Figure 1. Reported changes in the family systems.

(Legend: 1. greater care of sick child 2. mother abandons job 3. mother changes job 4. more time devoted to children 5. stronger ties between spouses 6. family more coherent 7. parents more responsible 8. change of career plans 9. greater fear 10. closer ties with relatives 11. pauperization 12. severed ties with friends 13. increased religiousness.)

closer ties with relatives (10%). The organization of the family changed little. The mother gave up employment in 16% of families. Career plans altered for 4% and duties for 8% of parents. The most notable change was a greater feeling of responsibility for the family's existence (42%). Illness of child caused pauperization in 32% of families. Least importantly, relationships with the external world altered. Associations between change classes were also found. Change in internal relationships was correlated with change in family organization ($r=0.514$, $p<0.001$).

The family system from the perspective of Olson's Circumplex Model

The majority of families were mid-range (52%), the remaining were unbalanced (28%) or balanced (20%). Search for differences between these families revealed that the age of the sick child was highest in unbalanced families ($x=13.6$ years), while in mid-range and balanced families it was 10.48 and 10 years, respectively. The Wilcoxon rank test (Brzeziński, 1997), a nonparametric equivalent of the Student's t-test, was used to compare the results for unbalanced and balanced families, revealing statistically significant differences ($u=1.990$, $p<0.05$). The same test was used for comparisons of illness duration between the groups. The duration of ALL was shortest in balanced families (4.3 years), slightly longer in mid-range (4.5) and longest in unbalanced families (6.9). The difference between balanced and unbalanced families was significant ($u=1.9615$, $p<0.05$). Approximately 80% of sick children in balanced families were the second oldest, in contrast to unbalanced families where the illness predominantly affected the oldest child (58%). Families of each type adopted similar number of changes although in different areas (Figure 1). Balanced families often reported closer ties between parents (60%), more attention toward the sick child (60%) and increased coherence (50%) in the wake of the illness. Changes predominating in unbalanced and mid-range families were: focusing of attention on

the sick child (72.4 and 80%, respectively), fear (72 and 64%, respectively), and increased family involvement (50 and 40%, respectively). Fear is least often encountered in balanced families with manifested religiousness (40% vs. 20 in mid-range and 21% in unbalanced families).

Discussion and Conclusions

Changes within the family occur as a reaction to child's illness. In this process the entire family tries to cope with illness of a child. Our project revealed multiple changes occurring within studied family systems. When faced with child's illness, almost half of the families showed increased coherence and stronger marital ties. Our results confirmed the results of Barbarin and colleagues (1985), who found increased family cohesion as a result of childhood cancer and strong support between spouses. Over time, however, they found the marital quality and spousal support to decline. At the same time our results differed from later studies showing decreased family cohesion as a result of childhood cancer (e.g. Dahlquist, et al., 1993). In our study, every fourth family developed stronger religious faith. Many authors have stressed the importance of religion and belief in God as well as hope (with or without faith) as crucial for obtaining solace (as in: Mood 1991). Other studies of coping in families of leukaemia children established a connection between coping and openness in communication, quality of marital relationship, family income, religious beliefs (e.g. Kupst & Schulman, 1988; Midence, 1994).

In almost all of the studied families ill children received more attention. Parents' behaviour characterized by greater care towards the child was seen as a natural reaction to a threatening disease (risk of second cancer). Children from families volunteering for our study were in the second or third stage of leukaemia treatment (consisting of three stages: 1. intensive treatment; 2. maintenance of remission;

3. follow-up). Prolonging focus on the child (in the context of high level of anxiety and uncertainty within the family system) may disturb child's proper development. More studies of Polish population are needed to verify this hypothesis. Research carried out in the United States of long-term survivors of childhood cancer has indicated adequate overall psychosocial adjustment, which suggests that most survivors of childhood cancer do well in terms of general psychological outcome (among others: Brown, et al., 1992; Spirito, et al., 1990; Kazak, et al., 1994). This may be considered as an indirect evidence of insignificant role of this problem in studied populations. However, in a study performed in Europe with patients suffering from another chronic childhood disease, diabetes overprotection was apparent in 28 out of 30 studied families (Tsamparli, & Kounenou 2004).

Most families involved in our research project experienced uncertainty and fear. Uncertainty with regard to what the illness is and how it would develop has been identified as one of the major stressors influencing family functioning. Despite of its importance, relatively little research has been devoted to the influence of uncertainty in childhood chronic conditions on families (e.g. Patterson & Garwick, 1994). To date this problem was approach mostly from theoretical perspective (Sharkey, 1995; Mishel, 1991). According to Sharkey (1995) uncertainty surrounding the nature and the course of a chronic condition increases family distress. Prolonged uncertainty within a family can disrupt its ability to function effectively. Recent review of the literature on uncertainty, conducted by Mishel (1999) calls for more research to be devoted to uncertainty experienced by families. Up to date research on this topic focuses mostly on adults with acute or chronic illness. (cf. Dodgson, et al., 2000).

When faced with child's cancer almost half of the families increased coherence with spouses exhibiting stronger marital ties. Parents devoted more time to the care of their children. Parents felt greater responsibility for the existence of the family. As religious faith grew stronger, relationships with the external world slightly improved but only in the form of closer ties with the relatives. It could be concluded that changes were mostly directed at the internal relationships within families. Relationships with the external world altered only slightly. Associations between change classes were also found. Changes in internal relationships correlated with changes within the family. Thus, greater uncertainty and fear favoured greater family coherence, supporting in turn the process of change in family functioning. Responses of Polish families to threat were described in the older literature on this subject by the following observation: "Strong emotional ties within groups are one of the key features of the Polish society. Difficulties and problems, frustrations and helplessness are coped with by Poles chiefly with the aid of the family, friends, and colleagues at work." (Koralewicz, & Wnuk-

Lipiński, 1987, p. 209). Our findings suggest that this type of reaction to threatening circumstances is still typical for Polish families. In case of families involved in our project this mostly reflected an idealistic approach. Families with a sick child, although more coherent, were left to themselves, receiving help mostly their relatives. Narrowing of the social sphere to the family represented social disintegration and exerted a disintegrative influence on the family itself (Tarkowski, & Tarkowska 1990, pp. 40-42). Such findings have been attributed to a centralized political system which prevailed in Poland for the last fifty years. A family-oriented attitude represented a lack of control over the external world and fate, leaving the individual feeling dependent. Such behaviours were usually observed in systems characterized by submission and subordination. It is difficult then to determine why Polish families reacted to their childhood cancer by increasing their isolation. It might be rooted in culture, but that would need to be determined in the course of further research. A similar phenomenon has been described by Tsamparli and Kounenou (2004) with respect to Greek families of a child with diabetes. Their research has shown that parents reacted to their child's illness by reducing their contacts with friends and relatives. Families involved in their study neither engaged in social interactions for several years after diagnosis nor accepted help from relatives. Authors have stressed that their findings were atypical for a Greek family, which by no means can be considered nuclear. Greek families always interact closely with members of the extended family, who provide family members with emotional and practical support. "Families seem to perceive social reality as dangerous: the world outside the family is not safe" (Tsamparli, & Kounenou 2004, p. 1652).

Having considered the above, one may conclude that Polish families of children with cancer are exceptionally deprived of control over the course of events. This can be explained by the nature of the stressor, but it can be also attributed to the social experience of parents. Although the family itself becomes more coherent when faced with cancer, little change occurs within the family structure or relationships with the external world. Fear immanently linked with the disease prevents the introduction of new elements and ties into the family system. Changes in the family involve maximum use of the existing resources. Families showing much self-orientation are prone to transforming into hermetic systems. Changes reflecting possible introduction of new elements to the family system were noticed in five families only ("We became more efficient in finding sources of subsistence" – 2 families; "We are better prepared to cope with crisis" – 3 families). Analysis using Olson's Circumplex Model revealed that most families of children with cancer were mid-range; close to one third were unbalanced; and only every fifth family - balanced. In a study carried out by Kazak and colleagues (1994) with parents of adolescent cancer survivors, scores

on FACES-III show that parental reports of cohesion were within the separated and adaptability (structured) ranges that were developmentally appropriate and consistent with FACES-III norms. Differences between our findings and the findings of other authors quoted in this paper may result from differences between the populations (see above) and differences in psychological care (less extensive/lower standard in Poland).

Search for differences among families involved in this study revealed that the age of the sick child was highest in unbalanced families, while in mid-range and balanced families it was significantly lower. The duration of cancer was shortest in balanced families, slightly longer in mid-range and longest in unbalanced families. These results underlined the importance of the duration of illness for the functioning of the family. Emerging from the shock upon receiving a diagnosis of cancer, parents resorted to their experience from before the illness and were thus able to function normally, albeit for some time. The duration of illness brought with it changes narrowing the sphere of awareness of the family. Apparently, memory of what is normal i.e. how life was before illness was also affected. The highest mean age of sick children (most of them teenagers) were found in unbalanced families, suggesting that problems in the family aggravate with maturation of ill children. Parental focusing of attention, care and guidance were more acceptable to young children. This attitude towards a teenager seemed to result from suppression of normal development of the family caused by the illness. Approximately 80% of sick children in balanced families were the second oldest, in contrast to unbalanced families where the illness predominantly affected the oldest child (58%). Apparently, a serious illness of the oldest child has a greater impact on family functioning. The firstborn has a special position within the family and therefore exerts the strongest impact on its functioning. The birth of the first child exposes hidden problems, fears and myths of the family, but on the other hand it brings new emotions and thus may compensate for emotional deficiencies of the parents. Derangement of this process by illness, particularly in families with unsolved problems, can contribute to increased tension. Families of each type adopted a similar number of changes although in different areas. Majority of balanced families reported closer ties between parents, more attention and care towards the sick child and increased coherence in the wake of the illness. The following changes dominated in unbalanced and mid-range families: focusing of attention on the sick child, fear, and increased family involvement. Fear was least often encountered in balanced families with manifested religiousness.

A life-threatening event is bound to alter family life, perhaps forever. When faced with child's illness, families should strive to institute new patterns of functioning. It is critical to consider the family's appraisal of the situation throughout the course of child's cancer. Stressors, such as

deterioration in the child's condition may push the family to view its situation as unmanageable or unmeaning. Repeated care is what Hawley (2000) termed necessary for such families.

Families experience plenty of stressful situations. Whether they will function normally or find themselves in crisis depends on how well they cope with stress. Illness in the family must be confronted with reorganization of the family and strengthening of relations with the external world. Unfortunately, in most cases this process is not observed. Circulating opinions on cancer and the prevailing social experiences prevent families from learning how to cope with this illness. Post-war ideology has made it difficult for people to correctly identify danger. Existential fear has been suppressed by visions of a stable and safe country. No place has been left for fear in the perception of the society by the public and the individual. Fear has to be conquered and replaced by rational action (identification of danger and search for optimal solutions). As a result, we have seen growing inflexibility of attitudes, reluctance to adopt change, increased family coherence and migration of fear (health disorders). One of the key aims of the present work was to examine changes in family cohesion, if any, resulting from childhood cancer. Shared danger rests at the bottom of increased coherence and creation of combat or fear groups. Combat groups are common in animals caring for and protecting their young (Eibl –Eibesfeldt, 1987). Parents of a seriously ill child would be expected to form the same type of group in view of the character of the threat but this was not the case for most of the families studied. Formation of a combat group involves increased contacts with the outside world and internal reorganization of the family. It is true that the examined families became more coherent in view of the illness. Fear brings people closer to each other and helps build stronger relationships. However, chronic fear may limit the ability of the individual to function independently. Paradoxically, total dependence of family members on themselves eventually prevents satisfactory contacts. As Namysłowska and Siewierska (1994, p. 553) noted: „Fear is destructive when... it becomes the chief factor of coherence, replacing true closeness based on understanding of needs and respect for the autonomy of others”.

Our findings show that most families transform into fear groups when confronted with child's cancer. Changes in the family are steered chiefly by emotions related to the child's serious illness. Fear prohibits them from searching for new solutions, producing inflexibility of attitudes and reliance on acquired behaviour. A prerequisite for change to take place is acceptance of the irreversibility of events, as proposed by Prigogine (1978), who introduced the term “evolutionary feedback” and “order through fluctuation”. The family as a kaleidoscope has minimal chances to return to the previous organization or function. Paradigms which help maintain a balanced system in harmony with the environment

become inadequate in the face of new conditions. Change becomes necessary and transformation must take place. Prigogine and Stengers (1984) believes in the operation of the irreversibility principle during change, i.e. conditions precedent are the fruit of evolution and continue to evolve into states of the same class. "Irreversibility is the source of order at all levels. Irreversibility is a mechanism extracting order out of chaos" (Prigogine & Stengers, 1984, p. 311). On individual level, irreversibility is implicitly linked with human existence. Our feeling of irreversibility is not just related to our awareness but stays in harmony with the outside world and its dominating existential paradigm. When life of a family member is threatened, the entire family must develop a higher level of awareness, accepting an end to the past and looking at the future with limited hope. Experiences of families in the present study facilitate reflections on human existence in a dangerous and uncertain world (Andersen, 2002). Only limited hope can be justified, as God beheld during creation of the world according to the Talmud. "The world was not created at once in the hands of God. Events described in the Book of Genesis were preceded by 26 attempts, all of which were destined to fail. The world of man emerged out of chaos from a primordial rubble, without any guarantees for the future. It may also collapse and return to nothingness. 'May this one last (Halevay sheyaamod)' exclaims God after creating the world. This hope reappears throughout the history of the world and mankind showing right from the start that our existence is marked with complete uncertainty" (Prigogine & Stengers, 1984, p. 33).

References

- Andersen, T. (2002). Blinding and Deafening Moments, and Threatening Futures. *Family Process*, 41, 11-14.
- Barakat, L., Kazak, A., Gallagher, P., Meeske, K., & Stuber, M. (2000). Posttraumatic stress symptoms and stressful life events predict the long-term adjustment of survivors of childhood cancer and their mothers. *Journal of Clinical Psychology in Medical Settings*, 7, 189-196.
- Barakat, L., Kazak, A., Meadows, A., Casey, R., Meeske, K., & Stuber, M. (1997). Families surviving childhood cancer: A comparison of posttraumatic stress symptoms with families of healthy children. *Journal of Pediatric Psychology*, 22, 843-859.
- Barbarin, O., Hughes, D., & Chesler, M. (1985). Stress, coping and marital functioning among parents of children with cancer. *Journal of Marriage and the Family*, 47, 473-480.
- Bateson, G. (1988). *Mind and Nature. A Necessary Unit*. New York: Bantam Books.
- Bowen, M. (1960). The family as the unit of study and treatment. *American Journal of Orthopsychiatry*, 31, 40-60.
- Brown, R., Kaslow, N., Hazzard, A., Madan-Swain, A., Sexson, S., Lambert, R., & Baldwin, K. (1992). Psychiatric and family functioning in children with leukemia and their parents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 31, 495-502.
- Brown, R., Kaslow, N., Madan, S., & Doepke, K. (1993). Parental psychopathology and children's adjustment to leukaemia. *Journal of the American Academy of Child and Adolescent*, 32, 554-561.
- Brzeziński, J. (1997). *Metodologia badań psychologicznych* [Methodology of Psychological Research]. Warsaw: PWN.
- Clarke-Steffen, L. (1993). Waiting and not knowing: the diagnosis of cancer in a child. *Journal of Pediatric Oncology Nursing*, 10, 146-153.
- Clubb, R.L. (1991). Chronic sorrow: adaptation patterns of parents with chronically ill children. *Pediatric Nursing*, 17, 461-466.
- Comaroff, J., & MaGuire P. (1981). Ambiguity and the search for meaning: childhood leukaemia in the modern clinical context. *Social Science and Medicine*, 158, 115-123.
- Dahlquist, L., Czyzewski, D., Copeland, K., Jones, C., Taub, E., & Vaughan, J. (1993). Parents of children newly diagnosed with cancer: Anxiety, coping and marital distress. *Journal of Pediatric Psychology*, 18, 365-376.
- Dodgson, J.E., Garwick, A., Blozis, S.A., Patterson, J.M., Bennett, F.C., & Blum, R.W. (2000). Uncertainty in Childhood Chronic Conditions and Family Distress in Families of Young Children. *Journal of Family Nursing*, 6, 252-266.
- Eibl-Eibesfeldt, I. (1987). *Love and hate: The natural history of behavior patterns*. (G. Strachan, Trans.). New York: Schocken.
- Eiser, C. (1998). Practitioner review: Long-term consequences of childhood cancer. *Journal of Child Psychology and Psychiatry*, 39, 621-633.
- Fife, B., Norton, J., & Groom, G. (1987). The family's adaptation to childhood leukaemia. *Social Science Medicine*, 24, 159-168.
- Frailty, A.M. (1986). Chronic sorrow in parents of premature children. *Children's Health Care*, 15, 114-118.
- Grootenhuis, M., & Last, B. (1997). Adjustment and coping by parents of children with cancer: a review of the literature. *Supportive Care in Cancer*, 5, 466-484.
- Hawley, D. (2000). Clinical implications of family resilience. *American Journal of Family Therapy*, 28, 101-116.
- Hoekstra-Weebers, J., Jaspers, J., Kamps, W., & Klip, E. (1999). Risk factors for psychological maladjustment of parents of children with cancer. *Journal of the American Academy Child and Adolescent Psychiatry*, 38, 1526-1535.
- Kaplan, D.M., Smith, A., Grobstein, R., & Fischman, S.E. (1973). Family mediation of stress. *Social Work*, 18, 60-69.
- Kazak, A., Boyer, B.A., Brophy, P., & Johnson, K. (1995). Parental perceptions of procedure - related distress and family adaptation in childhood leukemia. *Children's Health Care*, 24, 143-158.
- Kazak, A.E., Christakis, D., Alderfer, M., & Jo Coiro, M. (1994). Young Adolescent Cancer Survivors and Their Parents: Adjustment, Learning Problems, and Gender. *Journal of Family Psychology*, 8, 74-84.
- Kazak, A.E., & Nachman, G.S. (1991). Family research on childhood chronic illness: Pediatric oncology as an example. *Journal of Family Psychology*, 4, 462-483.
- Kazak, A.E., Barakat, L.P., Meeske, K., Christakis, D., Meadows, A., Casey, R., Penati, B., & Stuber, M. (1997). Posttraumatic Stress, Family Functioning, and Social Support in Survivors of Childhood leukaemia and Their Mothers and Fathers. *Journal of Consulting and Clinical Psychology*, 65, 120-129.
- Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1996). Family response to childhood chronic illness: Description of management styles. *Journal of Pediatric Nursing*, 11, 315-326.
- Koch-Hattem, A. (1987). Families and chronic illness. *Family Therapy Collections*, 22, 33-50.
- Koralewicz, J., & Wnuk-Lipiński, E. (1987). *Życie rodzinne, towarzyskie i publiczne. Wartości i deprywacje*. [Family and social life. Values and deprivation]. In: E. Wnuk-Lipiński (Ed.). *Nierówności i upośledzenia w świadomości społecznej* [Social inequalities and discriminations in social consciousness] (pp. 207-260). Warsaw: IFiS PAN.

- Kupst, M. J., & Schulman, J. L. (1988). Long-term coping with pediatric leukemia: A six-year follow-up study. *Journal of Pediatric Psychology, 13*, 7-22.
- Manne, S., DuHamel, K., Gallelli, K., Sorgen, K., & Redd, W. (1998). Posttraumatic stress disorder among mothers of pediatric cancer survivors: Diagnosis, comorbidity, and utility of the PTSD checklist as a screening instrument. *Journal of Pediatric Psychology, 23*, 357-366.
- Mishel, M.H. (1991). Reconceptualization of the uncertainty in illness theory. *Image, 22*, 256-262.
- Mishel, M.H. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research, 17*, 269-299.
- McCubbin, M., Balling, K., Possin, P., Friedrich, S., & Bryne, B. (2002). Family resiliency in childhood cancer. *Family Relations, 51*, 103-111.
- Merton R.K. (1979). *Qualitative and Quantitative Social Research: Papers in Honor of Paul F. Lazarsfeld*. New York: The Free Press.
- Midence, K. (1994). The effects of chronic illness on children and their families: An overview. *Genetic, Social and General Psychology Monographs, 120*, 311-326.
- Minuchin, S. (1974). *Families and Family Therapy*. Boston: Harvard University Press.
- Morval, M., & Biron, G. (1993). Family rituals. *Therapy Familiale, 14*, 149-167.
- Namysłowska, I., & Siewierska, A. (1994). Lęk w systemie rodzinnym [Anxiety in family system]. *Psychiatria Polska [Polish Psychiatry], 5*, 547-556.
- Olson, D.H. (1986). Circumplex Model VII: validation studies and FACES III. *Family Process, 25*, 337-351.
- Olson, D.H., (2000). Circumplex Model of Marital and Family Systems. *Journal of Family Therapy, 22*, 144-167.
- Olson, D.H., Sprenkle, D.H., & Russell, C. (1979). Circumplex model of marital and family systems: I . Cohesion and adaptability dimensions, family types, and clinical applications. *Family Process, 18*, 3-28.
- Patistea E., Makrodimitri, P., & Panteli, V. (2000). Greek parents' reactions, difficulties and resources in childhood leukaemia at the time of diagnosis. *European Journal of Cancer Care, 9*, 86-96.
- Patterson, J.M., & Garwick A. W. (1994). The impact of chronic illness on families: A family systems perspective. *Annals of Behavioral Medicine, 16*, 131-142.
- Pelcovitz, D., Goldenberg, B., Kaplan, S., Weinblatt, M., Mandel, F., Meyers, B., & Vinciguerra, V. (1996). Posttraumatic stress disorder in mothers of pediatric cancer survivors. *Psychosomatics, 37*, 116-126.
- Prigogine, I., & Stengers I. (1984). *Order out of chaos*. New York: Bantam.
- Prigogine, I., (1978). Time, structure and fluctuation. *Science, 201*, 777-795.
- Radochonski M. (1987). *Rodzina a choroba [Family and Illness]*. Reshow: WSP.
- Ranson, D., & Vonderroot, M. (1973). The Development of Family Medicine. *Jama, 228*, 1098-1102.
- Ross, S.A. (1989). Childhood leukaemia: The child's view. *Journal of Psychosocial Oncology, 7*, 75-90.
- Sabbeth B. (1984). Understanding the impact of chronic childhood illness on families. *Pediatric Clinics of North America, 31*, 47-56.
- Shapiro, J. (1986). Assessment of family coping with illness. *Psychosomatic, 27*, 262-271.
- Sharkey, T. (1995). The effects of uncertainty in families with children who are chronically ill. *Home Healthcare Nurse, 13*, 37-42.
- Spirito, A., Stark, L., Cobiella, C., Drigan, R., Androkites, A., & Hewitt, K. (1990). Social adjustment of children successfully treated for cancer. *Journal of Pediatric Psychology, 15*, 359-371.
- Stuber, M. (1995). Stress responses to pediatric cancer: A family phenomenon. *Family Systems Medicine, 13*, 162-172.
- Stuber, M. (1997). Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of Consulting and Clinical Psychology, 65*, 120-129.
- Stuber, M., Christakis, D., Houskamp, B., & Kazak, A. (1996). Posttrauma Symptoms in Childhood Leukaemia Survivors and Their Parents. *Psychosomatics, 37*, 254-261.
- Tarkowski, J., & Tarkowska, E. (1990). „Amoralny familizm” czyli o dezintegracji społecznej w Polsce lat osiemdziesiątych [„Amoral familial loyalty” – social disintegration in the 1980s in Poland]. In: E. Wnuk-Lipiński (Ed.). *Grupy i więzi społeczne w systemie monocentrycznym [Social groups and bonds in centralized political system]* (pp. 37-70). Warsaw: IFiS PAN.
- Tsamparli, A., & Kounenou, K. (2004). The Greek family system when a child has diabetes mellitus type 1. *Acta Paediatrica, 93*, 1646-1653.
- Walsh, F., (1982). *Normal family processes*. New York: Guilford Press.
- Ward, J. (2000). Pediatric cancer survivors: Assessment of late effects. *Nurse Practitioner, 25*, 18-37.
- Wertheim, E.S. (1973). Family unit therapy and science and typology of family systems. *Family Process, 12*, 361-367.
- Wertheim, E.S. (1975). The Science and Typology of Family Systems II. Farther Theoretical and Practical Considerations. *Family Process, 14*, 285-303.
- Zahr, L., Kurdahi, K., & Saound-Nabil, B. (1994). Chronic illness in Lebanese preschoolers. Impact of illness and child temperament on the family. *American Journal of Orthopsychiatry, 64*, 396-403.