
Environmental Mastery and Autonomy of Parents in Childhood Cancer

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Abstract: Malignant childhood diagnosis is a very difficult experience for the child and for the entire family, is a constant stress on which the family needs to adapt. In this period, with many emotional burden, parents face an increase in parental responsibility and the need to have an optimal function in to cope with the new situation. This study aims to explore the ability of parents to control the environment and to be autonomous in cases of childhood cancer. The research is quantitative and descriptive. Participants were 52 subjects: parents of patients with malignant diagnoses, who received hospital or day treatment at the Service of Pediatric Onco-Hematology, UHC of Tirana. For the selection of the participants was used census for the period from 10.2.2014 to 15.6.2014. For data collection were used two subscales of the psychological wellbeing scale. Statistical analysis showed that the average of parents had somehow high scores in autonomy and slightly high scores in environmental mastery. None of the parents had low scores. Parents who lives in towns, those with higher educational level, fathers and parents whose children are in the last part of treatment have had high scores. Parents have the ability to manage complex environmental and be autonomous. These dimensions are contoured by type of treatment and the parental characteristics such as: gender, place of residence and educational level.

Keywords: Psychological Well Being, Parental Coping, Parental Autonomy, Parental Environmental Mastery, Childhood Cancer

1. Introduction

1.1. Parents and Childhood Cancer

Childhood malignant diseases are very difficult situations for the child and for his entire family. This diagnoses first put the child's life at risk. The complications extend beyond the physical, emotional behavioral part of the child and include the emotional, psychological and economical part of the family [1]. Besides their physical aspect and medical treatment, efforts are made for children to have a good psycho-social functioning and a full life within their physical abilities. The child's well-being is always related to that of his family and inversely. The literature found that the emotional state and behavior of parents can influence the psychological functioning of the child. In childhood cancer this kind of relationship is evident [2]. Child's condition is significantly affected by the way parents react, adapt and act.

Children represents hope, energy and health and when a

child loses life or his life is in risk challenges our understanding of life, belief and security for the future. Childhood malignant disease are seen as constant stress to which the parents should adapt. Parents face daily challenges: when they discover the diagnosis, when the child is hospitalized and when suffer from side effects of the chemotherapy. Moving forward in stressful period is difficult. Parents of children with cancer are a unique group, few people can really understand what they feel and experience [3].

1.2. When Parents Take the Child's diagnosis

The diagnosis of the child immediately leads them to a shock, the passage is fast and destructive. Parents have strong emotional, anxiety and fear of losing their child [4]. The parents' grief for the child is common even when the prognosis is good, they are sad for the loss of normality, for the fact that life will no longer be the same, for losing their dreams for their child [5]. Studies emphasize the fact that getting the diagnosis

and the first stage of the disease is the most difficult for the parents with many emotional burden [6]. The first stage also put them in front of many duties, responsibilities and decisions, the realization of which requires a complete psychological and social functioning. They need to adapt roles in the new context, provide emotional support for the sick child and other children, moderate their emotions, establish good communication with the medical staff, modify the family routine, pay attention to the medication and its side effects [7]. Parents should have a good psychological well-being and good functioning in order to positively influence the ill child and other family members.

Although distress is always reported, parents also show resilience, they find a new meaning in life, are grateful for the help they receive from relatives and friends. They can also find personal benefits from this experience as: gaining confidence, a better understanding of the elements in their lives and reconfirming relationships with relatives [8]. As the treatment continues, the hopeless situation begins to fade and parents begin to regain a sense of reality [5]. Many studies have been focused on to parent's protecting and adapting factors more than their perceived stress. Stressors affect the family at different stages of the disease, so adaptation and coping strategies are different for each stage of the disease [9].

1.3. Coping with the Diagnosis

By coping, we refer to what people do in order to protect themselves from the difficult and tense situations of life. Coping refers to behavior that protects people from being psychologically attacked by problematic social situations [10]. Other authors defined coping as a willing effort to control cognitions, emotions, psychological reactions, and the environment in response to stressors, and may include adaptation to stressors and non-adaptation. It can be defined as a cognitive and behavioral effort to manage the situation. The three factors that affect the results of parental adaptation are: 1. the diagnosis and the duration of the therapy; 2. life events and the parent's personality; 3. the way of coping with the disease and the quality of the marital relationship [6].

1.4. Factors That Help the Way Parents Cope with the Diagnosis

Based on interview, are identified flexible factors that help the family recover from these situations: family strength, reorganization domestic family strength, a new way of assessing the situation to make it more meaningful and more manageable, social support from medical staff, relatives, peer community [6].

Each stage of the illness puts parents in front of different situations and problems, so it requires learning of new strategies of coping, and this is not a linear process but effected by unpredictable event.

1.5. Social Support

Many studies upon parent's behavior when their children suffer from malignant diseases have been focused on social

support and the role it has in adapting and coping with diagnosis and treatment. Social support is seen in some perspectives: some studies has been focused on how individuals use their social networks such as the number of people they have contacts with and other studies cases on the assessment of the services and social support that parents receive [14]. An important aspect to determine social support and to understand the role it plays is the assessment of self-perceived social support. When the support perception of the parents is good and when they have numerous relief supplies to cope with the situation, it creates more opportunities for the individual to react positively against the situation [15].

Social support is seen as protective factor against distress and psycho-pathology development and the lack of this support is associated with various difficulties of parents during treatment and the risk of developing posttraumatic stress symptoms [16]. It is also thought that parents who have been able to adapt well to their child's illness have had a good social support [17] and always social support and good adaptation to the disease are connected in a reciprocal way [18]. The social ecological perspective regarding social support extends factor analysis beyond individual characteristics and coping behavior of parents to supporters in the family environment and community conditions. This sociological perspective emphasizes the need to support parents from several levels [8].

1.6. Family Relationships

The family plays an important role in the psychological functioning of both the parents and the sick child themselves [15]. The assessment of family functioning is important to identify hope that serves as a protecting factor to increase coping and minimizing the effects of stressors. The family functioning is seen in different ways, in some cases is seen as a result of the situation and in some other studies as an important factor to cope with the situation [9].

These findings are in the same line with researches on other chronic illnesses highlighting the importance of family cohesion and adaption in coping and adapting to chronic illnesses [20]. Psychological adaptation is influenced by both factors related to the disease and other personal or family factors.

1.7. Resilience of the Family and the Ability to Find Benefit from the Situation

Even though it is a traumatic experience studies have shown that children and their parents report the ability to gain benefits from this experience. After this experience, parents regenerate and renew strengths, improve communication, trust, improve relationships and support among spouses [21]. A review made by Philips (2005) provides numerous data that support the opinion that many of the children who have suffered from cancer have healthy adaptation and experience a little psycho-social distress in the years of treatment. In this difficult situation, the parents attitude represent not only personal opportunities, but also the impact of the whole

community context, both medical and social, and all this affects in the decreasing of psycho-social experiences of children and the prevention of mental health disorders [21].

1.8. Autonomy and Environmental Mastery

Autonomy and environmental mastery are important parts of psychological wellbeing. These two components of wellbeing help parents in affronting the childhood cancer.

The six components of psychological well-being try to show what it means to function positively. These components are summed up in a great psychological well-being umbrella, which in ancient times called by Aristotle "eudaimonia" a term used to describe the best of the individual, referring to the realization of true individual potential [11].

Autonomy is defined as self-determining and independent; able to resist social pressures to think and act in certain ways. Autonomy is the ability to make choices for life and for themselves even if these choices go against conventional knowledge. Individuals who have autonomy have a sense of self-determination, are independent, are able to withstand the pressure to think and act in a certain way, evaluate themselves based on personal standards. Individuals with low autonomy are concerned about the assessment and expectations of others, are dependent on the judgment of other individuals to make important decisions, fit with social pressure.

Environmental mastery is defined as competence in managing the environment; controls complex array of external activities; makes effective use of surrounding opportunities; able to choose or create contexts suitable to personal needs and values. Control the environment, means to manage responsibilities and opportunities in the individual's environment so that it is in line with personal needs and capabilities. When the parents have the ability to control the environmental they have competence in the management of the surrounding environment, control of activities and the effective use of the opportunities that this environment provides. Parents who can't control the environment are not able to cope with everyday life activities, they can't improve or change the context in which they live [22].

2. Methodology

2.1. The Purpose of the Study

The purpose of this study is to explore the autonomy and environmental control of parents when children are suffering from malignant diseases and the impact that may have: diagnosis and phases of treatment and personal factors of parents such as gender, educational level and place of residence, in their autonomy and environmental control.

2.2. Objectives

-Explore autonomy, environmental control, personal development in the presence of malignant diagnosis and long and difficult medical treatment.

- Provide useful data for exploring and predicting parental behavior.

-The evaluation of the results provided by the parents.

2.3. Variables of the Study

The dependent variables

Autonomy-will be measured through the participants' ability to make choices for life and for themselves, to be independent, to withstand pressure, to think and to act in a certain way, and to assess themselves based on personal standards

Environmental control-will be measured through the competence in the management of the surrounding environment, the control of the activities and the effective use of the opportunities that the environment provides.

Independent variables

The type of diagnosis - can be part of two diagnosis groups: tumor diagnoses and leukemic diagnoses.

Phases of treatment - will be measured through three phases of treatment, first phase or assault, second or consolidation stage and third phase or retention phase. Treatment protocols are very specific to each diagnosis, in the case of Leukemia it continues in four phases, where the second and third stages of induction and consolidation have very similar psycho-social characteristics, are taken both in hospital conditions, for this is reason they are summarized in a single phase (in our case the second phase), meanwhile the treatment of tumors generally is divided into three phases.

Educational level - will be measured by educational levels conducted by the participants in the study: elementary school, secondary and higher education level.

Gender - will be seen if gender affects dependent variables.

Residence - village, town; it will be seen whether the place where family lives affects the dependent variables.

2.4. Participants

Participants in this study are parents of children suffering from malignant diseases and treated with chemotherapy at the University Hospital Center "Mother Teresa" in Tirana (QSUT), in the Pediatric Hematology Service. The children of the parents participating in the study are treated with chemotherapy some as indoor patients (for the first and second phase of treatment) and as outdoor patients (the third stage of treatment).

2.5. The Procedure of the Study and the Selection of the Participants

For data collection was used census for the period: 10.2.2014 to 15.6. 2014. The census was used because the number of children suffering from these diagnoses and being treated near Q.S.U.T is small and does not give the opportunity to sample the population. All parents were participants on the one whose children are hospitalized for the first and second cycle of chemotherapy and parents whose children receive daily treatment for the third cycle of chemotherapy. The information obtained from the parents was analyzed through descriptive statistics.

2.6. Instruments

For data collection were used: 1. Questionnaire for personal data, 2. two subscales of the psychological wellbeing scale [12]. Psychological well-being consists of 6 dimensions: autonomy, environmental mastery, personal

growth, positive relations with others, purpose in life, self-acceptance. Is a self-report scale, to assess individual's well-being at a certain moment in life. Individuals respond to various statements and indicate on a 6-point Likert scale how true each statement is of them. Higher scores on each on scale indicate greater well-being on that dimension.

3. Results and Discussions

3.1. Demographic Data of Participants in the Study

Table 1. Data for the type of diagnosis and the phases of treatment.

	Type of diagnosis		Phases of treatment		
	Tumor	Leukemi	Phase I	Phase II	Phase III
Number of parents	31%	69%	23%	33%	44%

The number of children diagnosed with malignant disease is small, so the number of children who receive the first phase of treatment with chemotherapy is small. Children receiving medication in the second phase are more than those of the first stage because it is a phase that lasts longer in time and includes the children, with leukemia, who receive treatment for the second and third phase of chemotherapy (in

the study are summarized in a single phase) and children with cancer diagnosis who receive treatment for the second phase. The third stage of treatment has the largest number of children for two reasons: it lasts longer and children that take one-day chemotherapy are children diagnosed for a period of two or more years.

Table 2. Data for the parents characteristic: gende, educational level and place of residence.

	Gender		Educational level			Place of residence	
	Male	female	Elementary	Secondary	High	City	Village
Number of parents	38%	62%	52%	29%	19%	46%	54%

The participants of the study are more mothers than fathers because mostly the mathers take care of the children and expecially when he is hospitalized. Children suffering from these diagnoses are from all parts of the country and there is no apparent difference among those living in rural and urban areas, and therefore the difference between the parents living in the village and those living in the city is small. The education level of the parents in generally is low.

3.2. Environmental Mastery and Autonomy of All Participants in the Study

Table 3. Results of environmental mastery and autonomy for all participants in the study.

	Environmental mastery	Autonomy
Very low	0%	0%
Somehow low	0%	0%
Slightly low	0%	0%
Slightly high	31%	12%
Somehow high	50%	50%
Very high	19%	38%

Statistical analysis showed that the average of parents had somehow high scores in autonomy and slightly high scores in

environmental mastery. None of the parents had low scores.

Parents have a good control of the environment, the average of them have somehow high control of the environment, 19% of them have high control of the environment. These values show that parents have a sense of organizing the environment, controlling activities and effectively using the opportunities that this environment provides. Parents' ability to manage the environment is very important, especially for children, both in hospital and home conditions. From the statistic data results that the parents have a high level of autonomy. The average of them have somehow high autonomy and 38 % of the parents have very high autonomy, this demonstrates the ability they have to make choices for children and for themselves in the context of malignant disease and to be independent in their choices. Autonomy (as it is used in the theory of self-determination) means to act trough the experience of choice, so it is possible to be autonomous while supported by others (Deci, Ryan, 2006). The ability to make independent choices and to withstand pressure is very important for parents in this situation that is full of choices and decision-making, especially for child's health. Parents tend to be more autonomous rather than to control the environment.

3.3. Environmental Mastery and Autonomy of Parents Regarding child's Diagnosis, Phases of Treatment

Table 4. Results of parental environmental mastery regarding child's diagnosis and the phases of treatment.

	Type of diagnosis		Phases of treatment		
	Tumor	Leukemi	Phase I	Phase II	Phase III
Very low	0%	0%	0%	0%	0%
Somehow low	0%	0%	0%	0%	0%
Slightly low	0%	0%	0%	0%	0%
Slightly high	25%	33%	58%	23%	21%
Somehow high	56%	47%	33%	65%	49%
Very high	18%	20%	9%	12%	30%

Table 5. Results of parental autonomy regarding child's diagnosis and the phases of treatment.

	Type of diagnosis		Phases of treatment		
	Tumor	Leukemi	Phase I	Phase II	Phase III
Very low	%	%	%	%	%
Somehow lower	%	%	%	%	%
Slightly lower	%	%	%	%	%
Slightly higher	12%	11%	33%	6%	4%
Somehow higher	50%	50%	50%	47%	48%
Very high	38%	39%	17%	47%	48%

Even though these diagnosis are both malignant, they differ in terms of treatment, prognosis and duration of hospitalization. The first stage of treatment is particularly difficult for the child's health condition and for the emotional experiences of the parents, facing with the diagnosis and the side effects of the treatment, adapting and coping with the new situation. The second stage lasts longer, meanwhile the medication has provided its improvements and the parents have adapted to the situation and have created a new normality. In the third stage, the child and the family return to normality. These changes in parents' experiences can also

affect the way they experience and adapt to the child's diagnosis.

Environmental mastery and Autonomy results almost the same for parents whose children suffer from Leukemia and for parents whose children suffer from Tumor, they try to manage the surrounding environment and to preserve individuality and make choices despite the child's diagnosis. Passing from the first stage to the second and then in the third stage of treatment parents become more autonomous and can manage better the surrounding environment.

3.4. Environmental Mastery and Autonomy of Parents Regarding their Characteristics

Table 6. Results of parental environmental mastery regarding their characteristics.

	Gender		Educational level			Place of residence	
	Male	female	Elementary	Secondary	Hight	City	Village
Very low	0%	0%	0%	0%	0%	0%	0%
Somehow low	0%	0%	0%	0%	0%	0%	0%
Slightly low	0%	0%	0%	0%	0%	0%	0%
Slightly high	25%	37%	48%	13%	0%	13%	54%
Somehow high	40%	53%	45%	74%	40%	54%	39%
Very high	35%	10%	7%	13%	60%	33%	7%

Table 7. Results of parental autonomy regarding their characteristic.

	Gender		Educational level			Place of residence	
	Male	female	Elementary	Secondary	Hight	City	Village
Very low	0%	0%	0%	0%	0%	0%	0%
Somehow low	0%	0%	0%	0%	0%	0%	0%
Slightly low	0%	0%	0%	0%	0%	0%	0%
Slightly high	0%	15%	18%	0%	0%	0%	18%
Somehow high	55%	50%	56%	67%	20%	42%	57%
Very high	45%	35%	26%	33%	80%	58%	25%

Mother and father take different responsibilities during the child's treatment. Most of the time the mothers take care of the child, when he is in hospital or at home, meantime the fathers keep their jobs, try to take care of the rest of the family, siblings, and other family concerns. The fathers tend

to be more autonomous than mothers, this difference is more evident in environmental mastery, they have more possibilities to make choices, sometimes they have more information about the diagnosis and have more opportunities to face the problems.

Parents that live in the city are more autonomous and can manage the environment better than the parents that live in the village. The cultural difference between the village and the city and the different perception about these diagnoses, it is thought to affect parents' response to malignant disease. Parents living in the city have more information about these diagnoses and their treatment, they are more autonomous in decision making process and manage better the environment, setting more goals and objectives for themselves.

The results of the study show a significant impact of educational level of parents in their autonomy and environmental mastery. With the increase of the educational level increases even the ability of parents to make independent choices and decisions and to control and utilize the environment.

4. Conclusions

- 1) Parents have the ability to manage complex environmental and be autonomous during childhood cancer.
- 2) Parents try to have a good function in order to cope well with the situation, they maintain a good level of psychological dimensions such as autonomy and environmental control.
- 3) These dimensions of psychological well-being are contoured by the type of treatment and the parental characteristics such as: gender, place of residence and educational level.
- 4) Parents who live in the city and those with high education level are more autonomous. Parents whose children are in the first stage of the treatment and those who live in village are less autonomous.
- 5) Fathers, parents with high education level and those living in the city have more control of the environment. Mothers, parents living in the village, those with low education level and those whose children at the first stage of the medication have less control of environment.

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