

"Trajectories of experiencing cancer by children, adolescents and their parents"

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The dissertation discusses the life situation of a family struggling with a child's cancer. The source were partially-structured interviews with the elements of a biographical interview conducted with fourteen respondents - parents of child cancer patients of the Department of Pediatric Hematology, Oncology and Transplantology of the Children's Hospital in Lublin. The main aim of the thesis was to indicate the factors that shape the trajectory of a child's cancer and to describe the experiences that accompany the illness. The description of the research tools, the research process and the study group is included in Chapter V which is devoted to the research methodology.

Chapter I outlines the medical conditions of cancer trajectories of children and adolescents: the etiology and epidemiology of children's cancers, their symptoms, types of treatment and side effects of cancer therapy, as well as medical regimes accompanying the treatment process.

Subsequent theoretical chapters of the dissertation are devoted to the discussion of the sociological theories that allow to describe the studied phenomenon. Chapter II discusses A. Strauss's concept of a chronic illness as a trajectory. It describes the stages of the chronic illness trajectory and types of work undertaken in the course of illness. It also presents R. L. Woodgate and L. F. Degner's concept of cancer symptom transition periods of children and their families. Chapter III discusses A. Strauss's biographical conception of body and biographical body conception chain (BBC Chain), as well as the conception of biographical work which is strictly associated with the former two. It also describes B. Glaser and A. Strauss's contexts of awareness and M. Bluebond-Langner's stages of aquisition of disease-related information and contexts of awareness in leukemic children

The chapter also discusses the kinds of illness awareness in patients according to K. Charmaz's conception of the reconstruction of self in chronic illness.

Chapter IV discusses the relevant literature on the changes in family life that accompany a child's cancer, including: changes in the family's life, family's adaptation to a new situation, changes in family relations, the appearance of specific needs of each family member as well as the need for support at various levels of family life.

The empirical part consists of five chapters, which include analyses of the research material in the context of the concepts and theoretical issues discussed in the theoretical part.

Chapter VI indicates several different factors that impact the trajectory of cancer both during the diagnostics period as well as at subsequent stages of the trajectory. These include: symptoms, the type of disease, the therapeutic triad: the sick child – the doctor – the parent, as well as the information and experience collected by the child patient and his parents

Chapter VII analyses the parents' perception of the child's disease, as well as the changes in the contexts of children's awareness, especially at the terminal stage of the cancer trajectory. Taboo topics, the appearance of turning points, and the access to the key information at a given stage of the trajectory are of great significance for the phenomena described. What is also important for the course of the trajectory is the loss of hair by sick children and adolescents, which is a ritual transition from the world of the healthy to the world of the sick.

Chapter VIII deals with the analysis of the trajectory of family life: the new division of roles in home and hospital care, the evolution of marital relations, as well as the support of parents and child patients in battling cancer in terms of care, services and financial assistance, the main source of which is the family.

Chapter IX focuses on discussing the trajectory of everyday life during the hospitalisation period. It analyses the sources of support at the clinic and the manners of facing the challenges involved in battling the disease: medical procedures and regimes, stages of treatment, as well as behavioural problems accompanying the therapy process.

Chapter X analyses the relationship between sick children and their healthy siblings. It discusses the difficult situation of healthy brothers and sisters, as well as their attitudes towards the illness of a child patient and the loss of their previous roles and the development of new ones as a result of the illness. The research indicates the importance of the sick child's home passes for the course of treatment, as well as for the relation between the healthy and the sick siblings.

The dissertation ends with a chapter summarising the analyses contained in the empirical chapters. It also presents several practical recommendations concerning the support of the hospitalised children and their families.

1. It is necessary to expand the living space of sick children with non-medical areas at the clinic, where teaching and therapeutic activities, which support treatment, would be available.

2. The attitude towards child patients' parents should be changed in terms of care and appropriate support offered to them.

3. Sick children should be enabled frequent contacts with family members, especially healthy siblings, during the hospitalisation period.

4. It is necessary to provide professional care to healthy siblings, both in terms of individual and group support. This support should be offered in their both living environments: schools and hospitals.

5. While dealing with a sick child, we are dealing with a sick family - a community of suffering, thus all family members should be offered assistance in the medical, psychological, social and spiritual dimension.

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