EXPERIENCE OF A FATHER CAREGIVER DURING THE HOSPITALIZATION OF HIS DAUGHTER

EXPERIÊNCIA DO PAI ACOMPANHANTE DURANTE HOSPITALIZAÇÃO DA FILHA

ABSTRACT
Objective: to report the experience of a father caregiver during the hospitalization of his daughter, who had a chronic disease. Method: experience report. This descriptive study reports the difficulties of a father caregiver, a 40-year-old farmer who had his life changed after learning about his 5-year-old daughter’s diagnosis of leukemia. The study emerged from a field survey conducted in June 2011 with five children/adolescents aged between 5 and 15 years who had chronic illnesses and were inpatients of a teaching hospital in Paraíba, Brazil. Results: the transformations in family life, as well as the pain and suffering experienced during the hospitalization of his daughter encouraged the father caregiver to accompany his child and take responsibility for her care, especially after his wife's death. Conclusion: the experience of being a father caregiver was exemplary, since the child needs to be accompanied by a loved one. Descriptors: Father; Pediatric Nursing; Hospitalized Child; Caregivers.

RESUMO
Objetivo: relatar a experiência de um pai acompanhante/cuidador durante a hospitalização da filha com doença crônica. Método: estudo descritivo, tipo relato de experiência, que relata as dificuldades de um pai acompanhante, agricultor, 40 anos de idade, que teve sua vida modificada após o diagnóstico de Leucemia da filha de apenas cinco anos de idade. O estudo emergiu a partir da realização de uma pesquisa de campo realizada em junho de 2011, com cinco crianças/adolescentes dos 5 aos 15 anos de idade com diagnóstico de doença crônica, internados em um hospital escola da Paraíba. Resultados: as transformações na vida da família, a dor e o sofrimento vivenciados durante a hospitalização da filha enorçaram o pai/cuidador a acompanhá-la, se responsabilizando pelo cuidado, especialmente após a morte da esposa. Conclusão: a experiência de ser pai/cuidador foi exemplar, tendo em vista que a criança necessita estar acompanhada por um ente querido. Descritores: Pai; Enfermagem Pediátrica; Criança Hospitalizada; Cuidadores.

CASE REPORT ARTICLE

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INTRODUCTION

Life with a chronic illness and its aggravating effects acquires a more complex dimension when the child needs to be regularly hospitalized. The illness and hospitalization process alter the family dynamics due to the routines of the institution. Consequently, there are changes in personal, dietary, sleeping and eating habits. Moreover, therapeutic interventions cause physical discomfort, fear and anxiety. In order to minimize such situations and help children and their families cope with the disease, health care in the hospital environment should be guided by integral health care actions that include the proper welcoming of patients/families and the creation of bonds.1

Hospitalization is a complex experience in the life of any human being, especially a child. Depending on their age and stage of development, children may have doubts about their well-being, the severity of their condition, and its outcome. The hospital is an unknown and threatening environment that generates anxiety, and where children are left at the mercy of strangers and painful procedures. In this context, the support necessary for coping with the situation comes from the presence of their parents, who represent comfort and security.2

For the family, the hospitalization of the child is a potentially stressful event, because she/he is inserted in an environment that often threatens his/her sense of security and competence.3 Studies on caregivers reveal that women, especially mothers, are the only or primary caregivers of ill family members, be they their own children or not.4 This contributes to a culture in which the father or male figure takes no responsibility for the care process. The responsibility of caring for a child is exclusively attributed to the mother. However, this reality is being altered by the historical changes currently experienced by families.

According to the Statute of Children and Adolescents - ECA5-12, Article 12 “In the case of hospitalization of children or adolescents, health care establishments should provide conditions for full-time residence of a parent or legal guardian”. Current law does not stipulate the sex of caregivers, however, differences between male and female emerge culturally and have repercussions on hospitalization issues. The roles of men are constructed, interpreted, internalized and personalized depending on the specific characteristics of each society and their life cycles. Men are socially seen as providers of the family, as powerful, dominant, virile, and hard beings.6

Fathers usually need more information about their children and their practical care than mothers. This is due to the fact that mothers usually are more actively involved in the care of the child. Thus, Nursing may represent an important help to support fathers in their role of caregivers in the hospital.7 Although the presence of fathers as caregivers of hospitalized children may be an unusual event in the hospital, there is an urgent need for the healthcare team (especially the nursing staff due to its continuous monitoring of hospitalization) to be prepared to deal with this new kind of demand for health care services. The Nursing team, with actions based on integral care, needs to establish a relationship of trust and construction of bonds because the father needs to be recognized in his uniqueness and provided with tools to care for his children, especially when he is the only responsible for the child’s welfare.

Thus, this study aims to report the experience of a father caregiver during the hospitalization of his daughter, who had a chronic disease.

METHOD

Experience report. This descriptive study reports the difficulties of a father caregiver, a 40-year-old farmer who had his life changed after learning about his 5-year-old daughter’s diagnosis of leukemia.

The study emerged from a field survey conducted in June 2011 with five children/adolescents aged between 5 and 15 years who had chronic illnesses and were inpatients of a teaching hospital in Paraiba, Brazil. All ethical criteria were satisfied. Three children had female caregivers and two had male caregivers.

Initially, the subjects of the study were hospitalized children and adolescents with chronic diseases. Interviews were recorded during hospitalization after a legal guardian signed the informed consent form (ICF). Before the ICF was signed, it was read and explained in detail to the guardians. Any doubts were clarified. Children/adolescents were asked beforehand if they wanted to answer the questions and if their answers could be recorded. This study was approved by the Research Ethics Committee (REC-UEPB, CAAE-0216.0.133.000-10).

The speech of the interviewees was often interrupted by their caregivers. It was from
Experience of a father caregiver during... has shown to be a cheerful child, who was happy just for having her father next to her.

It was noticeable that the father was trying to distract his daughter, who also had to face the loss of her mother and the treatment against leukemia. He created strategies to minimize the hostility of the hospital environment and the stress caused by the treatment and procedures. He told stories, they drew pictures and watched television together. "She does not complain about anything, thank God, so far ..."; "Here day-to-day life is even good!". These statements of the father show his effort to meet the needs of his daughter, because in this situation he had to play the role of father and mother simultaneously.

His daughter’s diagnosis and treatment of leukemia, together with the loss of his wife, were events that suddenly changed his life. He had no time to adapt to the transformations that resulted from these moments of crisis. He immediately had to reorganize his life in order to take responsibility for the care of his daughter: he moved to another city, started living in the shelter home, left his job as a farmer. The whole situation could have led him to surrender to suffering and pain. However, this father was able to adjust to the new routine, and became a role model for father caregivers.

DISCUSSION

Hospitalization is a stressful experience. It brings pain and suffering, especially when they occur frequently, because the children and their families are subjected to restrictions and specific care required by the situation.  

The chronic condition causes a functional disruption in the family. When its members cannot play their usual role, there is a disturbance of interpersonal relationships, and the manifestation of emotional reactions such as anxiety. The father caregiver in this study had to cope with several difficulties. Losing his wife, the person who used to accompany his daughter during treatment, only aggravated his problems. This event generated more suffering, since he already had to deal with the fear of losing his daughter to leukemia.

The death of a loved one requires reorganization of the family and social dynamics in order to return to the daily routine. People have to cope with pain and sorrow, and regain the functionality of a “normal” everyday life. Caring for sick children who need special attention presents...
a challenge to the family. The knowledge and practices needed for this purpose do not belong to the context of their lives, but to the hospital context. This is a problem especially for fathers who often have to perform this caregiving role without any previous preparation.\(^\text{11}\)

During hospitalization and the therapeutic process, the support of family and friends is essential. Parents are a source of support and serenity to the children. When they are anxious, upset or insecure, children notice their feelings and also get scared; when the opposite happens, they also recognize the security around them and “incorporate” the feeling they found as their own.\(^\text{12}\)

In their role of caregivers, counselors, and health providers, health professionals often experience feelings of powerlessness. These feelings are common to the healthcare teams when dealing with death. In these situations, they do not achieve the desired success, and are confronted with the revelation of human frailty. This leads them to experience feelings of doubt and uncertainty about their professional practice. Death is an inevitable experience, however, health professionals have difficulties in dealing with it and, for that reason, they feel unprepared.\(^\text{13}\)

It is common to see that health professional guidance and counseling are almost exclusively directed to mother and child. The participation of the father as a member of the family and caregiver is forgotten.\(^\text{7}\) According to the case presented here and to other studies\(^\text{14,5}\), the number of fathers who accompany their children during hospitalization is increasing, either temporarily or as the sole caregivers. This helps to strengthen the father-child bond. This new care demand needs to be brought to discussion. In these situations, the binomial is constituted by father and child, and, thus, health professionals need to be able to meet the demands of this dyad.

It is essential to properly welcome and provide the caregiver with tools, so that the child is given the best possible quality of care. In order for that to happen, the healthcare team must provide daily help and support.\(^\text{16}\) Therefore, it is important to know the needs of the families and the caregivers (be they fathers, mothers, grandparents, siblings or other persons), to promote integral care and contribute to improving the quality of life of children and their caregivers.\(^\text{17}\) For just as the child experiences difficult times, so does her family.\(^\text{18}\)

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### FINAL REMARKS

Dealing with chronic diseases generates unavoidable changes in the daily routines of hospitalized children and adolescents. The whole family experiences the difficulties of having to adjust to a new unknown reality, full of uncertainties, anxieties, fears, doubts, and even the possibility of death.

Death creates in most people a feeling of helplessness or guilt, because they believe they could do something to prevent it. This makes the feeling of inability to continue life normally without the company of their loved one grow stronger. However, although the loss of someone important is a depressing experience, a major blow to self-esteem, it is necessary to develop a resilient attitude. Life needs to be seen with a positive outlook, despite the problems faced.

Due to the fact that the child lost her mother in a critical stage of her life, the father had to find the necessary power and strength to help his daughter cope with and be minimally traumatized by the changes consequently brought to their lives. It is important to highlight the relevance of the humanization of health care for the care of the caregiver. Bonds should be created, knowledge should be gained on the needs and problems of parents, a trust relationship should be built, and professionals should learn to deal with the life and death cycle of human beings.

The nursing staff on their role as caregivers, counselors, and health care providers, should provide the father, especially the caregiver of a child who has a complex chronic disease and whose prognosis is unknown, with tools to face the challenges and surprises that come with the child's disease.

The father needs to be well prepared to understand the general characteristics of child development, because children are unique, dynamic, complex beings who are full of potential and constantly changing. In order to feel safe, welcomed and in good company, they constantly need to have someone they trust, and who knows and values them by their side.

The experience of being a father caregiver was exemplary, since the child needs to be accompanied by a loved one. However, there is still lack of preparation of some health professionals to welcome and assist a male caregiver, especially when they need to be provided with tools for the joint participation in childcare. Therefore, there is an urgent
need for the healthcare team to be trained to properly support the father caregiver in the pediatric wing. They should always be aware of the importance of his presence for the recovery or even the well-being of the hospitalized child.

REFERENCES


Experience of a father caregiver during...