

The Process of Informing Parents about Child’s Illness
Child’s Right to be Informed



Social Sciences

Keywords: terminal illness, child & parent information, experience.

Matilda Memaj

University of Tirana, Faculty of Social Sciences, Department of Social Work and Social Policies “Gjergj Fishta” Boulevard, Tirana, Albania.

Irida Agolli (Nasufi)

University of Tirana, Faculty of Social Sciences, Department of Social Work and Social Policies “Gjergj Fishta” Boulevard, Tirana, Albania.

Abstract

This study aims analysing the importance of informing parents and children during hospitalization period. Albania doesn't offer many studies that address psycho-social problematic of patients during hospitalization because this is a new area developed recently. In order to accomplish study objectives, the study uses mix methodology for data gathering; quantitative method which helps finding what is typical, average, representing the population and qualitative method to deeply understand experiences, parents' feelings on sharing information about illness. Study results show that, in general, sharing information with parents is a sporadic and different process according to the specific case. Doctors are not always comprehensive with the information they share. Parents get more information from other parents at the time of hospitalization. Parents need to be informed about the illness and in general, they do not want to inform their children because they want to protect them. Parents see it as very traumatic to inform their children but it is necessary that both parents and children get the right information about the illness of their children and be part of services that are to be offered to the child.

1. Introduction

Information is perceived as a form of knowing control and it has got one informing element and one supporting element (Van Der Molen, 1999). The information that is to be communicated during paediatric cancer care is complex and may be unsure; emotional which might lead to misunderstanding (Sobo, 2004). Due to fragmentary nature of cancer care, there are often health care professionals to be consulted (Van Der Molen, 1999). Professionals' communication with parents offers the basis of determining patient and family needs, evaluating the efficacy of medical staff in addressing these needs, and having knowledge about the staff taking care of the patient and family progress.

There exist strong evidence that the information on diagnosis and treatment may reduce uncertainty thus it may be considered, by the sick child and specific family, as a source. Parents are often a main source of information and transmitters of information between professionals of health care and their children (Scott, Harmsen, Prictor, Sowden, & Vat, 2003) and their outlook affects child's thinking about the illness (Chesler&Barbarin, 1987 ; Clarke et al, 2005).

According to Mack and Grier (2004), in order for the information to become a source, it is important to make possible that information exchange between patient, family and doctor continues whereas, the shock of the initial diagnosis will reduce. The information on diagnose, treatment, treatment goals (active or relieving treatment) and causes are necessary. These last ones are considered important enough especially by these authors while many families try and seek an understanding for such a destructive event and they may irrationally blame themselves for something they didn't have control. If doctors need to have a source of sharing information they need to be guided by the emotional need of the child and families and their need for information (Mac & Grier, 2004).

The notion of death being discussed with a child that can die may seem terrible for some doctors. But a recent study on parents of children dead from cancer shows that, none of the parents did not regret have talked with their children about death; (Kreicbergs, et al. 2004). Health care takers and parents may deal with fragile conversations with patients without causing damages or further psychological disturbance for children with a life threatening illness. In approaching these discussions, there are to be taken into consideration the age and the

level of child development as well the use of creative approaches like the art and music therapy (Himmelstein, 2006).

Study Goal

- To examine the importance of information share with the families and children during hospitalization period.
- Identification of information share experience and parents and children feelings in the moment of being informed about their illness.

2. Background and Methodology

Data are gathered in the UniversityHospitalCentre ‘Mother Theresa’ in the city of Tirana, at Onco-haematologypaediatric ward. Parents interviewed had their children in difficult stages of terminal illness.

To accomplish objectives of the study, it is used the mix methodology of data gathering. Literature review as a first step served to prepare instruments and create the base for the preparation of study framework. The use of quantitative method aims to gather general information on what parents think regarding information share about the sickness, the people who share this information, their reactions in the moment of being informed. This method helps in finding what is typical, average and what represents the population.

For a deep analysis it is used the qualitative method of gathering data. This qualitative research may be described as an effective model happening in its natural environment giving the researcher the possibility to explore and explain the world (Creswell, 2003). The qualitative research tries to explore and explain the world (Mays & Pope, 1995) through social actors by evidencing data which are not very accessible by the quantitative method, which is the case of violence and homosexuality.

The sample included in this study were questionnaires for parents (N=28).15% of parents with hospitalized children during the period of study were included in the research. There were intense interviews developed with 8 parents, 3 doctors and 1 social worker for deeper information that connects with experiences during hospitalization. Some parents refused to be part of the study because they had not passed the phase of acceptance which also made it difficult to share information with the others.

3. Results

From the gathered data it is reported that it is not always easy for the medical staff to share information with mothers about the illness even if in most cases there are mothers who take care of their sick children. Fathers are seen by the medical staff as stronger to share information. Then fathers transmit information with the mothers, or mothers understand it from the surroundings and from what they discuss with other parents that have their children hospitalized in the ward.

The place of information about the illness

Referring to the answers of medical staff, they say that parents get informed about the illness of their children when they are in the hospital room, studio, at child’s bed or in the hall. Most of parents didn’t like to be informed in the room where the child lies, since they didn’t want to transmit the information to the child and the proper surrounding for them depending on situational factors, was the hall as e neutral environment for communication and information about child illness.

Comprehension of information by the part of parents and sick children

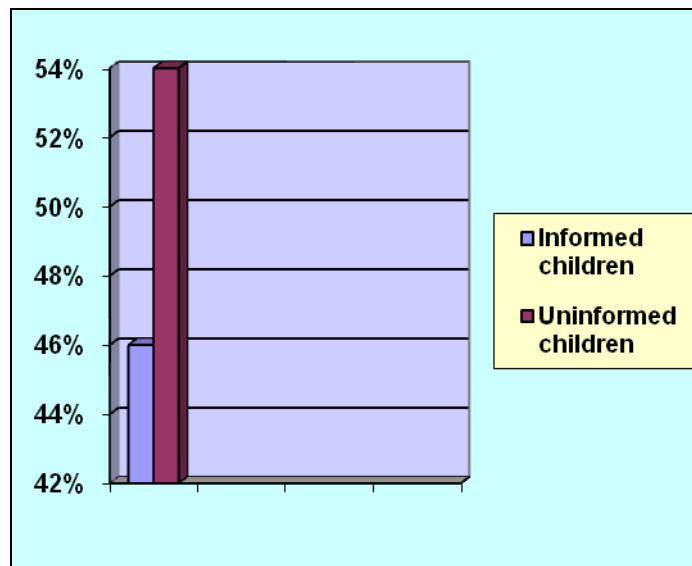
Parents say that the information is not always clear and easily understood. Parents themselves explain their children illness in a confusing way often using Latin terms and sometimes they even forget the name of the illness. Parents get clearer information by other parents with children of same diagnose. On the other hand, based on the examination of one-year rapports, the social worker in this hospital didn't do any informing role about the illness to the parents or to the children. From data gathered by the doctors, parents reactions toward the information taken are various, from waiting patiently to traumatic reactions and irresistible.

Informing children about their illness

Informing children about the proper illness is very important because this enables children to clarify their actual physical conditions and body pains. 54% of parents say that children are not informed about their illness. 46% of parents say that children are informed about their illness. Among them in the 43% of cases the parents are the source of information for the child, and only 3% of cases the source of information have other members of family.

In general, parents say that they wouldn't like their children to have information about the illness as a form of protecting them. According to the parents, they inform children because of their age, due to the fear of not being informed by other people. Smaller children are easier to be manipulated, lied about their illness. In the case of adolescents parents say that it is difficult for them to find the right words to share information with the children, since the age itself makes it difficult the process of communication.

Figure 1. Informing children about their illness



As it is seen from the data below, in most cases parents are the ones who inform children. In general, doctors do not take over the responsibility to inform, because the communication required needs consideration also of the emotional development, social and psychological development of the child and parents. Parents themselves do not want doctors to inform their children about their illness; they do not consider it as a right of the patient/child to be informed about the illness.

Table 1. Source of Information for the Children.

Source of information for the children	Frequency	Value in percentage
Parent	12	42.9 %
Other family members	1	3.6 %
Have not been informed	15	53.6 %
Total	28	0 %

The medical staff says that informing children is done according to their age and only when the child insists or when the child says that he/she has information and requires confirmation from the doctor. Reactions of children are different; mainly they are not able to completely understand the illness rather than its consequence. For example, they know that they will remain in hospital in order to recover than return home or to their friends. Some of experiences of children reported by parents are: physical pain, exhaustion, and fear from pains caused by medical devices, boredom, closure in themselves and inability to express their feelings like before, longing to recall things from home, friends, experience of shame due to their illness, and do not want others to call them sick. Feel less fear than before hospitalization, they can't wait to leave hospital, they want to play with other children, they get continuously traumatized by syringe drilling serum, anxiety, bickering, they use expressions like 'medicine are bad.'

Parents prefer to be the ones who inform their child with the idea that they know children better and that it is their decision whether to tell about the illness.

Table 2. Informing Children by Medical Staff

Has it happened that medical staff has informed children about their illness?	Frequency	Value in percentage
Often	5	20.0 %
Sometimes	7	28.0 %
Never	13	52.0 %
Total	25	100.0 %

Techniques used to inform children about their illness.

Techniques parents or caretakers use are various. Referring to the answers from the open questions, parents/relatives who take care of the child tell the methods they use to inform their children about their illness:

- Convincing the child to take the necessary medication, by simplifying as much as possible the consequences of illness.
- Communicating illness and hope that soon they will leave hospital even at cases when this is not true.
- By not telling the truth, since the bad illness cannot be told.
- In cases of non-information parents say that they do this to protect their children because their minor age makes them unable to understand illness. Some parents say that fear of telling about the illness because they fear children reaction.

The cause of emotions showed by children during hospitalization

Referring to the answers taken by parents, factors that cause such emotions are: (1) 43% by medical devices (needle, cannula, serum, medications, etc.); (2) 18% of them as a result of not knowing the environment; (3) 7% as a result of contact with the doctors or white shirts; (4) 7% from surgeries; (5) 11% due to all above mentioned components. Only 11% of children experience calmness due to familiarization with the hospital surrounding.

Table 3. Factors that Cause Psycho-Social, Physical and Emotional Condition

Factors that cause feelings on children during hospitalization	Frequency	Value in percentage
Doctor	2	7.1 %
Hospital surrounding	5	17.9 %
Surgeries	2	7.1 %
Medical devices	12	42.9 %
All	3	10.7 %
Familiarization with the hospital	3	10.7 %
Didn't answer the question	1	3.6 %
Total	28	100.0 %

Relating with the qualitative data of the questionnaire for parents, emotions experienced by parents during the time of hospitalization are as follows: they feel depressed about their condition; they experience fear for the future of their child's health; they feel anxious about the rest of the family especially for the smaller children under the care of the father who spends most of the day at work, or grandmother who is not completely able to take care of them due to the age; they experience worry about pending works and the risk of being thrown out from the job because of relatively long disengagement; they experience anxiety especially during long waiting for the analyses results; some of them say that they feel spiritual pain; some others say that they are experiencing 'a deep economic pain;' referring to the data gathered from the questionnaire for parents they say that hospitalization of their children has had an economic effect: 78% of them say that this has impacted negatively and has made their life very difficult, whereas 18% say that hospitalization of their children has not affected their economic life.

4. Conclusions

Hospitalization experience can be strongly or naturally felt by the children depending on how prepared they are or not for the process of hospitalization. In fact, recent researches show that preliminary preparation of family and child about hospitalization helps in reducing stress and anxiety that children and their familiars feel when involved in the hospitalization process.

From the data gathered it is evidenced that there is lack of preparatory procedures for the process of hospitalization, based on various studies. Not being prepared, children increased anxiety, fear and uncertainty as well as their parents involved in the process of hospitalization. A considerable number of parents participating in this study have chosen to not inform their children about their illness and to not let the medical staff or professionals of psycho-social service do the same. This is a form of protection from the information which according to parents would damage child's wellbeing.

References

1. Van Der Molen, B. (1999). Relating information needs to the cancer experience: Information as a key coping strategy. *European Journal of Cancer Care*, 8, 238-244.
2. Sobo, E. J. (2004). Good communication in pediatric cancer care: A culturally-informed research agenda. *Journal of Pediatric Oncology Nursing*, 21, 150-154.
3. Chesler, M., &Barbarin, O. (1987). *Childhood cancer and the family: Meeting the challenge of stress and support*. New York: Brunner/Mazel Inc.
4. Clarke, S., Davies, H., Jenney, M., Glaser, A., &Eiser, C. (2005). Parental communication and children's behavior following diagnosis of childhood leukemia. *Psycho-Oncology*, 14, 274-281.
5. Scott, J. T., Harmsen, M., Prictor, M. J., Sowden,A. J. & Watt, I. (2003). Interventions for improving communication with children and adolescents about their cancer. *The Cochrane Database of Systematic Reviews*, 3. Art No.:CD002969. doi: 10.1002/14651858.CD004511
6. Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approach*(2nd ed.). Thousand Oaks, CA: Sage.
7. Mays, N., Pope, C., 1995. Rigour and qualitative research. *BMJ*;311: 109–12.
8. Kreicbergs U, Valdimarsdottir U, Onelov E, et al. Talking about death with children who have severe malignant disease. *N Engl J Med* 2004; 351:1175–86. [PubMed: 15371575]
9. Himmelstein BP. Palliative care for infants, children, adolescents, and their families. *J Palliative Med* 2006;9:163–81.