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Feelings of Women Accompanying Children Hospitalized in a Paediatric Intensive Care Unit

ORIGINAL

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Abstract

Objective: Assessing feelings of women accompanying children in a paediatric intensive care unit

Materials and Methods: Data were collected from August to October 2015 by the authors from individual interviews recorded with 15 women. The instrument was structured with the identification of qualitative variables, described in absolute and relative frequencies, and a guiding question. The "corpus" of each interview was electronically transcribed, floating readings were held and statements were categorized and analysed according Analise Content.

Results: 14 (93%) are biological mothers; average age 30 years; 11 (73%) have completed primary education; six (46%) have an occupation or a profession. The four themes were inferred: ambivalence of feelings and coping were related to how individuals express and deal with the hospitalized patient's situation; empathy with the health team and the structural condition of the critical environment can also generate feelings. Nursing diagnoses were formulated from the reported feelings.

Conclusion: It was observed that the health-illness hospitalization process as well as the structural components of the critical environment could originate the feelings identified.

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Introduction

Hospitalization, inevitably, causes sensation of fragility and fear to any human being [1]. In the case of hospitalization of a child in an Intensive Care Paediatric Unit, whose goal is to save lives of children

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at imminent risk, it generates stress and emotional distress to parents/guardians, either concerning the hospitalization of the child, as for temporary separation from the family [2].

In this context, there are alterations in the family dynamics due to the child absence in the family environment, especially when he/she is hospitalized in distant municipalities from the city of origin [3-4].

The mothers, usually the main caregivers of the interned children, are temporarily distant from the family, have distinct functions as wife / partner, mother and housewife, being responsible for household chores, also work as company employees, and many times are deprived from vanity and self-care, due to the time consumed between the institution where the children are hospitalized and their homes [5-6].

Many institutions offer support and shelter to caregivers of children hospitalized providing meals and night rest. They remain most of the day in the paediatric ward, with the hospitalized child. At the PICU, the mother's contact with the child is shorter, due to the critical environment, subject to complications and procedures to be performed, so, the children remain longer with the professional team [7-8].

Regarding this role of expectant mothers/women accompanying care and procedures towards their children, feelings such as anxiety, doubt, fear and helplessness are associated [9]. Thus, they demonstrate a great desire to be present and to take part on the assistance towards the child, to minimize the feeling of guilt, often present in the children's illness phase. Mothers' suffering, concerning hospitalization of the children decreases when they are inserted into the context, managing to reorganize their presence, taking care and offering love their children [9].

On the other hand, the presence of a companion and especially the mother provides protection to the child, making the hospital environment less aggressive, thus helping in the recovery and reducing the hospitalization period [10-11].

The nursing staff can offer support and help the accompanying women to face and minimize the children suffering during the hospitalization period, becoming able to identify the emotional phenomena involving centred care towards the children and family.

Considering the situation described and the dyad mother-child, whereas welfare of one affects the other [12], this study aims: to identify the socio-demographic profile of women accompanying children hospitalized in a PICU and, analise their feeling with the experience.

Materials and Methods

This is a quantitative and qualitative study, which employed, respectively, descriptive statistics with frequencies and percentages of variable categories and mean, median and standard deviation of quantitative variables, employing a theoretical and methodological framework of Bardin Content Analysis [13]. It was conducted in the PICU of Hospital of the Faculty of Medicine of Botucatu – UNESP, after approval by the Ethics Committee in Research, number 43959915.7.0000.5411, Platform Brazil. PICU has seven beds and admits children from 30 days old to 15 years incomplete and comprises a multidisciplinary team.

It was included in the study sample, 15 accompanying women of children admitted to the PICU from July to September 2015, who agreed to participate, after reading, understanding and signing the Informed Consent. The interview was conducted and recorded by the researcher, during 20 minutes, in a private room.

Data collection instrument comprised two parts. The first one consisted of 18 items related to socio-demographic profile, such as: degree of kinship with the hospitalized child, age, profession, educational level, marital status, offspring, experience regarding hospitalization, length of stay in the PICU, Hospital Support House permanence, hometown and causes of hospitalization.

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The second part of interview consisted of a question: "How do you describe your feelings about the hospitalized children in the PICU?".

The interviews speech units from the guiding question were classified and categorized after full electronic transcription and analysis according to the methodological framework.

The researchers realized readings from the "corpus" of the 15 interviews. For each interview, the recording units, representing the feelings expressed by the interviewees were identified. Three steps of reviews were performed to verify feelings with the same meaning. The results were described by categories and themes.

Results

Characterization of participants

A total of 15 women were interviewed considering that most of the accompanying women of children admitted at PICU were biological mothers; only one of them was sister; more than half were housewives who dedicated themselves to home and family care.

Some of them quit their jobs to accompany their children to medical appointments, hospitalizations and children care. Six (46.66%) interviewed women, in addition to accompanying their children during hospitalization and being responsible for their homes, have professions, such as: autonomous (1), seamstress 1 (6.77%), caregivers 1 (6.77%), maid 1 (6.77%), manicure (6.77%) and industry worker 1 (6.77%).

Regarding the education level, 11 (73.33%) respondents have completed elementary education and four (26.67%) have completed high school.

It can be observed that 13 (80%) of the women interviewed have a partner, and seven (46.67%) reported being married.

A total of 10 (53.34%) live in cities distant 100 km from the city hospital; one of them comes from another state.

As for the amount of off springs, five (33.33%) of the respondents have one child, five (33%) have three children, three (20%) have two children, one (6.67%) has four children and one (6.67 %) has seven children.

More than half of the interviewees reported previous hospitalizations experiences, concerning off springs and other family members; hospital hosting support home was used for six (40%) of the respondents.

In relation to causes of children hospitalization, it was observed: pneumonia, five (33.33%); chronic diarrhoea, two (13.33%). Other pathologies were represented by: asthma, one (6.67%); stroke, one (6.67%); heart disease, one (6.67%); colon correction, one (6.67%); diaphragmatic hernia, one (6.67%); sepsis, one (6.67%); nephrotic syndrome, one (6.67%), and brain tumour, one (6.67%).

Feelings of women accompanying children hospitalized in a PICU

According to the methodological framework of content analysis, it reached 27 feelings of denominations: *sadness; anguish; faith; fear of child's death; safety; victory; lack of empathy of the team in relation to the accompanying person; nervousness; agony; pain; resignation; fear of infection in the PICU; suffering; despair; insecurity; impotence; concern; confidence towards the PICU team; loneliness; divided between PICU and home; quit doing everything in life; insomnia; loss of appetite; separation; scared; relieved by information on reason for hospitalization in the PICU.*

From the meanings assigned by the content analysis inferences, the four themes were described, according to the nature of the identified feelings: Feelings of ambivalence; Coping; Empathy with the Health Team and Structural Condition of the Critical Environment.

The themes Ambivalence of Feelings and Coping were related to how subjects express and deal with them, that is, how they respond to the health-dis-

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ease process of the hospitalized child. The other two themes, Empathy with the health team and Structural condition of the critical environment were analyzed regarding how they could generate feelings and emotional reactions.

Discussion

Characterization of participants

Regarding the socio-demographic profile of the interviewees, most of them are biological mothers, average age 30 years. Other studies cited and identified them as main companions of the hospitalized child. [6-10]

The variable profession informs that most of them perform an occupation and not a profession. The accompanying mothers face difficult situation as home responsibilities, while they want to fulfil their caregiving duties beside the hospitalized child [14].

The finding that only 26.66% have completed high school supports this fact. The researchers' perception about the communication process during the interviews was positive, which shows that even not having secondary and higher education levels, women expressed their feelings calmly and demonstrated some interest in the research, valuing and understanding the importance of the study.

Regarding marital status, most women have a life partner who helps coping with the illness and hospitalization of the child, as emotional support. Family is essential to support the accompanying person and provide encouragement, so that she can stay with the hospitalized child, as emotional comfort, financial support, home organization, assistance in routine maintenance of other children, and patient scort relay [15].

Few respondents come from towns located 15 minutes away from the children's hospital, which can facilitate the family network and social support. But more than half of them come from more distant towns. The distance can worsen feelings of loneliness, sadness and influence negatively towards coping hospitalization. Thus, social relations prove to be essential in the lives of mothers who face stressful situations, and are often alone, far from home and family, requiring the necessity of being included in the nursing care plan [14].

Data from this study reveal that approximately 10 (66%) of the respondents have up to five children. Despite the new Brazilian family profile, the amount of off springs is decreasing; this study found that women still predominate in taking care of home and family, consequently the main caregiver of the hospitalized children.

Most of the interviewees have previous experience concerning family hospitalization, as: sons, daughters, fathers and mothers; and stayed in hospital hosting support home which is inside the University Campus, where the hospital is located, facilitating mobility, helping to alleviate the sense of separation, as mentioned by the interviewees.

Pneumonia was responsible for one third of hospitalization. Lung infections are major causes for morbidity and mortality of children in developing countries. Risk factors for hospitalization due to respiratory diseases in childhood are: impaired nutritional status, lack of breastfeeding, low parental education, low weight of the child at birth, housing conditions, presence of smokers in the house and socioeconomic conditions of the family can trigger pneumonia. [16]

Diarrhoea is still responsible for a high amount of children's death under 5 years, only backed by pneumonia. The disease affects children at an early age in rural areas of developing countries without adequate sanitation [17]. Data from this research are in agreement with other studies of the same nature, observing pneumonia and diarrhoea as most common among children [16-17]. The sociodemographic profile of the interviewees of this study identified low education levels and lack of a profession which

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could lead to social and health problems due to poor living conditions. These problems require attention of the society and from the PICU nursing team.

The nurses can diagnose this fact by getting closer to the family, helping them with referrals to Social Work, and mainly collect important information to provide appropriate care for the hospitalized children.

Themes

The four themes that emerged on the inferences are represented according to the registration units and the interview number (E).

1. Ambivalence of feelings

Is represented by: joy and sadness, fear and safeness, simultaneously. Examples of the registrated units:

...sometimes I have good news, sometimes I have not ...
E1.

Before I was afraid, but not now. Now I'm confident...
E2.

...I'm afraid, you know, of what can happen.
E8.

...some days I am fine, when I see that she is well, other days she is not...
E3.

2. Coping

Coping is defined as a process of dealing with environmental stress, and was reported by the interviewees responses, and how they dealt with the child hospitalization process at the PICU environment. Their statements represent them

There are times when we fall, but then we raise again!
E2.

I have faith that things will change ... And they will change! God is great.
E4.

Being monitored 24 hours, so this brings me some peace.
E13.

Because at home I have no treatment for her, right? So, if she is here, this is good...
E7.

Regarding the coping context, from the content analysis, it is possible to infer nursing diagnoses (NDs) Domain 9, according to NANDA-I [18] guidelines, listing defining characteristics (DC) and related factors (RF) expressed in the statements identified as "feelings". The NDs identified are: Anxiety; Death Anxiety; Powerlessness; Chronic Sorrow; Grieving; Readiness for enhanced coping.

Anxiety and Anxiety concerning Death were characterized by: crying, nervousness, fear of child´s death, sorrow, anguish, related to death threats and the current condition of the hospitalized child. It is possible to validate the NDs according to the interviewees' statements:

...I came here with my daughter almost dead, it is a very difficult feeling, isn´t it?
E1.

I feel sad because she is not at home... I feel sad because she is interned here
E13.

It's sad, very sad!... It's distressing, very stressful. It's a mix of feelings.
E4.

Sadness, great sadness and afraid that he could die ...(crying). I felt agony when I went there and saw him in that situation, swollen ... that's it." "I just cried in the PICU.
E5.

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Oh, it's very sad, I can not write down. Oh, pain, sorrow, anguish, fear ... these things, all mixed.
E6.

It's a lot of suffering .. it is hopeless. I was afraid... afraid he could get worse....
E8.

Oh, I'm sad, you know ... and worried too.
E10.

Oh well, I find it sad... I get nervous, some days I do not eat, I can not sleep because of her .. it´s hard for me, I have nobody.... Some days I feel lonely ... I'm kind of lost.. I cry for a few minutes... I quit everything to take care of her.
E14.

Besides the above NDs mentioned, the ND Powerlessness was characterized by the sensation of insufficient control concerning the child hospitalization, and frustration related to the PICU complex treatment regimen. The statements below have validated them:

There is nothing else to do, right? It depends on the hospital... how she will react, right? So there is nothing to talk about, you know.
E7.

Oh, it's a feeling of helplessness because we can not do anything and everything depends on the doctors... we feel insecure... it's very distressing
E11.

Because the last time I had to stay 10 days in Bauru, right? Alone with him, and he.... The way he is hospitalized, I quit everything in my life to be with him, right, but I´m going on... because the last time...
E12.

Grieving can be characterized on E14, according to the statements below, by sleep pattern changes, daily life level of activity, disorganization related to anticipation of child loss. It is defined by NANDA-I [18] as a "normal and complex process that includes emotional responses and, physical, spiritual, social and intellectual responses and behaviours by which the individuals, families, and communities incorporate an actual, anticipated or perceived loss into daily lives.

...Because after I came here my life stopped. Everything changed! Because I work, I have my things and then I quit everything to help her. It is very sad.
E14.

Chronic Sadness, strongly identified in E14 was characterized by the feeling of prolonged sadness related to the long period of several hospitalizations and worsening of the child's illness condition.

Why do we have to stay in a place like that?... one month, two months, we feel suffocated, sometimes I do not know if it's day or night...

...She was hospitalized several times, due to urine infection, bowel.. Then she spent two, three, four days here, and then returned home...

I get a little lost in relation to the facts, I talk to the doctors and I cannot think, then... after some time I ask again... I cannot understand everything, because she has been interned many times..
E14.

Readiness for enhanced coping is defined by NANDA-I [18] as "a pattern of behavioral and cognitive efforts to deal with demands concerning welfare, which can be strengthened." This diagnosis is characterized by the expression at improving the use of strategies aimed at health problems and hos-

pitalization of the child and employment of spiritual resources.

Like now, when I was there, there was a couple talking: "She did a little pee. So, for me, it was a great improvement.

E1.

Now I'm confident, you know, she's getting better, and she will improve more and more, right? There are times when we fall, right? But we stand up again!

E2.

...And I have much faith in God, right? I pray a lot, I trust God… God will heal her, so we can go home, right?

What is important? We need to have a religion, so that God may take care of us, give us strength to overcome all we have to go through, you know… And let's keep going ...

E3.

...Having faith can make things change... And they will change! God is the Almighty.

E4.

So I hope that he can get better soon, so I can take him home, because if he does not get better, I cannot take him.

E17.

God has to give us strength and so I go on... Oh, that´s it... Because it hurts us, mothers ... but what can we do? We have to accept.

E12.

3. Empathy with the PICU team

Refers to the external conditions of the PICU and their feelings regarding the team and the critical environment. The following statements are below:

...But here, in relation to... I, my city, the treatment that she's having here... Wow... I tell the girls here: they are angels sent by God. So the treatment, education... there is nothing to complain about.

...But the treatment here is excellent.

E1.

Oh very good... I have no complaints here. She is very well treated. From the first time, now it is the second... wow… the girls here are very good, you too!

E2.

...I miss a lot of information! We call, we need information, and they do not tell me. These days I called: ...tell me at least if she woke up? "No, I cannot say that to you." "You know, it is lack of ...One should be in the situation… to concern the other person. I think this part is missing.

So, I told that to the assistant, you know. And she said: we really cannot give information. But there are things... I'm not asking for her medical report...

There are little things that for them mean nothing... but for us they mean a lot. That's it, lack of information.

E4.

The psychologist helped me a lot, I just cried inside that PICU, and when I talked to her, I felt relieved.

E5.

Once my sister was there to ask about my daughter, and a nurse was very impolite to her.

E10.

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...Being monitored 24 hours, so there is me some peace... because if anything happens, the doctors are there, taking care... different than being in an infirmary.

Yes I talk to her... I talk about everything. I tell about things that are fine as well as the bad ones....Then she comes and we talk, I'm more relaxed ... and a psychologist acts like that, you talk, and so she understands our necessities

E13.

...Okay... they are taking good care of her... she is under observation... I'm relieved.

E15.

4. The structural condition of the critical environment

Comprises the relationship of its components, which influenced the development of feelings of the interviwee. The structural aspects mentioned in the interviews are: the waiting room for visitors and the communication concerning the patient's health.

No ... I observe lack of information! We call, we need information and they do not say anything. Some days ago I called: ... tell me at least if she woke up. ...I cannot tell you.

Only a small room to drink water, watch TV, to watch something different? Not sitting in that agony corridor.

Everything was very good... there should be a room while we were waiting to visit the patients, right?

E4.

Ah, PICU scares us. When they told me that she was coming here, I got scared. She is here for postoperative observation.

E15.

The unexpected results of this study refer to the ND findings, which were evidenced in the content analysis. Using the theoretical framework NANDA-I [18], it was possible to elaborate the ND relying on the reports of the interviews, listing DC and RF.

It becomes necessary to expand the mother and childcare in the hospitalization process at the PICU environment, in order to achieve better psychological support conditions. It is also important to provide adaptations of the physical structure in order to promote warmth and security to mitigate deleterious feelings of the caregivers during the patient hospitalization at PICU. [19, 20, 21, 22]

Conclusion

The sociodemographic profile was characterized by: most of them are biological mothers of the hospitalized children; housewives; married; with average age of 30 years; have occupation; have completed elementary school, and only one has completed high school; one third lives in the town where the child is hospitalized and have more than three off springs. Some caregivers stayed at the hospital hosting support home. Pneumonia and diarrhoea were the main causes of hospitalization.

Feelings identified comprised 27 categories, such as: sadness; anguish; faith; fear of child´s death; safety; victory; lack of empathy of the team with the accompanying person; nervousness; agony; ache; resign; fear of infection in the PICU; suffering; despair; insecurity; impotence; concern; confidence in the PICU team; loneliness; division between PICU and home; quit doing everything in life; insomnia; loss of appetite; separation; fear; relief by information regarding hospitalization in the PICU.

The four themes that emerged after the inference were: Ambivalence of Feelings, Coping, Empathy with the health team and Structural environmental condition.

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