

MEANINGS ASSIGNED BY A PEDIATRIC INTENSIVE CARE UNIT NURSING TEAM ON THE PROCESSES OF DEATH AND DYING

SIGNIFICADOS ATRIBUÍDOS PELA EQUIPE DE ENFERMAGEM EM UNIDADE DE TERAPIA INTENSIVA PEDIÁTRICA AO PROCESSO DE MORTE E MORRER

SIGNIFICADOS ASIGNADOS POR EL PERSONAL DE ENFERMERÍA DE LA UNIDAD DE CUIDADOS INTENSIVOS PEDIÁTRICOS AL PROCESO DE MUERTE Y A MORIR

Camilla Delavalentina Cavalini Marques¹
Marly Veronez²
Marina Ribeiro Sanches³
Ieda Harumi Higarashi⁴

¹ Registered nurse; post graduate candidate (*lato sensu*) in oncology at the Brazilian Institute of Therapies (IBRATE); post graduate candidate in nursing at the State University of Maringá (UEM). Maringá, PR – Brazil.

² Registered nurse; Neonatal Intensive Care Unit at the Maringá University Hospital; post graduate candidate in nursing at the State University of Maringá (UEM). Maringá, PR – Brazil.

³ Registered nurse; post graduate candidate (*lato sensu*) in occupational health nursing at the Institute of Education, Training and Post-Graduation in Health Sciences and Humanities (INDEP); nurse of the Family Health Strategy program. Andradina, SP – Brazil.

⁴ Registered nurse; PhD in education sciences; Professor at the nursing department and coordinator of the post graduate program in nursing (PSE) of the State University of Maringá (UEM). Maringá, PR – Brazil.

Corresponding Author: Camilla Delavalentina Cavalini Marques.

E-mail: delavalentina_cavalini@yahoo.com

Submitted on: 06/20/2012

Approved on: 09/26/2013

ABSTRACT

This is a qualitative, descriptive and exploratory research performed at a teaching hospital between August and September 2011. Data was collected through a questionnaire applied to the nursing team of a Pediatric Intensive Care Unit. The study objective was to identify the feelings experienced by the nursing team in the face of death of a pediatric patient. Data analysis (Minayo, 2010) identified three categories: "feelings of the nursing team towards death"; "possibilities and limits of dealing with the loss of those who remain"; "experiencing the dying process in the work environment". The results revealed that facing death requires a cautious approach that considers the needs of individuals involved: children, family and nursing team. This issue is still little explored and discussed in healthcare sciences programmes and that specific support services in all institutions could contribute to a more qualified attention in these contexts.

Keywords: Child; Nursing Care; Intensive Care Units; Death.

RESUMO

Pesquisa de natureza qualitativa, descritiva e exploratória, realizada em hospital de ensino do Paraná entre agosto e setembro/2011. Foram entrevistados 17 profissionais de Enfermagem, atuantes na Unidade de Terapia Intensiva Pediátrica. Objetivou-se compreender os sentimentos vivenciados pela enfermagem diante da morte do paciente pediátrico. Da análise dos relatos depreenderam-se três categorias temáticas: sentimentos da equipe de enfermagem frente à morte; lidar com a perda dos que permanecem: as possibilidades e os limites do cuidado com famílias; e vivenciando o processo do morrer no ambiente de trabalho. Os resultados mostraram que o enfrentamento da morte constitui uma situação delicada, demandando abordagem cautelosa que considere as necessidades de todos os envolvidos: criança, família e equipe. Evidenciou-se que a temática da morte permanece pouco explorada e discutida na formação profissional e que a organização de serviços de apoio específicos nas instituições poderia contribuir para uma atenção mais qualificada nesses contextos.

Palavras-chave: Criança; Cuidados de Enfermagem; Unidades de Terapia Intensiva; Morte.

RESUMEN

Se trata de una investigación cualitativa descriptiva exploratoria llevada a cabo en un hospital universitario de Paraná entre Agosto y Septiembre de 2011. Se realizaron entrevistas con 17 profesionales de enfermería de una unidad de cuidados intensivos pediátricos con miras a comprender los sentimientos de dichas personas ante la muerte del paciente pediátrico. Del análisis de los informes se obtuvieron tres categorías: sentimientos de los profesionales de enfermería ante la muerte; cómo enfrentar la pérdida de los que permanecen: posibilidades y límites de atención a las familias y vivir el proceso de muerte en el ambiente de trabajo. Los resultados señalaron que vivir la muerte es una situación delicada que requiere un planteo prudente que tenga en cuenta las necesidades de todos los involucrados: niños, familia y personal de enfermería. Se observó que el tema de la muerte sigue siendo poco elaborado y discutido en la formación profesional y que la organización de servicios específicos de apoyo en las instituciones podría contribuir a dispensar atención más calificada en estos contextos.

Palabras clave: Niño; Atención de Enfermería; Unidades de Terapia Intensiva; Muerte.

INTRODUCTION

The human approach to death changed significantly over time.¹ Death rituals in the Middle Ages for instance were more natural: one asked for God's forgiveness, bequeathed one's properties and waited to die. Today, it is taboo; its scenario is hospital not home. Death is no longer treated as a natural life event: it is cold, hidden and unwelcome.²

All human beings at some point in their lives, directly or indirectly, and with varied frequency are required to face death. Although they are able to recognize its inevitability as a natural consequence of biological life, the desire to live forever is cherished in Western culture and influences how terminal illnesses are dealt with.

Recent studies revealed that healthcare professionals are more likely to present psychological problems due to constant contact with unhealthy environments and a repetitive routine in which pain and death are recurrent.³

There is no denying that death is a common reality in hospitals, especially in Intensive Care Units (ICU). In these contexts, the clash between the arsenal of modern medicine resources and the severity and complexity of cases is the background to the practice of healthcare professionals, often powerless against the inevitability of death.

The constant possibility of death allied to the loneliness of the patients' coping process makes such context difficult and challenging.

Death in a hospital environment is closely tied to the routine of healthcare professionals (amongst them, the nurses) since they perform their duties in direct contact with the patients and their families, following the progression of the disease.⁴

Nurses direct their practices according to certain ethical, professional and institutional standards in order to save lives and prevent death. However, when the latter is not likely to be achieved, the situation can lead to sadness, frustration and stress due to the loss or failure represented by a patient's death.⁵

In case of a child's death, such feelings are intensified because, even though death is inevitable, it is extremely difficult to accept that it can happen so early in life. Dealing with this event is difficult and it is even more painful for the families.⁶ Their reaction is largely guided by the principle that that human being has not lived long enough; it defies the logic of the natural and complete cycle of human life.

According to the authors the nurse realizes that, in many cases, in spite of all efforts the child will not survive. This circumstance and the doubts and insecurities it generates leads to the review of concepts and feelings about death and enables the development of coping strategies.

On experiencing and, consequently, reflecting about this process, nurses feel compelled to redefine their concept of death as well as rethink their role in a Paediatric Intensive Care Unit (PICU). Their working experience contributes to appease any

guilty feelings, allowing health professionals to perform their duties judiciously and sensibly, taking more effective decisions, even when those do not concern directly the patient's care.

From this perspective, the present study aimed at highlighting the feelings of a nursing team on the death of a paediatric patient, in order to define this particular context from the perspective of the social players involved in it.

METHOD

This is a qualitative, descriptive and exploratory study conducted at a teaching hospital in north western Paraná between August and September 2011. The participants were the institution's PICU nurses with at least six months work experience in the area.

It was approved by the Human Research Ethics Committee of the State University of Maringá (resolution No 262/2011), according to Resolution No 196/96 of the National Health Council.

All participants were informed about the objectives of the study and signed two copies of the Term of Free and Informed Prior Consent, being one copy for the study participant and another for the researcher.

Data was collected through individual semi-structured interviews and analysed via content analysis that includes systematization, classification and analysis of identified categories.⁷ Similar data was grouped into thematic categories through the reading of the narratives and subsequent identification of units of meaning.

To ensure the anonymity of research participants their names were replaced by letter N for nurses and T for technical nurse followed by a number that represents the order of the interviews.

RESULTS AND DISCUSSION

The researchers analysed the narratives of eighteen nurses, being eleven registered nurses and seven technical nurses. The average length of experience in the area was seven years.

The analysis of the subjects' narratives identified three themes: "feelings of nursing team towards death"; "possibilities and limits of dealing with the loss of those who remain"; "experiencing the dying process in the work environment".

FEELINGS OF THE NURSING TEAM TOWARDS DEATH

The death of a patient has a great impact on the personal and professional identity of the healthcare professional team, especially the nurse.⁸ The peculiarities of the nursing responsibilities explain in part the intensity of this impact, when compared to other professionals of the healthcare team. The first

concerns the working shifts and the long periods these professionals spend in contact with patients. Another aspect is the nature of such contact that is direct, continuous and characterized by periods in which the patient is frail, anxious and dependent on nursing care.

In an ICU environment the relationship nurse-patient develops through 24 hour shifts or on-call scheduling. Additionally, because it is a high-complexity "closed unit" area, it restricts the contact of the patients with people other than those in the healthcare team.

It is a highly dramatic situation that emphasizes the extreme vulnerability of the hospitalized individuals, their families and the professionals involved in it.

The nursing team experience regarding death combines numerous feelings and coping strategies. The analysis of the participants' narratives revealed that, although death is regarded by them as frequent in a PICU routine, it evokes feelings of professional limitation and failure:

I feel impotent; there is nothing you can do. I try to make the process as dignified as possible; and I feel sad for the child and for the family (N1).

I feel incompetent; the ICU is sad because of that, we always work with children at risk of death, and not all of them have a good prognosis. Those who die leave us with this feeling of incompetence (T2).

Death in childhood is not well accepted for it is unexpected and tragic for both the family and the professional who provides direct care.⁵ An early death means not having the opportunity to live long enough to justify having come to this world and it is always cause for outrage.

Some deaths are premature (T4).

Death is always death; I think only the age is different. A child's is always more difficult to accept (N9).

The narratives reveal the professionals' concern for the children's state in their final moments and the health team emotional responses that depend on the circumstances surrounding the dying process of each child:

It is inevitable and sometimes it is best for the child, when her condition cannot improve and there is great suffering. When it happens suddenly, then it's very sad (N3).

It's very hard...the longing, the parting and the pain (N4).

I experience many feelings: cool when I have to go through the procedures... it depends on the clinical picture: relief when the patient has no chance, pain when we get attached to them, shock when death happens suddenly... I always get emotional (N9).

The participants' accounts reveal that an unexpected death is more difficult to cope with and assimilate than death due to chronic illnesses whose process could drag on for a long period. Pain and suffering in these latter cases are gradually absorbed and the individual can develop strategies for their management. The prospect of death in this context is a constant companion to family and healthcare team involved. Although inevitable and painful, the child's demise is easier to cope with once parents and professionals have been able to prepare themselves for it. A sudden death however catches everyone off guard; its outbreak is extremely painful because parents and professionals feel unprepared and surprised by the loss.

In contexts in which death is a constant possibility, it is necessary to establish measures so healthcare teams can be properly prepared to deal with it and offer adequate support to families and patients.

A study carried out with children with a chronic condition and their families confirms that close-knit families that share good and bad everyday experiences are more confident to approach the process of the child's death.⁶

The same study revealed that critical care should be individualized, free from rigid protocols, aimed at the biological, psychological, social and spiritual dimensions of the children. It should also encompass the family, allowing them to participate in the child's care, respecting their beliefs and preferences, enabling their presence in the PICU and providing the necessary support throughout the process. Therefore, the healthcare team should facilitate farewell rites and even the contact with the child after her departure, that is to say, they should enable a dignified death.⁹

A dignified death is a wide and varied concept; it can be defined as the absence of pain and physical discomfort (support for the children and their families), or even the absence of interventions to prolong life.¹⁰⁻¹²

Nurses have therefore a crucial role in promoting a space for family participation, letting them share the child's hospitalization, demonstrating their interest and willingness to support, offering information and the necessary logistical support in the child's last days of life.

The study participants try to see death as a natural event, a part of the life cycle of human beings. This perspective would bring the reassurance and stability needed to face death, to conceive it in the likelihood of its happening in their daily routine and not as a hindrance.

I'm very sensitive, but I can deal with death. I can go through the care procedures to the end. I do not suffer outside the hospital... I forget... maybe it's a kind of defence. I have the strength to deal with it, but then I forget it, perhaps it's self-protection (N8).

THE POSSIBILITIES AND LIMITS OF DEALING WITH THE LOSS OF THOSE WHO REMAIN

There is a relationship between death and chronological order of life. In this conception, elderly people should leave first while the younger should remain and live through the various stages of life in pursuit of their objectives, goals and dreams. This conception, in our current society, explains people's reaction to a young individual's death. The PICU nursing team are not particularly affected by death per se but by its happening to a child. Even health professionals expect health improvement or cure in paediatric cases.¹³

The significance given to a life at the beginning of its unfolding reveals the need of human beings to protect the future and renew hope through the new generations.

Furthermore, due to its fragility and its dependence on the care of adults, child protection is an inalienable responsibility of all civilized society. Thus, when a child falls ill and needs medical care, health professionals take upon themselves the responsibility to save that life. In case this objective is not achieved, feelings of loss, helplessness and failure appear.

A study carried out in the state of Rio Grande do Sul highlights that the child's age and her degree of familiarity with her relatives or nursing team make it more difficult to face her demise. When strong bonds are created (in case of older children) between the nursing staff and the family it is even harder to accept and cope with death.⁵

In addition to the challenges related above, dealing with death in childhood has other implications specific to this particular context. The presence of parents-caregivers is common in the PICU, and should even be encouraged. The Statute of Children and Adolescents (Law No 8069 of 1990) supports that right. Given these guidelines, hospitals must provide conditions for the full-time permanence of a parent or guardian during hospitalization.

The care provided by the nursing team is not restricted to hospitalized children, but also extended to caregivers and this principle enables the creation of an important bond between nurses and parents. This relationship, well managed and structured, benefits all individuals involved since it promotes team work and encourages the participation of caregivers in nursing, i.e. it improves the quality of care.

This partnership becomes decisive when parents and health professionals are forced to face the death of hospitalized children. The trusting relationship established between

the nursing team and the family does not quell the pain and suffering but it is conducive to an attitude of mutual support to cope with the loss.

Death in a PICU affects mainly the mother, and you have to work with her. (N1)

[...] We have to deal with the mother's loss, dealing with such a vulnerable child and with the expectations placed on that child [...]. (N4).

Here, I think we bond with the family, with parents... it makes things difficult (N10).

The high-tech equipment available in this sector is considered a facilitator factor by some professionals. The ICU is a department designed to provide high complexity care as well as qualified professionals whose main objective is to save the lives placed under their responsibility. This circumstance can reassure parents and professionals that all available health care is being offered; it helps them to accept theirs as an inevitable loss and not as the result of a particular decision or action:

When someone dies here [PICU], we know that it happened because it was a very serious case (N2).

Death in the PICU... it happens, but you know that everything has been done; if someone dies, it's because it had to happen (N5).

[...] Perhaps here we can offer better care (E8).

Despite that fact the professionals also argue that the same resources used in order to save the lives of these children sometimes paradoxically prolong the dying process and extend the suffering of the child, parents and caregivers:

Here death is much more invasive, aggressive, because we try everything! In the case of children [...] there are cases in which life and suffering are extended. In some cases it is as if the child is already dead, but she is still here (T5).

It is different because of the technology used here, it prolongs death... I mean, death comes slower and also brings the family more pain because it creates expectations (T6).

Technological advances increased substantially life expectancy of critically ill patients and the stigma attached to death

generated a therapeutic investment with a cost (not financial) extremely high for the terminal patient. It can be said that today the patient dies no more in his/her time but at the time determined by the health team.¹⁵

For some authors¹⁰, the decreased mortality among child hospitalizations today is due to the many therapeutic and technological advances. However, these resources end up creating an artificial life: we forget that at the other side of the tubes, monitoring wires and drains there is a suffering human being. The authors also highlight the difficulty in determining which terminal stage the patient is in, due to the great complexity of the cases and the serious responsibilities involved in this diagnosis.

EXPERIENCING THE DYING PROCESS IN THE WORK ENVIRONMENT

Reporting a child's death to the family is not an easy task for anyone; nurses and physicians are the professionals more likely to exercise this function. The daily routine at an ICU makes this event an everyday no less difficult reality.

The narratives of the professionals interviewed revealed some strategies for undertaking so hard a task; it ranges from the request of other professionals' help, to the empirical knowledge resulting from their own professional or scientific-religious experience.

The doctor calls the nurse, the social services, and therapists and together they approach the case. I talk to them slowly, calmly, starting with the way the child's case evolved... (N8).

[...] I always try to stimulate the faith in the parents, but after the child dies, I cannot deal with the explanations why it happened (T2).

In acute cases which are hard it is the empathy, comfort, spirituality, give the shoulder, a hug (N4).

According to the study participants, religious and spiritual beliefs provide a way to address the concerns of the family and are a source of relief and support to those grieving individuals. In such ways, people assign meanings and receive answers to existential questions in the face of illness and death.

These findings are corroborated by other studies that demonstrate that spirituality and religiosity seem to be important allies in the process of adjusting to illness and death.¹⁶

Among all the strategies to approach families and caregivers when announcing a child's death, the most used were: affection, solidarity and willingness to help.

I try to comfort the mother, sometimes just with a hug, sometimes talking to her about the general state of the child, and tell her to lean on religion (N1).

[...] I allow them to take the child in their arms, see the child here, every situation is unique, and there is no rule. I try to be with the mother when someone is breaking the news, even if I keep quiet; sometimes you don't need to say anything because we already are the reference (N2).

I try talking to them, guiding, supporting the parents. The parents and we feel "ungrounded" and we try to help with the legal paperwork; I try to make myself available to whatever their needs (T5).

Although professionals are willing to support the families, there are still many gaps regarding a systematic approach to such situations. Each professional has an almost instinctive and particular attitude to address death but there is no organized or institutionalized service able to provide the specific and necessary support to nursing teams and families who share this experience.

I ask for my brother-in-law's help. He is a psychiatrist. We talk a lot (N1).

I go to psychotherapy [...] I read about the issue [...] I talk with my friends [...] (N2).

[...] I vent with my family and it relieves a bit, I cry and move on [...] (T5).

Research indicates that university curricula lack this specific subject.^{1,2,16} This context is further complicated because hospitals provide little or no psychological support to these professionals which may result in harm to the mental health of the nursing team. These studies also emphasize that many professionals move away from the family in order to deal with the situation.⁴

The present study demonstrated that nursing still faces many difficulties to deal with death at work. The narratives reveal that the nurses know their limits to adequately perform the task; thus they tend to transfer it to other people they consider more prepared.

We still fear breaking the news. We try to leave it to the doctor [...] (N3).

If there is someone more skilled... That is the one. It's a way out, but [...] they might be better than me at doing that (N5).

I try to avoid the family. I think this is a way out; for me it is difficult to accept death (N6).

I prefer not to break the news [...] (T3 and T4).

[...] I think we have not been really prepared for this. It's not something that you are taught when you are studying. We try to help with our personal experiences (T5).

A study carried out with 22 nurses at a hospital in São Paulo showed that 59% of the participants had never participated in activities focussed on how to face death and cope with the loss of a close one.⁴ Another study, conducted with 23 psychology students at a public university, found that death is not part of the syllabus and this gap in university education causes dissatisfaction among them.³ The studies in question reveal this is also a characteristic of other healthcare sciences programmes.

Health professionals react to loss and death in their daily routine in a variety of ways: from sharing the family's pain and suffering, to rationalization and a stance of apparent coldness and neutrality.

Some cases have great impact on you; you feel distressed, mourn with the family and do not have someone to turn to for help (T5).

Life and death are intertwined. I see death as something natural; it is part of life (T6).

Previous experiences are mentioned as important, but not enough to overcome the discomfort and distress that characterizes each case.

Through my work experience I'm getting more mature and stronger (N9).

[...] The experience taught me mechanisms to stay outside each situation. I care for chronic children with love, but I'm working inside of me that she will not stay here, that death is better for her, because of her condition (N4).

At first I got very involved, but I learned that that pain is not mine, but the relatives'. So today, not to suffer I detach myself from the patient's personal life (T6).

The health professionals' discourses mention professional experience as a field for the exercise and construction of private means for coping with the challenges of their daily practice, which includes grief and loss. Along the lines of other strategies, emotional detachment allows them to overcome challenges with less chance of damage to their psycho-emotional integrity.

Previous experiences alone do not replace the need for more appropriate support to professionals and family members, and that is a significant flaw in the organization of health services.

I think it is important to have an available team of psychologists to work with the entire team and other professionals such as a psychiatrist or nurse psychiatrist (E1).

FINAL CONSIDERATIONS

The moment of facing death is extremely delicate and must be approached with much caution and sensitivity. Even though it is a routine event in a Paediatric Intensive Care Unit, there are still difficulties in its correct management.

Its high incidence in a PICU does not justify the trivialization of strategies for coping with death with minimal damage to all players involved.

The present study described this coping process from the perspective of the nursing team. The research design evidenced that dealing with death is little explored by education programmes which results in the perpetuation of the work challenges imposed by terminal paediatric clients and their families.

The analysis of the narratives highlighted the feelings and behaviours that characterize the health professional attitude in the face of death and dying. Feelings of fear and insecurity for not knowing how to cope with death or even the adoption of a detached stance towards the patient and family as a form of protection were cited by the professionals. Furthermore, the need for a network of institutional support was emphasized as an important instrument so these professionals can act more effectively in such situations, especially when dealing with the pain of death is something inevitable for instance, when they are supposed to announce the child's death to the family.

Thus, although hospitalization in an intensive care unit provides some relief to families and professionals in their elaboration of mourning, it does not lessen the difficulties in dealing with the loss of a young life and the collapse of projects for that child.

The limits of the study reinforce the need for further discussions on the subject, in different work contexts with other peculiarities and difficulties in order to instigate measures to transform these realities, optimizing the creation of services aimed not only at the recovery of patients but also at healing the anguish of the human condition.

REFERENCES

1. Vargas D. Morte e morrer: sentimentos e condutas de estudantes de enfermagem. *Acta Paul Enferm.* 2010; 23:404-10.
2. Santos JL, Bueno SMV. Educação para a morte a docentes e discentes de enfermagem: revisão documental da literatura científica. *Rev Esc Enferm USP.* 2011; 45: 272-6.

3. Aquino TAA. Visões de morte, ansiedade e sentido da vida: um estudo correlacional. *Psicol Argum*. 2010; 28(63):289-302.
 4. Araújo SAN, Belém KF. O processo de morte na unidade de terapia intensiva neonatal. *Com Scientiae Saúde*. 2010; 9: 290-9.
 5. Rockembach JV, Casarin ST, Siqueira HCH. Morte pediátrica no cotidiano de trabalho do enfermeiro: sentimentos e estratégias de enfrentamento. *Rev RENE*. 2010; 11: 63-71.
 6. Poles K, Bousso RS. Compartilhando o processo de morte com a família: a experiência da enfermeira na UTI pediátrica. *Rev Latinoam Enferm*. 2006;14:207-13.
 7. Minayo, MCS. O desafio do conhecimento. Pesquisa qualitativa em saúde. 12ª ed. São Paulo: Hucitec; 2010. 407 p.
 8. Souza DM, Soares EO, Costa KMS, Pacífico ALC, Parente ACM. A vivência da enfermeira no processo de morte e morrer dos pacientes oncológicos. *Texto Contexto Enferm*. 2009; 18:41-7.
 9. Poles K, Bousso RS. Morte digna da criança: análise de conceito. *Rev Esc Enferm USP*. 2009; 43:215-22.
 10. Garros D. Uma "boa" morte em UTI pediátrica: isso é possível? *J Pediatr (Rio Jan)*. 2003; 79(Supl 2): S243-54.
 11. Arrambide MS, Poc OG, Miravete JLM, Pérez-YARZA eg, Caro IA. El pediatra ante La muerte del niño: integración de los cuidados paliativos em La unidad de cuidados intensivos pediátricos. *An Pediatr*. 2005; 62:450-7.
 12. Johnson CB. Hospice: what gets in the way of appropriate and timely Access *Holistic Nurs Pract*. 1998; 13:8-21.
 13. Batista ACF. Os sentimentos da equipe de enfermagem diante da morte da criança e adolescentes hospitalizados: uma revisão integrativa [monografia]. Porto Alegre: Universidade Federal do Rio Grande do Sul; 2010.
 14. Brasil. Estatuto da Criança e do Adolescente. Lei nº 8.069 de julho de 1990. Brasília: Congresso Nacional; 1990.
 15. Oliveira SG, Quintana AM, Bertolino KCO. Reflexões acerca da morte: um desafio para a enfermagem. *Rev Bras Enferm*. 2010; 63):1077-80.
 16. Bousso RS, Poles K, Serafim TS, Miranda MG. Crenças religiosas, doença e morte: perspectiva da família na experiência de doença. *Rev Esc Enferm USP*. 2011; 45:397-403.
-