Experiences and needs of parents of adolescents with self-harm behaviors during hospitalization

Vivências e necessidades dos pais no internamento do filho adolescente com comportamento autolesivo
Experiencias y necesidades de los padres durante el internamiento del hijo adolescente con comportamiento autolesivo

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Abstract

Background: The family is particularly designed to enable family members to achieve fulfillment, helping adolescents to grow in a synchronic harmony, since self-harm behaviors are more common at this stage of life, particularly among girls.

Objectives: To identify the experiences/needs of parents of adolescents aged 13 to 18 years with self-harm behaviors and who were admitted to the emergency department of a pediatric hospital.

Methodology: This is a qualitative, exploratory-descriptive study with a phenomenological approach, using a convenience sample composed of 38 parents. Semi-structured interviews were conducted and later analyzed following the content analysis technique.

Results: Four categories emerged: Reaction to the news; Feelings/Emotions; Thoughts; and Needs. The Feelings/Emotions category is divided into two subcategories: Negative and Positive.

Conclusion: Results showed that this situation causes mixed Feelings/Emotions in parents, who expressed the desire to talk to the nurse about what was happening, receive guidance on how to deal with their child, but, above all, not to feel criticized and stigmatized.

Keywords: family; adolescent; self-injurious behavior; life change events; needs; hospitalization

Resumo

Enquadramento: A família é um agregado especialmente destinado à realização dos seus elementos, ajudando o adolescente a crescer num sincronismo harmonioso, visto serem os comportamentos autolesivos mais frequentes nesta etapa da vida, particularmente entre as raparigas.

Objetivos: Identificar as vivências /necessidades dos pais dos adolescentes com idade entre os 13 e os 18 anos com comportamento autolesivo, e que ficaram internados no serviço de urgência de um hospital pediátrico.

Metodologia: Estudo qualitativo, exploratório-descritivo, com abordagem fenomenológica, numa amostra de conveniência constituída por 38 pais. Foi utilizada a entrevista semiestruturada com posterior análise de conteúdo.

Resultados: Da análise, emergiram 4 categorias (Impacto da notícia, Sentimentos/Emoções, Pensamentos, Necessidades). Sendo que a categoria Sentimentos/Emoções apresenta duas subcategorías (Negativo/Positivo).

Conclusão: Os resultados obtidos evidenciaram que esta situação provoca Sentimentos/Emoções ambivalentes nos pais que manifestaram o desejo de falarem com o enfermeiro sobre o sucedido e poderem ter orientação de como lidar com o filho mas, sobretudo, sem serem criticados/estigmatizados assim como o adolescente.

Palavras-chave: família; adolescente; comportamento autolesivo; acontecimentos que mudam a vida; necessidades; hospitalização

Marco contextual: La familia es un grupo especialmente destinado a la realización personal de sus individuos, y a ayudar al adolescente a crecer en un sincronismo armónico, ya que los comportamientos autolesivos son más frecuentes en esta etapa de la vida, particularmente entre las chicas.

Objetivos: Identificar las experiencias y las necesidades de los padres de los adolescentes con edades comprendidas entre los 13 y los 18 años con comportamiento autolesivo, y a los que se les internó en el servicio de urgencias de un hospital pediátrico.

Metodología: Estudio cualitativo, exploratorio y descriptivo, con enfoque fenomenológico, en una muestra de conveniencia constituida por 38 padres. Se utilizó la entrevista semiestructurada y posteriormente el análisis de contenido.

Resultados: Del análisis surgieron 4 categorías (Impacto de la noticia, Sentimientos/Emociones, Pensamientos, Necesidades). A su vez, la categoría Sentimientos/Emociones presenta dos subcategorías (Negativo y Positivo).

Conclusión: Los resultados obtenidos mostraron que esta situación provoca Sentimientos/Emociones ambivalentes en los padres que manifestaron la ocasión de hablar con el enfermero sobre lo sucedido y poder recibir orientación de cómo lidiar con el hijo y, sobre todo, sin ser criticados y estigmatizados, ni ellos ni el adolescente.

Palabras clave: familia; adolescente; conducta autodestructiva; acontecimientos que cambian la vida; necesidades, hospitalización

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Introduction

The family is particularly designed to enable family members to achieve personal fulfillment; however, family identity is no different from each individual’s identity, nor is it superior or sovereign. As a group, it seeks to achieve a state of well-being, both for the family as a whole and each of its members (Campos & Campos, 2016) by providing protection, affection, and social and civic education, as well as by gradually promoting the adolescent’s autonomy and socialization (Relvas, 2004).

Adolescence is usually a healthy stage of life, with low levels of morbidity and mortality in comparison to childhood and adulthood. However, when faced with multiple changes and demands, the need for adjustments and readjustments, both at the internal and external levels, and instability and imbalance, some adolescents experience difficulties in managing their healthy development in the emotional, personal, family, academic, and socialization dimensions. For these reasons, they become more vulnerable to self-harm behaviors (Trinco & Santos, 2015). These behaviors cause constant feelings of sadness, distress, anxiety, guilt, and fear of the future in parents (Greene-Palmer et al., 2015).

The National Plan for Suicide Prevention 2013-2017 (Direção-Geral da Saúde, 2013) defines self-harm behavior as a behavior that involves self-harming acts with or without suicidal intent, such as: ingesting a non-ingestible substance or object, taking medications in excess of the prescribed therapeutic dose, ingesting an illicit drug or psychoactive substance with deliberate intention of self-harm, jumping from a high place, and self-cutting. Sometimes, this type of behavior implies individual and family changes that will have an impact on both adolescents and parents at the structural, procedural, cognitive, and emotional levels (Ferrey et al., 2016).

In a systematic literature review, we have identified authors, such as Morgan et al. (2013), Buus, Caspersen, Stenager, and Fleischer (2014), Greene-Palmer et al. (2015), and Ferrey et al. (2016), who investigated the experiences and needs of parents when confronted with their child’s self-harm behavior. Each family experiences this situation differently, but their needs are transversal and primarily based on establishing a helping relationship for themselves and the adolescent. However, all studies were conducted in outpatient settings; thus, this issue was not analyzed in inpatient settings.

In view of the above, we intend to adopt a qualitative research paradigm, using structured interviews to parents with the purpose of expanding the knowledge about their experiences and identifying their needs during their child’s hospitalization. In this way, we expect to contribute to improving nursing care delivery by promoting assertive practices in the interaction with the family and helping the family members to enhance their skills to better cope with these issues.

We have developed this project with the purpose of better understanding the care delivered to the families, namely understanding parents’ experiences during the hospitalization of a child with self-harm behavior and identifying their needs during hospitalization.

Background

The definitions of family have changed over time in societies, with significant cross-cultural differences among its members, as well as regarding what is expected from each member and the family as a whole. Therefore, the diversity of family models makes it difficult to reach a consensus on a single definition for family, although we all share a common concept and core attitude towards it (Hanson, 2005).

The family must be considered from a systemic perspective, in which it is seen as an open, social, and self-organized system in constant transformation, thus allowing for a
better understanding of the specificity and complexity of the family as a relational group. The family is defined by the meaning that it assigns to interpersonal relationships, in which internal and external demands require permanent flexibility to address new circumstances and resolve crises without compromising its continuity, cohesion, coherence, functioning, and identity (Alarcão, 2006).

It is in this permanent balance between homeostasis and transformation that a family with adolescent children experiences a period of transition and greater vulnerability in its lifecycle and that the family, as a system, must find a new balance to overcome these crises in the best way possible (Dias, 2011).

Adolescence is considered to be a critical period in the development and assimilation of healthy or risky behaviors and attitudes that may jeopardize the adolescent’s future health (Ordem dos Enfermeiros, 2010). Risk behaviors often lead to self-harm behaviors, for which reason adolescents and families go to the emergency department. However, according to the Hawton, Saunders, and Connor (2012), only a small proportion of these adolescents have direct contact with health care services. Literature suggests that these self-harm behaviors begin in adolescence, among which the most common methods are self-poisoning and medication overdose without suicidal intent and self-cutting (Direção-Geral da Saúde, 2013). Self-harm behaviors without suicidal intent are more common in girls (Zetterqvist, 2015; Guerreiro, Sampaio, & Figueira, 2014). These behaviors are a public health issue (Carvalho, Castilho, Motta, Caldeira, & Pinto-Gouveia, 2015) that must be understood and monitored within their complex biopsychosocial, relational, and family interaction due to their increasing incidence, which compromises a healthy future.

In Portugal, Guerreiro et al. (2014) showed that 7% to 43% of the sampled adolescents reported having one self-harm behavior throughout their lives. Trinco and Santos (2015) also observed that 8% to 12% of hospitalized adolescents with behavioral changes were admitted to the hospital for self-harm behavior, namely self-cutting, self-poisoning, and medication overdose without suicidal intent.

A family member may accompany these adolescents during the entire hospitalization process. It is in this context that this study seeks to identify the experiences and needs of these family members, particularly parents, given their demanding and complex role within the family structure. The parents’ performance is essential to ensure the homeostasis of survival, safety, development, and growth of children. The hospitalization of a child is a distressing process for the entire family structure (Arbuthnott & Lewis, 2015).

According to the Portuguese Order of Nurses, the presence of adolescents and their families in the healthcare units is a unique opportunity for care promotion among young people and their family, giving priority to family-centered care, rather than an exclusively patient-centered care (Ordem dos Enfermeiros, 2010). In accordance with its regulation, the nurse specialist in pediatric and child health nursing should use a conceptual care model focused on the parent-child pair. Understanding how parents experience these transitions in terms of their role as a family at a moment that is critical, both for them and the child, is of utmost importance for pediatric nursing to the extent that nurses are the main caregivers not only of these adolescents but also their families. Nurses should help them throughout the different transitions and new stages by facilitating the skill acquisition process since some critical events and circumstantial changes may trigger changes in both adolescents and families that result in behavioral disorders, identity problems, or even performance issues (Meleis, Sawyer, Im, Hilfinger Messias, & Shumacher, 2000). Morgan et al. (2013), Buus et al. (2014), Greene-Palmer et al. (2015), and Ferrey et al. (2016) describe the event as critical for parents; however, there is no scientific evidence on the hospitalization of the adolescent and
his/her family. The nursing team should facilitate this transitional process by integrating the family and the adolescent as care partners while recognizing and enhancing family empowerment to cope with the situation. Therefore, we found it relevant to conduct more research on this reality with the purpose of understanding parents’ experiences and needs in these moments. In this way, we intend to contribute to improving pediatric nursing practices by providing nurses with new tools to cope with this issue.

Research questions
What are the experiences of parents of adolescents with self-harm behaviors during their hospitalization in a pediatric hospital?
What are the needs of parents of adolescents with self-harm behaviors during hospitalization?

Methodology
Given the complexity of the experience of being parent to an adolescent with self-harm behavior who is hospitalized in a pediatric hospital, we conducted a qualitative, exploratory-descriptive study, based on a phenomenological approach. Fortin (2009) corroborates our decision by arguing that qualitative research is particularly designed to study little-known phenomena and issues through an in-depth analysis of a concept or experience or the meaning assigned to it. This analysis aims at better understanding the facts in an interactive process that helps to clarify the participants’ experience and meaning assigned to it, thereby producing scientific knowledge with an impact on the consolidation of nursing as a science and a discipline.
According to the above-mentioned author, the experience is directly understandable by those who have experienced it and can only be authentically described by them. Thus, to substantiate the research, semi-structured interviews were conducted with parents who accompanied their children with self-harm behaviors during hospitalization, based on a script with questions on the family’s sociodemographic characteristics and an open-ended question about how they experienced this situation and the needs that they felt during the hospital stay. The interviews were audio-recorded, transcribed, and analyzed.

Sample
Participants were selected using a convenience sampling method to obtain specific and differentiated answers. Data were collected between January and November 2015 in the emergency department of a pediatric hospital in the central region of Portugal. The sequential sampling technique was used to include all parents who met the inclusion criteria and agreed to participate in the study. The final sample was composed of 34 mothers and four fathers of adolescents aged 13 to 18 years (exclusive) who were admitted to the emergency department of the pediatric hospital after deliberate self-poisoning and/or self-cutting without suicidal intent. The participants lived in the districts of Coimbra, Aveiro, Leiria, and Guarda; 37 were biological parents and one was an adoptive mother. The following exclusion criteria were applied: accompanying persons who were not the adolescent’s father/mother, adolescents with suicidal intent, families experiencing a mental health-related crisis.

The Ethics Committee of the institution issued a favorable opinion (Reference No. CHUC-110-13). All participants agreed to participate in the study and signed the informed consent form, after being explained about the purpose of the study and ensured about data anonymity and confidentiality. The Nurses’ Code of Ethics principles were observed.

Data collection procedure
Data were collected using a semi-structured
interview, which is the best technique to allow interviewees to express their thoughts clearly. Parents were invited to participate in the study, after being ensured that the data would remain confidential and anonymous and that they could withdraw from the study at any time without prejudice. All parents who agreed to participate in the study signed an informed consent form.

Interviews took place after the first post-discharge consultation at the child and adolescent psychiatry unit of the hospitals in the participants’ area of residence. They were audio-recorded in an environment free from interruption and noise. Interviews had a mean duration of 60 minutes (the shortest interview took 33 minutes and the longest 90 minutes) and were later transcribed and analyzed. We concluded that no new data was obtained after 38 interviews, so we decided to stop them. Notes were taken during the interviews to better understand parents’ answers about their experiences.

The most significant findings on parents’ experiences of having hospitalized adolescent children who self-harmed and their needs during the child’s hospital stay that resulted from the data collection process were later analyzed, with the purpose of answering the research questions initially set out.

**Results and discussion**

Bardin’s content analysis technique (2009) and NVIVO8 software were used to better understand and interpret the collected data. The steps for encoding and creation of categories and subcategories were followed. Categories and subcategories emerged from the content analysis of the interviews, which are relevant data for understanding how parents reacted to the news, what were their feelings/emotions and thoughts about the situation, as well as their needs during the hospital stay, as can be observed in the figures below.

![Figure 1. Categories and subcategories of the experiences of parents of adolescents with self-harm behaviors without suicidal intent during their hospitalization.](image)
Experiences and needs of parents of adolescents with self-harm behaviors during hospitalization

Narrative synthesis of the identified categories

Reaction to the news
In this category, parents admitted that their child’s hospitalization had a major negative impact on their lives. Parents reported having reacted with surprise, followed by a mix of anger, despair, and shame.

Parents’ accounts are very enlightening about their reaction to the news: “I never thought that she would do that . . . it came as a big, sad surprise when I saw the letter that she had written and the cuts, I was knocked off my feet . . . I felt so angry” (I33, 7 August, 2015); “I had absolutely no reaction, I was so ashamed, I only felt like hitting her” (I35, 23 September, 2015).

Feelings/emotions
Feelings and emotions are often expressed throughout the interviews because accompanying their child during his/her hospital admission and subsequent hospitalization causes mixed feelings and emotions in parents. On the one hand, parents experience moments of sadness, suffering, concern, pain, confusion, despair, and apathy; on the other hand, they believe that this can be a key moment to resolve the issue.

This ambivalence is evident in the parents’ accounts, as shown in the following narratives: “I was very sad, and I only felt like crying . . . it’s too much suffering” (I23, 30 June, 2015); “If she doesn’t answer the phone, I panic, I’m always worried” (I28, 9 July, 2015).

Some parents also reported having thought that this moment could make a difference in their lives and that the adolescent could realize that he/she was on the wrong path: “This may serve to make him think about his life and see that what he did was wrong” (I31, 4 August, 2015).

Thoughts
During the interviews, parents described their thoughts about their children’s deliberate act. They expressed the need to know why, what they could do now, the guilt about what had happened, their bewilderment and hopelessness when faced with the situation; however, some also seemed to underestimate the situation. Parents’ first thought was to try to find out why their child had done it, as the following accounts show: “I don’t think about the future, nor do I want to think about it” (I2, 5 fevereiro, 2015); “This is very difficult, I sometimes lose hope in the future . . . I’m terrified of the future” (I17, 9 junho, 2015); “Feeling a failure as parents. . . where did I fail” (I34, 26 August, 2015; I14, 1 June, 2015).
2015). “I failed completely. . . I’m negligent . . . It’s a project in ruins” (I16, June, 2015). This situation makes them feel that their parental skills are inadequate, although some parents reported that they had done everything to protect their children. Some parents also expressed disorientation, as seen in the following narratives: “What will happen to my daughter? What do I do now?” (I1, 23, January, 2015; I33, 7 August, 2015). The parents felt completely disoriented without knowing what to do in that situation, but all of them went to the hospital. Some parents’ first thought was that their child was attempting to manipulate them and initially underestimated this situation, but, when confronted with the reality, they took their child to the hospital. One mother said: “I thought that . . . he was trying to get on my nerves, but then I realized that it wasn’t it” (I10, 14 April, 2015; I21, 22 June, 2015). Parents reported that they were overcome with hopelessness, particularly when the adolescent relapsed: “I don’t think about the future, nor do I want to think about it” (I2, 5 February, 2015); “This is very difficult, I sometimes lose hope in the future . . . I’m terrified of the future” (I17, 9 June, 2015).

Needs
Parents need to have knowledge and information about how to care for their child after discharge. Information is imperative for parents and their capacity to resolve crisis or stress, thus minimizing their feelings of uncertainty. Hospitalization makes parents feel even more vulnerable and overcome by pain, doubt, and despair when faced with this new situation, which is aggravated by the lack of information or emotional support. Parents’ accounts showed that the experience of their child’s hospitalization has such an impact on their lives that eventually their own needs emerge. Most parents indicated their need for understanding, including the dialog with nurses and the emotional support. Some parents reported that the health professionals’ lack of attention made them feel even more distressed:

I felt very lost and in need of help but no one ever helped me/talked to me . . . or asked me if I was cold or not (I30, 31 July, 2015). Not even a glass of water. . . no one told us anything; they did what they had to do to her, without saying too much. I wasn’t even there, no one asked me anything or told me what was going to happen (I31, 4 August, 2015).

Parents often felt that professionals, besides not communicating, also stigmatized them: “Sometimes, I feel bad because of how they look at me, as if they’re going to shoot me, no one said a word of understanding” (I8, 10 March, 2015); “They passed right by me and even looked at me sideways. I just wanted to crawl into a hole and disappear . . . I felt guilty for having Benuron® at home” (I33, 7 August. 2015).

During the interviews, we observed that parents needed to know what was going on with their child and how things would unfold: “They would just tell me the basics, not much, and only if I asked. Otherwise, no one told me anything” (I8, 10 March, 2015; I15, 1 June, 2015). Parents also reported feeling the need to receive specific guidance on how to help their child when returning home, and that these recommendations were very scarce: “When I took her home, no one told me anything in particular” (I12, 19 May, 2015); “I went home desperate for not knowing what to do” (I3, 11 February, 2015). A mother even suggested “a group for us to talk about this, because we don’t know how to deal with them in these situations. There are support groups in other cases, why not here too?” (I2, 5 February, 2015).

Parents expressed their own needs regarding hospitalization; thus, if they do not know what is going on with their child, or do not receive information about their child’s health status, if they do not feel listened or understood, they may feel increasingly frustrated and unable to understand what happened, as well as neglected and ignored. If the family’s needs are not adequately understood, the resources will not be adequately implemented. Parents’ accounts allowed us to identify several areas for nursing intervention, namely
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Conclusion

This study aimed to understand the experiences and needs of parents of adolescents with self-harm behaviors during their hospitalization. The results obtained indicate that this situation has a significant impact on parents, causing mixed feelings/emotions (although mostly negatives ones).

The hospitalization of a child with self-harm behaviors causes an emotional upheaval in parents, who need psychological support to cope with this moment of crisis. Thus, parents expressed the desire to speak with the nurse about what was happening, receive guidance on how to deal with their child, and, most of all, not to feel criticized and stigmatized, along with their child, in this situation.

Therefore, the nursing team should acknowledge and provide an adequate response to the needs of parents of adolescents during their children's hospitalization. In view of the above, nurses' skills should be further enhanced with the purpose of providing better care to children/adolescents and families, rather than just focusing on body care. This need became evident in the literature review that we have performed, which revealed a lack of studies where the family is seen as a care partner in these situations.

Pediatric nursing should provide a comprehensive view on the family and the adolescent. Both should be viewed as care receivers, and this requires identifying parents' needs and focusing care on addressing those needs, as well as nurses' awareness about the inclusion of the family as a care receiver in these situations.

Communication and time availability must be a priority in the nurse/family/adolescent relationship to allow a more humanized nursing care. Nurses should be able to listen, clarify doubts, and understand feelings but, above all, they should maintain a relationship of respect and empathy.

Implications for practice

Pediatric nurses have a privileged role in family-centered care and should possess comprehensive knowledge to understand the impact of a child's self-harm behavior on the parents. These parents have particular needs that require nurses to have a constant systemic knowledge, and to create strategies that improve the existing resources and turn into systematized activities. These activities should be part of nurses' daily practice, and be focused on meeting the parents' needs to achieve a holistic and humanized care.

References


