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The caregiver in the child/adolescent hospitalization context[1]

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Abstract: Introduction: The full time permanence of a caregiver with hospitalized child and adolescents, as determined by the Brazilian Child and Adolescent Statute ("Estatuto de Criança e do Adolescente" – ECA), in 1990, is an essential humanization issue, which leads to a change in the formal structure of hospital organization. **Objective:** Knowing the current research trends on caregivers in the children and adolescent hospitalization environment and identifying actions directed to them. **Methodology:** the search was held in September 2014 in the LILACS database of Health Virtual Library ("Biblioteca Virtual em Saúde" – BVS), using the keyword search, with the keywords: "caregivers" or "patient's companions" or "parents" and "hospitalization" or "hospitalized child" or "hospitalized adolescent". **Results/Discussion:** We selected 11 papers; 71% of those were from Nursing; 81% were performed in the Southern Brazil; 10 were qualitative researches e 1 qualitative-quantitative; 8 studies revealed that most of the participants were the hospitalized child/adolescent's mother. The caregivers highlighted that in 82% of the papers, the participants brought up the importance of the connection established by the caregivers; in 73% of them, the caregivers highlighted the communication between caregivers and the health staff; 64% pointed out the rules and hospital routines and 45% mentioned the faith and religiousness aspect. **Conclusions:** It is believed that these results may contribute to improve the comprehension of the hospitalized children and adolescents caregivers needs. Thus, this work will be able to help creating a more humanized hospital assistance and to improve the quality of services provided.

Keywords: *Caregivers, Parents, Hospitalization, Child, Adolescent.*

O cuidador no contexto da hospitalização de crianças e adolescentes

Resumo: Introdução: A permanência de um acompanhante em período integral com a criança e o adolescente hospitalizado, conforme determinado pelo Estatuto da Criança e do Adolescente (ECA), em 1990, é um fator essencial de humanização e acarreta uma modificação da estrutura formal de organização hospitalar. **Objetivo:** Conhecer as tendências atuais de estudo sobre cuidadores em ambiente de hospitalização de crianças e adolescentes, e identificar as ações direcionadas a este público. **Metodologia:** A busca foi realizada em setembro de 2014 na base de dados LILACS da Biblioteca Virtual em Saúde (BVS), utilizando-se a pesquisa por descritor de assunto, com os descritores "cuidadores" ou "acompanhantes de pacientes" ou "pais" e "hospitalização" ou "criança hospitalizada" ou "adolescente hospitalizado". **Resultados/Discussão:** Foram selecionados 11 artigos, com as seguintes características: 71% eram da área da Enfermagem; 81% foram realizados na Região Sul do Brasil; dez pesquisas foram qualitativas e uma, qualiquantitativa; oito estudos revelaram que a grande maioria dos participantes foi constituída pelas mães das crianças e dos adolescentes hospitalizados. Foram identificados alguns pontos em comum, levantados pelos cuidadores. Em 82% dos artigos da amostra, os cuidadores abordaram os vínculos estabelecidos por estes; em

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73%, destacaram a comunicação entre os acompanhantes e a equipe de saúde; em 64%, apontaram as normas e rotinas hospitalares e, em 45% dos trabalhos, ressaltaram o aspecto da fé/religiosidade. **Conclusões:** Acredita-se que tais resultados poderão contribuir para a melhor compreensão das necessidades dos cuidadores de crianças e adolescentes hospitalizados. Dessa forma, este trabalho poderá auxiliar na construção de uma assistência hospitalar mais humanizada, melhorando a qualidade dos serviços.

Palavras-chave: *Cuidadores, Pais, Hospitalização, Criança, Adolescente.*

1 Introduction

When a child or adolescent is hospitalized, they often face a new and unknown situation, undergoing treatments, tests, and procedures that many times are invasive and/or painful. This child or adolescent confronts with a new patient status and occupies a depersonalized space, far from their belongings and their individuality (ALAMY, 2007). It is seen that child development may be compromised by the experiences that the child is forced to face (CHIATTONE, 2012a).

In this context, the most difficult experience against childhood illnesses is the separation of loved and meaningful people to children and adolescents, generating feelings of abandonment. The separation of the mother, for example, in a crisis situation, when the child needs support and affection, leading to several problems, such as depression, weight loss, apathy, lack of appetite, anxiety, sleep disorders, delayed development, regression in psycho maturation process and lack of cooperation in the treatment (ALAMY, 2007). Thus, it is essential that the family remains close to the child or adolescent during hospitalization, in which this staying is a central factor in the creation of child development (CHIATTONE, 2012b).

Facing this need, the Children and Adolescents Statute (BRASIL, 1990, p. 3) in Title II from the Fundamental Rights, Chapter I, of the Right to Life and Health, Article 12, determined that: “Healthcare establishments should provide full-time staying conditions for one parent or caregiver in the case of children or adolescents hospitalization [...]”. Thus, rooming-in was created in hospitals to care for children and adolescents.

It is seen that the full-time presence of a companion with the child or adolescent brings a restructuring of pediatric units by changing the formal structure of hospital organization (COLLET; ROCHA, 2004). However, in the practices of the authors of this study, it is observed that this process is still under construction in the care of children and adolescents in hospitalization environment because despite the advances obtained, there are limitations identified in the integration of companions in the treatment process.

Thus, this study aimed to know the work developed in Brazil in the last ten years with the caregivers of hospitalized children/adolescents and help to identify the current trends of studies and actions for this population. From this analysis, it is expected to gather subsidies for the development of strategies for the caregiver in this context, so that health services can offer a more resolute care to patients and their families.

2 Methodology

The search was conducted in September 2014, in the LILACS database (Latin American and Caribbean Health Sciences) of the Virtual Health Library (VHL), using a research by subject descriptor. The keywords used were “caregivers” or “patients’ companion” or “parents” and “hospitalized” or “hospitalized children” or “hospitalized adolescent”. There were 87 articles found.

Of these, articles that had focused on the caregiver; published in Portuguese; in the last ten years, from September 2004 to September 2014 and that contained the specificity of work with caregivers of children and/or adolescents in hospital environment in the summary were selected.

Articles with the summary not available in the database used, focused on tests and/or assessments for caregivers or the perception of the health team were excluded.

After analyzing the criteria, out of the 87 articles initially found, there were 11 selected, whose main results will be presented and discussed below. In the results, the search area, the region of conducting the study, the type of research – quantitative or qualitative – the sample and also some common topics addressed more frequently in the works used were considered: links, communication, rules and routines, and faith/religion.

3 Results

Initially, the results of the articles will be presented, followed by the topics mentioned before and then the common topics identified will be addressed.

From the total of 11 articles found, ten were from the Nursing area, and only one article was from the psychology of Quintana et al. (2011).

Concerning the region of carrying out the studies, nine articles were conducted in the southern Brazil and only two in other regions, Sampaio et al. (2009) in the Southeast and Andraus et al. (2007) in the Brazilian Midwest.

Regarding the types of research, ten of them were qualitative and one was qualitative-quantitative research. Six of the qualitative research were characterized by the authors as descriptive and exploratory, one as descriptive, exploratory, and interventionist, and only one as descriptive. In other qualitative studies found, the type of research was not specified.

Regarding the sample, it was identified that in the eight articles that brought this information, most of the study participants were composed of the mothers of children or adolescents, with an average of their participation of 88%. The following Table 1 shows the percentage of mothers among the participants of the studies.

Referring to the results presented in each article, some common things were identified raised by the caregivers/companions, called as "links", "communication", "standards and routines" and "faith/religion", presented in Table 2, followed by the comments.

One aspect pointed out was the importance of caregivers, the bonds they establish in the hospitalization situation of the child and adolescents as a very significant support in coping with their difficulties. This issue is addressed by 82% of the sample articles. The links with healthcare professionals, with other caregivers in the hospital and family members, relatives, friends and neighbors were highlighted.

Some authors (SILVA; WEGNER; PEDRO, 2012; GOMES et al., 2011; SAMPAIO et al., 2009; CENTA; MOREIRA; PINTO, 2004; ANDRAUS et al., 2007) showed positive links established between the health team and caregivers as a factor that interfered in assessing the quality of care provided in the hospital, favoring a trust relationship between them. However, some studies (WEGNER; PEDRO, 2009; MILANESI et al., 2006) brought the disregard of caregivers by the health team as a negative aspect, which ends up negating the possibility of having the family as an ally in the hospitalization of child and adolescents.

Also in the establishment of bonds, several articles highlighted (DUARTE; ZANINI; NEDEL, 2012; QUINTANA et al., 2011; GOMES et al., 2011; MILANESI et al., 2006; ANDRAUS et al., 2007), the important bond between caregivers in the hospital environment, which seems to be a supportive tool for the identification that occurs between them. Such contact seems to minimize the feeling of loneliness

Table 1. Percentage of the quantity of mothers.

	Reference	Percentage of mothers among the participants
Article 1	Xavier, Gomes and Salvador (2014)	It did not bring this information
Article 2	Silva, Wegner and Pedro (2012)	13 participants, 12 mothers and one father – 92% of mothers.
Article 3	Duarte, Zanini and Nedel (2012)	13 participants, nine mothers, two fathers and one couple – 77% of mothers.
Article 4	Quintana et al. (2011)	Ten participants, all mothers – 100% of mothers.
Article 5	Gomes et al. (2011)	It did not bring this information.
Article 6	Melo, Marcon and Uchimura (2010)	It did not bring this information.
Article 7	Wegner and Pedro (2009)	Nine participants, eight mothers, and one father – 89% of mothers.
Article 8	Sampaio et al. (2009)	15 participants, all mothers – 100% of mothers.
Article 9	Andraus et al. (2007)	103 participants, 78% of mothers.
Article 10	Milanesi et al. (2006)	Eight participants, seven mothers and one father – 88% of mothers.
Article 11	Centa, Moreira and Pinto (2004)	18 participants, 15 mothers, two fathers and one grandmother – 83% of mothers.
	Average of these articles	88% of participants: mothers.

Table 2. Division of the articles by addressed topics.

Bonds (82% of the samples' articles addressed this issue)	• Article 2: Silva, Wegner and Pedro (2012). • Article 3: Duarte, Zanini and Nedel (2012). • Article 4: Quintana et al. (2011). • Article 5: Gomes et al. (2011). • Article 7: Wegner and Pedro (2009). • Article 8: Sampaio et al. (2009). • Article 9: Andraus et al. (2007). • Article 10: Milanesi et al. (2006). • Article 11: Centa, Moreira and Pinto (2004).
Communication (73% of the samples' articles addressed this issue)	• Article 2: Silva, Wegner and Pedro (2012). • Article 3: Duarte, Zanini and Nedel (2012). • Article 6: Melo, Marcon and Uchimura (2010). • Article 7: Wegner and Pedro (2009). • Article 8: Sampaio et al. (2009). • Article 9: Andraus et al. (2007). • Article 10: Milanesi et al. (2006). • Article 11: Centa, Moreira and Pinto (2004).
Standards and routines (64% of the samples' articles addressed this issue)	• Article 1: Xavier, Gomes and Salvador (2014). Article 3: Duarte, Zanini and Nedel (2012). Article 4: Quintana et al. (2011). • Article 7: Wegner and Pedro (2009). • Article 9: Andraus et al. (2007). • Article 10: Milanesi et al. (2006). • Article 11: Centa, Moreira and Pinto (2004).
Faith/Religion (45% of the samples' articles addressed this issue)	• Article 3: Duarte, Zanini and Nedel (2012). • Article 5: Gomes et al. (2011). • Article 8: Sampaio et al. (2009). • Article 9: Milanesi et al. (2006). • Article 10: Centa, Moreira and Pinto (2004).

and helplessness during hospitalization, providing complicity, solidarity and better acceptance of admission of the child or adolescent.

It is also noteworthy (QUINTANA et al., 2011; GOMES et al., 2011; ANDRAUS et al., 2007) the importance of the family, relatives, friends and neighbors as a support to hold the absence of the main caregivers in the domestic environment as well as being relevant as an aid in the care of the hospitalized child and the caregiver. There was a relevance of hospital visits and phone calls, since they allow that contact.

Regarding the aspect of "links", Duarte, Zanini and Nedel (2012), Gomes et al. (2011) and Andraus et al. (2007) stressed the need for the hospital, through the health care team, to stimulate the creation and maintenance of networks and links that help in coping with everyday hospitalization by the companions.

Another aspect pointed out by caregivers was the communication between caregivers and the health care team, and this issue was highlighted in 73% of articles. Duarte, Zanini and Nedel (2012) pointed out that knowledge about the disease is essential for parents since the feelings of insecurity and guilt can be reduced needing to remedied information. Melo, Marcon and Uchimura (2010) stated that the satisfaction with the information received is of utmost importance to decrease anxiety and to promote acceptance of the disease and hospitalization of children by their parents. These authors pointed out that, on the other hand, lack of communication is one of the factors that characterize a non-humanization care, which, according to Milanesi et al. (2006), it generates a constant alertness of caregivers, motivated by their concern.

In several studies (SILVA; WEGNER; PEDRO, 2012; MELO; MARCON; UCHIMURA, 2010; SAMPAIO et al., 2009; MILANESI et al., 2006; ANDRAUS et al., 2007), the participants showed lack of communication from the team, identifying superficial and insufficient guidance and/or information received; lack of clarification of the procedures performed; lack of knowledge of medical diagnosis, and vertically not compatible communication. Centa, Moreira and Pinto (2004) also indicated that some parents reported that they received information, but often did not understand what was explained or informed due to tension, stress, and fatigue.

Thus, the articles indicate the need for greater attention from health professionals for this aspect, as well as a readjustment of language and terminology used.

Another point raised by caregivers was the issue of standards and hospital routines, and the ratio of caregivers with them. Such issues were addressed by 64% of the sample articles. Centa, Moreira and Pinto (2004), Andraus et al. (2007), Wegner and Pedro (2009) and Quintana et al. (2011) pointed out that the caregiver sees inflexibility of hospital rules as restrictions by the institution, which impacted on family autonomy of the caregiver of their son. Xavier, Gomes and Salvador (2014) assessed that the rules and routines are considered by caregivers as important tools for organization of the labor process, but, according to them, most of them are elaborated to benefit professionals at the expense of children and family, which, as noted Milanesi et al. (2006), generating psychological distress. It was found that it is important for the health team to integrate family childcare, easing standards, when possible, to allow a more harmonious coexistence between them.

It was also noted in 45% of works, the aspect of faith/religion as a significant strategy for coping hospitalization by the participants, which it should be also considered by health professionals in the hospital context. According to Duarte, Zanini and Nedel (2012), faith/religion plays an important role in emotional balance, acceptance and coping with the disease, which, according to Sampaio et al. (2009), Milanesi et al. (2006) and Centa, Moreira and Pinto (2004), source of hope, regardless of religion or creed. Furthermore, Gomes et al. (2011) stated that the hope for the recovery of the child or adolescent is presented as a support to hold and strengthen the family emotionally.

It should be also noted that all the articles have strategies to solve some of the difficulties pointed out, such as the importance of health promotion with the health education model (WEGNER; PEDRO, 2009); humanization care, approaching the patient in their biopsychosocial and spiritual dimensions (XAVIER; GOMES; SALVADOR, 2014; DUARTE; ZANINI; NEDEL, 2012; SAMPAIO et al., 2009; MILANESI et al., 2006); greater integration of the family in the therapeutic process (MILANESI et al., 2006; CENTA; MOREIRA; PINTO, 2004), understanding that the family members/caregivers also need health team care (DUARTE; ZANINI; NEDEL, 2012; QUINTANA et al., 2011); the caregiver right guaranteed to be properly guided and informed, stimulating listening, dialogue and understanding (SILVA; WEGNER; PEDRO, 2012; DUARTE; ZANINI; NEDEL, 2012; MELO; MARCON; UCHIMURA, 2010; SAMPAIO et al., 2009; ANDRAUS et al., 2007; MILANESI et al., 2006; CENTA; MOREIRA; PINTO, 2004) and also the recognition and strengthening of networks supporting family members/caregivers (GOMES et al., 2011; ANDRAUS et al., 2007).

4 Discussion

Initially, the sample articles used in this study were highlighted for the prevalence of publications in Nursing – ten out of 11. It is noteworthy that the database used was restricted to LILACS, may be explaining the high concentration of studies of this subject. It is pointed out the importance of the subject approach by the nursing professional because they keep a close and prolonged contact with the patient and his family. However, it is known that there are publications on the subject in other lines of work and the participation of researchers from different areas becomes essential for patient care and his family to be effective, since there is a diversity of professionals who work with this people at the hospital.

In addition, it was observed that most of the studies, nine out of 11 were held in hospitals in southern Brazil. Perhaps this discrepancy is also related to the limitations of this research, found only in one database and a small number of articles in the composition of the sample.

It was also identified that the selected sample any articles that specifically address interventions with caregivers/companions was not found. All found work had qualitative/qualitative-quantitative research on the caregivers´ perception on hospitalization. The perception research are relevant because, as shown by Silveira, Angelo and Martins (2008), the evaluation of the structure and family dynamics is very important for the promotion of appropriate actions to the needs of the family unit. However, it is necessary to develop care strategies for families during the hospitalization, because, as stated by Wanderbroocke (2005), this is the main source of support to the patient and should also be the focus of professional intervention. Barros, Andrade and Siqueira (2013) cited that the family caregivers are more likely to become ill than other members of the family because, in addition to direct contact with the patient, which already causes suffering and mobilizes content relating to death, their lives are abruptly modified.

Of the 11 articles of the sample, eight studies presented the information that the mother of the hospitalized child or adolescent was the main participant, averaging 88% of the participants being mothers. This finding is consistent with other works, such as the research of Sabatés and Borba (2005), whose sample of 50 parents interviewed in children and adolescents´ hospitalization had 82% of mothers. Wanderbroocke (2005) states that the act of caring for a sick family is a female profile and, in most cases, limited to the nuclear family, being exercised by only one person. Barros, Andrade and Siqueira (2013) point out that when only one family is responsible for the care, he faces alone the difficulties and suffering to the patient and may develop symptoms such as depression, sleep disturbance, social and emotional isolation, and lack of life perspective. It is emphasized the importance of social support network, strengthening the contribution of health services to strengthen these networks, facilitating access to them and also consisting of a source of support to the caregiver.

Concerning to the results of the analyzed articles, there were both aspects that favor and those that hinder the integration of caregivers in the care of children and adolescents hospitalized. It is assessed that there is considerable progress, emphasizing the achievement of this right in decreasing the hospitalization impacts on the health of patients. Currently, the humanization of care and family-centered care are the focus of attention of professionals and should guide health practices. However, it is clear that there are still flaws in the process. It seems that there is a lack of preparation of some professionals that are reflected in the organization and dynamics of services, leading to problems in communication, misinformation, lack of support and conflicts with the caregiver, generating a fragmented care.

Sabatés and Borba (2005) in a study of parents of hospitalized children, also pointed out that they are not fully satisfied with the information received during the hospitalization of the child, concluding that their information needs are not being met. Collet and Rocha (2004), also in a research with caregivers in a pediatric unit, found that the nursing staff does not establish a dialogue with their mothers make a deal with the division of labor, characterizing a domination-subordination and not collaboration relationship. Thus, it is concluded that it is indispensable to reinforce the importance of empathy attitudes to create an environment in which mothers feel safe and empowered. Oliveira, Dantas and Fonseca (2004) pointed out that despite the fact that pediatric rooming-in is relevant to minimizing the impact of hospitalization, sometimes the infrastructure of hospitals associated with the Unified Health System (SUS) hinders the presence of companions in the hospital.

Therefore, it is clear that there must be an investment in the health professionals training, integrating this discussion in the curricula of the courses and also in continuing education and training of professionals. It is identified that managers need to consider the caregiver and their needs when planning the structure and dynamics of hospital care, favoring their access and permanence with more comfort and quality.

It is also identified as important to conduct research in the area to validate investments in caregiver´s health, generating lower costs and length of hospital stay, and reduced conflicts between caregivers and staff, reflected in improving health professional and higher satisfaction with care reported by caregivers and patients.

5 Conclusion

It is estimated that this study has some limitations such as the use of only one database to reduce the number of articles found, enabling the analysis. In addition, most of the articles' sample focused in nursing area, in the south of the country, are qualitative research of perception of the caregivers about the hospitalization of children and adolescents. These limitations restrict the representativeness of the sample of the articles to understanding the Brazilian context of recent scientific publications – the last ten years – in this area.

However, through this work, it was possible to identify some factors that favor or hinder the integration of the caregiver in the treatment offered to children and adolescents, such as the establishment of links with the team, with other caregivers and family members, relatives, friends and neighbors; communication with the health team; standards and hospital routines, and faith/religion.

Thus, it is clear that, from the factors identified, it was possible to achieve the goal of the study to gather support for the development of strategies for the caregiver in this context. It was noted also the importance of considering the demands of the caregiver when structuring the hospital routine, standards and rules, and the need for readjustment of the hospital's physical structure. It was also identified that it is essential to enable the establishment and maintenance of social support networks and the times when the links are strengthened, such as through hospital visits and phone calls, as well as the exercise of religion.

In this way, it is believed that progress will be made on the construction of a more human hospital care for children and adolescents. These changes will help to improve the quality of services, resulting in benefits to patient care, with better results, their greater satisfaction and their families, and to improving the working environment for health professionals.

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Author's Contributions

Maristela dos Guimarães Peixoto e Rúbia Marques Pyló: elaboration of the study, data analysis and article edition. Kátia Maria Penido Bueno: guidance in all the stages of the study and article review. All authors approved the final version of the article.

Notes

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