

# The recovery process of children after discharge from hospital: an integrative review

O processo de recuperação da criança após a alta hospitalar: revisão integrativa

El proceso de recuperación del niño después del alta hospitalaria: una revisión integradora

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#### ABSTRACT

**Objective:** To identify the available knowledge about the process of recovery of hospitalized children and their families after discharge. **Methods:** Integrative review of literature in databases - national and international - with a qualitative approach. **Results:** The 16 selected articles belonging to international journals were published between 1990 and 2005; they allowed the identification of the following topics: biopsychosocial manifestations of the child and his family; Biopsychosocial factors related to the manifestations of the child and his family; benefits of early discharge of the child; and, information and support needed. **Conclusions:** The interventions focused on the child and his family should be started in the hospital check-in in order to improve their ability to cope with the situation. There is need to enhance research on this topic in developing countries, including the prospect of the family as a unit.

Keywords: Child, hospitalized; Convalescence; Family; Pediatric nursing; Patient discharge

#### **RESUMO**

Objetivo: Identificar o conhecimento disponível a respeito do processo de recuperação da criança hospitalizada e de sua família após a alta. Métodos: Revisão integrativa da literatura realizada em bases de dados, de âmbito nacional e internacional, com abordagem qualitativa dos dados. Resultados: Os 16 artigos selecionados pertencem a periódicos internacionais, foram publicados entre 1990 a 2005 e permitiram a identificação dos seguintes temas: Manifestações biopsicossociais da criança e da família. Fatores relacionados às manifestações biopsicossociais da criança e da família; Benefícios da alta precoce da criança e Necessidades de informação e apoio. Conclusões: As intervenções voltadas à criança e à família devem ser iniciadas ainda na hospitalização, a fim de melhorar sua capacidade de enfrentamento. Há necessidade de aprimorar as pesquisas sobre essa temática nos países em desenvolvimento incluindo a perspectiva da família como unidade.

Descritores: Criança hospitalizada; Convalescença; Família; Enfermagem pediátrica; Alta do paciente

# RESUMEN

Objetivo: Identificar el conocimiento disponible sobre el proceso de recuperación de los niños hospitalizados y sus familias después del alta. Métodos: Revisión integradora de la literatura en bases de datos nacionales e internacionales, con enfoque cualitativo de los datos. Resultados: Los 16 artículos seleccionados pertenecientes a las revistas internacionales, fueron publicados entre 1990 y 2005, estos permitieron identificar los siguientes temas: manifestaciones biopsicosociales del niño y la familia; factores biopsicosociales relacionados con las manifestaciones del niño y la familia; beneficios del alta temprana del niño; y, necesidades de información y apoyo. Conclusiones: Las intervenciones dirigidas al niño y la familia se deben iniciar durante la hospitalización con la finalidad de mejorar su capacidad enfrentamiento. Se concluye, que existe la necesidad de mejorar la investigación sobre este tema en los países en desarrollo, incluyendo la perspectiva de la familia como una unidad.

Descriptores: Niño hospitalizado; Convalecencia; Familia, Enfermería pediátrica; Alta del paciente

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# **INTRODUCTION**

Patients have been discharged from hospitals earlier and earlier, before diseases are properly treated and health is recovered. Such practice has been justified by the need for more beds, and decreases in hospital costs<sup>(1-6)</sup>, by technological advances in the health area, and risks inherent to hospital admissions<sup>(3-6)</sup>.

This fact has been generating studies that aim to verify how patients experience home recovery and the implications for families<sup>(1,5-6)</sup> after hospital discharge. In a review about the theme, contemplating several studies performed as of 1951, authors described adult recovery from a psychosocial perspective and physiologic variables; however, little attention was given to the post-discharge period. In the first studies, recovery was understood as an abandonment of the diseased role. A subsequent study describes it as the process towards going back to normal, comprised of three phases: passivity, restarting activities, and stabilization of health. It also reveals that the recovery process can be extended beyond hospital discharge<sup>(1)</sup>.

In the pediatric area, hospitals have also been choosing to discharge children early, adding to the reasons above mentioned the fact that reducing admission time minimizes the harmful effects of separation between a child and his/her family<sup>(6)</sup>.

It is known that concluding a child's recovery process at home makes the family responsible for care giving out of the hospital until health is completely recovered, once care received during admission is only a part of what the diseased individual needs<sup>(7)</sup>. Nevertheless, the children's recovery profile, created so as to reduce admission time, has not been effective for professionals to appropriately respond to children's and their families' needs after discharge<sup>(6)</sup>.

Besides, activities developed in the hospital with focus on families so as to assist them to deal with the admission experience are frequently not enough to prepare them for the period after hospital discharge<sup>(6)</sup>. The number of re-admissions in the pediatric area is also concerning, along with the lack of follow up after hospital discharge, which impedes an assessment of the conditions that favor such fact<sup>(8)</sup>. Therefore, it is relevant to know how the recovery of health has been experienced by children and their families at home, once the hospital discharge planning is a nurses' job<sup>(9)</sup>, and following up on children's health out of the hospital is part of children's healthcare<sup>(10)</sup>. In order to contribute to the theoretical subsidies in the hospital nursing area, and to the children's and families' follow up after hospital discharge, the present study aimed to identify available knowledge about a child's recovery process after hospital discharge and the family role in it.

#### **METHODS**

This is an integrative literature review, whose method allows simultaneous inclusion of several research design types, aiming to broaden comprehension about a fact<sup>(11)</sup>.

Inclusion criteria to select articles were: to contain field research results, to have been published in a national or international journal, indexed in informatized databases in Portuguese, Spanish, or English, as of 1990; to approach biopsychosocial aspects of children who have been admitted to a hospital aiming to completely recover health after being discharged. Articles that included children with chronicle conditions, such as: cancer, diabetes, mental illnesses, and articles that only approached the physiological aspects of a child's recovery were excluded.

The period when articles were published was chosen due to the fact that children's healthcare, as well as the correspondent literature, started to include families and their members as caregivers, mainly after 1990<sup>(12)</sup>.

The researched databases were Literatura Latino-Americana e do Caribe em Ciências da Saúde – LILACS (Latin-American and Caribbean Health Sciences Literature), National Library of Medicine (PubMed), Cochrane Library, and Base de Dados de Enfermagem – BDENF (Nursing Database). Key words used to find articles in the Regional Medical Library (Bireme) were convalescence and patients' discharge, each one related to children and family. The word convalescence presented similarities with the meaning of recovery, understood as going back to the conditions prior to the disease.

The qualitative approach has been recommended for the data synthesis analysis in an integrative review model. Upon such recommendation, after reading abstracts and selecting articles, data were analyzed, focusing on the results presented by the studies. Each article was submitted to a first reading, when data regarding the sample criteria were considered. Again, themes concerning children's recovery process were highlighted in each article, for further grouping and synthesis, according to similarities and existing relationships<sup>(11)</sup>.

#### RESULTS

#### Sample characterization

Sixteen articles were selected, all of which had been published in international journals, by foreign authors, between 1990 and 2005. Among these, 12 studies had been performed by nurses, 3 by doctors, and 1 by a psychologist; 11 studies employed quantitative analysis methods; 10 took place in the United States of America, and the others, in developed countries. All of them investigated, either separately or together, children's and families' experiences after hospital discharge, except one,

which approached recovery initiated in the hospital and expectations regarding life out of the hospital institution. It is worth highlighting that this study was the only one to employ the word "recovery" as a describer, although it is not present at Bireme's inventory. Data were obtained through interviews, mainly with the children's mothers.

There was a great variation with regard to age bracket of children admitted – ranging from 0 to 17 years old – cause of admission, and admission unit types, which included emergency rooms, intensive care and general care units. Some studies did not explore the admission context, but in general, admission causes were related to clinical and surgical conditions with a potential for recovery, such as: pneumonia, gastroenteritis, viruses, stomatitis, herniorrhaphy, appendectomy, fractures, among others.

# Integrated themes

The articles analysis enabled the identification of the following themes, which comprised the family members' experience upon the child's recovery: Children's and families' biopsychosocial manifestations; Factors related to children's and families' biopsychosocial manifestations; Benefits of home care; and Need for information and support.

# Children's and families' biopsychosocial manifestations

Such manifestations can be observed in how families deal with the situation after hospital discharge. In an individual approach, manifestations were identified in both the child and parents.

There were harms to family cohesion along the recovery process after hospital discharge, mainly when families had seriously diseased children(12-13), and mothers were less satisfied with the family cohesion than fathers<sup>(12)</sup>. After hospital discharge, families were still suffering with routine alterations due to the need for the child to be taken to medical appointments, following up on the recovery process<sup>(14)</sup>.

Although families try to cope with the new demands, they suffered due to the lack of ability to deal with them after hospital discharge<sup>(12-13)</sup>.

On the individual level, biopsychosocial manifestations, such as behavior and physiological alterations, were identified in both the child and parents. After hospital discharge, children who had been admitted to intensive care units (ICUs) with a perspective of discharge and complete recovery, presented eating disorders, apathy, aggression, separation anxiety, and trouble sleeping<sup>(12)</sup>. During the first month of home care, after admission for pneumonia, it was also observed that children presented insomnia, loss of appetite, more weeping, fever, cough, and sleepiness. After 60 days,

42% of these children still presented noisy breathing, and most of them had not reached behavior indicators presented by the control group<sup>(14)</sup>.

Children's parents identified other behavior alterations after hospital admission (and further discharge) for small surgeries<sup>(15)</sup> and fractures<sup>(16)</sup>. Post-operative pain indicators were observed through non-verbal expressions, such as a different voice tone, or different weeping, staying in bed when friends visited, and irritation<sup>(15)</sup>. Most of the children presented limited mobility and self-care ability after six months of hospital discharge<sup>(16)</sup>.

Problems in children's behaviors, such as lower concentration ability, difficulties controlling the intestines, and feeling more afraid were other manifestations found after 6 months of ICU discharge<sup>(17)</sup>.

Parents presented biopsychosocial manifestations even after being prepared for hospital discharge. Decreasing hospital admission time provoked anxiety in parents, who were not sure they could take care of the child, or did not feel confident health was going to be recovered, even while the child was still an inpatient<sup>(5)</sup>. Some studies investigated the level of anxiety for parents, especially the mother, and verified that it is higher just after hospital admission<sup>(13,18)</sup>. Parents who had to follow up on children's recovery after hospital discharge mentioned the feeling of isolation<sup>(19)</sup>. Some mothers reported having less health after their child had been discharged from hospital in comparison to the period prior to admission<sup>(13-14)</sup>.

# Factors related to children's and families' biopsychosocial manifestations

Factors that influenced children's and families' manifestations are related to the number, time, and cause of hospital admissions, to the quantity of invasive procedures performed during hospital admissions, children's age and gender<sup>(15-20)</sup>. With regard to parents, studies aimed to find correlations between how serious the disease was, how long children were admitted for, and how long they would have to stay at home after hospital discharge.

Admission time was verified to be a factor that influenced children's and parents' biopsychosocial manifestations. Longer admission times, with the risk of re-occurrence, worsened children's behavior problems<sup>(12,18,21)</sup> and generated more anxiety for parents, in comparison to those who had their children admitted for less time<sup>(18)</sup>.

When children underwent surgeries, behavior disorders did not depend on the admission time<sup>(22)</sup>. When children were admitted due to respiratory diseases, behavior indicators, stress level, and health improved in the first 4 days after hospital discharge<sup>(14)</sup>.

The relationship between children's anxiety and their age, gender, and number of hospital admissions experienced was analyzed in one of the studies. The level of anxiety among children from 5 to 7 years old was higher and slower to decrease than among children from 8 to 11 years old. The same results were found for boys in relation to girls, and to those children being admitted for the first time<sup>(20)</sup>. Hence, children's anxiety perception by parents was different, once they perceived children were more anxious than mothers<sup>(12)</sup>.

Children who had gone through more invasive procedures during admission time presented more post-traumatic stress symptoms, such as: being afraid of medical examinations, and feeling that they might need to be admitted again at any time<sup>(17)</sup>.

As to admission causes, functional alterations provoked by fractures of the lower limbs impacted on the return to a normal routine, which happened after a year, with children going back to performing usual activities and not presenting behavior alterations. Children's immobilization degree overloaded families' routine along such period<sup>(16)</sup>. When admission is due to a more serious disease, children's post-traumatic stress is higher<sup>(22)</sup>, as well as mothers' post-discharge stress<sup>(21)</sup>.

The disease seriousness was correlated to the time at home after hospital discharge, indicating there were damages to families' routines for up to three years after children's admission, regardless of being at an ICU or at a general care unit<sup>(23)</sup>.

Time children had to stay at home after hospital discharge influenced parents' anxiety level, and children's behavior. Although parents' anxiety decreased after the child's hospital discharge, it was still higher than usual (13,18). There was a significant decrease of mothers' anxiety after the 4th day after children with respiratory diseases had been discharged. However, after two months, these mothers' anxiety levels were still higher than those presented by mothers in the control group, that is, whose children had not been admitted<sup>(13)</sup>. A study that compared post-discharge stress among three groups of mothers whose children had different diseases, with different levels of seriousness, concluded that symptoms faded and reached similar levels after six months children had been discharged for all groups. Even mothers with a lower stress level assessed that their family routine got worse along the 6 months investigated by the research<sup>(21)</sup>.

Mothers' stress level was proportional to their concern regarding their child's recovery, their partners, extended family, and friends' reaction<sup>(16)</sup>.

Researches identified that the family budget was another aspect related to families' dynamics, once expenses increase due to transportation and medication<sup>(14-21)</sup> costs, and parents miss days at work, especially mothers<sup>(14)</sup>.

### Benefits of children's early hospital discharge

In the selected studies, parents indicated the elements that led them to approve their children's discharge, even upon the knowledge they would have to take care of them at home.

Parents appreciated admission time reduction, for they could assume their personal and family responsibilities earlier<sup>(24)</sup>. At home, they continued with their usual tasks and were satisfied actively participating in their child's care, learning how to recognize signals and symptoms that required intervention, document children's progress, monitor temperature, administer medication and inhalation<sup>(25)</sup>.

Home environment factors were beneficial to children's recovery, considering they were together with their family members, more relaxed, accepting to eat, and could play with their own toys. Children themselves affirmed they would rather remain at home than in the hospital, saying that they felt safer, and could play with their own toys. Parents affirmed they had more freedom, and comfort, received individual attention from the nursing team, continued the family's normal life, decreased financial costs, observed that children were better recovering at home, and that the disease was not so serious<sup>(25)</sup>.

#### Support and information needs

In order to face recovery time at home, parents talked about the need for information regarding the disease and how to take care of their child at home. Information requested was related to the disease cause and progress, what they should expect during the recovery time, and how they should care for the child at home<sup>(2,5,13,19,24)</sup>. Orientations concerning nutrition, behavior, going back to school, symptom re-occurrence prevention, and use of the medication prescribed were other mentioned themes<sup>(19)</sup>.

Parents affirmed they would like the team to have more time to guide them after hospital discharge<sup>(19)</sup>, and complained saying orientations were too generalized<sup>(2)</sup>. Nonetheless, they demonstrated to be calmer after perceiving that information received after the discharge corresponded to what they were experiencing at home, regarding their child's health recovery<sup>(24)</sup>.

Another need pointed out by parents was the family and healthcare professionals' support, which was considered relevant when taking care of the child at home. Family was seen as a source of support, when they participated in the process and knew what was going on<sup>(24)</sup>, although mothers who experienced home care believed the responsibility was mainly theirs<sup>(5)</sup>. They affirmed that they would approve some follow up out of the hospital<sup>(2,5,19)</sup>, preferably by a healthcare professional who knew their child's case<sup>(19)</sup>. The nursing

team commitment to visit and provide orientation concerning home care made parents feel more confident taking their children home and continuing with the recovery process<sup>(24-25)</sup>. Individualized attention provided by the nursing team during the follow up after hospital discharge made parents feel constantly informed<sup>(25)</sup>.

### Children's health recovery meaning

Only one of the studies aimed to understand the mother's perception of their child's health, revealing that for her the recovery of health started during admission, before discharge, when she identified her child was more active, willing to eat and play. Because the study was developed during the child's admission, the recovery meaning also included a perception of the recovery from the anesthetics, and the concerns regarding future home care<sup>(6)</sup>.

# **DISCUSSION**

The themes identified evidenced that health recovery and discharge, although desired by children and their families, can be permeated by the emergence of biopsychosocial disorders that might last indeterminately.

Upon such fact, a child's health recovery process and its consequences should be monitored by the healthcare team. Therefore, hospital discharge planned along with the family and home visits become important sources of support and help minimize anxiety, offering information, individualized attention, and follow up.

However, it is necessary to improve researches, once there are knowledge gaps that need to be fulfilled. Most of the studies performed were quantitative studies, and one of the gaps was related to the need for new studies, with larger samples, testing other variables, such as gender, longer follow up times, and children's ages<sup>(13,20)</sup>.

Mothers are the main informants for the researches, which was criticized by authors who affirmed information about fathers was also necessary for investigations regarding children and families' health<sup>(20)</sup>. Nevertheless, they are present during recruitment, and often do not want to participate in the researches<sup>(16)</sup>.

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Researches are necessary to explore problems such as families' adaptation after children's hospital admission. In order to do so, other data should be correlated, besides disease and admission location, namely: family resources and family type, parents stress symptoms, and the family adaptation after the child's hospital discharge<sup>(16)</sup>. The lack of studies assessing the home recovery process financial costs also corroborate to this gap<sup>(15)</sup>. Studies demonstrated there is a concern regarding the hospital admission impact, and children's recovery at home with their families; however, such data can be improved: through researches with other samples and investigation methods that explore the suggested variables and interactions among family members along the child's recovery process<sup>(15-16)</sup>.

Authors also recommended that additional studies are performed to assess parents' participation in the invasive procedures, and that methods are developed so as to ease stress upon the situation<sup>(13)</sup>.

Papers do not mention if parents stayed with their children during the hospital admission. Hence, such factor could be investigated and correlated to children's behavior after hospital discharge.

All aspects of the disease, admission, time spent in the hospital, and discharge impact on the way the recovery will be managed at home, thus it is relevant that interventions are originated during the hospital admission and continue during follow up, after discharge.

### **CONCLUSION**

Besides the fact researches reviewed have consecution gaps, results reflect families' experiences during children's health recovery in developed countries, where the healthcare system is different from the Brazilian system. Taking this into consideration, it is important that researches aiming to understand children's and families' health-disease process both in the hospital and after hospital discharge are performed so as to enable the healthcare team to come up with interventions that increase families' adaptation ability, reducing post-traumatic stress risks for children and their families, and the number of frequent re-admissions in the pediatric area.

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