■ Original Article
doi: https://doi.org/10.1590/1983-1447.2018.2017-0290

Chronic disease in children and adolescents: professional-family bond for the promotion of social support

Doença crônica infantojuvenil: vínculo profissional-família para a promoção do apoio social

Enfermedad crónica infanto-juvenil: vínculo professional-familia para la promoción del apoyo social

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How to cite this article:
Machado NA, Nóbrega VM, Silva MEA, França DBL, Reichert APS, Collet N. Chronic disease in children and adolescents: professional-family bond for the promotion of social support. Rev Gaúcha Enferm. 2018;39:e2017-0290. doi: https://doi.org/10.1590/1983-1447.2018.2017-0290.

ABSTRACT

Objective: To analyze the bond in social support delivery by a multidisciplinary team to families during the hospital stay of children/adolescents with chronic disease.

Method: Qualitative research, conducted in the pediatric unit of a public hospital in Paraíba State, Brazil, from November 2012 to July 2013, involving fourteen health professionals, by means of a semi-structured interview. The data were subjected to thematic analysis.

Results: The bond between the team and the family is promoted by dialogue and listening, which are recognized sources of social support. The encountered difficulties that interfered with the delivery of social support were weakness in team-family communication and interaction, gaps in the organization of the work process and lack of hospital infrastructure. Possible approaches to overcome these obstacles were follow-up beyond hospital discharge and a stronger team-family bond.

Conclusion: Satisfying social support has an influence on coping with chronic disease in children and adolescents, and its proper delivery relies upon bonding and embracement.

Keywords: Social support. Chronic disease. Family. Professional-family relations. Child.

RESUMO

Objetivo: Analisar o vínculo na promoção do apoio social ofertado pela equipe multiprofissional de saúde às famílias durante a hospitalização de crianças/adolescentes com doença crônica.

Método: Pesquisa qualitativa, realizada em unidade pediátrica de um hospital público da Paraíba, de novembro de 2012 a julho de 2013, com quatorze profissionais de saúde, por meio de entrevista semiestruturada. A interpretação dos dados foi mediada pela análise temática.

Resultados: O vínculo equipe-família é promovido pelo diálogo e escuta, reconhecidos como fontes de apoio social. Evidenciaram-se dificuldades como a fragilidade na comunicação e interação entre equipe-família; lacunas na organização do processo de trabalho e falta de infraestrutura hospitalar, que interferem na oferta de apoio. Como caminhos para superar os obstáculos, evidenciou-se o seguimento após alta e fortalecimento do vínculo equipe-família.

Conclusões: O apoio social satisfatório influencia o enfrentamento da doença crônica infantojuvenil e, para sua oferta, o vínculo e o acolhimento são indispensáveis.

Palavras-chave: Apoio social. Doença crônica. Família. Relações profissional-família. Criança.

RESUMEN

Objetivo: Analizar el vínculo en la promoción del apoyo social ofertado por el equipo multiprofesional de salud a las familias durante la hospitalización de niños/adolescentes con enfermedad crónica.

Método: Investigación calitativa, realizada en unidad pediátrica de un hospital público de Paraíba, de noviembre de 2012 a julio de 2013, con catorce profesionales de salud, por medio de entrevista semiestructurada. La interpretación de los datos fue mediada por el análisis temático.

Resultados: El vínculo profesional-familia es promovido por el diálogo y la escucha, reconocidos como fuentes de apoyo social. Se evidenció dificultades como la fragilidad en la comunicación e interacción entre equipo-familia; las lagunas en la organización del proceso de trabajo y la falta de infraestructura hospitalaria, que interfieren en la oferta de apoyo. Como caminos para superar los obstáculos, se evidenció el seguimiento después del alta y fortalecimiento del vínculo equipo-familia.

Conclusiones: El apoyo social satisfactorio influencia el enfrentamiento de la enfermedad crónica infanto-juvenil y, para su oferta, el vínculo y el acojimiento son indispensables.

Palabras clave: Apoyo social. Enfermedad crónica. Familia. Relaciones profesional-familia. Niño.

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INTRODUCTION

Chronic disease in children and adolescents can promote family imbalance due to the changes that are triggered in family dynamics and in the patients' lives, and it has been a relevant issue of reflection regarding the organization of the health care work process across different levels of attention[1].

In a 2010 survey conducted in Brazil, at least one chronic disease was identified in 9.1 % of children aged between 0 and 4 years; in 9.7 % of children between 6 and 13 years; and in 11 % of adolescents aged 14 to 19 years[2]. Support delivered to the families of these children and adolescents by professionals is crucial to help them handle the demanding tasks of coping with chronic disease. This support is necessary because chronic disease impacts the whole family with regard to their relationships and their emotional, financial and health-related wellbeing due to the adaptations in their daily life needed to overcome the implications of the disease[1]. A study from the Netherlands also emphasizes how important it is for parents to receive information from health care professionals on how to manage the disease so that they can balance their personal life with the responsibilities of providing care to their chronically ill child[3].

Social support implies help as affection, trust and empathy support, and this offer can comprise emotional, material and affective support by the social network of the individual, so that the supported person feels satisfied with the help[4]. The support that the multidisciplinary health care team offers to families is one type of social support, and it contributes to a better management of the implications arising from chronic disease. However, the family must recognize this support as a benefit for their quality of life, with positive repercussions on the care provided to the child/adolescent[5]. Thus, the team must know whether the support they are offering meets the needs and expectations of the families.

In this sense, it is of paramount importance that the multidisciplinary health care team guide its actions by qualified listening and awareness of reflections, experiences and knowledge of those involved with the disease to prioritize the families' needs rather than solely limiting care to therapeutic impositions[6], since qualified listening leads to bond establishment.

The concept of bonding is polysemic and, in this study, will be "understood as an interpersonal relationship that is established over time between health care users and health professionals and is characterized by trust, responsibility and a sharing of commitments"[7].

In view of this definition, the listening-trust relationship is important for bonding. In contrast, one study has shown that lack of attentive listening and dialogue with those seeking health care services can weaken or even break the bond, entailing damage to care delivery[8] and the family's lack of interest in establishing a bond.

Thus, attentive listening is an important tool in the care of children and adolescents with chronic disease, and professionals must recognize its importance and its role in the support network of this population since, when supported, the families and children/adolescents feel empowered to face the implications triggered by chronic disease. However, the absence of this support by the health team worsens the situation experienced by this population[6].

In this context, the present study aimed to direct a sensitive look at the response of health care professionals at the hospital level towards those who experience the suffering of chronic disease, thus encouraging reflection and changes in the work process. To build care for the children/adolescents and their families based on integrity, respect for life and citizenship, health care professionals must know the specificities of this population to reorganize their work process according to their specific reality.

In view of the above, a question arose: Has the professional-family bond offered satisfying social support to the family during the hospital stay of children/adolescents with chronic disease? Thus, the objective of the present work was to assess the bond in the promotion of social support by the multidisciplinary health care team for families during the hospital stay of children/adolescents with chronic disease.

METHOD

The present study is a qualitative descriptive exploratory survey conducted at a pediatric inpatient unit of a public hospital in Paraíba State, Brazil, from November 2012 to July 2013. The hospital was chosen because it is a reference point for the treatment of rare and chronic diseases and serves as a training field for health care students. These aspects raise the discussion on the role of the multidisciplinary team in health care as members of the social support network for children/adolescents with chronic disease and their families, considering their commitment to improve the quality of care.

Fourteen professionals from the multidisciplinary team of the pediatric unit of the above hospital, whose work process is based on the philosophy of teamwork, participated in the study. This team is composed of nurses, physicians, social workers, dieticians, nursing technicians and psychologists responsible for the comprehensive care of children

and adolescents hospitalized in the studied unit, which also offers outpatient support. Team members were selected randomly and met the following inclusion criteria: have been working at the studied unit for more than one year and see children/adolescents with chronic disease. Professionals who were absent due to vacation, leave or other reasons during data collection were excluded. It seems that having worked at the unit for more than one year widens the professional's view in perceiving the unique needs of chronically ill children and adolescents.

Empirical data were collected by means of a semi-structured interview[9] that participants agreed could be recorded and transcribed in its entirety. The first question of the interview was: Which actions do you adopt in your daily routine that, according to your perception, strengthen the bond and provide some kind of support to the families of children/adolescents with chronic disease? All interviews were conducted in the pediatric unit of the studied hospital, in a private room, during the time scheduled by the participant, who had been contacted prior to the interview. Professional categories of service were identified by visiting the unit before the beginning of data collection. Data were collected to the point of theoretical saturation, which is when empirical material allows for a comprehensive design of the studied object[10].

The data were interpreted by means of thematic analysis. First, the material was organized, with exhaustive and repeated reading of the texts, detecting the core meanings that emerged from cross-reading. Relevant themes were then grouped before proceeding to final analysis[9].

This research has been approved by the Research Ethics Committee under the CAAE No. 0466.0.000.126-11. All participants signed an informed consent form as determined by Resolution 466 of December 12, 2012, of the National Health Council. In the results section, statements are identified by the letter E in brackets, accompanied by an ordinal numeral that represents the order in which interviews were conducted.

RESULTS AND DISCUSSION

The studied sample was composed of five nurses, two nursing technicians, two nursing auxiliaries, one pediatrician, one resident pediatrician, one psychologist, one dietician and one social worker, all aged between 26 and 61 years. The mean time of occupation in the pediatric unit was approximately 13 years.

The interpretation of empirical material yielded several themes that allowed for the construction of the following core meanings: "Bonding as a source of social support", "Obstacles in bonding that interfere with the delivery of social support" and "Ways to overcome obstacles in bonding to deliver satisfying social support".

Bonding as a source of social support

The way work is organized in the hospital environment can reduce suffering from hospitalization or worsen it, depending on the health care team's focus of attention.

> *[...] you stop by a ward, chat a bit, because sometimes they (the mothers) need it, the mothers more than the children. It's about coming and saying hello, smiling. [...] Give a little bit of yourself to make them feel better (E10).*

> *Our job is really to listen. [...] some people don't like getting involved with the patients. I hug them, "do you need a hug?!" Sometimes a hug cures the anguish, the sorrow. Sometimes the patients need you to hold their hand, chat with them, and give them an injection of spirit. [...] Medicine is care, love (E1).*

In agreement with this finding, one study[8] affirms that a service that does not promote embracement and does not provide the necessary social support can cause suffering for the children/adolescents and their families, in addition to other difficulties in facing the disease, including the exacerbation of sadness and fear, a conflicted relationship between professionals and families and the feeling of being subordinate to health care services. Further, embracing families with responsibility and resolution in the hospital builds bonds and minimizes the implications generated by the disease, thereby helping the family see health care professionals as a source of support.

Due to the length of hospital stays and recurrent hospitalizations, professionals and the families of the children and adolescents with chronic disease have the opportunity to establish a relationship of closeness and to improve the families' adaptation to the situation. To take responsibility for delivering care to others in the daily routine, one needs to be open and willing to establish a bond with the family so that they can trust the professional. Dialogue based on attentive listening is an important tool for the multidisciplinary team.

> *When we manage to convince them that we are trying our best, it might not be within their expectations, but it is what can be offered [...] This gives the families some peace, and us as well (E6).*

We try to provide the most information possible, because what you really want to know is what your child has. And if everyone tries to explain your child's disease in their way, it is much more probable that they will feel more supported [...] (E3).

Communication only happens when I listen to you and you listen to me. It's the same with the mother, with the family, the person will feel more confident in the efficacy of treatment. If I still don't have the answer [...], I have to tell the family the measures that are being taken in the search of treatment for that child (E11).

Social support provided by the multidisciplinary team is an essential part of the work process in health care and requires qualified listening, bond establishment between families and professionals and greater access to offered services. One study[11] has evidenced that these tools allow the creation of an interactive context of experiences in which the unique perceptions and knowledge of each family can be expressed. These actions are based on accountability and resolution of the needs of the children/adolescents and their families[11].

Thus, the bond between the families and professionals is essential for the identification of support needs, and the team must work on establishing this bond from first contact. This is a gradual process and built through a closer relationship with the carer during hospitalization. When families feel embraced in this environment, they begin to trust the professionals and confide their fears, distresses and needs. In contrast, an integrative review of the literature[12] shows that establishing interpersonal relationships in a technical and formal way causes difficulty in communication and actions aimed at providing care.

Professionals who appear accessible and open for dialogue in their daily routine become the main source of support for the carer during the hospital stay, and the carer will always seek this professional when he/she needs information, advice and emotional support to cope with circumstances or to clear doubts. Empathy, sympathetic care and support provided by professionals point to their bond with the family and strengthen the recognition of the team as part of the support network:

[...] families and children establish bonds with the professionals and they trust us, believe in us, feel safe when they are cared for by the professional with whom they have a bond. That's why I think that this bond is a source of support. [...] These moments of dialogue, [...] bring us closer together, allow us to support them with whatever they need (E5).

One study[13] asserts that attentive listening, hearing the family carer's worries and a caring attitude from the professional builds a relationship of closeness and trust with the families, which favors bonding. Faced with this behavior, the family carer begins to feel truly safe and expresses his/her support needs and trust to the professional, which thus enhances the coverage of comprehensive care delivered to the child/adolescent and the family.

Dialogue brings the team and the families closer, thus strengthening the existing bond, as well as expanding care and the support provided by the professionals, since the more the family trusts the professional, the more open it will be to revealing care needs. Conversely, when the team-family relationship is focused on technical health care, bonds are superficial, limiting the possibility of establishing genuine care with satisfying support to the families.

A real bond (must be formed) with the family and the patient. Often, you don't have time to establish this bond, and the relationship becomes very superficial, too professional, and really does not represent the bond that is necessary for the patient to get better (E6).

However, a study[14] on the care and conceptions of the nursing team regarding companion families of hospitalized children shows that the length of hospital stay, even in a strange and unpleasant environment, favors the development of a bond with the children and their families that extends beyond technical care.

Furthermore, when a bond is established with the families, the health care team has a greater capacity to provide humanized and comprehensive care, transforming their work process to the perspective of co-accountability between the team and the family, in which the latter participates actively in the therapeutic project[15]. In this process, for the professional to be recognized as a source of social support, he/she needs to be aware of the family's unique needs to consider them from the perspective of care.

(It is important) to plan hospital discharge according to the socioeconomic status, and to prepare a diet plan to be followed at home (E14).

Thus, independently of their time working in pediatric care, the participants in the present study recognized the importance of listening, dialogue and bonding as ways of providing efficient social support for the families of children/adolescents with chronic disease. However, the actions of the multidisciplinary team do not always converge with the perspective of bonding that provides satisfying

support to the families of children and adolescents with chronic disease during their hospital stay. When this is the case, factors that hinder bond establishment are found that weaken the support provided to the families by the team.

Obstacles in bonding that interfere with social support delivery

Organizing the work process of the multidisciplinary team depends on the conceptions of the health care professionals regarding the meaning of teamwork and its relevance to achieve quality of care, with comprehensive attention paid to the needs of children/adolescents with chronic disease and the family carer.

In the daily routine of services, professionals identified difficulties that interfered with bonding with the families and thus delivering support. Among these, weak interaction, interdisciplinarity and communication among team members; work overload with a resulting reduction in available time to spend with the carer/child/adolescent; bureaucracy of health services; and the lack of privacy are aspects that weaken the dynamics of service and the quality of care:

> *Here, there is no multidisciplinary team. Here, there is a team with several professionals [...] A multidisciplinary team has several professionals, all speaking the same language. [...] During ward rounds, the whole team should participate. Then, if anything happened with the child, everybody would be up to speed (E2).*

> *I think that, in general, what is really lacking is this different perspective throughout the hospital to meet the needs more specifically. The team that stays here often has its hands tied, tries to solve (problems), but does not manage due to lack of time and hospital bureaucracy (E4).*

> *There is little communication within the team. And if there is no such communication within the team, there can be no multidisciplinary support. Support is isolated. Actions are isolated. [...] The ideal would be if everybody spoke the same language, to avoid confusion in the mothers' heads (E5).*

The absence of teamwork weakens the assistance to the patient/family pair and the work process. When there is no communication between team members, the bond with the family is weakened, thus compromising the delivery of social support. These findings are in agreement with a study that shows that weak delivery of social support leads to difficult situations for those who are receiving care, thereby negatively impacting their lives[1]. Another study with family members of children with special health needs also revealed the importance of support provided by the multidisciplinary team in health care delivery to this population, considering the implications that chronic diseases trigger in the lives of these patients and their families, especially with respect to rehabilitation and reduction of health-related complications[16].

In addition to impairing the delivery of support, weak communication within the hospital team also entails further physical and emotional distress for the young patient's carer during hospital stay:

> *This communication must improve and the professional must not feel inhibited or overrun when somebody asks, when somebody questions something. [...] Often, I am about to conduct an interview and I postpone it, because, on that day, the patient has already gone through several professionals (E11).*

Effective communication between team members favors a broader perspective of care and enables the identification of needs to be addressed by means of support. The well-being of the families in the hospital reduces their distress and that of the team, thus strengthening the relationship between the families and the professionals, as well as the quality of care.

Thus, the team needs to elaborate strategies to establish more effective dialogue between its members and with the families, because chronic disease demands a distinctive perspective that promotes continuous care and can identify and resolve changes triggered by the disease:

> *The chronic patient is a labor-intensive patient who needs to be seen not only as a repetition of treatments, but each day, the perspective must be directed not at the disease but at the patient (E6).*

In general, chronic disease requires a variety of procedures and consultations. This must not become an event in which care and support are delivered by means of overlapping actions of different team members, but, rather, all must work from the perspective of comprehensiveness[11]. Thus, the multidisciplinary team must plan and develop single and complementary actions to deliver support according to the needs of the families.

Furthermore, continuity and quality of the social support provided by professionals to the family carers become weaker when the team is not supported by the institution

to provide comprehensive care. This impediment characterizes the work process in health care by mechanized actions that merely technical, thereby hampering humanized actions and the delivery of social support to the families and children/adolescents during their hospital stay. When professionals do not understand their role in this process, sympathetic care is weakened and the families do not receive the support they need.

The lack of institutional support often hampers professionals' work, weakening the quality of the service and keeping the families from recognizing the team as a source of support during the hospital stay. Nonetheless, the lack of support to the families and professionals by the institution hampers continuity and quality of support, resulting in weak care and merely momentary support. From this perspective, the lack of privacy in wards, at times, causes embarrassment and limits the actions of the professionals.

> *You encounter difficulties with the issue of space itself. Sometimes you are seeing a patient [...] and it's difficult, because the space is too small. Sometimes the person [...] is inhibited from saying certain things, because the patient in the next bed can hear it [...] (E8).*

The hospital infrastructure must ensure comfort, privacy and safe recovery[17] to children/adolescents with chronic diseases. Often, the arrangement of furniture in the wards does not ease the work of the professionals but, rather, hampers the actions of comprehensive care, especially regarding the needs of the families and children/adolescents. A study[18] from England emphasizes the need to respect confidentiality and privacy of the children/adolescents and their families, since the relationships and interactions among children, parents and the team can be significantly affected by the type of organization of the hospital spaces.

Thus, means must be found to overcome the obstacles to establishing bonds that ensure the delivery of satisfying social support to the families during the hospitalization of children and adolescents with chronic disease.

Ways to overcome obstacles in bonding to deliver satisfying social support

Among the ways to overcome obstacles in bonding to deliver satisfying social support to the families, the participants of this survey emphasized follow-up after hospital discharge of the child/adolescent. For this, they stressed the formation of an outpatient team specialized in the treatment and follow-up of this population, in addition to the incentivization and sensitization of the families regarding the importance of continuity and completing treatment.

> *[...] my suggestion is that a team should be set up for chronic patients or somebody who was seeking to know how these patients are, if they are doing well, if they are following the treatment, if they are changing their dressings, if they are in physiotherapy [...] (E9).*

> *[...] when they are discharged from the hospital, we should explain [...] how important it is that they return to the outpatient unit, how important it is that they do not abandon treatment, and how important it is to make appointments [...] (E13).*

Follow-up of children/adolescents with chronic disease is crucial in disease management. Thus, a social support network must be available to the families, and it must have the ability to recognize and meet the health demands of and offer satisfying support to this population. In view of this, the bonds established with the families are of paramount importance, since one study[15] notes that supporting, educating, advising, providing emotional support and ensuring continuity of care to children/adolescents and their families is the pillar of comprehensive care of children/adolescents with chronic disease. This crucial nature implies including the families in the perspective of care so that they feel taken care of and can thus develop abilities to cope with the chronic disease, relying on a strong social support network.

As for intrahospital treatment, the health team noted actions that could bring the families and the team closer together, strengthening the bond for better delivery of support.

> *We could always be guiding, making meetings, [...] always be in conversation with the person, offering patient-comforting support, especially to the companions, because they are dedicating themselves to their children and their days are tiresome, always being there night and day with their children (E7).*

> *The issue of flyers, folders, manuals, booklets with information on the disease, trying to show special care. There could even be a protocol of how to proceed if the child needed some referral, a reference, [...] the issue of reference, counter-reference, of referral to a specialized service, of expressing the importance of this mother to be included in this service (E12).*

There is a lack of spiritual support for those people who are weakened, so they have some comfort, support and embracement from the spiritual side also (E6).

For the family to feel capable of assuming this care, it needs to be aware of the disease and treatment, preparing for the care that will be delivered at home. The multidisciplinary team must be part of the social support network of these families and must thus offer the support they need to improve their quality of life, improving the well-being of these people. To accomplish this, they must establish a bond and obtain the family's confidence in care delivery. In this sense, one study[19] shows that support offered by professionals is mutual and contributes positively to the health and well-being of the family.

On the other hand, the absence of these actions in the hospital environment hinders carers from coping with the implications entailed by the chronic condition, given that it interferes with family functioning. Thus, regardless of the phase of the child's/adolescent's chronic disease, the family has unique needs regarding care that cannot be ignored by the professionals. Only a strong bond between the team and the family can open up ways to offer the needed support. Accordingly, one study[20] evidences the relevance of family-centered actions and of parental interventions to aid the family in developing competence and abilities in care, which contributes to reduced parental stress and improved well-being.

Furthermore, the participants of the present study mentioned gaps in care delivery, especially regarding the lack of support back-up, in which professionals recognize the family's abilities in providing care and coping with the disease, and of spiritual support, to help families handle the unknown and feel supported in their needs. Thus, weaknesses are evidenced that could be avoided if the team worked closer to the family carer.

The team recognizes the weaknesses of the provided support. However, it envisions ways to overcome them, which need to be discussed by the professionals and managers so that they are implemented in daily work. Thus, the team will be strengthening the bonds with the families of children/adolescents with chronic disease during the hospital stay, and the family carer will feel supported to face the implications entailed by chronicity and reinforced for the daily battle of providing care to his/her child.

FINAL CONSIDERATIONS

The present work shows that the multidisciplinary team applies strategies such as bonding and embracement to offer social support to children/adolescents with chronic disease and their families. However, the delivery of satisfying support to the families remains deficient, since problems arise from how bonds are established and from the lacking infrastructure of the hospital and organization of the work process in the multidisciplinary team.

By contrast, dialogue and listening, which promote a bond between the team and the families, were evidenced as sources of support. However, regarding the practice of care, there are still important obstacles to bonding, such as the organization of the multidisciplinary team's work process; weak interaction and communication between team members; work overload; increased bureaucracy of health services; and lack of institutional support, which need to be overcome so that the team can deliver care that meets the needs of the families.

As for practice of care, the present study shows that social support and humanized and comprehensive care provided to the families of children/adolescents with chronic disease during the hospital stay depends on the bond established between the professionals and this population, especially regarding nurses, who remain on site at the hospital 24 hours a day. It is believed that providing care to a child/adolescent with chronic disease and the child's family implies moving them to the center of action around which all falls into place, because humanized and comprehensive care are an obligation of health care professionals and their primary duty, not merely optional. Health care services need to focus their management on care policies and practices that boost humanized health care and offer quality and efficiency. In this perspective, further research must assess the limitations and potential of the work process in a hospital pediatric unit to render the team a source of social support.

The limitations of the present study include the small number of participants in each category of the multidisciplinary team and the fact that only one hospital that sees children and adolescents with chronic disease was included.

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Received: 01.16.2018
Approved: 04.16.2018