



GROUP OF ADOLESCENTS HOSPITALIZED WITH NON-COMMUNICABLE CHRONIC DISEASE AS A TECHNOLOGY OF NURSING CARE

GRUPO DE ADOLESCENTES HOSPITALIZADOS COM DOENÇA CRÔNICA NÃO TRANSMISSÍVEL COMO TECNOLOGIA DE CUIDADO EM ENFERMAGEM

GRUPO DE ADOLESCENTES HOSPITALIZADOS CON ENFERMEDAD CRÓNICA NO TRASMISIBLE COMO TECNOLOGÍA DE CUIDADO DE ENFERMERÍA

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ABSTRACT

Objective: to create a group of adolescents hospitalized with chronic non-communicable disease (NCD) as a nursing care technology. **Methods:** a descriptive study with a qualitative approach, conducted in the pediatric ward of a public hospital. The data was produced by a script and a field diary for four group meetings with adolescents hospitalized in May 2014. Then, the data were analyzed using content analysis technique in the thematic mode. **Results:** the adolescents reported on the impact of hospitalization on their daily lives, which limits them to develop routine activities like going to school, seeing the family and friends and playing, and they cited the family support, development of recreational activities and the regular use of medication as the disease coping mechanisms. **Conclusion:** the group constituted a space for dialogue and health education. **Descriptors:** Hospitalized Adolescents; Chronic disease; Nursing; Self-Help Groups.

RESUMO

Objetivo: criar um grupo com adolescentes hospitalizados com doença crônica não transmissível (DCNT) como tecnologia de cuidado de enfermagem. **Método:** estudo descritivo e exploratório, com abordagem qualitativa, realizado na enfermaria pediátrica de um hospital público. Os dados foram produzidos por meio de um roteiro e diário de campo durante quatro encontros de grupo com adolescentes hospitalizados em maio de 2014. Em seguida, os dados foram analisados pela Técnica de Análise de conteúdo na modalidade temática. **Resultados:** os adolescentes relataram sobre o impacto da internação no seu cotidiano, que os limita a desenvolver atividades rotineiras como ir à escola, ver família e amigos e brincar, e como mecanismos de enfrentamento da doença citaram o apoio familiar, desenvolvimento de atividades lúdicas e o uso regular da medicação. **Conclusão:** o grupo constituiu-se um espaço para diálogo e educação em saúde. **Descritores:** Adolescente Hospitalizado; Doença Crônica; Enfermagem; Grupos de Autoajuda.

RESUMEN

Objetivo: crear un grupo con adolescentes hospitalizados con enfermedad crónica no trasmisible (DCNT) como tecnología de cuidado de enfermería. **Método:** estudio descriptivo y exploratorio, con enfoque cualitativo, realizado en la enfermería pediátrica de un hospital público. Los datos fueron producidos por medio de una guía y diario de campo durante cuatro encuentros de grupo con adolescentes hospitalizados en mayo de 2014. En seguida, los datos fueron analizados por la Técnica de Análisis de contenido en la modalidad temática. **Resultados:** los adolescentes relataron sobre el impacto de la internación en su cotidiano, que los limita a desarrollar actividades de rutina como ir a la escuela, ver a la familia y amigos y jugar, y como mecanismos de enfrentamiento de la enfermedad citaron el apoyo familiar, desarrollo de actividades lúdicas y el uso regular de la medicación. **Conclusión:** el grupo es un espacio para diálogo y educación en salud. **Descriptores:** Adolescente Hospitalizado; Enfermedad Crónica; Enfermería; Grupos de Autoayuda.

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INTRODUCTION

Adolescents are an important part of the population. The demographic importance of this group and their vulnerability to health disorders, as well as economic and social issues in its educational aspects, labor, justice, sports and leisure, determine the need for more accurate and comprehensive attention.¹

In Brazil, the demographic profile is changing, but the adolescent population still plays a significant role in the country's constitution, justifying the need for studies on their follow-up. According to the 2010 Population Census in Brazil, there are approximately 21 million adolescents.²

Adolescence is an important time for adoption of good practices and the establishment of autonomy but also exposure to behavioral risk factors with effects on health in the short and long term. It may comprise a period of contradictions, turbulence, as there are noticeable physical, emotional, intellectual and social changes.³ There is a search for their identity, dreams with independence, mood swings and adolescents tend to be oppositional and give great importance to physical appearance. The adolescents experience with anxiety these changes happening in their body. Therefore, it is an experience phase of new behaviors and new ways of living that may be risk factors for health whose early exposure is associated with the development of most chronic non-communicable diseases (NCDs).^{4,5}

Chronic illness can be defined as a long-lasting condition that interferes with the individual functions in their daily activities for more than three months in a period of one year or which leads to hospitalization for more than one month.⁶ Its occurrence in adolescence implies in living with changes and effects caused by the disease, hospitalization, and treatment, besides issues about age, contextualized mainly through a phase of change.⁷

The adolescent with chronic disease may have great difficulty in dealing with this condition, because of the context of the disease in general, such as pain, hospitalizations, medications, and changes in daily life.⁵ In the case of NCDs, they may require long or for life treatments, which may require painful procedures, changes in diet and preventing the development of daily life activities. In this context, nursing care to adolescents should involve the family and its support in a full logic, seeking comfort

strategies, health education and minimizing the stress related to hospitalization.

In Brazil, it is estimated that 10-20% of all children and adolescents are people with some NCD⁸, asthma and diabetes mellitus type II being the most prevalent.⁹ These data confirm the importance of studies that focus on this population, since knowing the health status of adolescents is essential to the development of health promotion policies and prevention of chronic diseases that are efficient and sustainable.^{9:1879}

Faced with the above, the objective of this study is related to the impact of hospitalization on adolescents with NCD and the goal of creating a group of adolescents hospitalized with chronic non-communicable disease (NCD) as a nursing care technology.

METHOD

It is a descriptive study of a qualitative approach, performed in the pediatric ward of the University Hospital Antônio Pedro (HUAP), located in Niterói/RJ, with eight teenagers hospitalized aged between 12 and 16 years old since it is the age limit for admission to that infirmary of both sexes and various NCDs, who had experienced at least one previous hospitalization and experience of the hospitalization process. There was not a prior choice of a specific type of disease as inclusion criteria, aimed to understand meanings constructed by teenagers in the experience of one NCD, regardless of the type. The exclusion criteria were teenagers unaccompanied by a caregiver, who did not have verbal communication skills or bedridden.

The study was aimed at the creation of a group to listen to hospitalized adolescents as a health education strategy and to enhance the knowledge and experiences of the participants, involving them in the discussion, identifying and finding solutions to problems emerging from their everyday lives.¹⁰ Data collection was performed at the time of realization of the groups in four meetings in May 2014 through a questionnaire previously developed with six guiding questions related to the theme and objectives of the research, emphasizing as a chronic disease, in the vulnerable phase that the adolescence is, which modifies the adolescent's daily life, and notes were held in a field diary. Each meeting lasted an average of 35 minutes.

For the execution of the group, a team of one observer was created, who was responsible for taking notes in the field diary, also ensuring the registration of non-verbal

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information; a group coordinator, who led the group dynamics; and the main researcher of this study, who recorded meetings through digital audio equipment. The groups were formed by two teenagers each.

The data were analyzed by thematic content analysis whose operation involved three phases: (1) pre-analysis, consisted of the full transcript of the speech, organization, comprehensive and exhaustive reading of the material to be analyzed; (2) exploration of the material, allowing the fragmentation of content, looking for distributing excerpts and important phrases and highlight of the reporting units; at this stage, the texts found by themes were grouped; and (3) treatment of the results, with the interpretation of the findings.

The analysis generated two categories: hospital Impact on the routine of the adolescent with chronic disease and coping mechanisms of the disease and hospitalization.

The research followed the assumptions and the requirements of Resolution CNS/MS 466/2012, being referred to the Ethics and Research Committee (CEP) institutionalized, with the Term of Informed Consent (TCLE) and Consent Agreement, informing all the intentions of the subjects involved and only started after the approval of the CEP of the HUAP with CAAE number 2330.65132.0000.5245; CEP 611,195, May 10 2014.

RESULTS

There were eight teenagers participating in the groups, four female and four male, aged 12 and 16, who have experienced the hospitalization at least twice. The average length of their hospitalization ranged from 30 to 40 days as a result of the following conditions: myasthenia gravis, sickle cell anemia, autoimmune hepatitis and pleural tuberculosis, systemic lupus erythematosus, recurrent pneumonia and asthma, diabetes mellitus (DM) and hypertension (HAS). The diseases that most often led to hospitalization were teenagers with DM, sickle cell anemia, and lupus.

It was observed that at the beginning of group dynamics, the teenagers were shy, just looked at each other embarrassed, perhaps for the recorder's presence; but in the course of the conversations, they were participating, talking and interacting.

♦ Hospital impact on the routine of the adolescent with chronic disease

Having a chronic illness and being hospitalized for more than once and for extended periods will affect and transform the daily lives of young people. The number of hospitalizations may make them more fragile. It is imperative that teenagers know their diagnoses and participate in treatment, identifying signs and symptoms to cope better with the disease, as expressed in the words:

*My health problem is sickle cell anemia [...].
I know my illness [...] very strong pneumonia [...].
I know [...] since I was twice hospitalized [...].
I know I have asthma and pneumonia.
I have high blood pressure.*

As shown in the following speeches, being hospitalized is not easy and also interferes with everyday teenagers lives being far from their families, friends, many times without doing routine tasks, playing sports, with limitations in the diet imposed by the disease.

*[...] I cannot go to school [...] I will be late.
I cannot see my family; I cannot go to school [...].
I'm away from my family and my friends [...].
I cannot go to school, play ball and eat junk food [...].
Staying out to see people, it is boring, not everyone can come here; I do not see my parents.
For me it is bad to be without seeing relatives, away from people, without playing, I could be at home.*

In the speeches, teenagers translate unpleasant experiences, but the ability of the teenager to see the future is going to turn this hospital into something he can take good meanings, as in interacting with other teenagers, staff that cares and watches and his family:

*It is bad, but I have to face these things.
It is too bad; I know that I have to live with it.
It is good and bad; the good thing is that I'm being taken care, and the bad thing is that there're much stuff I cannot do, as staying in the sun.
It is too bad, I'm dehydrated, they do not find the vein, every hour there is an exam, you have to stick your finger.
It is very annoying [...] being unable to do anything [...] the time never goes.*

Dietary restrictions as interference in the routine were also identified, the diet can be an added burden; restrictions and new dietary recommendations are one of the most difficult parts of treatment:

*[...] I cannot eat junk food.
[...] I cannot eat what I want [...].
[...] Mainly food, schedules, I have to have a more orderly life.*

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There are several things I'll have to cut now because of the disease.

◆ **Coping mechanisms of the illness and hospitalization**

To cope with the disease, the adolescents take strategies that can help them reduce the stress caused by new routines that are imposed, the symptoms and the hospitalization experience.

*I get distracted playing [...].
I think of good things [...].
Do paintings on fabric, crafts [...].*

In these teenagers' reports, it is clear that the used strategies seek to maintain the individual's well-being through mechanisms that reduce the stressful effect of the disease as in games that can be fun activities, listen to music, and chat with other teenagers and thinking positively; as well as the importance of adherence to the correct use of medications. In discussions group, some of them cited the medication correctly and regularly as a way to reduce risks and hospitalization, and the medicine associated with healing.

Take the right medicines.

One of the coping strategies mentioned in the reports of adolescents is to search support in the family and other hospitalized patients. Being able to rely on someone else strengthens the emotional balance.

*[...] I use my mother who is very fond of me.
[...] to make friends.
I talk to the girl by my side.*

DISCUSSION

The experience of a chronic disease becomes relevant because it will interfere with the routine of teenagers; their lifestyle will change, and the restrictions that will be imposed will prevent them from performing basic activities. The teenager will be forced to rearrange his life within the new possibilities. The disease and treatment will interfere with school performance and follow of the school year.¹¹

Furthermore, most of the chronic diseases imposes new eating habits and diets, which will hinder the return to school, social life; they want to eat what they like, being necessary a discipline and persistence, since diets may get them out of celebrations and parties.

A study conducted in Florianópolis with eleven adolescents with diagnoses of chronic disease pointed out that they have difficulties in everyday school life due to the care required for the disease, treatment, and limitations. Many times, repetitive

hospitalizations and even symptoms hinder to follow the school year.⁷

This same study also highlights the changes in food required when living with chronic illness, generating stress and imposing difficulties in routine life. Although they know their disease and the importance of diet compatible with the disease, many of them feel embarrassed to colleagues for feeding in different ways, which ultimately interfere with adherence to care required by health condition.⁷

In this context, one of the hardest adjustments may be the new goals that will have to be adopted by teenagers for their continued care, as with prolonged survival, young people with NCDs need to deal with new decisions and problems.¹² In this perspective, the adolescent ends up using coping strategies.

The coping is understood as a dynamic process by which the individual work relationship issues in a given context, being assessed on stress causes and the excitement it generates. It can also be defined as a set of strategies used by people to adapt to adverse conditions. This set of efforts (cognitive and behavioral) is used to deal with specific situations, such as in the case of an NCD, these efforts will vary from person to person according to past experiences.¹³

Coping strategies are related to the development process of the adolescent phase (developmental) and the individual's illness. The concept of coping seems to have today an important definition to think about coping with stress.¹⁴ They are considered mechanisms in an adaptive sense, when there is a situation of stress that exceeds the capabilities of the individual, bringing overload and threatening their well-being. Technically it can be divided between centered in the problem and centered on the emotion. When focused on the problem, they will act on the stress factor, and when centered on emotion they will suit the emotional response to the stressor event; the coping would then be a mechanism to control the stressor. The teenager will choose a specific strategy to address NCD, assisting in the search for a positive adjustment before the hospitalization.¹⁵

Coping mechanisms cited by adolescents in this study were not only activities which aim to reduce the stress caused by hospitalization and illness, like games, conversations with other hospitalized adolescents and watch television, but also the behaviors to reduce the incidence of new admissions, self-care taking medications and adhering to the diet.

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When teenagers face the new situation as a problem to be solved and an opportunity to learn, they become less vulnerable.¹² The way of coping will interfere with adolescent development, engagement with treatment, good habits and practices as a chronic process before the adolescent starts to become familiar with new routines, procedures, and medications.

Adherence refers to how well the patient's behavior reflects the acceptance and compliance with the treatment regimen to be submitted (medications, diet, changes in lifestyle). Strategies to improve adherence consist of interventions that include not only the teenager but the staff and the family.¹²

The adherence process to the treatment also involves an agreement between the professional and the patient about the best way of conducting their treatment regimen. As main factors related to adherence, there are the knowledge, insight and personal motivation for the pursuit of better health, obtaining and control of symptoms and change in lifestyle.¹⁶

It is important to note that adherence is very involved with the partnership together with the teenager's caregiver, so the link with the professional must be well structured. The professionals who care for adolescents should be well prepared and always seeking knowledge for informed action practices in full.¹⁷

It is very important that adolescents know their disease, as better knowing their diagnosis, the greater the likelihood of being active, achieve autonomy and also incorporate the idea of living with the disease. The information provided by staff and family will substantiate the concepts of the disease process. It is essential to create possibilities for their health education that will translate into quality of life.¹⁸

Health education is an intervention that promotes adaptation; teenagers need information about their condition and treatment plan. The information should be given gradually and, if necessary, described and repeated as often as situation demands.¹²

It is also important to give the opportunity to teenagers to find a better way to accomplish their treatment. In this sense, the therapeutic groups can play an important role, not only listening but recognition by other young people facing similar situations. Also, the group may be an important area for the development of strategies for the prevention and/or disease control. The health education fosters alienation,

transformation, and emancipation of the individuals involved.^{12:23}

It is noteworthy that the insertion of the family in this process is extremely important, especially because many teenagers turn to their support network, represented especially by parents and caregivers, to face the difficulties printed by health condition. Social interaction and leisure time with those we like bring health benefits and sense of well-being. The family is always seen as one that protects and helps.¹⁸

CONCLUSION

Nursing as part of a multidisciplinary team and the nurse as leader of a team are intended to encourage and stimulate always comprehensive care, which goes beyond the technical part, but cares the teenagers in their complexity.

The interaction between nurse and adolescents have to be based on trust, security, respect and dialogue. The professional must always act in a clear and objective way, give information and not impositions; listen to the teenager is crucial to be then able to take care of him and not let previous judgments interfere with the assistance.

On chronic disease, it may interfere with the adolescent relationship and in their social life by modifying their daily lives and requiring constant adjustment, but it will not stop being young with all the implications of this age group. Therefore, the professional, as well as touching on matters related to the disease, should also develop skills to deal with the theme of adolescence. To this end, the establishment of group dynamics can be effective in promoting therapeutic listening and, from this, there may be care strategies that go beyond the technique and thinking on the subject in a comprehensive and multidimensional way; listening shows the actual demand and imposes the challenge of going beyond what is presented, listen to the unspoken.

In this study, the group generated proximity between adolescents with chronic health problems, creating the opportunity of going out of bed and go to another room to talk. It proved to be a dialogic space, with the possibility of developing various activities that can help the teenagers to face sickness and hospitalization phase in a less stressful way.

With this study, it is expected to contribute to a broader discussion of what a hospital at that stage can lead as it is a vulnerable period of transition, and there is also a greater

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understanding of the multidisciplinary team of that reality. The team knows and understands the adolescent phase of reality offering a care to promote their well-being, facilitating and helping to develop skills and competencies that will enable them to face the disease, influencing the recovery positively.

REFERENCES

1. Ministério da Saúde (BR). Programa Saúde do Adolescente - PROSAD. 2nd ed. Brasília: Ministério da Saúde; 1996.
2. Instituto Brasileiro de Geografia e Estatística. Síntese de indicadores sociais: uma análise das condições de vida da população brasileira 2010. Estudos e pesquisas - informação demográfica e socioeconômica, n. 27. Rio de Janeiro: IBGE; 2010.
3. Gômez AM. Sou adolescente... Entenda-me! São Paulo: Paulinas; 2011.
4. Malta DC, Andreazzi MAR, OliveiraCampos M, Andrade SSCA, Sá NNB, Moura L, et al. Trend of the risk and protective factors of chronic diseases in adolescents, National Adolescent School-based Health Survey (PeNSE 2009 e 2012). Rev bras epidemiol [Internet]. 2014 [cited 2015 Mar 31];17(supl1):77-91. Available from: http://www.scielo.br/pdf/rbepid/v17s1/pt_1415-790X-rbepid-17-s1-00077.pdf doi: 10.1590/1809-4503201400050007
5. Costa JS, Santos MLSC. O enfermeiro na equipe multidisciplinar no cuidado ao adolescente hospitalizado: relato de experiência. Rev enferm UFPE on line [Internet]. 2015 [cited 2015 Oct 15];9(supl6):8725-30. Available from: http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/view/8001/pdf_8269 doi: 10.5205/reuol.7061-61015-5-SM0906supl201513
6. Silva EC, Lima CLJ, Batista JM, Silva KL, Costa MML. Nursing care of the child with a chronic disease: experience report. J Nurs UFPE online [Internet]. 2014 [cited 2015 Mar 31];8(2):464-70. Available from: <http://www.revista.ufpe.br/revistaenfermagem/index.php/revista/article/viewArticle/5784> doi: 10.5205/reuol.4688-38583-1-RV.0802201429.
7. Schneider KKL, Martini JG. Cotidiano do adolescente com doença crônica. Texto Contexto Enferm [Internet]. 2011 [cited 2015 Oct 15];20(Esp):194-204. Available from: <http://www.scielo.br/pdf/tce/v20nspe/v20nspea25.pdf>
8. Saito MI, Silva LEV, Leal MM. Adolescência: prevenção e risco. 2nd ed. São Paulo: Ateneu; 2008.
9. Braz M, Barros Filho AA, Barros MBA. Saúde dos adolescentes: um estudo de base populacional em Campinas, São Paulo, Brasil. Cad Saúde Pública [Internet]. 2013 [cited 2015 Oct 15];29(9):1877-88. Available from: <http://www.scielo.br/pdf/csp/v29n9/a26v29n9.pdf>
10. Ministério da Saúde (BR). Projeto Acolher. Um encontro da enfermagem com o adolescente brasileiro. Brasília: Ministério da Saúde; 2000.
11. Moraes EO, Enumo SRF. Estratégias de enfrentamento da hospitalização em crianças avaliadas por instrumento informatizado. Psico-USF [Internet]. 2008 [cited 2015 Oct 15];13(2):221-31. Available from: http://www.scielo.br/scielo.php?pid=S1413-82712008000200009&script=sci_arttext doi: <http://dx.doi.org/10.1590/S1413-82712008000200009>
12. Hockenberry MJ, Wilson D. Fundamentos de Enfermagem Pediátrica. 8th ed. Rio de Janeiro: Elsevier; 2011.
13. Leal DT, Fialho FA, Dias IMAV, Nascimento L, Arruda WC. Diabetes na infância e adolescência: o enfrentamento da doença no cotidiano da família. HU Revista [Internet]. 2009 Oct/Dec [cited 2015 Oct 15];35(4):288-95. Available from: <http://hurevista.ufjf.emnuvens.com.br/hurevista/article/viewFile/831/285>.
14. Iamim SRS, Zagonel IPS. Estratégias de Enfrentamento (coping) do adolescente com câncer. Psicologia Argum [Internet]. 2011 Oct/Dec [cited 2015 Oct 15]; 29(67):427-435. Available from: <http://www2.pucpr.br/reol/index.php/PA/pdf/?dd1=5788>.
15. Coletto M, Câmara S. Estratégias de coping e percepção da doença em pais de crianças com doença crônica: o contexto do cuidador. Diversitas perspectiv psicol [Internet]. 2009 [cited 2015 Oct 15];5(1):97-110. Available from: <http://www.redalyc.org/articulo.oa?id=67916259009>.
16. Ulbrich EM, Maferm MA, Labronice LM, Mantovani MF. Atividades educativas para portadores de DC: Subsídios para enfermagem. Rev gaúch enferm [Internet]. 2012 June [cited 2015 Oct 15];33(2):22-7. Available from: <http://www.scielo.br/pdf/rgenf/v33n2/05.pdf>
17. Cardim MG, Norte MS, Moreira MCN. Adesão de crianças e adolescentes à terapia antirretroviral: estratégias para o cuidado. Rev pesqui cuid fundam online [Internet]. 2013 Dec [cited 2015 Oct 15];5(n. esp.):82-94.

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Available from:
<http://bvsalud.org/portal/resource/pt/bde-25341>.

18. Araújo JB, Collet N, Gomes JP, Amador DD. Saberes e Experiências de Adolescentes Hospitalizados com Doenças Crônicas. Rev. enferm. UERJ [Internet]. 2011 Apr/June [cited 2015 Oct 15];19(2):274-9. Available from: <http://www.facenf.uerj.br/v19n2/v19n2a17.pdf>.

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