

Continued care for families of children with chronic diseases: perceptions of Family Health Program teams

ACOMPANHAMENTO DE FAMÍLIAS DE CRIANÇAS COM DOENÇA CRÔNICA: PERCEPÇÃO DA EQUIPE DE SAÚDE DA FAMÍLIA

SEGUIMIENTO DE LAS FAMILIAS DE NIÑOS CON ENFERMEDADES CRÓNICAS: LA PERCEPCIÓN DEL EQUIPO DE SALUD DE LA FAMILIA

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ABSTRACT

The objective of this study is to characterize how the Family Health Strategy teams in Brazil perceive their role to provide continued care to families of children with chronic diseases. This was a qualitative study that used symbolic interactionism as its theoretical framework, with content analysis for thematic categorical analysis. Focus groups with three Family Health Strategy teams were used for data collection, with a total of 32 study participants. The results were organized into three thematic categories: 1) *singularities of families that live with children with chronic diseases*; 2) *team, family and Family Health Strategy*; and 3) *limitations of care*. The teams' perception is that the design of the Family Health Strategy encourages access to the family experience, allowing the recognition of its specificities. Further, the data reveal team limitations regarding their capacity to provide care, and the need for investments in articulation with different social services, sectors, and equipment.

DESCRIPTORES

Family
Child
Chronic disease
Family Health Program
Pediatric nursing

RESUMO

Este estudo objetivou caracterizar como a equipe da Estratégia Saúde da Família percebe sua dinâmica de acompanhamento de famílias que convivem com a doença crônica da criança. Trata-se de uma pesquisa qualitativa que teve como referencial teórico o Interacionismo Simbólico e como método a Análise de Conteúdo, técnica de análise categorial temática. Para a coleta de dados utilizou-se o grupo focal, que foi desenvolvido com três equipes de Saúde da Família, totalizando 32 sujeitos. Os resultados foram organizados em três categorias temáticas: *Peculiaridades das famílias que convivem com a doença crônica da criança*; *Equipe, família e Estratégia Saúde da Família* e *Limitações para cuidar*. A percepção da equipe é que o desenho da Estratégia Saúde da Família favorece o acesso à experiência familiar, permitindo o reconhecimento de suas especificidades. Os dados revelam ainda as limitações da equipe em sua capacidade de resolução e a necessidade de investimentos na articulação entre os distintos serviços, setores e equipamentos sociais.

DESCRIPTORES

Família
Criança
Doença crônica
Programa Saúde da Família
Enfermagem pediátrica

RESUMEN

Este estudio tuvo como objetivo caracterizar la forma en la cual el equipo de la Estrategia Salud de la Familia percibe su dinámica de seguimiento de las familias que conviven con la enfermedad crónica del niño. Se trata de una investigación cualitativa cuyo referencial teórico fue el Interaccionismo Simbólico y el método fue el Análisis de Contenido. Para la recolección de los datos se utilizó la técnica de Grupo Focal que se desarrolló con tres Equipos de Salud de la Familia, con un total de 32 sujetos. Los resultados fueron organizados en tres categorías temáticas: *Peculiaridades de las familias que conviven con la enfermedad crónica del niño*; *Equipo, Familia y Estrategia Salud de la Familia* y *Limitaciones para cuidar*. La percepción del Equipo es que el diseño de la Estrategia Salud de la Familia facilita el acceso a la experiencia familiar, lo que permite el reconocimiento de sus especificidades. También revela las limitaciones del Equipo en su capacidad de resolución y apunta para la necesidad de inversiones en la mediación entre los diversos servicios, sectores y equipamientos sociales.

DESCRIPTORES

Familia
Niño
Enfermedad crónica
Programa de Salud Familiar
Enfermería pediátrica

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INTRODUCTION

According to the World Health Organization (WHO)⁽¹⁾, chronic conditions are responsible for 60% of all onus resulting from diseases worldwide, and by 2020, chronic conditions will be the etiological factor for about 80% of diseases in developing countries. Further, chronic conditions primarily emerge at the primary health care level, and their treatment should be prioritized in this ambit⁽¹⁾.

The policy of strengthening primary health care in the Brazilian Unified Health System (SUS, as per its acronym in Portuguese) is the Family Health Strategy (FHS), which has the directives of territorialization and accountability for population groups, team work, bond between team and SUS users, attention to health care needs and comprehensive care⁽²⁾.

In this scope, it is worth questioning how much the care developed by teams has in fact included the family, as well as what concepts of family, family health and intra- and extrafamily interaction are adopted in the care process⁽³⁾.

Family-centered care is an approach to care that can be adopted in the health care process, as it recognizes the partnership between health care professionals, patients and families, and emphasizes the center role of the family in health care⁽⁴⁾, which implies including them in decisions and in the care of its members, considering their real needs.

Living with a child's chronic disease generates specific demands related to care, such as reliance on continuous care, dietary needs, drug treatment, and constant concern about the child's clinical state, which imposes needs on the family⁽⁵⁾ that can and should be assumed by the SUS to alleviate the burden and suffering of the family⁽⁶⁾.

In order to better understand the scenario of care described above, this study sought to characterize the experience of FHS teams in their care dynamics towards families of children with chronic diseases. The study was based on the question, *how do FHS teams perceive the care offered to families of children with chronic diseases?*

This investigation and reflection on the scope and limits of the FHS will contribute to solve the new challenges faced by the SUS, primarily the establishment of a comprehensive health care system, and the various possibilities that could arise from the relationships between health care teams and families⁽⁷⁾.

METHOD

This was a qualitative study focused on the interactions in health care. Symbolic interactionism (SI) was used as the theoretical framework, which considers that the human

experience is mediated by a process of interpretation that results in human behavior⁽⁸⁾, which is correlated to meanings that emerge and are transformed in social interaction through interactive processes.

Focus groups were used for data collection, as these use interaction to generate data, and make intentional use of group interaction⁽⁹⁾. This aspect empowered the expression of team care, instead of care offered by individual professional health workers.

One focus group with FHS teams was conducted, based on the following request: *Think about the care you provide to a family living with a child with a chronic disease, and tell us about it.*

As the teams described the care, questions were formulated in order to better understand the dimensions of the phenomenon studied, in regard to concepts, beliefs, strategies used by the teams, bonds, partnerships, support resources, difficulties, concerns and other elements that constitute the teams' experiences providing care.

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The study participants belonged to three FHS teams from the same health care region in one municipality in the interior of São Paulo state. On the date the focus group took place, the average insertion time of the teams in their territories as a Family Health Unit (FHU) was eight years.

Thirty-two health care professionals participated in the study. Inclusion criteria for these participants included: being a team member of the FHU chosen for the study, or being a resident of the Multiprofessional Internship Program (MIP) of the municipality, and being inserted into the units studied. Another inclusion criterion was that the team needed to have experience in the care of at least one family of a child with a chronic disease.

All of the recommendations in resolution CNS/MS no. 196/96 of the National Health Council were observed, and the study proposal was approved by the Human Research Ethics Committee of the Federal University of São Carlos (UFSCar) under protocol No. 500/2009.

Data were collected between April and July of 2010. All of the focus group sessions were audio recorded and completely transcribed immediately. The resulting material was analyzed using the analytical processes recommended as per the content analysis method⁽¹⁰⁾, specifically the technique of thematic content analysis. The following operational stages were followed: preanalysis, with reading flowing from the empirical material; formulation and reformulation of hypotheses; exploration of the material, when it was codified and classified into categories; analysis of the results obtained, and their interpretation through a critical and reflective process.

RESULTS

Data analysis allowed to approach the experience of the Family Health Team in the care of families that live with children with chronic diseases. Table 1 presents information on the study participants and their roles in the respective teams, identified as 1, 2 and 3. All of the professional categories of the basic team recommended by the Brazilian Ministry of Health are present⁽²⁾.

Table 1 – Information on participants in the study, Continued care for families of children with chronic diseases: perceptions of Family Health Strategy teams – São Carlos, São Paulo, Brazil, 2010.

Professional Title	Focus Group Team 1	Focus Group Team 2	Focus Group Team 3	Total
Community Health Agent	5	6	3	14
Nurse	1	1	1	3
Nurse Technician	2	2	1	5
Dentist	1	1	1	3
Dental Office Assistant	1	1	–	2
Physician	1	1	–	2
MIP intern	1	–	2	3
Total	12	12	8	32

Three categories emerged from the analysis of the material: 1) singularities of families of children with chronic diseases; 2) team, family and Family Health Strategy; and 3) limitations of care.

Singularities of families of children with chronic diseases

According to the teams, the perception of the family dynamics is only possible due to the relationships with the families, enabled by the FHS. The dynamics of continuous care allows the team to identify a singular and differentiated organization in the families of children with chronic diseases, which is oriented towards responding to the health care needs of the child. Furthermore, these families are constantly challenged to adapt to the progression of the chronic disease.

...in my [home] visits, one thing I observe...is that there is a totally different routine, a very different organization...all focused on the child needs. They organize themselves to meet the needs [of the child]... (Team 1).

In order to remain responsive in this process, the families seek knowledge regarding: the illness of the child, its organic and physical repercussions, the ideal treatment versus that available to the child, the necessary resources and those obtained from the SUS.

...and the family has adaptations within the home...it organizes, does things in a different way, the needs of the child's disease come first, then the rest, only that this doesn't last for days; it is part of their lives ... (Team 2).

Team, family and the Family Health Strategy

This thematic category addresses the team's perception that the design of the FHS encourages access, knowledge and intervention focused on the family. In the FHS there is space to approach the realities of each family in the territory of the team, which allows it to identify the family's needs, and to intentionally practice equity. Approach is facilitated by the home visit, team meeting, inclusion and work by the community health agent, all of which are elements in the FHS work process.

The home visit allows for closer continued care with each family in our territory, primarily with the agents, who do most of the visits. We enter the home, and from there we have other perspectives that we wouldn't have from the office. So, the perspective that we have from the inside is very different than what the physician has in the office in any other [health care] service...and then later we discuss the situation in a meeting here at the unit. (Team 1).

In the dynamics of continued care of families with chronically ill children, the relationships established with the families are seen as the central element of this care, which is sustained by the bond established between team and family.

The fact that the family has chosen you to be the one who listens to what it has to say is emotional...it is recognition of your potential to help, even with the limits we have. For me, this is a strong sign of the bond... (Team 1).

The teams' capacity to listen to the family is an important tool to access the family's experience, needs and demands related to the chronic disease of the child. By interacting with family members in the space of listening, the teams reframe this moment as care offered, since it identifies the need of the family by listening to its experience.

In the interaction mediated by listening, the teams consider sincerity with the family to be an important element of care and maintenance of the bond.

...when you see what the family is doing, when you see the effort, the suffering...you need to praise them, and this is care too! But it can't be fake; it has to be genuine, when it's deserved, because the family knows when it's genuine and when it's not... (Team 3).

The teams point to the importance of the involvement of other state services in the care of the family, such as education, social services and transportation, since the health of the family entails other elements in addition to health care.

...we perceived that it is not just us from the SUS who have to support a child with a chronic disease. We

need the Department of Education, Social Services, all of it. We often get stuck on some issues, for example, transportation. So we make headway, have big discussions, plans and those things, and when it comes time to make it operational, we often come across these issues, (Team 2).

Access to specialized care by families of children with chronic diseases is often permeated with difficulties that are negatively reflected in the dynamics of care offered by the health care professionals of the FHS team.

Limitations of care

Participants in this study expressed feelings of restriction and impotence when they are not able to effectively provide the continued care that the chronically ill child receives at other scopes of the SUS. This is related to the gaps in the referral and counter-referral system of the FHS and the SUS as a whole, which are insufficient to the families' realities, with little articulation between the FHS and the social support network, which, in the opinion of the professional members of the FHS teams, is fundamental for the care of families of children with chronic diseases. The teams expressed this inefficiency, repeatedly citing the hindrances existing in the communication with other distinct levels of health care services.

In this movement of the need for the SUS to complement its care and meet the needs of the family, the team identifies barriers in access to services. These barriers affect the FHS teams, which need more resources to care for children who are chronically ill, resulting in their inability to advance in the care plans established.

...we don't have enough resources for everything, and I needed the help of my pediatrician colleague. One pediatrician did not give me a satisfactory response, and I insisted to the mother, saying, 'Look, I think you need treatment, an investigation.' So we went to another pediatrician, who also did not provide a satisfactory response. So how do you provide care? (Team 2).

As I see it, it's not just this team that has its hands tied. If you begin to ask, you will see. (Team 1).

The feeling of impotence in the face of families' experiences is also permeated with frustration and discouragement when teams are not successful in their interventions with families, or when they are unable to put into practice the care that was planned due to restrictions from management and the organization of the SUS.

...sometimes it is demotivating. Sometimes I feel really demotivated by the situation, you know? So it is difficult to maintain motivation with such deadlock, you know? Sometimes we make an effort, I don't know how... Sometimes it is really demotivating..., (Team 3).

In response to the restrictions they experience, the teams seek to overcome the obstacles that the SUS structure imposes, seeking to transcend the limits to meet the needs

of the families of chronically-ill children, a result of the bond that the FHS promotes.

...we try to create mechanisms to go around the system, to see who we can contact and who will speak with us, help us solve...go beyond, you know? (Team 2).

DISCUSSION

Having a child with a chronic disease produces psychological and social repercussions on the family and its functioning. Thus, health care professionals need to understand how families are affected in different ways⁽¹¹⁻¹²⁾, because the complexity of each family's needs must be considered when planning care⁽¹³⁾.

The FHS professionals showed sensitivity in recognizing the needs of the family, because they report the perception of changes to the family functioning in face of requirements resulting from the child's illness. They demonstrate concern and make efforts to seek the resources that the family needs, aiming to support it in its care trajectory. This points to the capacity of these professionals to give a new role to the family as the subject of their care. However, they did not show practices sustained by theoretical knowledge of the family systems, functioning and dynamics, which confirms the findings of other studies⁽¹⁴⁻¹⁵⁾.

The finding above verifies that *the intimacy of the health team with the family thematic is insufficient*⁽¹⁴⁾, which shows the need to incorporate skills and knowledge of family concepts, dynamics and family-centered care, so that the team exercises a more conscientious and intentional practice in their care of families⁽¹⁵⁾.

The impact of the demands on the family is perceived by the teams during the course of care in distinct interactions. The professionals recognize that in order to care for the families in these conditions, it is necessary to know the family and its singularities, ways of confronting what it adopts, the difficulties experienced by the family as well as its potentials. These elements, cited by the teams as necessary to care for families of children with chronic diseases, already integrate the recommendations of a family-centered approach⁽⁴⁾.

The FHS teams demonstrate incorporation of principles into their practice that may result in support and strengthening of the families. This level is reached through proximity of the relationship established with the family⁽¹⁵⁾, which is a differential for comprehending its experience. The design of the FHS works to promote such relationships and processes of resignification.

The bond, home visits and long-term continuity of care of the families are highlighted as resources that determine a differentiated space of interaction, instigate affectivity, and the establishment of bond between the FHS professionals and families⁽¹⁴⁾. If adopted as forms of bureaucratic control, though, this potential is extinguished⁽¹⁶⁾.

The findings of this study confirm the potential of the FHS as suitable for family care⁽¹⁷⁾. The bond mobilized the team to seek care centered on the family, fomented ties of trust, mutuality, complicity and shared responsibility between professionals and families. This bond is the element that placed the subjects in authentic interaction, when the professionals were permitted to be affected by the families, their potential and fragilities. It provoked empathy, commitment, respect and trust in the family by the team, thereby generating shared responsibility.

Shared responsibility of a population from a specific territory affords shared attention, with the establishment of common objectives, and the creation of a bond between professionals and families⁽¹⁸⁾. This bond fomented the empathy and commitment verified in the results of this study, and nourishes identification of the professional with the suffering and struggle of the family in light of the care demands. With this bond, the FHS team dares to go beyond what the structure and organization of the work processes allow, joining with the family to transform reality. Yet not all of the families, which demonstrates that such movement is related to the interaction established through time.

The study also showed the importance of effective dialogue between the different levels of health care, and involvement of the other social services available in the territory, which are indispensable for comprehensive care⁽¹⁹⁾. Similar to these findings, one study that analyzed in-depth the attempt by families that live with chronic diseases to reclaim life balance showed that their attempts to attain balance were seriously damaged by fragmented services, complexity of transitioning between the different health care services, and the conflictual relationship with some health care professionals⁽²⁰⁾.

The transition between the different levels of care was shown to be an isolated and solitary search by each family or health care service professional, when it should be a commitment from the SUS⁽⁷⁾. Furthermore, the family that accesses the health care service via FHS cannot lose its care reference when it needs specialized care, so the FHS must be strengthened. Similar findings⁽¹⁸⁾ reinforce the need for investments in this sphere.

The findings of this study suggest that improvement is needed in the communication processes between the distinct levels of the SUS for children with chronic diseases and their families, specifically the system of referral and counter-referral⁽¹⁷⁾. This would contribute to make care less fragmented and disconnected, with more positive developments for the family and the FHS team in their search for meaningful care.

Greater attention must be given to intersectoriality, aimed to attain more effective and efficient health care results⁽²⁰⁾. Communication between social services, sectors and equipment is a great challenge⁽²¹⁻²²⁾. The complexity of

care demands integrated action from the health care sector, in which partnerships between different sectors and social segments contribute to the solution.

As identified, the everyday care by the teams with these families generates anxiety, and professionals coexist simultaneously with compassion and limiting factors to care. This anxiety impels the teams to be creative, transpose limits and seek innovative solutions⁽²²⁾, but also discourages them, primarily when they perceive through time that they are not able to help or attain the best care for families. Thus, in their care of families of children with chronic diseases, the team lives with the ambiguity between wanting and being able to provide care, which implies approximation with, or separation from, the family.

The environment and design of care via FHS encourages approximation with the families⁽¹⁹⁾. Nevertheless, when considering their insertion in the SUS, it is possible to identify important gaps in regard to the concept of line of care and intersectoriality, which limits the possibilities of effective care for the families.

CONCLUSION

This study confirms the potential of the FHS to establish actions promoting the care of families of children with chronic diseases. The bond between the FHS team and family stands out as a differential, as it is through this bond that the team, in its interactions with the elements of the history of each family, approaches and feels interested in supporting it in its trajectory.

On the other hand, the study showed theoretical weaknesses of the FHS professionals in regard to the concepts necessary for family-centered care, as well as difficulties of intersectoriality. These are aspects that limit comprehensive and effective care, and need to be studied more carefully.

Due to the shared responsibility for care, the team experiences anxieties, joys, disappointments and restrictions that end up impelling it to want to be with the family, or not, depending on whether it feels capable of supporting it. It defines and works in the continued care of families of children with chronic diseases, according to the meanings constructed there, which emerge from interaction with the family, and with the macrostructure of the health care system, and influence the attitudes of the professionals.

Reports of successful experiences of the care line and intersectoriality need to be published, as well as explorations of the line of intervention-action, with aims to produce scientific evidence that fill in the existing gaps in this sphere. Furthermore, it is necessary to study how and how much the family is impacted by the organization of the health care system.

REFERENCES

- World Health Organization. Global status report on noncommunicable diseases 2010 [Internet]. Geneva: WHO; 2011 [cited 2012 Mar 11]. Available from: http://www.who.int/nmh/publications/ncd_report2010/en/
- Brasil. Ministério da Saúde. Saúde da Família: uma estratégia para a reorientação do modelo assistencial [Internet]. Brasília; 1997 [citado 2012 mar. 17]. Disponível em: http://bvsm.s.saude.gov.br/bvs/publicacoes/cd09_16.pdf
- Oliveira RG, Marcon SS. Trabalhar com famílias no Programa de Saúde da Família: a prática do enfermeiro em Maringá-Paraná. *Rev Esc Enferm USP*. 2007;41(1):65-72.
- Swavarsdottir EK. Listening to the family's voice: Nordic nurses' movement toward family centered care. *J Fam Nurs*. 2006;12(4):346-67.
- Herzer M, Godiwala N, Hommel KA, Driscoll K, Mitchell M, Crosby LE, et al. Family functioning in the context of pediatric chronic conditions. *J Dev Behav Pediatr*. 2010;31(1):26-34.
- Bocchi SCM, Angelo M. Entre a liberdade e a reclusão: o apoio social como componente da qualidade de vida do binômio cuidador familiar-pessoa dependente. *Rev Latino Am Enferm* [Internet]. 2008 [citado 2011 mar. 20];16(1). Disponível em: http://www.scielo.br/pdf/rlae/v16n1/pt_02.pdf
- Hopia H, Paavilainen E, Astedt-Kurki P. Promoting health for families of children with chronic conditions. *J Adv Nurs*. 2004;48(6):575-83.
- Charon JM. Symbolic interactionism: an introduction, an interpretation, an integration. 3rd ed. Englewood Cliffs: Prentice Hall; 1989.
- Barbour R. Grupos focais. Porto Alegre: Artmed; 2009.
- Bardin L. Análise de conteúdo. Lisboa: Edições 70; 2008.
- Howe CJ, Ayala J, Dumser S, Buzby M, Murphy K. Parental expectations in the care of their children and adolescents with diabetes. *J Pediatr Nurs*. 2012;27(2):119-26.
- Fisher HR. The needs of parents with chronically sick children: a literature review. *J Adv Nurs*. 2011;36(4):600-7.
- Nuutila L, Salanterä S. Children with a long-term illness: parents' experiences of care. *J Pediatr Nurs*. 2006;21(2):153-60.
- Silva MCLSR, Silva L, Bousso RS. Approaching the family in the Family Health Strategy: an integrative literature review. *Rev Esc Enferm USP* [Internet]. 2011 [cited 2012 Mar 17];45(5):1250-5. Available from: http://www.scielo.br/pdf/reeusp/v45n5/en_v45n5a31.pdf
- Oliveira RG, Marcon SS. The opinion of nurses regarding the work they perform with families in the Family Health Program. *Rev Latino Am Enferm*. 2007;15(3):431-8.
- Matumoto S, Mishima SM, Fortuna CM, Pereira MJB, Almeida MCP. Family discussion in the Family Health Strategy: a working process under construction. *Rev Esc Enferm USP* [Internet]. 2011 [cited 2011 July 12];45(3):603-10. Available from: http://www.scielo.br/pdf/reeusp/v45n3/en_v45n3a08.pdf
- Kantorski LP, Jardim VMR, Pereira DB, Coimbra VCC, Oliveira MM. A integralidade no cotidiano de trabalho na Estratégia Saúde da Família. *Rev Gaúcha Enferm*. 2009;30(4):594-601.
- Villa EA, Aranha AVS. A formação dos profissionais da saúde e a pedagogia inscrita no trabalho do Programa de Saúde da Família. *Texto Contexto Enferm*. 2009;18(4): 680-7.
- Colomé ICS, Lima MADS, Davis R. Visão de enfermeiras sobre as articulações das ações de saúde entre profissionais de equipes de saúde da família. *Rev Esc Enferm USP*. 2008;42(2):256-61.
- Jeon YH, Jowsey T, Yen L, Glasgow NJ, Essue B, Kljakovic M, et al. Achieving a balanced life in the face of chronic illness. *Aust J Prim Health*. 2010;16(1):66-74.
- Silva KL, Rodrigues AT. Ações intersetoriais para promoção da saúde na Estratégia Saúde da Família: experiências, desafios e possibilidades. *Rev Bras Enferm*. 2010; 63(5):762-9.
- Gabardo RM, Junges JR, Selli L. Family Health Program professionals' view on family structures and health implications. *Rev Saúde Pública*. 2009;43(1):91-7.

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