

DISCOURSES OF THE COMMUNITY HEALTH AGENTS ABOUT THE CHILD AND ADOLESCENT WITH CHRONIC DISEASE ASSISTED IN PRIMARY CARE

DISCURSIVIDADE DE AGENTES COMUNITÁRIOS DE SAÚDE ACERCA DO CUIDADO À CRIANÇA E AO ADOLESCENTE COM DOENÇA CRÔNICA NA ATENÇÃO PRIMÁRIA

DISCURSIVIDAD DE AGENTES COMUNITARIOS DE SALUD SOBRE EL CUIDADO DEL NIÑO Y ADOLESCENTE CON ENFERMEDAD CRÓNICA EN LA ATENCIÓN PRIMARIA

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ABSTRACT

Objective: to show the discourse of the community health agents about the contribution of their care actions to the management of the chronic disease of children/adolescents in primary care. **Method:** this is a qualitative study, conducted in a municipality of Paraíba, from November 2015 to May 2016, with ten community health agents working in the *Estratégia Saúde da Família*. Data were collected through semi-structured interviews and interpreted based on discourse analysis. **Results:** in primary care, care actions do not meet the specific health needs of children/adolescents with chronic disease, and their monitoring by specialized services of the care network is necessary. The home visit is performed to achieve goals. Care is inarticulate among team members and is centered on acute conditions or updating prescriptions. Despite these weaknesses, the work process of the community health agents allows qualified listening, trust and security in the relationship with the family, creating a bond. The community health agents recognize the importance of expanded and resolute care for this population, including knowledge of the demands, the social context and the development of unique therapeutic projects. **Conclusion:** the community health agents need to be aware of the needs of children/adolescents with chronic disease and their families and seek effective communication in the teams, so shared care actions can be traced, aiming at the qualified management of the chronic disease.

Keywords: Child; Adolescent; Chronic Disease; Primary Health Care; Community Health Workers.

RESUMO

Objetivo: evidenciar a discursividade de agentes comunitários de saúde acerca da contribuição de suas ações de cuidado para o manejo da doença crônica de crianças/adolescentes na atenção primária. **Método:** estudo qualitativo, realizado em um município paraibano, de novembro de 2015 a maio de 2016, com 10 agentes comunitários de saúde que atuam na *Estratégia Saúde da Família*. Os dados foram coletados por meio da entrevista semiestruturada e interpretados com base na análise do discurso. **Resultados:** apurou-se que, na atenção primária, as ações de cuidado não atendem às especificidades das necessidades de saúde de crianças/adolescentes com doença crônica, sendo necessário o acompanhamento destes por serviços especializados da rede de atenção. A visita domiciliar é realizada para cumprimento de metas. O cuidado encontra-se desarticulado entre os membros da equipe e está centrado nas condições agudas ou na atualização de receitas médicas. Apesar dessas fragilidades, o processo de trabalho dos agentes comunitários de saúde permite escuta qualificada, confiança e segurança na relação com a família, possibilitando a formação de vínculo. Vale salientar que os agentes comunitários de saúde reconhecem a importância do cuidado ampliado e resolutivo a essa população, incluindo o conhecimento das demandas, o contexto social e o desenvolvimento de projetos terapêuticos singulares. **Conclusão:** os agentes comunitários de saúde precisam sensibilizar-se em relação às necessidades das crianças/adolescentes com doença crônica e suas famílias, e buscar, nas equipes,

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uma comunicação efetiva, para que sejam traçadas ações de cuidado compartilhadas, objetivando o manejo qualificado da doença crônica.

Palavras-chave: Criança; Adolescente; Doença Crônica; Atenção Primária à Saúde; Agentes Comunitários de Saúde.

RESUMEN

Objetivo: destacar el discurso de los agentes comunitarios de salud sobre la contribución de sus acciones al manejo de la enfermedad crónica de niños y adolescentes en la atención primaria. **Método:** estudio cualitativo realizado en una ciudad del estado de Paraíba, entre noviembre de 2015 y mayo de 2016, con 10 agentes comunitarios de salud del programa *Estratégia Saúde da Família*. Los datos se recogieron a través de entrevistas semiestructuradas y se interpretaron en base al análisis del discurso. **Resultados:** se observó que en la atención primaria las acciones no satisfacen las necesidades específicas de salud de los niños y adolescentes con enfermedad crónica y por ello precisan monitoreo de servicios especializados. Se realizan visitas a domicilio para lograr los objetivos. La atención está desarticulada entre los miembros del equipo y se centra en afecciones agudas o en actualizar recetas. A pesar de estas debilidades, el proceso de trabajo de los agentes comunitarios de salud permite la escucha calificada, confianza y seguridad en la relación con la familia y la posibilidad de establecer vínculos. Se realiza que los agentes comunitarios de salud reconocen la importancia de la atención amplia y eficaz para esta población, de conocer sus demandas, el contexto social y el desarrollo de los proyectos terapéuticos atípicos. **Conclusión:** los agentes comunitarios de salud deben ser conscientes de las necesidades de los niños y adolescentes con enfermedad crónica y de sus familias y buscar la comunicación efectiva entre los equipos para trazar acciones de cuidado compartidas con miras al manejo calificado de la enfermedad crónica.

Palabras clave: Niño; Adolescente; Enfermedad Crónica; Atención Primaria de Salud; Agentes Comunitarios de Salud.

INTRODUCTION

The chronic diseases as one of the chronic health conditions are characterized by gradual onset, usually uncertain prognosis, with long or indefinite duration. They have a clinical course that changes over time. They are responsible for a large number of hospitalizations and require a continuous care process that does not always lead to cure.¹ The daily lives of children and adolescents with some chronic disease undergo several changes, considering that their lives and their families will be guided by the disease and its treatment.

For children and adolescents population, the chronic disease will need the need for self-care; overprotection of parents; drug therapy; strict diet; limitations for school and social life; and the experience of various feelings during the disease, such as anguish, uncertainty, hope, and sadness.² In family dynamics, changes from those related to the performance of activities of daily living to the continuous need to live in health services, spaces may sometimes occur even unknown to the children/adolescents and their family.³

From this perspective, the health care network, especially primary health care (PHC) and the professionals who work in it, must be articulated and prepared to address the needs of these children/adolescents with chronic diseases and their families, respecting their uniqueness, and improving their quality of life.^{4,5}

Considering that, the community health agent (CHA) in PHC is the link between the community and the health services, and their care actions in the work process may enable the longitudinal follow-up of children/adolescents with chronic disease and their families. In this context, studies state that the CHA can develop care actions with active participation in solving community health problems because home visits and relationships in their work are essential in the territory where they operate. Since they are inserted in the community, they can better identify the needs of care actions and contribute significantly to the expected resolution of these problems.^{6,7}

Some of these actions highlighted are the home visits by CHAs as they promote direct contact with the population and enable the problems to be shared to the family health team (FHT), allowing care demands to be properly met in PHC.^{8,9}

In the child/adolescent with chronic disease and his family, a study showed that the care actions developed by the CHA are the identification of the young people, followed by their registration and follow-up through home visits.¹⁰ In these visits, they should survey relevant data and information on the health of children and their families, as well as guide measures to prevent and control chronic diseases.¹¹

Given the growing index of these young people affected by chronic diseases and the implications of this diagnosis, its complexity shows the continuing need for health care, especially at home, and the important role of the CHA is highlighted who developing their work process, they can promote the full monitoring of these population, effectively contributing to the proper management and control of the disease.

Therefore, the question is: have the care actions developed by community health agents contributed to the management of the chronic diseases of children/adolescents? The objective to answer the guiding question of this study was: to highlight the discourses of the community health agents about the contribution of their care actions to the management of chronic disease of children/adolescents assisted in primary care.

METHOD

This is qualitative research, based on the theoretical-analytical device of discourse analysis (DA) of French matrix,¹² whose data collection was performed in a big city of Paraíba, from November 2015 to May 2016, with ten community agents (CHA) working in the Family Health Strategy (FHS).

Two units of the 191 FHS units in the municipality under study representing each of the five health districts that organize the municipality's health care network were contemplated.

The units were chosen by lot, and one CHA/enunciator from each selected service that met the inclusion criteria were chosen randomly: working in the FHS for more than six months, knowing the territory; and following up the children/adolescents diagnosed with chronic disease and their families in their daily work. The exclusion criteria were: being on vacation or away from work on leave of any kind during the data collection period. None of the participants refused to participate after the study objectives and the presentation of the study, and there were no dropouts during the research process.

Empirical data were collected through semi-structured interviews, recorded on electronic media with an average duration of one hour and transcribed in full for their analysis. The interviews were conducted individually, in a reserved place in the units, ensuring participants the privacy and confidentiality of information. The closing of the collection of empirical material followed the criterion of sufficiency when there is a comprehensive picture of the objective of study.¹³

For the empirical material analysis, discourse analysis was used. Discourse is understood as "the place where the relationship between language and ideology can be observed, understanding how language produces meanings for the subjects".¹² For DA, there is the subjection of the individual in the face of ideology and, from the moment he is subjected, he speaks of the position determined by it.¹⁴

For this analysis, the conditions of discourse production were also observed because the meanings produced are not only in words but also in their relation to the circumstances in which communication happens.¹²

In the analysis process, the following steps were followed: floating reading of the empirical material; identification of textual marks, which are the entries in speech by language; identification of texts left out (discursive object); evidence of what these missing texts mean (discursive process); explanation of the properties of discourse and how the senses are organized (discursive formation); and finally, the ideological formation that supports the discourse, where the senses come from was approached.¹⁴

The methodological procedures adopted in DA involve the definition of the concept-analysis and the choice, interpretation, and analysis of the corpus, through three heuristic questions. The first question was: "what is the concept-analysis present in the text?". The concept-analysis is the very object of the investigation.¹⁴ In this study, the following concept-analysis defined *a priori* were: contributions of the

care actions developed by community health agents for the management of the chronic disease of the child/adolescent.

Then, the textual marks were identified, enabling to sharpen the meanings constructed for the proposed concept-analysis, answering the second heuristic question: "how is the concept-analysis being constructed?". After verifying the recurrence of these marks, it was proceeded to the third heuristic question: "what discourse supports this meaning?" aiming to relate the constructed meaning to the discursive and ideological formations.¹⁴

This study obtained a favorable opinion from the Research Ethics Committee under CAAE: 27102214.6.0000.5188. For the participants, the Informed Consent Form (ICF) was presented, and after signed it, it represented their consent and authorization for this study. Throughout the text, the reports are identified by the acronym CHA (community health agent) followed by the ordinal number of the order of the interviews.

RESULTS

The complete years of studies of the CHAs ranged from 11 to 16 years, two of them with completed higher education (Pedagogy and History). The time worked in the unit ranged from two to 13 years. The number of children/adolescents with chronic diseases followed by the CHAs ranged from one to six children/adolescents, whose diagnoses were: sickle cell anemia, chronic neuropathy, rheumatoid arthritis, hydrocephalus, childhood eye cancer, type I diabetes mellitus, asthma, heart disease, Down syndrome, mental, visual and motor impairment.

Even with the diagnostic diversity of children and adolescents treated by the CHAs, chronic diseases have implications, and care needs common to all, and the specific demands of their age and each disease. The enunciators spoke about the care actions directed to individuals with chronic disease in PHC and included the entire team, stating that these actions are based on meeting the needs that are not related to the chronic disease, as it is already accompanied in the services network specialists.

The basic that I say is when it comes to the FHP (FHS), the attention we give as a health agent, the doctor, the nurse, and the dentist. [...] The normal needs [of the child] are met here, [...] but, specialized [health service] we do not have, this is what is missing (CHA7).

Therefore, the care actions developed in PHC do not address the specificities of the chronic young condition, especially when the CHA does not recognize home visits

as necessary for these people. Also, home visits have been carried out to meet goals, focusing on medication therapy.

We go and do a normal visit, and we see if the child is taking the medication, these things, the follow-up is this, only in the visit (CHA1).

We visit monthly, when it is a child who has some extra problem, who has a disease, besides the chronic disease, we send them more often, but when not, the normal visit is routine, is monthly (CHA7).

Home visits for children/adolescents with chronic disease follow the same logic as those for the general population, with general guidelines, not considering the uniqueness of these individuals who need longitudinal, continuous and integral care. Besides, it is emphasized that PHC care is fragmented and inarticulate in members of the health team.

I'll even try to know with the nurse, with the doctor, what period this child has to be accompanied by a professional, the doctor in this case because the health agents are visiting, but I (CHA) need to know if they are being accompanied by a medical professional (CHA6).

Caring for food, hygiene issues, cleaning the house, dust, such things, taking medication at the right time, everything, this kind of guidance (CHA8).

Even with weaknesses in the actions developed by the CHA, it is possible to identify that their work process allows the construction of bonds with the family, facilitating the experience and coping with chronic diseases by the family, because the needs of children/adolescents are recognized, at least in part, favoring the resolution of some problems.

I think I'm important to her [child] because I am always present, I always know what is happening to her (CHA4).

It is his problem, his family's problem finding in us the way forward. [...] We know the whole process, everything of the child's life, so every step that happens, they come for guidance, [...] it's the bond, it's the bond, it's like we say: It is the bond. It's family, the CHA, the unit, you know? This bond must exist; it is very important (CHAS).

The textual marks highlighted the importance of the bond between the CHA and the family for the performance of care actions for children/adolescents with chronic diseases

in PHC, facilitated through the relationship of trust between these people.

If there was no such trust, how would we do it? How would I do my job with a person who doesn't trust me? What would be my relationship with this family? So if she gives me this confidence, it is very important, it is very good (CHA4).

The CHA 2 explains in its statement that seeks to know the social context in which the child/adolescent is inserted, by observing their daily school life when possible. On the other hand, the CHA 10 recognized the importance of the interaction between the health sector and the school, emphasizing that they need to go together to offer integral care to this specific population.

She [child] studies at a school near the health center [FHS], I stop by when I see the gate open, I see her playing, and there is a teacher who works with special children (CHA2).

Many people do not understand because health and education have to be together, [...] health is isolated, education is isolated, and they do not see the child as a whole (CHA10).

The CHA 10 also revealed the importance of the unique therapeutic project (UTP) for the greater resolution of care and also as a way to have more participation in this process and be recognized for their work.

Because we felt excluded and in the unique therapeutic project, he shows that we are important, because we know his family history, and sometimes we know the answer to that problem we find it together (CHA10).

In addition to recognizing the value of the unique therapeutic project, the CHA reinforced the difficulty for the team to refer children/adolescents with chronic diseases to other health care network services, especially for follow-up with specialist doctors.

We are from primary care if we need a specialist we have to go to a huge schedule queue (CHA10).

The enunciators mentioned that another difficulty to perform care was that this population does not seek the unit

of the FHS, because they do not believe in the resolution of the service and/or they have health insurance.

The family rejects I came to the unit [FHS], with a view that will not be resolved, it will take the time that the doctor has no specialty for that disease (CHA2).

The problem is that the mother does not look for us; the mother says: "she [child] has health insurance; it will not depend on SUS" (CHA9).

The analysis of the statements enabled to explain how care is provided and how it contributes to the management of children/adolescents with a chronic disease, as well as the difficulties faced for health care to take place effectively.

DISCUSSION

The care and the follow-up of children and young people with a chronic disease are not being perceived by some enunciators as PHC attributions, since the demands related to the needs of this population are met in the specialized services of the health care network or even, by private health insurance for the care of children and adolescents with chronic diseases.

By analyzing the textual marks, this discourse is constituted by an ideological affiliation to the biomedical model of health care, valuing specialized and hospital-centered care, centered on procedures, weakening the longitudinal and continuity that is so necessary for the proper management of the chronic disease.

Primary care is responsible for providing continuous follow-up and facilitating user access and displacement in the health care network to reduce unnecessary hospitalizations and urgency and emergency assistance, and to increase family satisfaction with the care provided.¹⁵ Thus, it is necessary to transcend the hospital-centered perception of care and seek to promote the continuity in PHC, coordination, and integral care.

The discursive analysis of the textual marks that address the home visits held by the CHAs highlights the discursive memories of a care in which these meetings are performed to meet goals, as well as a task to be generally fulfilled for the entire population, without preserving the uniqueness of the young population with chronic disease, whose care actions are centered on medical prescriptions. These discourses are constituted by an ideological affiliation to the capitalist system, in which there is a priority for the number of procedures performed and costs, disregarding actions with an integral view at the demands of individuals. Also, once the valuation of the

curative health care model again is shown, focused on drug treatment.

Different from these findings, a study reported that home visiting is considered a tool used by health professionals to monitor children/adolescents with chronic diseases and their families, especially when the CHA conducts it continuously. Periodic home visits are used to monitor risk situations and participate in actions that strengthen the links between the health sector and other policies that promote quality of life. They should be programmed with the team, considering the family vulnerability.¹⁶

The EqSF, as a whole, needs to work building links, co-responsibility and integral care, to recognize and meet the daily needs of children/adolescents with chronic disease and their family.^{17,18} When health professionals trained to monitor these users, especially CHAs who is the main link of the community with the EqSF, they can contribute to offering singular and effective care, enabling improvements in the quality of life of those who experience chronic diseases.

It is important to emphasize that care must transcend drug therapy, and it is relevant to promote a space for communication, dialogue, qualified listening, exchange of knowledge, feelings, anxieties, and resolution of doubts arising from the confrontation of chronicity. home visit, turn each meeting into a moment of care.¹⁹

The discursive analysis of some textual marks shows the ignorance of the follow-up performed, leading to a lack of responsibility for the care and even making the visits; the CHA does not know how the child's follow-up is performed by the specialist. During home visits, it is up to the CHA to know the concrete life situations of users/family/community, and other professionals should act technically by knowing such information. In this sense, it is necessary to advance in the perspective of complementarity and expanded care, aiming at the convergence between the various fields of knowledge and the understanding of the value of the contribution of each professional to the integral care of the user.¹⁶

Health teams need to be prepared to perceive and meet the needs of the chronic condition from the initial moments of signs and symptoms to relapses, providing humanized, longitudinal, continuous and resolute care.¹⁸

Even with the weaknesses in the care provided in PHC, the work process developed by the CHA allows the construction of bonds with the family. The analysis of the statements shows the importance to facilitate the horizontality in the care. By being bonded with families, they provide more satisfactory care support in the service, relieving suffering, and increasing the resilience of those who experience chronic diseases.

Corroborating these findings, a study conducted with children with chronic disease in outpatient follow-up reports

that an affectionate and differentiated bond established between health professionals, the family and the child/adolescent brings security and promotes confidence in each other and better coping with the disease.²⁰

During the home visit, the welcoming and bonding are established and strengthened, emphasizing the possibility of the professional building a dialogue, knowing the needs of families and assisting in solving the problems. At this time, there is also the possibility of encouraging the independence of the community and families in their own health production.¹⁶

The CHA discourse highlights the importance of trusting the family of the child/adolescent with a chronic disease, being essential for bonding. The statements showed that trust is fundamental for the development of their work process effectively in the relationship between the CHA and the families.

By identifying the family's reality, its problems, needs, and longings through home visiting, the CHAs can increase access to care and services and facilitate the appropriate use of resources available in the health care network. It is also responsible for transmitting health information to the population, enabling real knowledge of living conditions and contributing to the continuity of care.²¹

Some enunciators of this study showed that they seek to know, when possible, the daily school life of children/adolescents with a chronic disease who monitor and recognize that the interaction between the health and education sectors brings the possibility for the promotion of integral care. Thus, they explained a discursive memory of the school's contribution to the health-disease process of this population.

A study found that schools need to promote growth and development opportunities, articulating with the health sector, the family, and the community. This insertion of health in the school environment guides the family and society to care for children and adolescents, including those with a diagnosis of chronic disease, aiming at maintaining, obtaining health and controlling the disease, based on guidelines for the student to safe and healthy choices.²²

The CHA 10 highlighted the importance of UTP for more resolute care and to promote more participation of these subjects in the planned care. By discursively analyzing, there is the inference that CHAs feel excluded from decision-making related to care in children and young people with a chronic disease and perceive UTP as a facilitator for the exchange of knowledge, shared decision making and the uniqueness of the care provided.

Although the discourses reveal an appreciation of specialized care, there is a predominance of the discursive formation of the shared teamwork. CHAs can effectively participate in the process of building a UTP for a given family

in an attempt to provide a better quality of life through interdisciplinary action. Thus, the UTP is elaborated considering the health needs of each user, their way of understanding life, their subjectivities and singularities. Through horizontal interaction of the agents involved in care (workers and users), the technologies of relationships should be based on welcoming, listening and bonding, proposing new modes of health care at different levels of care.²³

The difficulty of the EqSF to send children/adolescents with a chronic disease to other services of the health care network, especially for follow-up with medical specialists is mentioned in the speeches. The discursive analysis shows it weakness referrals to other services of the care network, which may be related to the bureaucratization of the regulatory system and the reduced number of vacancies, hindering to continuously monitor children and adolescents with a chronic disease in the PHC. This situation also brings emotional burden to the CHAs, who suffer from not seeing the needs of users being met, due to difficulties of the health system.

From this perspective, a study corroborated these findings and notified that, in addition to the lack of reference and counter-reference, the challenges for continuity of care in PHC are related to the demand for care that is higher than possible, fragmented work by the health team, difficulty in inter-sectoral action and lack of inputs and technologies.¹⁰

Another difficulty identified by the CHAs is that the child/adolescent with a chronic disease and his family do not seek the FHS unit because they do not believe in the resolution of the service and/or have health insurance. These statements are constructed from their experiences, based on the disbelief in the PHC service by family members, either by the difficulty of access and resolution, as by the delay, leading them to seek other services of the health care network or even to invest in private health insurance to maintain ongoing monitoring of their children.

The weaknesses of the work organization in the health care network to meet the needs of this population make the families seeking alternatives to ensure health care for their children. However, when maintaining this mode of producing care, the construction of an ideological conception linked to the liberal market system is highlighted, in which the minimum state is not responsible, and individuals have to assume alone the driving and costs in caring for their care.

However, the family with private insurance justifies the non-acceptance of the CHA, saying they have access to health insurance and do not need the services provided by them. This often happens because the family is unaware of the importance of the integral, qualified and longitudinal care of this professional with other health professionals can provide when bridging the family and the EqSF.²⁴

One of the limitations of this study that the CHAs discourses are influenced by the conditions of their production, the place and position they occupy in the FHS, hindering to generalize the results to other contexts. However, the research enabled to broaden the understanding of the factors implicated in care actions directed to children/adolescents with a chronic disease and their families, indicating the importance of respecting CHAs in this process, as their actions are fundamental for a continuity interdisciplinary care.

FINAL CONSIDERATIONS

The care actions developed by the CHAs can favor the integral care to the child/adolescent with a chronic disease and their family, as their articulated action to the other members of the EqSF allows the establishment of a qualified listening and the early recognition of the needs presented in the daily life of the disease, contributing to the resolution and effectiveness of the service in PHC.

However, there are no systematic and specific actions aimed at this population, and therefore, they are carried out on a timely basis, causing the responsibility for the care provided to be erased. Therefore, the CHAs need to be aware of the unique needs of children/adolescents with a chronic disease and their families and seek effective communication in the teams so care actions are taken that to meet the demands of daily life.

The construction and implementation of the UTP in the PHC team members are important, directed to the children/adolescent with a chronic disease and their family, so a comprehensive and shared care management occurs, through the view of each professional segment. Also, it is essential to establish a care network, so PHC professionals know where to refer this population.

The behavior of the CHAs is influenced by their socio-historical-cultural context, as shown by the assumptions of the DA, involving their beliefs, experiences and educational background, and may have ideological affiliations with a biologist model focused on disease and drug therapy or a holistic model that values integral care. Thus, although the CHAs have the same work processes, their speeches allowed the understanding of how each one follow-up the children/adolescent with a chronic disease and their family.

Finally, this study highlights the need for further research, especially those to intervene in the reality, encouraging the transformation of practices, so more and more chronic disease in childhood and adolescence appears in the discussion centers, and there are improvements in the process developed by the CHA in the health care network, especially in primary care.

REFERENCES

1. Ministério da Saúde (BR). Diretrizes para o cuidado das pessoas com doenças crônicas nas redes de atenção à saúde e nas linhas de cuidado prioritárias. Brasília: MS; 2013[cited 2019 Feb 07]. Available from: http://bvsms.saude.gov.br/bvs/publicacoes/diretrizes%20_cuidado_pessoas%20_doencas_cronicas.pdf
2. Abreu IS, Nascimento LC, Lima RAG, Santos CB. Children and adolescents with chronic kidney disease in haemodialysis: perception of professionals. *Rev Bras Enferm*. 2015[cited 2019 Feb 06];68(6):712-8. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-71672015000601020
3. Silva MEA, Gomes IP, Machado AN, Vaz EMC, Reichert APS, Collet N. Implicações da condição crônica da criança para sua família. *Ciênc Cuid Saúde*. 2014[cited 2017 Dec 12];13(4):697-704. Available from: <http://www.periodicos.uem.br/ojs/index.php/CiencCuidSaude/article/view/20816>
4. Alves GV, Lomba GO, Barbosa TA, Reis KMN, Braga PP. Crianças com necessidades especiais de saúde de um município de Minas Gerais: Estudo descritivo. *Rev Enferm Cent-Oeste Min*. 2014[cited 2017 Dec 17];4(3):1310-21. Available from: <http://www.seer.ufsj.edu.br/index.php/recom/article/view/778>
5. Gomes LMX, Pereira IA, Torres HC, Caldeira AP, Viana MB. Acesso e assistência à pessoa com anemia falciforme na Atenção Primária. *Acta Paul Enferm*. 2014[cited 2018 Jan 10];27(4):348-55. Available from: <http://www.scielo.br/pdf/ape/v27n4/1982-0194-ape-027-004-0348.pdf>
6. Moura RFS, Silva CRC. Afetividade e seus sentidos no trabalho do agente comunitário de saúde. *Physis*. 2015[cited 2017 Dec 06];25(3):993-1010. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-73312015000300993&lng=pt-pt
7. Speroni KS, Fruet IMA, Dalmolin GL, Lima SBS. Percepções dos Agentes Comunitários de Saúde: contribuições para a gestão em saúde. *Rev Cuid*. 2016[cited 2018 Jan 07];7(2):1325-37. Available from: <https://www.revistacuidarte.org/index.php/cuidarte/article/view/338/731>
8. Santana JCB, Fortes NM, Gonçalves CP, Moura IC, Porto PA. Visita domiciliar dos Agentes Comunitários de Saúde no planejamento das ações das Estratégias da Saúde da Família: avanços e desafios. *Enferm Rev*. 2015[cited 2018 Jan 13];18(2):18-28. Available from: <http://200.229.32.55/index.php/enfermagemrevista/article/viewFile/11691/10335>
9. Paiva PC, Torrenté MON, Landim FLP, Branco JGO, Tamboril BCR, Cabral ALT. Sofrimento psíquico e a abordagem da comunidade na voz do Agente Comunitário de Saúde. *Rev Esc Enferm USP*. 2016[cited 2017 Dec 28];50(spe):139-44. Available from: http://www.scielo.br/pdf/reeusp/v50nspe/pt_0080-6234-reeusp-50-esp-0139.pdf
10. Duarte ED, Silva KL, Tavares TS, Nishimoto CLJ, Silva PM, Sena RR. Cuidado à criança em condição crônica na atenção primária: desafios do modelo de atenção à saúde. *Texto Contexto Enferm*. 2015[cited 2017 Dec 17];24(4):1009-17. Available from: http://www.scielo.br/pdf/tce/v24n4/pt_0104-0707-tce-24-04-01009.pdf
11. Knochenhauer CCLS, Vianna KMP. Percepção dos agentes comunitários de saúde quanto aos agravos fonoaudiológicos. *CoDAS*. 2016[cited 2018 Feb 08];28(6):697-703. Available from: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S2317-17822016000600697&lng=en
12. Orlandi EP. *Análise de discurso: princípios e procedimentos*. 8ª ed. Campinas (SP): Pontes; 2009.
13. Fontanella BJB, Luchesi BM, Saidel MGB, Ricas J, Turato ER, Melo DG. Amostragem em pesquisas qualitativas: proposta de procedimentos para constatar saturação teórica. *Cad Saúde Pública*. 2011[cited 2018 Jan 20];27(2):389-94. Available from: <http://www.scielo.br/pdf/csp/v27n2/20.pdf>
14. Souza SAF. *Análise de discurso: procedimentos metodológicos*. Manaus (AM): Instituto Census; 2014.
15. American Academy Of Pediatrics. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics*. 2014[cited 2018 Jan 06];133(5):1451-

60. Available from: <http://pediatrics.aappublications.org/content/pediatrics/133/5/e1451.full.pdf>
16. Andrade VMP, Cardoso CL. Visitas domiciliares de agentes comunitários de saúde: concepções de profissionais e usuários. *Psico-USF*. 2017[cited 2019 Feb 05];22(1):87-98. Available from: http://www.scielo.br/scielo.php?script=sci_abstract&pid=S1413-82712017000100087&lng=en&nrm=iso
17. Sandor ERS, Marcon SS, Ferreira NMLA, Dupas G. Demanda de apoio social pela família da criança com paralisia cerebral. *Rev Eletrônica Enferm*. 2014[cited 2017 Dec 21];16(2):417-25. Available from: <https://revistas.ufg.br/fen/article/view/21112/17258>
18. Okido ACC, Cunha ST, Neves ET, Dupas G, Lima RAG. Criança dependente de tecnologia e a demanda de cuidado medicamentoso. *Rev Bras Enferm*. 2016[cited 2017 Dec 20];69(4):718-24. Available from: <http://www.scielo.br/pdf/reben/v69n4/0034-7167-reben-69-04-0718.pdf>
19. Nobrega VM, Damasceno SS, Rodrigues PF, Reichert APS, Collet N. Atenção à criança com doença crônica na Estratégia Saúde da Família. *Cogitare Enferm*. 2013[cited 2018 Jan 10];18(1):57-63. Available from: <http://revistas.ufpr.br/cogitare/article/view/28517>
20. Matos APK, Canela PC, Silveira AO, Wernet M. Revelações manifestas por crianças pré-escolares portadoras de doenças crônicas em tratamento ambulatorial. *Acta Paul Enferm*. 2014[cited 2017 Dec 15];27(2):126-32. Available from: <http://www.scielo.br/pdf/ape/v27n2/0103-2100-ape-27-02-0126.pdf>
21. Costa SM, Araújo FF, Martins LV, Nobre LLR, Araújo FM, Rodrigues CAQ. Agente Comunitário de Saúde: elemento nuclear das ações em saúde. *Ciênc Saúde Colet*. 2013[cited 2017 Feb 10];18(7):2147-56. Available from: <http://www.scielo.br/pdf/csc/v18n7/30.pdf>
22. Alvarenga WA, Silva MEDC, Silva SS, Barbosa LDSC. Ações de educação em saúde realizadas por enfermeiros na escola: percepção de pais. *REME Rev Min Enferm*. 2012[cited 2017 Dec 13];16(4):527-22. Available from: <http://www.reme.org.br/artigo/detalhes/557>
23. Jorge MSB, Diniz AM, Lima LL, Penha JC. Apoio matricial, projeto terapêutico singular e produção do cuidado em saúde mental. *Texto Contexto Enferm*. 2015[cited 2019 Feb 07];24(1):112-20. Available from: http://www.scielo.br/pdf/tce/v24n1/pt_0104-0707-tce-24-01-00112.pdf
24. Baralhas M, Pereira MAO. Prática diária dos agentes comunitários de saúde: dificuldades e limitações da assistência. *Rev Bras Enferm*. 2013[cited 2018 Feb 02];66(3):358-65. Available from: <http://www.scielo.br/pdf/reben/v66n3/a09v66n3.pdf>
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