

Families' knowledge about children and adolescents with neural malformation about their rights in health

Conhecimento das famílias de crianças e adolescentes com malformação neural acerca dos seus direitos em saúde

Conocimiento de las familias de niños y adolescentes con malformación neuronal sobre sus derechos en materia de salud

Sarah Vieira Figueiredo¹

Ilvana Lima Verde Gomes¹

Maria Veraci Oliveira Queiroz¹

Déborah Danna da Silveira Mota¹

Ana Carla Carvalho de Sousa¹

Cristiany Macêdo Peixoto Vasconcelos¹

1. Universidade Estadual do Ceará.
Fortaleza, CE, Brazil.

ABSTRACT

Objective: This study aimed to understand the information quality offered to the families of children and adolescents with myelomeningocele about their rights in health and identify how has been occurred the process of guidance on public health policies. **Methods:** Qualitative research conducted in a pediatric referral hospital in Ceará. Fifteen families participated in a semi-structured interview, developed from September 2013 to February 2014. The data were submitted to thematic categorical analysis. **Results:** Families had insufficient information about the rights of their children, aspect that is related to the gaps in the orientation transmitted by health professionals and results in economic difficulties due to the high costs with the necessary supplies in day to day. **Conclusion:** The study disclosed the need to expand the training of professionals, improving their skills for providing assistance to these families, contributing with information on its rights and autonomy.

Keywords: Disabled Persons; Chronic Disease; Child Advocacy; Health Public Policy; Meningomyelocele.

RESUMO

Objetivo: Compreender o conhecimento das famílias de crianças e adolescentes com mielomeningocele sobre os seus direitos em saúde e identificar como tem ocorrido o processo de orientação acerca das políticas públicas de saúde. **Métodos:** Estudo qualitativo, realizado em hospital de referência pediátrica no Ceará, onde desenvolveram-se entrevistas semiestruturadas com 15 famílias, de setembro de 2013 a fevereiro de 2014. Os dados foram submetidos à análise categorial temática. **Resultados:** As famílias possuíam pouca informação acerca dos direitos de seus filhos, aspecto que esteve relacionado às lacunas existentes na orientação dos familiares por parte dos profissionais de saúde. Esse desconhecimento repercutiu em dificuldades econômicas, devido aos altos custos com os insumos necessários no cotidiano. **Conclusão:** Conclui-se ser necessário investir na formação dos profissionais, favorecendo a sua aquisição de competências para atuar junto às famílias, de modo a contribuir para a sua apreensão de conhecimentos e autonomia.

Palavras-chave: Pessoas com Deficiência; Doença Crônica; Defesa da Criança e do Adolescente; Políticas Públicas de Saúde; Meningomielocele.

RESUMEN

Objetivo: Comprender el grado de conocimiento de las familias de niños y adolescentes con mielomeningocele con respecto a sus derechos en materia de salud, e identificar como ha sido el proceso de orientación acerca de las políticas públicas de salud. **Métodos:** Estudio cualitativo realizado en hospital pediátrico de referencia en Ceará, donde se han desarrollado entrevistas semiestructuradas con 15 familias, de septiembre 2013 a febrero de 2014. Los datos fueron sometidos al análisis categorial temático. **Resultados:** Las familias tenían información insuficiente sobre los derechos de sus hijos, aspecto que se relaciona con las lagunas en la orientación transmitida por profesionales de salud y resulta en dificultades económicas debido a los altos costos con los insumos necesarios en el día a día. **Conclusión:** Se necesita ampliar la capacitación de profesionales, confiéndoles habilidades para prestación de asistencia a las familias, contribuyendo con la información de sus derechos y autonomía.

Palabras clave: Personas con Discapacidad; Enfermedad Crónica; Defensa del Niño; Políticas Públicas de Salud; Meningomielocele.

Corresponding author:

Sarah Vieira Figueiredo.

E-mail: sarahvfigueiredo@gmail.com

Submitted on 06/26/2015.

Accepted on 10/09/2015.

DOI: 10.5935/1414-8145.20150090

INTRODUCTION

The neural tube malformations occur in the early stages of fetal development, between the third and fifth pregnancy week, and affect the primitive neural tube framework that will originate the structures of the nervous system, such as the brain and the spinal cord. While these compromises can be surgically repaired, nerve injuries are permanent and offer different types of complications¹.

With regard to the world of birth defects, incidence data show variation between 0.79 and 6.39 per 1000 live births². However, data of the national literature about this rate are scarce, with only a few specific studies. Among these, one held in Minas Gerais showed a prevalence of 4.3 per thousand births between 1990-2000, and another in Recife, found prevalence of 5 per thousand births in 2000-2004^{3,4}.

Among these malformations, myelomeningocele (MMC) represents approximately 75% of cases of spina bifida (defect that affects the spinal cord, as well as the structures that protect it) being the most severe form as a result of the sequelae resulting from exposure of the nerve tissue^{5,2}.

The diagnosis of MMC during pregnancy promotes early intervention plan, since at the birth of the child, is indicated the surgery, more precisely in the first 24 hours, with the purpose to reduce the aggravation of the clinical picture and possible sequelae. The most common complications are paralysis of lower limbs, skin sensitivity disorders, urinary and bowel incontinences and musculoskeletal deformities and sexual dysfunction⁵⁻⁷.

Because of these complications and the need for continuous health monitoring and treatment for children and adolescents with this malformation, it is necessary the involvement of family members. These chronically diseased individuals will face several challenges in conducting their daily life activities, mainly because of limited mobility and the possible presence of fecal and urinary incontinence, situations that require the performance of some household procedures such as Bladder Relief Probing (BRP), and use of equipment for locomotive support^{5,8}.

Thus, the MMC is considered a chronic disease, since it demands uninterrupted treatment, prolonged professional care and frequent hospitalizations⁹. Chronic diseases are the leading causes of death and disability in the world, being defined as those that have long permanence, slow evolution, usually recurrent, and, consequently, contribute to the suffering of individuals, families and society, requiring continued attention and efforts of a set of equipment and public policies¹⁰.

Families are the most engaged social support to children and adolescents with chronic disease. On the other hand, they need to receive attention from government agencies, including health professionals and support networks that favor, as well as materials and supplies for the care, also the exchange of information and sharing of experiences that will facilitate knowledge and therapeutic interventions for maintaining healthy life of diseased ones.

Thus, it advocates that for the realization of professional care in health services, family care at home and thereby improve the life quality of users with MMC, Public Health Policies are needed to provide support to their caregivers.

The Ministry of Health, over the past few years, has established some laws, decrees and ordinances ensuring rights that promote people who have some chronic diseases such as: Osteogenesis imperfecta, neuromuscular disorders, Down syndrome, autism, among others. However, there is a need for the evaluation of existing public policies as to its actual implementation and expanded for people with other chronic health needs, such as the serious defects of the neural tube, in the case under discussion - MMC.

In Brazil, the movement for democratization of health, which involved the country in the second half of the seventies, favored the construction of the Health Reform Project, and in this scenario, was elaborated, in 1988, the current Brazilian Constitution, which revolutionized by ensuring, in its Article 196, that health is "a universal right and duty of the state, guaranteed through social and economic policies aimed at reducing the risk of disease and other health problems and universal and equal access to the actions and services for its promotion, protection and recovery"¹¹.

The discussion about the rights of people with disabilities, originating whether or not from a chronic illness, precedes this Constitution, even if in a limited way, without so many benefits. However, the guidelines relating to public health policies for this population and its implementation have been guaranteed from that Constitution and its dismemberment.

Thus, one can envision that children and adolescents with sequelae of neural malformation can be benefited, especially when, depending on the characteristics and level of their injury, present disabilities, have limitations for the development of activities of daily life and are dependent on care technologies. This legally guarantees them to receive some of the rights of persons with disabilities, although there are no specific policies for that portion of the population^{12,13}.

In this sense, it is emphasized that when the population is aware of their guaranteed rights by means of public policies, they are aware to judge situations and fight for them. In these cases, they also have the opportunity to act with autonomy their role in society as citizens, which contributes to the effectiveness of these policies¹⁴.

In this way, so that children and adolescents with neural tube malformations among other chronic diseases achieve their rights, it is essential that families receive support and exchange of information, sharing of experiences beyond illness and treatment, as well as guidance on the existing public policies and actions that are developed to reach them.

Thus, viewing in practice many instances of children and adolescents with MMC, their demands and needs, which transcend hospital treatment, it was perceived the need to study the subject, to involve the families of children and adolescents

with MMC about their rights to health, and what learnings have been built on the existing public policies that contemplate this health condition.

Therefore, the research aimed to: understand the knowledge of the families of children and adolescents with myelomeningocele about their rights in health and identify how the orientation process has been occurring about these public health policies.

METHODS

Qualitative study, in line with Minayo, to whom this approach falls within the field of subjectivity, with the universe of meanings, beliefs and values; space of relation, processes and phenomena in a deeper way, that cannot be summarized to variables¹⁵. Thus, there was the intention to understand a situation from the perspective of people who live it.

The project was approved by the ethics and Research Committee (opinion nº 401,189) of the hospital object of the study, tertiary care unit, reference in attention to children and adolescents, located in Fortaleza, Ceará, Brazil. It is noteworthy that users with MMC receive ambulatory monitoring in various medical specialties and from other professionals.

The participants were 15 families of those users, selected based on the following inclusion criteria: being responsible and/or caregiver of the child or adolescent's family in order to share information with the highest level of details about the goals of this research be present during the monitoring and treatment in hospital and present availability time to participate. Exclusion criteria: family members who presented some mental deficit that impaired their participation in interviews and have little knowledge of the child's or adolescent's daily life.

Semi-structured interviews were conducted from September 2013 to February 2014, using a script containing the characterization of the participants and questions concerning their knowledge about health rights for children and adolescents with MMC and in which situation, how and with who, they obtained such knowledge. The interviews were recorded and transcribed by the researchers, preserving the originality of the speeches.

For the analysis of the information, we decided to adopt the recommendations of the Bardin's Categorical Thematic Analysis, which guides the dismemberment of a text into units and categories through analog groups¹⁶. Among the different forms of categorization, the investigation through themes is considered effective and fast in perspective applied to simple and direct speeches. Thus, these steps were followed: pre-analysis; exploration of the material; treatment of results, inference and interpretation. From The analytical phase resulted the following thematic categories: knowledge of the families of children and adolescents with myelomeningocele about their rights in health; reality of the process of guidance to families by health professionals.

All standards of Resolution 466/2012 have been complied and some precautions were taken in order to protect the identity

of the participants, professionals cited in the reports, health institutions and the municipalities of origin of respondents. As well, respondents received fictitious name and were replaced the names of people, services and locations mentioned in the speeches for letters, as precepts of Ethics in Research.

RESULTS AND DISCUSSION

Initial results show the socioeconomic characteristics of these families and the main clinical complications of children accompanied in the service by the illness condition for MMC.

The presence of mothers (14) predominated in the study, because, mostly, they were the main caretakers and caregivers, with the participation of just a father who exercised this role. This corroborates reports of literature pointing the mothers as main caretakers to children with special health needs^{5,17-19}. Regarding to the age group, it was observed that this ranged from 18 to 46 years, with a predominance of participants between 30 and 40 years (10), that is, people who may have greater life experiences.

In relation to the degree of education, more than half had attended elementary school complete or incomplete (8), representing a low educational level, which may have influenced the understanding of the questions during the interviews, since there was a need for further explanation on issues of the study and some terms to participants. In this sense, it alerts to the fact that this lack of knowledge can limit the performance of households in various forms of struggle, as well as their understanding of the process of illness and health rights.

Regarding marital status, the majority were married or living in a stable union (11), a situation that related to the family dynamics after the arrival of the child at home in postpartum period, depending on the possibility of the partner to assist or not the family financially and in some cases contribute with care. There was a predominance of people who did not exercise formal jobs (14), and the minority participated occasionally in family farming activities (4). In General, the actions of home and child care were highlighted, focusing on children and adolescents with MMC, a fact that justified the impossibility for some to exercise a formal job due to large demands of monitoring to health care and home care.

With regard to origin, only two were residing in Fortaleza, the capital of Ceará, and the majority in the countryside of the state (7) and the metropolitan area (6), composed of municipalities near the capital. With regard to family income, the majority (10) lived with one to two minimum wages monthly, highlighting the Continuing Cash Benefit (CCB) to children and adolescents, because of their disabilities, amounting to a monthly minimum wage as currently promoted by Decree Nº 7,617 of 2011²⁰.

In relation to children of participants with MMC, prevailed the female (10) and the age ranged from 3 months to 13 years. With regard to schooling, of the nine children and adolescents in the mandatory age (from 4 years) for enrollment in educational teaching, six attended the school²¹.

The main reasons for which the parents had not enrolled their children, according to their reports, were related to the aftermath of the MMC, such as the difficulty of walking and family belief that the school environment was not suitable for their children. For the families, this place presents complications, because the absence of schools with physical and structural support that could allow the proper study of the child or adolescent. However, such justifications are remarkable for the national educational guidelines, which advocate free access of these people to a quality school environment^{21,22}.

With regard to complications arising from the MMC, it was noted, among those who had already been detected with some of the sequelae (13), a higher occurrence of children and teens with urinary incontinence (11) and/or fecal (10). This finding corroborates the scientific literature, because several studies show high prevalence of renal and vesical defects in people with MMC, neurogenic bladder, which requires the completion of intermittent emptying through the BRP^{23,24}.

About the complications of locomotion, four children had not yet been diagnosed with this sequel due to age, eight did not walk and three had a non-functional march, that is, walk with difficulty, needing the wheelchair or other supports for locomotion.

In this sense, it highlights the importance of equipment that help those people in moving their limbs during daily activities. In the study, eight were using wheelchairs, four had orthotics in the arms and/or legs and one was using a walk support. It should be noted that some of these users, even requiring such material, did not use it due to financial difficulty to acquire or even to have access to such equipment through public service.

Knowledge of the families of children with myelomeningocele about their health rights

In that category, it was seized the attention of the family members about the rights to health and, specifically, in their situation when taking care of a child in special condition.

It is important to emphasize that some health rights provided by Brazilian legislation give coverage to people who have disabilities and chronic diseases, such as neural tube malformation, although not specific to these diseases. In this sense, depending on the information and knowledge they have, the individuals that present this pathology and/or their family members will have more opportunities to request them or, by judicial process, fight for their benefits. It should be noted that once obtained these rights, these people will have, consequently, better conditions of survival.

In this regard, it was noted that families had insufficient information about the guarantees provided by the law to their children. More frequently, they cited the CCB, as shown by the transcribed speeches:

Only the little I know is that he is entitled to a benefit (Priscila).

[...] I know she has the benefit, and I also know that the money is to take care of her (Marta).

These findings diverged partially from the found in another survey conducted in Ceará involving people with disabilities, in which it noted that they had greater knowledge of their rights, despite also reporting failures for its full implementation²⁵. However, it should be noted that the study was conducted with adults with disabilities, who had longer period of experience in the struggle for their rights, which may have influenced the degree of knowledge.

In the following study, the financial benefit has emerged as one of the most important rights for these families, because most do not have subsidies to support its members due to the withdrawal from formal employment. In this case, the absence of income worsened after the simultaneous rise of respondents spending for home care, treatment and continuous monitoring of children with special health care needs to the health services.

The right to receive materials to the required care at home was also commented by family members, who highlighted to believe that children and adolescents should be benefited with diapers by the government, because it is a frequently used material, requiring large monthly investments for acquisition.

I have heard that she is entitled to receive all the materials she uses, diaper [...] (Penha).

I think so, these diapers, because I paid more than 100 reais in her diapers, it is overpriced (Samara).

The complication of urinary incontinence can lead users to the need to use the BRP, but comfort can be extended with the use of the disposable diaper. However, the Brazilian legislation does not guarantee the offer of that product to the population with MMC or other special need with similar care, although it can be established decrees, ordinances or municipal or state laws, to ensure this type of provision. It is also highlighted that, in Ceará, such regulations were not found. Only existing commercial services that offer discounts on the purchase of diapers for the use of people with special needs and philanthropic institutions that can offer financial help for this or certain acquisitions.

Other emphasized rights in health that correspond legally to existing policies were receiving orthotics, medicines and materials to perform the BRP^{12,26} access and quality of health services, as a priority^{27,13}. Family members stressed also the right to education, leisure and school transportation service.

The only right that I think she has, this orthosis, I think the Mayor, someone had an obligation to donate at least half (Rafaela).

[I think] better care at the corners [health services], because it is kind of complicated [...] (Samara).

Health first, education, transport [...] medicine, diapers, cate material [BRP] (Sandra).

This larger knowledge, beyond the mere understanding about the right to receive a financial benefit, has been demonstrated only for a small portion of respondents. In addition, the reported information was mainly based on assumptions and there is no conviction on the part of some families that constituted, in fact, rights. It was noted, therefore, real ignorance of many families members from different municipalities of Ceará, about public health policies that can favor their chronically diseased children and help them achieve better qualities of life.

Reality of the process of guidance to families by health professionals about their health rights

The results showed that the guidelines received by family members appear to be limited in shape, quantity of the contents on public health policies, with little resonance in the knowledge of the rights of children and adolescents with MMC. Thus, there were gaps in the form of guidance and education of families by health professionals, in order to allow the family conditions to take decent care and the struggle for social and citizenship rights, which transcend the receipt of a minimum financial benefit, unable to meet the needs of these users. In the reality of these families learning resides mainly in the CCB, since they are predominantly oriented on the procedures required to obtain it.

Doctor J, before I left, she gave me a certificate, explained every little thing as it was, I sought the benefit, she had earned (Marta).

Until this moment, I only heard about the benefit and it was the doctor who told me (Mara).

It was observed that, among health professionals, the doctor was the main adviser on the rights, by virtue of being responsible for drawing up the certificate, with the user's health problem report, so that families are able to receive the financial benefit at the National Institute of Social Security (NISS), having had thus greater emphasis on the provision of information about the CCB.

It should be noted that for the users to have access to their rights, being assured the public policies in their favor, it becomes imperative greater disclosure about its existence, in order to make them known by health professionals and the population¹⁴.

Despite being a sector related to this kind of guidance, social services was cited by a minority of respondents. In this sense, it is emphasized that, according to the professional regulatory law states, among the powers of social workers, guide groups and individuals in order to identify resources and use them in defense and in the care of their rights²⁸. However, through the experiences of the participants of this research, it is realized great work of these professionals with regard to the guidance on the rights of children and adolescents with MMC in most health institutions where they are accompanied.

It also highlights the importance of comprehensive care, according to which all employees participate actively, with a comprehensive overview of the needs of the subject being cared, including those not directly linked to this disease. This design

includes post-discharge care and all necessary guidance on home-based care and rights of this child/adolescent, according to the Brazilian Laws and Regulations.

A rehabilitation health service stood out in the statements of family members, as being of great importance in relation to the guidelines, in addition to inform about the financial benefits for other data about the various rights and clarify their doubts, as the form of ownership, as shown the line:

Hospital X [HR] gave me a paper with everything she needed and the laws that are in the Constitution. Then I took her to the city hall, that is with about four years. Until then I didn't get nothing, I bought. A long time I was buying, then the HR guided me to go in the secretariat. He gave me a list with all rights, was my salvation (Jane).

The report shows that the referred health institution had important role in the life of these families, since, although their children have to be accompanied in other pediatric reference services from birth, had not received guidance on all rights to them. It is noteworthy that the lack of guidance from the beginning has imposed great challenges in the everyday life of these people, forced to spend high values for the purchase of materials essential to the treatment with BRP, essential medication in the presence of sequels, among other inputs for the daily care, and transportation to health services, these rights guaranteed by the law.

One mother voiced the long period of approximately four years, to have access to information on current public policies that could benefit her daughter and legal ways to achieve their rights. It emphasizes, however, that despite the CCB to be of great importance and assistance to these families, other guidelines are also fundamental to the families dealing with different sequelae of MMC.

This statement is reinforced when it is observed that the benefit has proved unable to supply all the demands of those expressing the magnitude of the importance of family members being trained on the legislation, clearly and in simple language, so that people can live better.

However, it is observed by some health professionals, little attention to guidance to users about their rights, perhaps by ignorance or even absence of training on such policies. In this sense, the presence of weaknesses related to clarification, or even to social rights, education becomes especially worrisome in the institution where the study was conducted, since at this location many professionals are working with children and adolescents who chronically diseased.

When I left here, the nephrologist just gave me a paper with the number of a probe for me to buy [when asked about receiving information on the rights of the child, after discharge of the reference service] [...] She spent a lot of time using antibiotics and medicine for the kidneys, long time I bought [not knowing who had the right to receive, even being accompanied in a reference center (Jane)].

Despite regulatory provisions contemplated to ensure the receipt of medicines and therapeutic material for BRP as according to Decrees N^o 3298 and N^o 7,508^{12,20} for many years these families faced financial obstacles to offer treatment and proper care for the children, by not being aware of rights provided for in Brazilian legislation for decades. To Soares, Moreira and Monteiro, there are laws guaranteeing minimum rights for people with disabilities in Brazil, however, are little known by most people, which affects its effectiveness and applicability²⁹.

It is believed that health professionals who assist chronically diseased users since its birth should be the main source of guidance for families. So, should clarify the daily care, treatment, illness, rehabilitation process and also about the benefits they are entitled to promoting the exchange of information and increasing their level of understanding about public health policies.

However, was observed in this study, it still has prevailed the biomedical character in assisting these professionals, which makes it necessary to look beyond illness and the physical body, which is more comprehensive, human, involving the various dimensions of living of children and adolescents with special needs.

In this context, what has been seen in health institutions are professionals less committed to users and principles of the SUS, which makes it urgent to reformulate the health professional training, in order to change the existing social models. To this end, the courses should prioritize the formation of technically competent people to take care in a humanized form, ethical, responsible and with quality³⁰.

Similar research showed that most of those responsible for children and adolescents with spina bifida had received guidance related to some legal benefits in health services, although only slightly over half has been guided by health professionals. Thus, it becomes necessary to emphasize social actions on the subject among these professionals in order to promote the dissemination of information in its context of care¹⁷.

In addition to health care professionals, relatives with a greater degree of guidance and education may represent a source of information for families, as well as others responsible for individuals with special needs, the television media, social networks and health support institutions.

I know, I think from watching television, then I asked him if he [doctor] could give [certificate], then he said he gave (Safira).

There is an association, its very good, half the things I've learned until today was through the Sspinal cord and brain association that has membership in the municipality H, then we made part of it. It has the President who is a very nice person, he has taught a lot, through it was that I entered in those rights, in those few rights that I'm knowing (Ezequias).

In a similar context, research developed in Rio de Janeiro in order to understand the access to some legal benefits, 33.75% of the responsible for people in chronic illness demonstrated having received this information in the waiting room of health services, during conversation with other relatives, and 12.5% through the media¹⁷.

About the informal networks of guidance, a study held with young Brazilians and Americans who have spina bifida showed that they sought support in these areas as well as among friends, in order to obtain information about their rights, leading to serious problems, due to acquire erroneous information and often outdated. On the other hand, young Americans had other sources more accessible and reliable in obtaining the information (schools, health institutions and associations), facilitating awareness of their rights²⁹.

In relation to the information acquired without the guidance of health professionals, it was observed that many were also focused on financial benefit. Without doubt, the access to this benefit has been facilitated, and constitutes one of the first guidance provided to the families and that they seek to take ownership of, since it represents essential aid to those with low socioeconomic status.

Thus, it is essential to train health professionals to work with children who exhibit various types and degrees of physical and mental disabilities, through the implementation of disciplines that address the SUS and its public health policies, especially for this excluded population from society as a result of organic and social limitations.

In addition, it is also imperative to putting in all the services of the health care network, a process of continuing education for professionals, so that they can guide the families about the benefits provided in the public health policies, to which children and adolescents with special needs are entitled. That way, there will be a greater degree of understanding of the family and, therefore, more access to benefits and a better quality of life.

CONCLUSION

The research enabled to understand the knowledge of the participants in the study about public health policies in Brazil for children and adolescents with severe neural malformations, such as MMC. There was partial understanding of the rights, emphasized in monthly financial benefit guarantee for users with disabilities resulting from neurological complications, although in some cases have obtained this information far ahead. The sources of information are different to make them aware of this benefit, besides those from the health professionals, however, still insufficient and with weaknesses, as regards the search for further knowledge of these families.

Thus, the observed aspects in this study infers that the ignorance of families and/or user of their rights implies even more difficulties and challenges to the everyday life of these

people, because they need to fight constantly for acquisition of medicines, hygiene materials, equipment of locomotion and other inputs necessary for the treatment of children and adolescents with MMC.

The weaknesses in the process of guidance and family education on the part of health professionals, active in the health care network, appears to influence the knowledge of these families, since many participants demonstrated not knowing the public health policies for the benefit of users with chronic situations, in this case, neurological congenital diseases. Such diseases present few prospect of recovery of the deficiencies, but significant possibilities for rehabilitation and improvement of the quality of life and, therefore, the people affected by them must be included in multiple instances of social rights and citizenship. Certainly, the situation identified in health services becomes an obstacle for these families to have more empowerment and take advantage of their rights, since they are not properly oriented on how they should act to achieve them.

It is necessary to acquire skills and abilities on the part of health professionals to enable them to act together with these families, thus favoring their greater empowerment with regard to clinical aspects of treatment, backed by public health policies, making them more autonomous citizens and subject to the existing social rights in the country. To this end, it is believed that the formation of these professionals must be anchored in debates and knowledge of SUS and its guidelines, and their own health services should provide, permanently, training programs for these important actors in the process of guidance and education of families, about public policy and users rights.

ACKNOWLEDGMENT

To Conselho Nacional de Desenvolvimento Científico e Tecnológico (CNPq), for the scientific initiation scholarship provided to the development of this study.

REFERENCES

- Santos LMP, Pereira MZ. Efeito da fortificação com ácido fólico na redução dos defeitos do tubo neural. *Cad Saúde Pública*. 2007 jan;23(1):17-24.
- Bowman RM, Boshnjaku V, Mclone DG. The changing incidence of myelomeningocele and its impact on pediatric neurosurgery: a review from the Children's Memorial Hospital. *Childs Nerv Syst*. 2009;25(7):801-6.
- Aguiar MJB, Campos AS, Aguiar RALP, Lana AMA, Magalhães RL, Babeto LT. Defeitos de fechamento do tubo neural e fatores associados em recém-nascidos vivos e natimortos. *J Pediatr*. 2003;79(2):129-34.
- Pacheco SS, Souza AI, Vidal AS, Guerra GVQL, Filho MB, Baptista EVPB, et al Prevalência dos defeitos de fechamento do tubo neural em recém-nascidos do Centro de Atenção à Mulher do Instituto Materno Infantil Prof. Fernando Figueira, IMIP: 2000-2004. *Rev Bras Saúde Matern Infant*. 2006 maio; 6(supl. 1):35-42.
- Cipriano MAB, Queiroz MVO. Cuidado com a criança portadora de mielomeningocele: vivência da família. *Rev Rene*. 2008;9(4):72-81.
- Mcdonald MG, Seshia MMK, Mullet M.D. (1975). Avery, neonatologia: fisiopatologia e tratamento do recém-nascido. Tradução de Vasconcelos MM, Voeux PL. Rio de Janeiro: Guanabara Koogan; 2007.
- Cornegé-Blokland E, Jasen HE, de Jonq-de Vos van Steenwijk CC, Poenaru D. Quality of life of children with spina bifida in Kenya is not related to the degree of the spinal defects. *Trop Med Int Health*. 2011 jan;16(1):30-6.
- Sousa NAD, Barros ASS. Percepções de mães acerca da inclusão escolar de crianças com lesão medular por mielomeningocele. *RBSP*. 2010;34(4):758-72.
- Gaiva MAM, Corrêa ER, Santo EARE. Perfil clínico-epidemiológico de crianças e adolescentes que vivem e convivem com espinha bífida. *Rev Bras Crescimento Desenvolvimento Hum*. 2011; 21(1):99-110.
- World Health Organization. Preventing Chronic Diseases a vital investments. 1ª ed. Genebra: WHO; 2005.
- Artigo n.196 da Constituição Federal do Brasil de 1988 (BR). Dispõe sobre a Constituição da República Federativa do Brasil. *Diário Oficial da União* [periódico na internet], Brasília (DF). 1988 [acesso em 9 jan 2015]. Disponível em: http://www.planalto.gov.br/ccivil_03/constituicao/constituicaoconsolidado.htm
- Decreto nº 3.298 de 20 de dezembro de 1999 (BR). Dispõe sobre a Política Nacional para Integração da Pessoa Portadora de Deficiência. *Diário Oficial da União* [periódico na internet], Brasília (DF); 21 dez. 1999 [acesso em 9 jan 2015]. Disponível em: http://www.planalto.gov.br/ccivil_03/decreto/d3298.htm
- Decreto nº 5.296 de 2 de dezembro de 2004. Regulamenta as Leis nos 10.048, de 8 de novembro de 2000 e a 10.098, de 19 de dezembro de 2000, e dá outras providências. *Diário Oficial da União* [periódico na internet], Brasília (DF). 2004 [acesso em 9 jan 2015]. Disponível em: http://www.planalto.gov.br/ccivil_03/_ato2004-2006/2004/decreto/d5296.htm
- Santos ECB, Teixeira CRS, Zanetti ML, Santos MA. A efetivação dos direitos dos usuários de saúde com diabetes mellitus: responsabilidades entre poder público, profissionais de saúde e usuários. *Texto Contexto Enferm*. 2011;20(3):461-70.
- Minayo MCS, organizadora. O Desafio do Conhecimento. Pesquisa Qualitativa em Saúde. São Paulo: Hucitec; 2010.
- Bardin L. Análise de conteúdo. Tradução Luís Antero Reto e Augusto Pinheiro. São Paulo: Edições 70; 2011.
- Elias MP, Monteiro LMC, Chaves CR. Acessibilidade a benefícios legais disponíveis no Rio de Janeiro para portadores de deficiência física. *Ciênc saúde coletiva*. 2008;13(3):1041-50.
- Pavão SL, Silva FPS, Rocha NAC. Efeito da orientação domiciliar no desempenho funcional de crianças com necessidades especiais. *Motricidade*. 2011;7(1):21-9.
- Astolpho MP, Okido ACC, Lima RAG. Rede de cuidados a crianças com necessidades especiais de saúde. *Rev Bras Enferm*. 2014;67(2):213-19.
- Decreto nº 7.617 de 17 de novembro de 2011. Altera o Regulamento do Benefício de Prestação Continuada, aprovado pelo Decreto no 6.214, de 26 de setembro de 2007. *Diário Oficial da União* [periódico na internet], Brasília (DF). 2011 [citado 9 jan 2015]. Disponível em: http://www.planalto.gov.br/ccivil_03/_Ato2011-2014/Decreto/D7617.htm
- Lei nº12.796 de 4 de abril de 2013. Altera a Lei nº9.394, de 20 de dezembro de 1996, que estabelece as diretrizes e bases da educação nacional. *Diário Oficial da União* [periódico na internet], Brasília (DF). 2013 [citado 9 jan 2015]. Disponível em: http://www.planalto.gov.br/ccivil_03/_ato2011-2014/2013/lei/l12796.htm
- Brasil. Governo Federal. Secretaria de Direitos Humanos. Plano Nacional dos Direitos da Pessoa com Deficiência - Viver sem Limite. *Diário Oficial da União* [periódico na internet], Brasília (DF). 2011 [citado 9 jan 2015]. Disponível em: http://www.pessoacomdeficiencia.gov.br/app/sites/default/files/arquivos/%5Bfiel_generico_imagens-filefield-description%5D_0.pdf

23. Sbragia L, Machado IN, Rojas CEB, Zambelli H, Miranda ML, Bianchi MO, et al. Evolução de 58 fetos com meningomielocoele e o potencial de reparo intra-útero. *Arq Neuropsiquiatr*. 2004;62(2):487-91.
24. Bergamaschi AMT, Faria TCC, Santos CA. Perfil dos pacientes portadores de mielomeningocele na cidade de Mogi das Cruzes. *Rev Neurocienc*. 2012;20(3):345-49.
25. Sousa AF, Fraga MNO. Como as pessoas com deficiência avaliam as políticas públicas de saúde no Ceará. *Revista de Avaliação das Políticas Públicas*. 2008;1(1):81-90.
26. Decreto nº7.508 de 28 de junho de 2011. Regulamenta a Lei nº 8.080, de 19 de setembro de 1990, para dispor sobre a organização do Sistema Único de Saúde - SUS. *Diário Oficial da União [periódico na internet]*, Brasília (DF). 2011 [acesso em 9 jan 2015]. Disponível em: http://www.planalto.gov.br/ccivil_03/_ato2011-2014/2011/decreto/D7508.htm
27. Lei nº 8.069 de 13 de Julho de 1990. Dispõe sobre o Estatuto da Criança e do Adolescente. *Diário Oficial da União [periódico na internet]*, Brasília (DF). 1990 [acesso em 9 jan 2015]. Disponível em: http://www.planalto.gov.br/ccivil_03/leis/18069.htm
28. Conselho Federal de Serviço Social. *Legislação e Resoluções sobre o trabalho do/a assistente social*. Conselho Federal de Serviço Social - Gestão Atitude Crítica para Avançar na Luta. Brasília: CFESS; 2011.
29. Soares AHR, Moreira MCN, Monteiro LMC. A qualidade de vida de jovens portadores de espinha bífida brasileiros e norte-americanos. *Ciênc saúde coletiva*. 2008;13(2):2215-23.
30. Erdmann AL, Backes DS, Klock P, Koerich MS, Rodrigues ACRL, Drago LC. Discutindo o significado de cidadania a partir dos direitos dos usuários da saúde. *Rev enferm*. 2008;16(4):477-81.