Esc Anna Nery 2022;26:e20210236

RESEARCH | PESQUISA

www.scielo.br/EAN

Search for quality and safety in child care: family interactions with home care professionals

Busca de qualidade e segurança no cuidado ao filho: interações familiares com profissionais de Home Care

Búsqueda de calidad y seguridad en cuidado al hijo: interacciones familiares con profesionales del Home Care

Roberto Corrêa Leite[1]
Circéa Amalia Ribeiro[2]
Mariana Lucas da Rocha Cunha[1]
Edmara Bazoni Soares Maia[2]
Luiza Watanabe Dal Ben[3]
Fabiane de Amorim Almeida[1]

1. Faculdade Israelita de Ciências da Saúde Albert Einstein. São Paulo, SP, Brasil.

2. Universidade Federal de São Paulo, Escola Paulista de Enfermagem. São Paulo, SP, Brasil.

3. Faculdade de Educação em Ciências da Saúde, Hospital Alemão Oswaldo Cruz. São Paulo, SP, Brasil.

Corresponding author:
Roberto Corrêa Leite.
E-mail: leite.rc@uol.com.br

Submitted on 06/27/2021.
Accepted on 09/15/2021.

DOI:https://doi.org/10.1590/2177-9465-EAN-2021-0236

ABSTRACT

Objective: to understand the experience of family caregivers of children/adolescents assisted by the multidisciplinary team in home care. **Method:** this is a qualitative study, with Symbolic Interactionism as a theoretical framework, carried out with nine families of children/adolescents in home care, assisted by a home care company located in São Paulo. Data were collected between April and October 2017, through semi-structured interviews, and submitted to qualitative analysis of conventional content. **Results:** the subcategories *Living in a constant state of alert* and *Taking a step forward to ensure safe and qualified care* showed that family members give new meaning to care, showing themselves to be alert, in the sense of redirecting their actions to provide idealized care. **Conclusion:** home care requires family members to face new challenges and difficult adaptations, in addition to the concern with safety and quality of care, leading them to develop strategies to deal with the situation. **Implications for practice:** family members' speeches signal the urgency of inserting the theme of pediatric home care in the agendas of academic debates and discussions, and its unfolding in investments by managers and home care services, in order to ensure a safe assistance to children/adolescents and their family.

Keywords: Caregivers; Pediatric Nursing; Quality of Health Care; Patient Safety; Home Assistance Services.

RESUMO

Objetivo: compreender a vivência do cuidador familiar de crianças/adolescentes assistidos pela equipe multiprofissional em *Home Care*. **Método:** estudo qualitativo, tendo o Interacionismo Simbólico como referencial teórico, realizado com nove famílias de crianças/adolescentes em internação domiciliar, atendidas em uma empresa de *Home Care* localizada em São Paulo. Os dados foram coletados entre abril e outubro de 2017, por meio de entrevistas semiestruturadas, e submetidos à análise qualitativa de conteúdo convencional. **Resultados:** as subcategorias *Vivendo em constante estado de alerta* e *Dando um passo à frente para garantir um cuidado seguro e qualificado* evidenciaram que os familiares ressignificam o cuidado, mostrando-se alertas, no sentido de redirecionar suas ações para prover uma assistência idealizada. **Conclusão:** o *Home Care* exige dos familiares o enfrentamento de novos desafios e difíceis adaptações, além da preocupação com a segurança e qualidade do atendimento, levando-os a desenvolverem estratégias para lidar com a situação. **Implicações para a prática:** os discursos dos familiares sinalizam a urgência da inserção da temática do cuidado pediátrico em *Home Care* nas pautas de debates e discussões acadêmicas, e seu desdobramento em investimentos por parte de gestores e serviços de atendimento domiciliar, a fim de garantir uma assistência segura à criança/adolescente e sua família.

Palavras-chave: Cuidadores; Enfermagem Pediátrica; Qualidade da Assistência à Saúde; Segurança do Paciente; Serviços de Assistência Domiciliar.

RESUMEN

Objetivo: comprender la experiencia de los cuidadores familiares de niños/adolescentes asistidos por el equipo multidisciplinario en *Home Care*. **Método:** estudio cualitativo, con Interaccionismo Simbólico como marco teórico, realizado con nueve familias de niños/adolescentes en atención domiciliaria, atendidos en una empresa de *Home Care* ubicada en São Paulo. Los datos fueron recolectados entre abril y octubre de 2017, a través de entrevistas semiestructuradas, y sometidos a análisis cualitativo de contenido convencional. **Resultados:** las subcategorías *Vivir en constante estado de alerta* y *Dar un paso adelante para garantizar una atención segura y calificada* mostraron que los familiares dan un nuevo significado al cuidado, mostrándose alerta, en el sentido de reorientar sus acciones para brindar un cuidado idealizado. **Conclusión:** *Home Care* requiere que los familiares enfrenten nuevos desafíos y adaptaciones difíciles, además de la preocupación por la seguridad y la calidad de la atención, lo que los lleva a desarrollar estrategias para enfrentar la situación. **Implicaciones para la práctica:** los discursos de los familiares señalan la urgencia de insertar el tema de la atención pediátrica en *Home Care* en las agendas de los debates y discusiones académicas, y su despliegue en inversiones de los administradores y de los servicios de atención domiciliaria, con el fin de garantizar la seguridad del cuidado infantil/adolescente y su familia.

Palabras clave: Cuidadores; Enfermería Pediátrica; Calidad de la Atención de Salud; Seguridad del Paciente; Servicios de Atención de Salud a Domicilio.

INTRODUCTION

In general, the population's living conditions have improved in recent years, significantly contributing to the increase in survival not only for adults and the elderly, but also for children and adolescents in complex health care.[1] In this context, faced with a limiting and life-threatening disease, represented by congenital anomalies, cancer and neurological conditions, children are increasingly directed to palliative care at home.[2]

This fact is also linked to scientific advances and the insertion of new technologies in hospital environments and in home care services.[1]

Moreover, the encouragement of safe early de-hospitalization and the concern with a better quality of life for patients with chronic diseases and technology users have been increasing the demand for home care services, which has positively impacted the reduction of healthcare costs in the population.[1,3]

It is noteworthy that, in supplementary health, the request to monitor a patient through home care depends on the submission of a medical report to a health care provider. This document, prepared by the assistant physician, details clinical conditions, history, prescriptions, tests, complications and the justification for patient discharge, linked to home care. Based on this conduct, a health care provider requests an assessment for one of its accredited home care companies and awaits the opinion of the health team with the return of a home care plan.[4]

It is worth noting that home care is not yet a type of service regulated by the Brazilian National Supplementary Health Agency (*Agência Nacional de Saúde Suplementar*), being considered a concession to users of private health care plans and still a challenge to be conquered.[4,5]

Thus, in view of the strategic importance of de-hospitalization, changes in the demographic and epidemiological profile of the world population, added to social and cultural transformations, it is essential to rethink the health care model with emphasis on home care, represented by the home care services.[3,6,7] Nursing represents the largest contingent of professionals involved in home care;[3] however, given a growing demand for these services, there is a shortage of labor in this context.

In the pediatric care scenario, this reality is even more adverse, since health care directed at this clientele demands specific skills and competences, being permeated by challenges, physical and emotional weaknesses that make care difficult and reflect on relationships with the families.[8]

When the care setting is at home, these difficulties are naturally accentuated, added to the challenges inherent to the home care service itself.[8] Thus, this service impacts the daily lives of families, by changing the routine of the house and the definition of roles, interfering with the freedom and autonomy of the family system in the face of the constant presence of professionals. It also causes emotional and physical wear, insecurity and caregiver burden, who also experience their own unpreparedness for home care when support networks are insufficient and professionals are not qualified.[2,9,10]

Thus, the work of professionals at home requires specific skills and profile that allow them to offer quality care, as their work will be developed in family intimacy.[11] In this scenario, the health team interacts with different family arrangements, constituted by their own cultures, beliefs and values, in addition to different expectations. This requires, on the part of professionals, a great effort to expand their view beyond the biological and an adequate adaptation, in order to provide the best experience for patients and their family.[4,9]

Furthermore, professionals must be sensitized to understand that the constant coexistence of parents with the possibility of imminent loss of their child is among the most stressful parental experiences. In this process, the family caregiver develops some strategies to deal with the situation, such as avoiding showing their emotions to keep the imminent feeling of losing a child under control, seeking support and taking control to provide the ideal child care, adapting and accepting the changes that are underway.[12]

All of this reinforces the need for professional development of skills, in order to support and welcome the family in the situation of having children under home care, and strengthen the bond between professional and family to obtain effective, quality and safe care.[8]

The Brazilian Society of Pediatric Nurses recently published its position on the essential competencies inherent to nurses working in pediatric nursing, emphasizing their important role in the recovery, rehabilitation and palliative care of children and adolescents, at different levels of complexity, in order to achieve their well-being and the quality of health care.[13]

However, in our professional experience, interacting with families of children/adolescents assisted in home care, we observe a great concern of the family with patient safety and the quality of care related to technical, relational and care environment issues.

Thus, aiming to better understand this scenario and not finding answers in the literature, this study aims to understand the experience of family caregiver of children/adolescents assisted by the multidisciplinary team in a home care company.

METHOD

This is a clipping of a master's thesis, with a qualitative approach, having Symbolic Interactionism as a theoretical framework.[14] For interactionists, society and the individual are closely related, through individual and collective actions, and feelings and attitudes are built from the meanings people attribute to objects and symbols. It is based on the conception that the human being acts in relation to the world according to the meaning that things have for them.[14]

In turn, the meanings of things have their origins in the social interaction between people; from this interaction, they learn to see the world through an interpretive process used by the individual when

relating to things or objects.[14] In this perspective, the framework allowed to broaden the understanding of the meanings that the family caregiver attributes to their interaction with home care professionals during the care of children/adolescents at home.

Participants were selected by intentionality,[15] according to the first researcher's previous experience with families assisted by a home care service, which he was the nurse in charge. The following selection criteria were established: families of children/adolescents aged between two and 16 years; in home care for six, 12 or 24 hours, whose family caregiver had performed this role for over a year.

From this, eligible family caregivers were invited to participate in the study through telephone contact, at which time the objectives, risks, benefits and how their participation in the research would be presented. The interviews were scheduled according to caregivers' availability, being agreed upon at the time of invitation. All invited families agreed to participate in the study and signed the Informed Consent Form.

Were interviewed 14 family caregivers of children/adolescents with chronic illnesses, belonging to nine families assisted in a private home care company located in the countryside of the state of São Paulo. According to their financial income, participants belonged to the middle class, aged between 19 and 47 years old, nine of which were mothers, seven were married, one was divorced and one was separated. Only one was the child's/adolescent's brother and four were parents who helped in care. The minimum educational level of caregivers was complete high school, with three having completed higher education, and two, postgraduate studies. As for the occupation of the mothers who participated in the research, five were housewives, one was a speech therapist, one was a merchant, one was a toll collector and one was a human resources manager. As for parents, one was a boilermaker, one was a civil engineer, one was a systems analyst, one was a mechanic and the other was a toolmaker.

About children/adolescents, nine were between two and 16 years old, had neurological diseases and congenital malformations. Seven were dependent on technologies, such as mechanical ventilator, presence of tracheostomy and gastrostomy, and were in home care with 24 hour nursing care, one with 12 hours and the other with home care for 6 hours. The service time in home care ranged from 8 years and 9 months to 1 year and 3 months. Data collection was carried out in the homes, by the first researcher (master's student in nursing), through a semi-structured audio-recorded interview, with an average duration of 80 minutes, held between April and October 2017.

To favor communication and the establishment of a bond with caregivers, a genogram and an ecomap were used as the initial approach strategy, emphasizing, however, that these records did not constitute objects of analysis.[16] After this stage, the interviews were guided by the following question: how do you perceive the role of the home care multidisciplinary team when dealing with your child?

The inclusion of new participants was interrupted from the moment the theoretical saturation occurred, i.e., when it was realized that the data obtained were already sufficient to allow the understanding of the phenomenon.[15]

The systematic of data analysis followed what was determined by conventional qualitative content analysis, which constitutes a methodological resource in which the coding of categories derives directly from the empirical data.[17] Its application is justified by the fact that it provides direct information from participants without imposing preconceived theories or categories. Furthermore, this approach is appropriate when the phenomenon to be studied lacks greater understanding. Thus, after exhaustive reading of the data, the analysis went through the four stages recommended by the method: data codification, categorization, integration and category description.[17]

The study was approved by the Institutional Review Board, under Opinion 1.906.931 and CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 63242316.6.0000.0071. All ethical precepts were respected and to ensure anonymity, fragments of family members' statements were identified by their role in the family, father or mother, followed by the order number of their interview.

RESULTS

The content expressed by the interviewees allowed the construction of the central category *Seeking to ensure the safety and quality of care for children in home care*, which highlights the constant concern of the family in providing safe and qualified child care. For this, they give new meaning to this care, show themselves alert and decide to redirect actions in a movement to provide the idealized care. This category consists of two subcategories: *Living in a constant state of alert* and *Taking a step forward to ensure safe and qualified care*, and will be discussed below.

Living in a constant state of alert reveals that parents, when interacting with the multi-professional team at home, are often faced with the inexperience, technical unpreparedness and lack of skills of these professionals to deal with children/adolescents. This situation is defined by them as a great challenge to be faced, which makes them live in a constant state of alert, generating physical and emotional overload and altering the meaning of their lives. In this interaction, the family expects professionals to be experienced in caring for children, gradually becoming disappointed when they perceive a more hospital-oriented attitude, valuing the disease at the expense of attention to the peculiarities of the family inserted in home care.

> *Oh, the professionals who started working in home care; in the beginning, we thought that, because it was health, the professionals who would come were professionals who had experience, and then a greater challenge was generated. And what was it? How are we going to do it? Because there was already a problem with physiotherapist,*

> *with speech therapist, now the nursing team arrives... people have no experience. So, we were no longer had a life! (Father, Family 8).*
>
> *Father: When we came home with home care, we had no idea what we were going to find. Mother: So much disqualification, people we see unprepared for this type of care. Father: They did not have, (nursing professionals), so to say, skills to deal with a baby (Father and Mother, Family 3).*
>
> *The people who had experience were the worst people to work with M. (child). It took us a while to figure that out, didn't it? Many come with a very hospital look! (Mother, Family 8).*

From parents' perspective, home hospitalization is different from hospital and has a palliative condition. In this daily life, concerns emerge that range from the perception that the nurse in charge is far from supervising home care to the observation of the nursing technician's lack of aptitude, leading him to make mistakes during care. Therefore, parents question themselves and are insecure in delegated responsibility for child care to an unprepared professional.

> *We see home care as a condition... a palliative... a parallel to a hospital stay [...] so we often realized that, in addition to the technician not being able, the supervision of this technician is very distant. So, he (nursing professional) often does wrong, due to distance from his supervision (Father, Family 8).*
>
> *[...] so, how do you do? How do you leave your child? The one you prepared, planned, stayed, abandoned everything, dropped out of profession, dropped everything, lived five months in a hospital... to come to anyone (health care professional) and do anything? (Mother, Family 3).*

Another mother expresses frustration regarding professionals' work who, in her perspective, do not seem to bother to perform to the maximum to improve children's quality of life. This implies concern about the lack of technical competence of professionals, triggering insecurity and poorly slept nights, requiring a greater mother involvement in child care.

> *I have to give the maximum quality of life to this person, in what I'm going to do. I think this way! I'd like everyone to do this to my son and that's not what I live for. This concern is ours (parents), isn't it? Not bring more difficulty to L. (child) and more complications to him. That's why we insist on professionals who have a little more quality (Mother, Family 3).*
>
> *So, I mean... I can rest, but with someone who is already adapted with E. (child). But, when the person is new (nursing professional), I follow her up. Then the routine is like this... I sleep very little (Mother, Family 2).*
>
> *I did not know the team. So, until I could relax and have a nice night, it took almost a month. I used to take naps. Why? Because I know if (mechanical ventilator) disconnects and no one listen, my son will die, right? (Mother, Family 5).*

According to one parent, working in home care service means for professionals a secondary source of income or an opportunity to gain more experience and, in the future, to achieve better positions in the labor market, such as working in hospital institutions.

> *From the experience we have inside the house, everyone enters with the dream of entering the hospital. Everyone has this desire. It's a trampoline, isn't it? Because hospital does not hire without experience... many professionals also see it as a gig (home care work) (Father, Family 8).*

Despite the wear on the family resulting from the constant concern with professionals' work, there are affective bonds that are also built, causing the family to suffer from professional turnover in home care service. Moreover, this constant exchange of professionals is also perceived as exhausting for children and for the home care company itself.

> *Mother: One of the points that is very exhausting for both us and for them (nursing professionals), I believe that for home care as well and for M. (child), mainly, is the exchange. Father: You know, we know that she (nursing professional) will get a job and then we will suffer. Who suffers? We do... (Mother and Father, Family 8).*

One of the mothers reports that the professionals who work in the administrative area of home care, in this case nurses, are indifferent to the care of her child.

> *Here, (professionals' work at home) for me, is great. It seems like: they (nurses working in the administrative area of home care) are not in here, so whatever. [...] so, for me, my positive side is the professionals inside my house, the treatment with my daughter and the negative side is the outside (administrative area) (Mother, Family 6).*

Subcategory *Taking a step forward to ensure safe and qualified care* reveals that, from caregivers' insecurity considering the multidisciplinary team's technical unpreparedness, with emphasis on nursing professionals, family members mobilize themselves in the search for knowledge, which they did not have until then, striving to learn from more experienced professionals, best way to take care of children.

And now? (team's technical unpreparedness) We are with nursing, what will we have to do? You're going to have to practice. But we don't have enough knowledge, I don't know. So, what did we do? We went to try to.... learn. So, we had one of the techniques, which already worked in the ICU of the hospital... She set out to work from home. It was right at the beginning [...] as the hospital greatly intensified training, it helped us a lot (Father, Family 8).

Oh! So, they (nursing professionals) trained me at the hospital. You know? They said: we will train you because you will need to do this in your house [...] you know, I thought I wasn't going to make it, but I did it! (Mother, Family 9).

Thus, in view of this condition of insecurity, parents perceive themselves in the obligation to seek knowledge and teach professionals to take care of their children/adolescents at home.

I had to teach... So... there is no problem with me teaching, [...]. but the basics that is aspirating (tracheostomy), home care has to send people who know how to aspirate, and when the girl (nursing professional) came, the one we hired, she came the day I went to work. I said: no, I will not, I have to wait! I arrived late that day at work... (Mother, Family 5).

So, we had to know how all her medications work. Yes, and we have the controlled medications, which is the: if necessary! As controlled, we isolate from the room. Why? Girls (nursing techniques) mix [...] no one administers Diazepan in her other than us (parents) (Father, Family 8).

In this sense, seeking to guarantee the technical quality of care, family members strive to defend the permanence as long as possible of the same nursing professionals on the service scale, softening the impact of child and family adaptation to the new employee.

I even fought to keep the girls (nursing professionals) who already cared for him (child), who were already used to. I think it's neither healthy for him (child) nor anyone else to keep this lot of change (turnover on the nursing scale) too (Mother, Family 5).

In an attempt to take a step forward to ensure child safety, the mother decides to interview the newly admitted professional in the home service before starting to work in her home, seeking to know better their profile and if it corresponds to the family's expectations.

I do interview when there is a need for a technician (nursing professional) and if I see that the person is very out of the profile of the entire home care team... of the team here, of nursing... doctor, physiotherapist... I already ask not to come (Mother, Family 2).

Finally, although family members recognize that home care is not an easy task, they highlight the importance of achieving and establishing mutual trust with the multidisciplinary team.

So, it's not easy. You need to have a good team... you need to gain their (nursing professionals') trust, they gain their trust. That's all... all a set. [...] but that can also generate trust for the whole family! (Mother, Family 1).

DISCUSSION

Among the findings, the search for patient safety and quality of health care are aspects that mark the family's daily life with children in home care. The interaction is permeated by concerns about failures in the quality of care delivery, characterized by the absence of an adequate flow of information exchange between the team working in home care and family caregivers, in addition to evident weaknesses in relation to the skills and abilities in the administrative area of this system.

Living in a constant state of alert emerges from the recognition of technical vulnerabilities by the family, which are signified in the interaction with the multidisciplinary team. Thus, the members of this family feel obliged to take the lead in child care. The responsibility and concern of family caregivers with themselves and with the other is noted,[14] represented in this scenario by children/adolescents. This would be an expected action in home care so that this caregiver could progressively be main actors of the care of their children. However, this role cannot impose itself due to the technical and relational unpreparedness of those who, par excellence, should provide quality and safety in the service.

Studies emphasize the need for professional training in order to ensure a safe transition between hospital and home care, respecting all their peculiarities, especially in the care of children with complex conditions. They also emphasize that knowledge contributes to the empowerment of these professionals, which would probably make them better qualified to perform this activity and bring greater security to families.[7,18]

A survey conducted with a focus on the perspective of professionals working in home care service points out that maintaining high levels of family and patient satisfaction is closely related to investment in training programs for these professionals, before starting to work in homes.[19]

However, in the context of home care, this "empowerment" is influenced by the production and exchange of knowledge wrapped in meanings that guide the actions of caregivers and the multidisciplinary team, resulting from interactions with the routines of each household and the experience within a private space that does not belong to everyone involved.[20] And it is

because of this characteristic of home care that training curricula must enable the development of skills and an ethics that consider the complexity and specificity of home care.[9]

Therefore, training to work in home care services must consider, in addition to the mastery of specialized technical procedures, the multiplicity of family dynamics and the ability of professionals to incorporate family's values, knowledge and potential through support, establishment of bonds and the development of specific skills and competences for this care.[9,21] This fact was not observed in this study, when the family sought to strengthen itself on its own initiative to protect children, relying on professionals with hospital expertise.

However, in this study, tensions are shown between professionals with little experience and technical inability, and professionals who have hospital experience, permeated by the lack of trust and bond in the work of both. Thus, even experienced professionals did not meet the expectations of family members in child care, due to their hospital vision. Possibly, this perception of caregivers is influenced by the biomedical model academic primacy, to the detriment of a practice centered on the patient and family, which restricts professionals' gaze to the sick person only, affecting trust and bonding.[22]

Still on this aspect, the importance of nurses learning in their training about the implementation of light technology in the family approach is highlighted. Its application involves human interactions, through active listening, which also favors bonding and trust between patients, families and professionals. Because it is so comprehensive and used in the application of other technologies, light technology is the biggest challenge for the training of nurses working in home care.[11]

Nurses have a fundamental place in the management of home care, helping families to organize themselves in the face of difficulties.[9] However, a qualitative study revealed that nurses' lack of ability to care for children at home is something common in families' routine, contributing to the increase in hospital admissions, medical procedures and the burden of caregivers who did not find a support point in nurses to take care of their children.[23] Similar data was highlighted in this study by parents, when they referred to the absence of nurses in direct supervision of home care.

Home care is recognized by the user as the best care option for clients with chronic diseases or dependent on technologies, providing them with the comfort of home and favoring the bond with the family and the team, in addition to overcoming barriers to access other points in the health care network. From users' perspective, home care presents new relationships that expand access, autonomy and quality of life for patients.[24] In this study, the lack of involvement of health professionals in promoting autonomy and valuing patients' quality of life towards rehabilitation were also reasons for dissatisfaction on the part of family caregivers, in addition to technical weaknesses.

Furthermore, for family caregivers to be satisfied and patients clinically evolve at home, it is necessary that the relationships between family and professionals are in balance, as both need each other's support.[25] Thus, the family must actively contribute and be involved in the definitions of actions taken at home.

From this perspective, it is necessary for health professionals to develop therapeutic plans based on goals that are in line with users' expectations, routine and family dynamics, and available resources. Therefore, taking into account the capacity and potential of patients and family caregivers in achieving the goals, they were based on consensual decisions among health professionals, patients, and caregivers.[26]

It is expected that in this way, it will be possible to promote an adequate rehabilitation of patients in the home environment, aiming at their autonomy according to their family's limits and hopes, towards comprehensive care and improved quality of life.[26]

A literature review found that, in general, within the Unified Health System (*Sistema Único de Saúde*), families feel satisfied with the service provided by home care teams; however, they point out that such an assessment can be linked to feelings of gratitude for the public and free nature and not for the understanding of health as a right, making it difficult to express criticism and dissatisfaction with the service provided.[9] In this study, which was developed in the context of private health care, families proved to be powerful in the assessment and recognition of the team's technical and relational weaknesses.

The results show that professional turnover in nursing was a relevant issue and highlighted by the family as a reason for dissatisfaction. In general, in the private home care setting, patients are assisted by self-employed professionals or those coming from a work cooperative. In this practice, it is observed that professionals' length of stay in the residence depend on their adaptability and good interaction they establish with patient and family as well as clinical conditions presented by patients.

Thus, it is not possible to accurately predict whether professionals will adapt to a particular residence, since, in the private system, family and patient can choose the professionals who will work at home. The concern with professional turnover was also reported in another study carried out in the *Programa Melhor em Casa*, pointing out as a risk the quality of care, due to the breaking of the bond with users and interference in the therapeutic plan conduction.[25]

In this context, the literature also highlights the relevance of asking clients what they believe to be most important in the care provided. This initiative allows for greater flexibility in the care plan when considering their needs, understanding that they are in the best position to know what their preferences are.[27]

However, it was found that the family mobilizes, *Taking a step forward to ensure safe and qualified care* for children, due to the insecurity with the team's performance and the lack of leadership and supervision of nurses, thus deciding to take over this role. Thus, in the face of stressful situations experienced, caregivers developed strategies to adapt and readapt to the new reality of caring for children/adolescents at home, which influenced the family functioning and well-being maintenance. Here, the first

premise of Symbolic Interactionism is evident, in which the way individuals act depends on the meaning that things have for them:[14] caring for their children with quality and safety.

In this sense, wanting to learn about professional care, among other strategies mentioned in this study, is part of this process of adaptation of families, which occurs as caregivers receive information and are guided by the multidisciplinary team.[28] On this aspect, the literature highlights the hybridity between professional and family activities, caused by the mutual interference of these logics, based on the interpretations of symbolic aspects between subjects in the daily life of home care.[20]

According to Symbolic Interactionism, the human being's ability to foresee a future event is achieved when they puts themselves in the other's shoes.[14] Considering in this study, the other symbolized by children/adolescents, family caregivers interacting with the technically debilitated nursing team, acquired skills to anticipate what the other's reactions would be; and from that, they developed strategies so that they could learn about care, providing support and protection to their children.

Faced with the context of technical weakness experienced by family caregivers in child care, it is worth emphasizing the importance of health professionals, especially nurses, in preparing them, even during hospitalization, in relation to autonomy to perform complex care at home, focused on clinical, nutritional, social conditions, and the use of technologies and medicines.[29]

In practice, it is observed that the process of education and preparation of family caregivers for discharge is still incipient, does not follow defined norms and standards among the multidisciplinary team members, resulting in insecurity for family members to perform home care. In this regard, the hospital must ensure that family caregivers are oriented before discharge is emphasized regarding the continuity of home treatment, reinforcing their autonomy as the main actor of care.[30,31] From this, caregivers would be better prepared to handle the lack of technical team training and the vicissitudes that will come after the process of de-hospitalization of their children.

Finally, given the growing demand of patients dependent on home care, there is an urgent need for restructuring educational programs in nursing, with a view to providing better preparation for professionals in training, and optimizing access to practices based on scientific evidence.[7,11]

Moreover, it is necessary to rethink health policies aimed at home care towards full regulation of the sector in Brazil. In praxis, in the supplementary health system, its access is still not equal to the entire population, since this procedure is not provided for in the list of the Brazilian National Supplementary Health Agency. In this regard, there is no obligation for the health plan operator to provide this assistance to its users.[4,5]

Thus, patients with the same clinical care needs will not always be authorized for this benefit, having to resort to a possible judicialization. In view of so many uncertainties, disparities, exceptions and the lack of standardization of conduct related to home care authorization emerge in this relationship, which reflect on the daily quality of care.[4,5]

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

This study reveals that home care requires family caregivers to face new challenges and difficult adaptations as well as the development of strategies to deal with the situation. The concern of family members with the safety and quality of health care provided to children/adolescents is evident, in order to prevent the occurrence of iatrogenic events, due to the turnover and lack of qualification of professionals working in homes.

Considering the uniqueness of home care present in the context of pediatric nursing, the family members' speeches signal the urgency that the theme of home care offered by nursing enters the agendas of academic debates and discussions and unfolds into investments by managers and home care services, in specific professional training programs for child/adolescent care and their family.

Furthermore, in view of a reality with so many particularities, such as home care, the need for nurses to take over their role as care manager is reiterated, integrating all professionals in the planning of home care, in actions that provide support, quality and safety in the daily care of these families.

A limitation was presented in a sample composed of caregivers from the same home care service, which may have influenced the results obtained, due to the company's cultural and organizational characteristics. The development of new studies involving the multidisciplinary team's perspective on the subject is recommended, in order to broaden the understanding of working conditions, how managers deal with the team's inexperience, and above all, how it is for professionals to take over this role and be in that position.

AUTHOR'S CONTRIBUTIONS

Study design. Roberto Corrêa Leite. Fabiane de Amorim Almeida. Circéa Amalia Ribeiro.

Data collection and production. Roberto Corrêa Leite.

Data analysis. Roberto Corrêa Leite. Fabiane de Amorim Almeida. Edmara Bazoni Soares Maia. Circéa Amalia Ribeiro. Mariana Lucas da Rocha Cunha.

Interpretation of results. Roberto Corrêa Leite. Fabiane de Amorim Almeida. Edmara Bazoni Soares Maia. Circéa Amalia Ribeiro. Mariana Lucas da Rocha Cunha.

Writing and critical review of the manuscript. Roberto Corrêa Leite. Fabiane de Amorim Almeida Edmara Bazoni Soares Maia. Circéa Amalia Ribeiro. Mariana Lucas da Rocha Cunha. Luiza Watanabe Dal Ben.

Approval of the final version of the article. Roberto Corrêa Leite. Fabiane de Amorim Almeida. Edmara Bazoni Soares Maia.

Circéa Amalia Ribeiro. Mariana Lucas da Rocha Cunha. Luiza Watanabe Dal Ben.

ASSOCIATED EDITOR

Aline Cristiane Cavachilli Okido

SCIENTIFIC EDITOR

Ivone Evangelista Cabral

REFERENCES

1. Rajão FL, Martins M. Home Care in Brazil: an exploratory study on the construction process and service use in the Brazilian Health System. Cien Saude Colet. 2020;25(5):1863-77. http://dx.doi.org/10.1590/1413812320202552.34692019. PMid:32402051.
2. Winger A, Kvarme LG, Loyland B, Kristiansen C, Helseth S, Ravn IH. Family experiences with palliative care for children at home: a systematic literature review. BMC Palliat Care. 2020;19(1):165. http://dx.doi.org/10.1186/s12904-020-00672-4. PMid:33099303.
3. Ministério da Saúde (BR). Atenção domiciliar no SUS: resultados do laboratório de inovação em atenção domiciliar/Ministério da Saúde. Organização Pan-Americana da Saúde. Brasília (DF): Ministério da Saúde; 2014.
4. Ribeiro C. Atenção Domiciliar: princípios, práticas e perspectivas. São Paulo: Eureka; 2019.
5. Resolução Normativa (RN) n. 465, de 24 de fevereiro de 2021 (BR). Atualiza o Rol de Procedimentos e Eventos em Saúde que estabelece a cobertura assistencial obrigatória a ser garantida nos planos privados de assistência à saúde contratados a partir de 1º de janeiro de 1999 e naqueles adaptados conforme previsto no artigo 35 da Lei n.º 9.656, de 3 de junho de 1998. Diário Oficial da União, Brasília (DF), 2 mar 2021.
6. Braga PP, Sena RR, Seixas CT, de Castro EAB, Andrade AM, Silva YC. Supply and demand in home health care. Ciênc Saúde colet. 2016;21(3):903-12. http://dx.doi.org/10.1590/1413-81232015213.11382015.
7. Jarrín OF, Pouladi FA, Madigan EA. International priorities for home care education, research, practice, and management: qualitative content analysis. Nurse Educ Today. 2019;73:83-7. http://dx.doi.org/10.1016/j.nedt.2018.11.020.
8. Machado AN, Nóbrega VMD, Silva MEA, França DBL, Reichert APDS, Collet N. Chronic disease in children and adolescents: professional-family bond for the promotion of social support. Rev Gaúcha Enferm. 2018;39:e20170290. http://dx.doi.org/10.1590/1983-1447.2018.2017-0290. PMid:30088608.
9. Procópio LCR, Seixas CT, Avellar RS, Silva KL, Santos MLM. A atenção domiciliar no âmbito do Sistema Único de Saúde: desafios e potencialidades. Saúde em Debate. 2019 abr/jun;43(121):592-604. http://dx.doi.org/10.1590/0103-1104201912123.
10. Dias BC, Ichisato SMT, Marchetti MA, Neves ET, Higarashi IH, Marcon SS. Challenges of family caregivers of children with special needs of multiple, complex and continuing care at home. Esc Anna Nery. 2019;23(1):e20180127. http://dx.doi.org/10.1590/2177-9465-ean-2018-0127.
11. Andrade AM, Silva KL, Seixas CT, Braga PP. Atuação do enfermeiro na atenção domiciliar: uma revisão integrativa da literatura. Rev Bras Enferm. 2017 fev;70(1):210-9. http://dx.doi.org/10.1590/0034-7167-2016-0214. PMid:28226061.
12. Verberne LM, Kars MC, Schouten-van Meeteren AYN, van den Bergh EMM, Bosman DK, Colenbrander DA et al. Parental experiences and coping strategies when caring for a child receiving paediatric palliative care: a qualitative study. Eur J Pediatr. 2019;178(7):1075-85. http://dx.doi.org/10.1007/s00431-019-03393-w. PMid:31104108.
13. Gaiva MAM, Silveira A, Viera CS, Maia EBS, Anders JC, Miranda JOF et al. Posição da Sociedade Brasileira de Enfermeiros Pediatras sobre as competências essenciais do enfermeiro neonatologista e pediatra. Rev Soc Bras Enferm Ped. 2020;20(2):116-33. http://dx.doi.org/10.31508/1676-3793202000016.
14. Charon JM. Symbolic interactionism: an introduction, an interpretation, an integration. New Jersey (US): Prentice Hall; 2004.
15. Hennink MM, Kaiser BN, Weber MB. What influences saturation? Estimating sample sizes in focus group research. Qual Health Res. 2019;29(10):1483-96. http://dx.doi.org/10.1177/1049732318821692.
16. Yorinobu AC, Andrade PR, Cruz AC, Silva L, Costa P, Belela-Anacleto AS. Contributions of genogram and ecomap in nursing consultations in child care. Rev Soc Bras Enferm Ped. 2019;19(1):16-22.
17. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15(9):1277-88. http://dx.doi.org/10.1177/1049732305276687. PMid:16204405.
18. Moreira MCN, Albernaz LV, Sá MRC, Correia RF, Tanabe RF. Recomendações para uma linha de cuidados para crianças e adolescentes com condições crônicas complexas de saúde. Cad Saude Publica. 2017;33(11):e00189516. http://dx.doi.org/10.1590/0102-311x00189516. PMid:29166490.
19. Alia A, Al-Salem A, Al-Ghunaim L, Al-Amri S. The quality of home healthcare service in Riyadh/Saudi Arabia. Asian Journal of Natural & Applied Sciences. 2016;5(2):72-81.
20. Borges MV, Silva ARL, Souza EM, Fantinel LD. Implicações simbólicas na organização de um home care: interpretações entre a equipe de saúde e os cuidadores familiares. REAd (Porto Alegre). 2016;22(1):52-76. http://dx.doi.org/10.1590/1413-2311.102014.53644.
21. Dias BC, Marcon SS, Reis PD, Lino IGT, Okido ACC, Ichisato SMT et al. Family dynamics and social network of families of children with special needs for complex/continuous cares. Rev Gaúcha Enferm. 2020;41:e20190178. http://dx.doi.org/10.1590/1983-1447.2020.20190178. PMid:32491146.
22. Carvalho NR, Andrade e Silva E, Moura de Oliveira D, Silva Cardoso Estevão A, Vieira Toledo L, Borges Figueiredo J. Percepções e práticas do técnico de enfermagem sobre a visita domiciliar na atenção primária. Rev Enf UFJF. 2019;5(1):1-17. http://dx.doi.org/10.34019/2446-5739.2019.v5.26768.
23. Mai K, Davis RK, Hamilton S, Robertson-James C, Calaman S, Turchi RM. Identifying caregiver needs for children with a tracheostomy living at home. Clin Pediatr (Phila). 2020;59(13):1169-1181. http://dx.doi.org/10.1177/0009922820941209. PMid:32672065.
24. Falkson S, Knecht C, Hellmers C, Metzing S. The perspective of families with a ventilator-dependent child at home. A Literature Review. J Pediatr Nurs. 2017;36:213-24. http://dx.doi.org/10.1016/j.pedn.2017.06.021.
25. Castro EAB, Leone DRR, Santos CM, Neta FCCG, Gonçalves JRL, Contim D et al. Organização da atenção domiciliar com o Programa Melhor em Casa. Rev Gaúcha Enferm. 2018;39:e2016-0002. http://dx.doi.org/10.1590/1983-1447.2018.2016-0002.
26. Dias JF, Grossi JB, Costa LA, Furtado SRC, Mancini MC, Sampaio RF. Atenção domiciliar no âmbito da reabilitação e prática centrada na família: aproximando teorias para potencializar resultados. Rev Ter Ocup Univ São Paulo. 2017 out;28(2):206-13. http://dx.doi.org/10.11606/issn.2238-6149.v28i2p206-213.

27. Wojtak A, Klopp J. Changing the conversation with home care clients. Healthc Q. 2015;18(3):23-7. http://dx.doi.org/10.12927/hcq.2015.24435.
28. Mendes AP. Uncertainty in critical illness and the unexpected: important mediators in the process of nurse-family communication. Esc Anna Nery Rev Enferm. 2020;24(1):e20190056. http://dx.doi.org/10.1590/2177-9465-ean-2019-0056.
29. Precce ML, Moraes JRMM, Pacheco STA, Silva LF, Conceição DS, Rodrigues EC. Educational demands of family members of children with special health care needs in the transition from hospital to home. Rev Bras Enferm. 2020;73(Suppl 4):e20190156. http://dx.doi.org/10.1590/0034-7167-2019-0156. PMid:32756741.
30. Silva KL, Sena RR, Castro WS. A desospitalização em um hospital público geral de Minas Gerais: desafios e possibilidades. Rev Gaúcha Enferm. 2018;38(4):e67762. http://dx.doi.org/10.1590/1983- 1447.2017.04.67762. PMid:29933425.
31. Góes FGB, Cabral IE. Discourses on discharge care for children with special healthcare needs. Rev Bras Enferm. 2017;70(1):154-71. http://dx.doi.org/10.1590/0034-7167-2016-0248. PMid:28226056.