Challenges for exercising health advocacy to hospitalized children during the COVID-19 pandemic

Desafios para o exercício da advocacia em saúde à criança hospitalizada durante a pandemia COVID-19

Desafíos para el ejercicio de la defensa en salud de niños hospitalizados durante la pandemia de COVID-19

Ana Carla Petersen de Oliveira Santos[1] https://orcid.org/0000-0002-9816-1560
Mara Ambrosina de Oliveira Vargas[2] https://orcid.org/0000-0003-4721-4260
Climene Laura de Camargo[1] https://orcid.org/0000-0002-4880-3916
Elaine Cristina Novatzki Forte[2] https://orcid.org/0000-0002-6042-5006
Cíntia Michelle Alexandria Nepomuceno[1] https://orcid.org/0000-0002-8304-7466
Carla Aparecida Arena Ventura[3] https://orcid.org/0000-0003-0379-913X

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Corresponding author
Ana Carla Petersen de Oliveira Santos
E-mail: acarlapetersen@hotmail.com

Associate Editor (Peer review process):
Rosely Erlach Goldman
(https://orcid.org/0000-0002-7091-9691)
Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brasil

Abstract

Objective: To analyze the challenges for exercising health advocacy to hospitalized children during the COVID-19 pandemic.

Methods: This is an online descriptive-exploratory qualitative study. Participants were 28 nursing professionals enrolled in the subject Nursing in Health Care for Children and Adolescents in a graduate program at a federal university in northeastern Brazil. Data collection took place in June 2021 through a conversation wheel and press conference. As instruments, we used Google forms and a semi-structured script. The study was approved by the Research Ethics Committee. As an analysis method, Discursive Textual Analysis (DTA) was used. For data organization, Atlas.ti 8.4.15 software (Qualitative Research and Solutions) was used.

Results: Two categories emerged: 1) Impacts of the pandemic on pediatric care and advocacy: child isolation and a health care scenario where children were placed in the background were observed. 2) Existing barriers that worsened with the health crisis: work overload, precarious structure and difficulty in working conditions were identified, which led to violations of children's rights and aggravated the overview of difficulties in the provision of pediatric services.

Conclusion: The challenges for exercising health advocacy for hospitalized children during the pandemic, evidenced by the impacts and barriers to care, have expanded health teams' work, making the exercise of advocacy in pediatric care even more difficult. It is necessary to rethink and adjust access and care policies after the pandemic to ensure that child care is not restricted.

Resumo

Objetivo: Analisar os desafios para o exercício da advocacia em saúde à criança hospitalizada durante a pandemia COVID-19.

Métodos: Estudo qualitativo descritivo-exploratório *on-line*. Participaram 28 profissionais de enfermagem matriculados na disciplina Enfermagem na Atenção à Saúde da Criança e do Adolescente em um Programa de pós-graduação de uma universidade federal do nordeste brasileiro. A coleta de dados ocorreu em junho de 2021 através de roda de conversa e entrevista coletiva. Como instrumentos utilizou-se: o formulário do *google forms* e roteiro semiestruturado. O estudo foi aprovado pelo Comitê de Ética em Pesquisa. Como método de análise, foi empregada a Análise Textual Discursiva (ATD). Para a organização dos dados, utilizou-se o *software* Atlas.ti 8.4.15 (*Qualitative Research and Solutions*).

Resultados: Emergiram duas categorias: 1) Impactos da pandemia para assistência e advocacia pediátrica, constatou-se o isolamento infantil e um cenário de atenção à saúde onde a criança foi colocada em segundo

[1]Universidade Federal da Bahia, Salvador, BA, Brazil.
[2]Universidade Federal de Santa Catarina, Florianópolis, SC, Brazil.
[3]Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo, Ribeirão Preto, SP, Brazil.

Conflicts of interest: extracted from the research "*Estratégias de advocacia em saúde no enfrentamento da violência institucional à criança hospitalizada durante a pandemia COVID-19*", developed by the *Universidade Federal de Santa Catarina* in partnership with the *Universidade Federal da Bahia*.

plano. 2) Barreiras existentes que se agravaram com a crise sanitária, identificou-se: sobrecarga de trabalho, precarização da estrutura e dificuldade nas condições de trabalho, que gerou violações nos direitos infantis e agravou o panorama de dificuldades na oferta de serviços pediátricos.

Conclusão: Os desafios para o exercício da advocacia em saúde à criança hospitalizada durante a pandemia, evidenciados pelos impactos e barreiras para a assistência, ampliaram o trabalho das equipes de saúde tornando o exercício da advocacia no cuidado pediátrico ainda mais dificultoso. Cabe repensar e ajustar políticas de acesso e atendimento após a pandemia para assegurar que o cuidado infantil não seja restringido.

Resumen

Objetivo: Analizar los desafíos para el ejercicio de la defensa en salud de niños hospitalizados durante la pandemia de COVID-19.

Métodos: Estudio cualitativo descriptivo exploratorio *en línea*. Participaron 28 profesionales de enfermería inscriptos en la asignatura Enfermería en Atención a la Salud del Niño y del Adolescente en un programa de posgrado de una universidad nacional del nordeste brasileño. La recopilación de datos ocurrió en junio de 2021 a través de rondas de conversación y entrevista colectiva. Como instrumentos se utilizaron: un formulario de *google forms* y un guion semiestructurado. El estudio fue aprobado por el Comité de Ética en Investigación. Como método de análisis, se utilizó el Análisis Textual Discursivo (ATD). Para la organización de los datos, se utilizó el *software* Atlas.ti 8.4.15 (*Qualitative Research and Solutions*).

Resultados: Surgieron dos categorías: 1) Impactos de la pandemia en la atención y en la defensa pediátrica, se verificó el aislamiento infantil y un escenario de atención en salud en la que el niño fue colocado en segundo plano. 2) Barreras existentes que se agravaron con la crisis sanitaria, se identificó: sobrecarga de trabajo, precarización de la estructura y dificultad en las condiciones de trabajo, lo que generó violaciones de los derechos infantiles y agravó el panorama de dificultades en la oferta de servicios pediátricos.

Conclusión: Los desafíos para el ejercicio de la defensa en salud de niños hospitalizados durante la pandemia, evidenciados por los impactos y barreras para la atención, ampliaron el trabajo de los equipos de salud, lo que dificultó aún más el ejercicio de la defensa del cuidado pediátrico. Cabe reflexionar y ajustar políticas de acceso y atención después de la pandemia para asegurar que no se restrinja el cuidado infantil.

Introduction

Health advocacy is defined as the practice of representing users' and families' needs, ensuring that decision-making in health is in accordance with the interests of those involved.[1] It can also be understood as the attitude of safeguarding, informing, valuing, mediating and defending individuals' rights in health care provision.[2]

In child care, health advocacy is exercised daily by nursing professionals, who defend children and families from adverse situations such as access difficulties, timely care, in addition to violations that cause them damage, such as psychological and physical violence, by loss of autonomy.[3,4] This concern becomes relevant when considering that in Brazil, despite policies and laws enacting recommendations to ensure care for children in health services, most of difficulties are supported, mainly, by the significant reduction of pediatric hospital beds in recent years, especially due to the lack of investments by the Unified Health System *(Sistema Único de Saúde*). According to the Brazilian Society of Pediatrics, 15,900 pediatric hospital beds were closed in Brazil in the last 10 years, which has resulted in the pilgrimage of children to health services.[4,5]

In fact, the global scenario that led to an increase in the demand for care in health services due to COVID-19, further increased the challenge for teams to guarantee safe care, free of violations and abuse for children, usually resulting from negligence and violence practiced in health institutions. Research confirms that professionals report numerous difficulties in providing comprehensive child care in health services during the pandemic, such as problems with access to health services, lack of information and reduced investment in the pediatric sector.[4,6,7]

These problems occurred, in part, due to the administrative political mismatch caused by the increase in demand and the real supply of services, which overloaded the health system, and led to the occurrence of violations, materializing institutional violence (IV) in health,[4] as seen in 2021, in the lack of oxygen for the treatment of COVID-19 in Manaus-Brazil.

VI in health can be evidenced by the violation of people's rights, which range from the pilgrimage of users to different services in search of care, to abuse, negligence and prohibitions during the period of hospitalization that violate patients' rights, causing mistreatment to users.[8]

The presence of mistreatment and violations of children's rights in health services are not rare, de-

spite the small amount of research. In Germany, a study confirmed that this type of violence can vary from a simple disrespect for privacy to omission of care and death.[9] In Brazil, a study also found IV to children, when they enter health services, due to hospital structure precariousness, abusive care practices and problems in the relationships between professionals, children and family.[10]

Thus, when considering the presence of IV in children during the time they are hospitalized and that research[9-11] points out that the problems caused by the difficulty in providing adequate care to children during the COVID-19 pandemic can lead to irreversible physical and psychological harm, it is necessary to discuss the challenges of nursing professionals in practice of advocacy, since this emerges as an essential function of the health team. In this perspective, this study aimed to analyze the challenges for the exercise of health advocacy to hospitalized children during the COVID-19 pandemic.

Methods

This is a qualitative, descriptive, exploratory study, carried out remotely. The research field was a nursing school at a federal university in northeastern Brazil.

The study included nurses who attended the subject Nursing in Health Care for Children and Adolescents in a graduate program of the aforementioned university. As inclusion criteria, participants should be enrolled in that discipline and have had experience with pediatric care during their training/professional activity. Not belonging to the nursing category was used as an exclusion criterion.

Data collection was described according to the COnsolidated criteria for REporting Qualitative research (COREQ). Data were collected in June 2021. Participants were chosen for convenience (because they were enrolled in the course), being invited to participate in two meetings on days and times previously established in the curricular component's schedule. There was no prior knowledge between researchers and participants. In the first meeting, the researchers introduced themselves and addressed IV to children, health advocacy and the research objectives. Later, they were invited and agreed to participate in the research, filling out the Informed Consent Form via Google forms. Participants also completed an electronic form for sociodemographic profile. Of the 29 students, only one did not participate in the research because he was not a nursing student.

In the second meeting, there was a conversation circle and a press conference, conducted by the researchers, in which professionals spoke openly about their experiences in health advocacy. A script was used to guide the press conference with questions: In your opinion, what are the barriers to advocacy for hospitalized children? What about barriers to childcare during the COVID 19 pandemic? In your opinion, how has the pandemic affected child care? The meetings took place completely online through the google meet platform, were recorded (totaling two hours and thirty-five minutes) and the chat records were rescued to compose the research *corpus*. After collection, data were transcribed and organized.

During the exhaustive reading of the material, it was noticed its saturation by repetition of statements. For data organization and processing, the Atlas.ti 8.4.15 software was used. The study used the Discursive Textual Analysis (ATD) method, which establishes the exercise of writing as a mediating tool in meaning production.[12] Thus, the texts were disassembled, relationships were established, a new emergent was identified and the findings were replaced in a self-organized process.

The research respected the principles established by the Brazilian National Health Council Resolution 466/2012, being submitted to the Research Ethics Committee of the field of study and approved with CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 45277021.9.0000.5531.

Results

A total of 28 nurses participated, with 89.3% being female, mean age 34.7 years; self-declared color black (64.3%) and white (35.7%). As for marital status, 50% were married and an equal proportion were single; most lived in Bahia (85.7%), Sergipe (10.7%), São Paulo (3.6%). In terms of academic training, the majority had specialization (53.6%), master's degree (28.6%), doctoral degree (3.6%) and 14.2% had only complementary training courses. Regarding time in pediatrics, 21.4% had worked in pediatrics for up to 3 years, 21.4%, between 4 and 9 years, 17.8%, for more than 10 years, and 39.3% worked in pediatrics only during graduation. As for location, 57.1% worked in a hospital, 14.3% primary care, 7.1% higher education institution, 3.6% pediatric Intensive Care Unit and 17.9% did not work. As for the employment relationship, 32.1% worked in public institutions, 21.4%, philanthropic, 17.9%, private and 28.4%, mixed or outsourced. The main contractual modality was formal contract (50%), civil servant (28.6%), temporary contract (14.3%), service provider (7.1%). Participants' speeches reveal a scenario of difficulties for the exercise of health advocacy in the field of pediatrics, with emphasis in two categories: *Impacts of the pandemic for pediatric assistance and advocacy*; and *Existing barriers that have worsened with the health crisis*.

The impacts of the pandemic for care and advocacy in pediatrics

The impacts of the pandemic on child advocacy and care emerged on two main issues. First, children took a backseat in health care, as seen in situations where: pediatric units reduced beds to meet the need for vacancies for adults; Basic Health Units reduced childcare and immunization services to care for patients with COVID-19; when non-COVID-19 comorbidities, in children hospitalized with COVID-19, did not receive adequate treatment. Secondly, child isolation during hospitalization was verified - due to the implementation of restriction policies - which affected the humanization of pediatric care. Figure 1 presents a diagram of these subcategories with participants' reports.

Existing barriers to the practice of law that have worsened with the health crisis

The pandemic has further increased existing barriers to advocacy for hospitalized children. The three barriers presented by nurses were: difficult working conditions, structure precariousness, and professionals' overload. Figure 2 presents the barriers to the practice of law, highlighting the strong relationship between them, configuring a triad that is difficult to face.

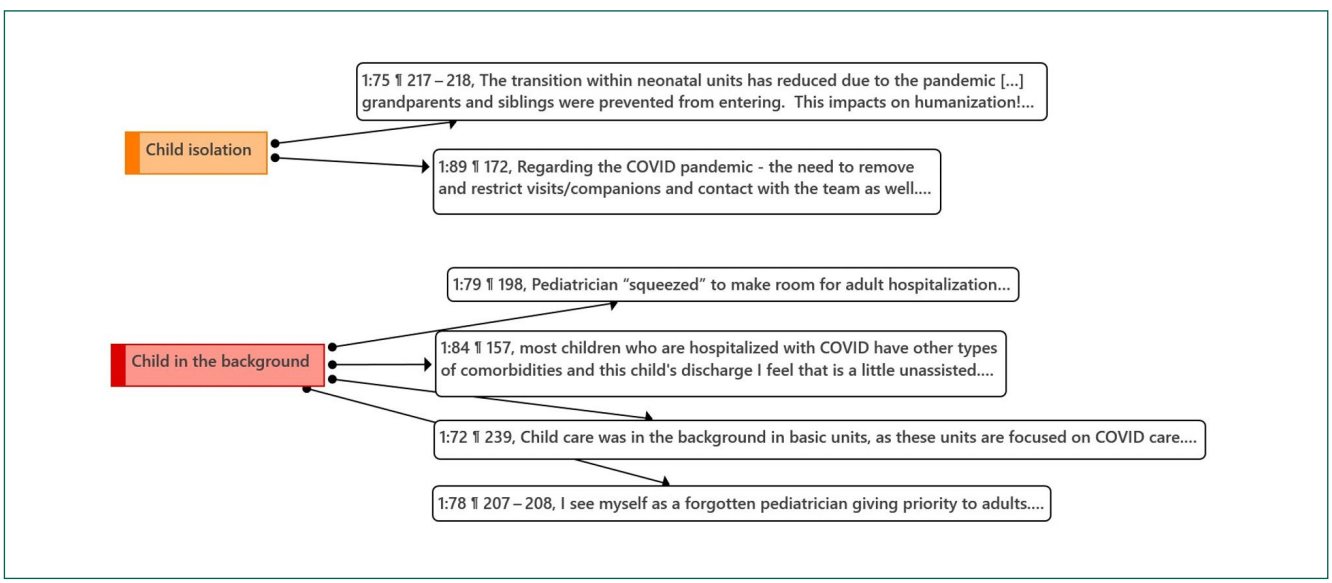

Figure 1. Impacts of the COVID-19 pandemic for advocacy and pediatric care from nurses' perspective

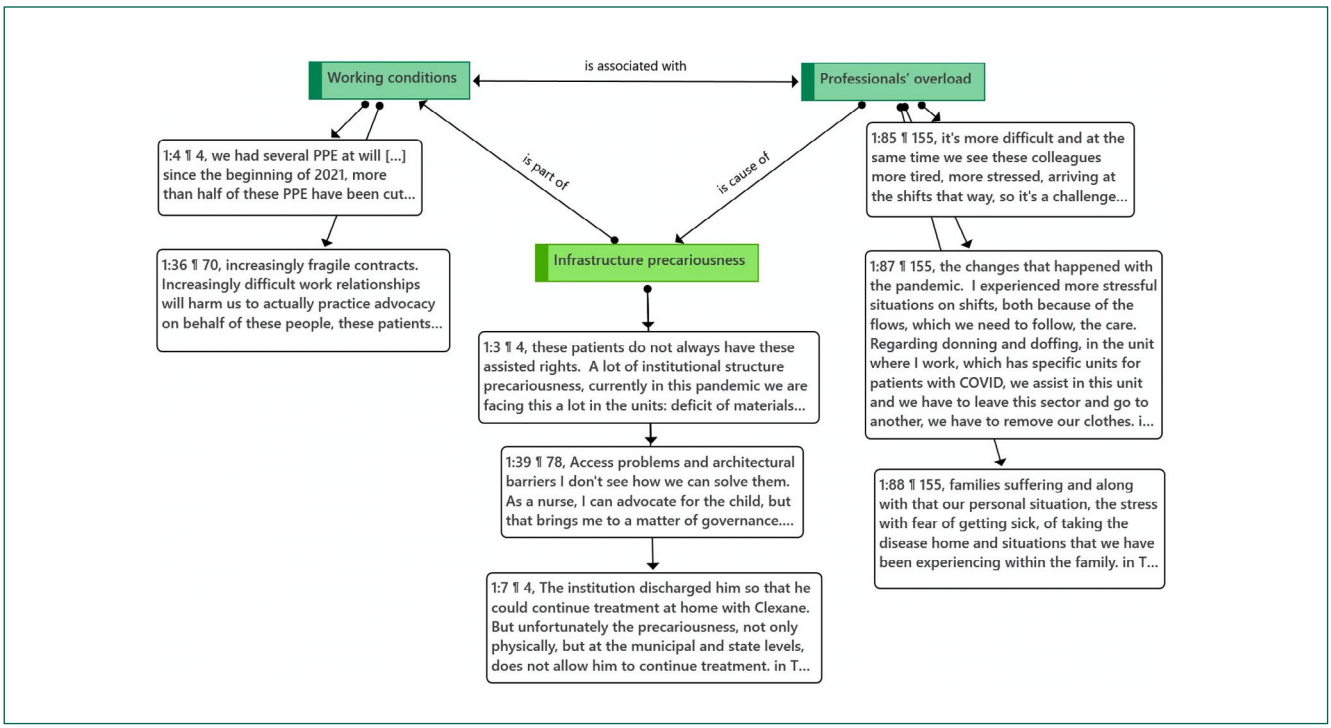

Figure 2. Barriers to health practice of advocacy during the COVID-19 pandemic from nurses' perspective

Discussion

The COVID-19 pandemic has emerged as one of the greatest challenges in health care worldwide and, although children have not constituted an obvious risk group, they have felt the impacts of this unprecedented health crisis.[7]

In this study, participants confirm that some of the main challenges in advocacy in pediatric care were the way in which children were placed in the background, as well as having to remain isolated, restricted when hospitalized. These obstacles caused a lack of assistance and obstacles to the humanization of care, compromising the physical and emotional health of children and family members.

The little emphasis given to pediatric care during the pandemic was encompassed by the unpredictable and complex world scenario, which resulted in the polarization of the attention of the main health organizations, by prioritizing care for COVID-19 patients, mostly adults and older adults.[11,13] Likewise, in Brazil, the reflection of this environment of extreme need for the care network specifically for individuals with COVID-19, of an older age group, led pediatric care to be in the background, contributing to the fact that many children's demands were not adequately met.[14]

The attitude of putting children in the background in health care is not a problem exclusively caused by the pandemic. A study that showed the invisibility of child care in hospitals confirmed the existence of violations of children's rights, namely: pilgrimage (difficult search for health care), shortage of materials, equipment, human resources and inadequate structure for child care.[4] Thus, it is clear that with the pandemic, not the emergence, but the expansion of invisibility of child care, which entails a greater risk of IV for children in this period.

Data from this research also showed infrastructure precariousness in health services to serve children. A similar reality was found in a study carried out in Peru, which found that the resources allocated to the care of children with COVID-19 are limited and need to be expanded.[13]

Furthermore, with the pandemic, health systems became saturated and access to basic health care became restricted. Services such as childcare, immunization, access to special medicines and oncological care had their offer reduced, hence the difficulty in dealing with the repressed demand.[12,14]

Another aspect identified as a challenge for the practice of advocacy in pediatric units was child isolation, due to the implementation of visitation restriction policies during the pandemic, as a strategy to minimize COVID-19 transmission in hospitals. This measure had a strong impact on the right of children to receive family support during hospitalization.

It is important to point out that the restriction policies are necessary and have been fulfilling the role for which they were instituted, since studies have shown a significant reduction in the transmission of respiratory infections associated with health care during visit restrictions.[15,16] Furthermore, the American Academy of Pediatrics recommended that health establishments encourage limited family presence (one or two people) during children's hospitalization as a way to ensure their safety. However, the ethical conflict around this issue has become evident, due to the increased risk of emotional and psychological problems for children and family members.[17]

Regarding the harmful effects of child isolation by visitor restriction policies, studies have revealed unintentional consequences of these, namely: physical problems (decreased food intake and activities of daily living, increased pain and symptoms of the treated disease), emotional problems (loneliness, depressive symptoms, agitation, aggression, reduced cognitive capacity) and general dissatisfaction.[16,18]

Moreover, family members and caregivers play a leading role in advocating for children's rights, as in addition to providing them with basic, emotional care, they know their health history, warning signs and act in substitute decision-making. Therefore, limiting the presence of family members increases the risk of damage and situations of violence while children are hospitalized. Thus, it is necessary to remember that supporting and comforting patients at the head of the bed reverberates in feelings of well-being for children and their caregivers, making the presence of family members an essential element to ensure child care quality.[15,17]

In this regard, studies that discuss the viability of visitation restriction policies in pediatric units propose that these occur in order to guarantee the presence of the family in adequate conditions of permanence, balancing risks and benefits, also bringing it as an important link to mitigate the risk of contamination, establishing a fair collaboration of all involved so that the visit takes place safely.[15,16]

Regarding the barriers reported by participants for the exercise of advocacy in pediatric care, three important aspects emerged as correlated characteristics, which is why they were described as a triad, consisting of hospital infrastructure precariousness, working conditions and professionals' overload.

Infrastructure precariousness, part of this triad, broadened the context of difficulties in assisting children. Nurses reported that the shortage of equipment and materials intensified by the pandemic compromised child care. Consequently, the scenario of scarce resources directly reverberated in the child health care network precariousness in all spheres. These conditions generate insecurity in professionals, considering the lack of control over these issues.

Studies indicate that the scarcity of materials results in fear and anxiety on the part of professionals, as they fear failing to protect themselves and others.[6,7,13] Fear of contamination is a stressor for nurses, related to the challenge of preventing the spread of the virus, while providing quality care without harming patients.[19,20] Professionals corroborate this problem by mentioning fear due to the lack of personal protective equipment, diagnostic tests and knowledge/information related to the disease, reduction of beds, supplies and the reduced number of nursing professionals.

Thus, infrastructure precariousness in health services has proved to be a crucial and at the same time transversal problem, with consequences at different levels of health care, by highlighting the structural nature of the violence that originates in health inequality. Infrastructural problems are often responsible for situations of increased pilgrimage to different health services, lack of attention and poor quality of care.[4] However, the pandemic ratified that the allocation of resources for health care is governed by political, local and economic interests, what could be seen with the opening of new hospitals, hiring of professionals and acquisition of ma-

terials and equipment for COVID-19 treatment, a reality that differs from what happens in child care.

The precarious working conditions that nursing professionals are exposed to emerged as an important issue, which had a negative impact on practice of advocacy. During the pandemic, working condition precariousness is reflected in the lack of personal protective equipment, problems in labor relations and fragile employment contracts, resulting from the emergence of the health crisis and its inadequate management. Studies show convergence when signaling that the deficit of professionals, the use of insufficient and inadequate protective equipment, work overload, excessive care demand, labor hiring format (with low pay and long hours) were already a common practice.[20-22]

These aspects are concomitantly enhanced, as never before experienced in Brazil and in the world. This situation led to the exhaustion, illness and death of these professionals.[20-22] It should be noted that, prior to the pandemic, nursing was already fighting against the under-sizing of teams and work overload, which will be aggravated by the content set forth in Provisional Measure (PM) 927/2020. COFEN filed a lawsuit against the PM, emphasizing that the document mocks those who are on the front lines of the pandemic, to guarantee assistance to the population.[23]

Work overload in this period is cause and consequence, as it makes professionals sick, stresses them out, alienates colleagues and intensifies professionals' fear of being contaminated and/or contaminating their family members. Similarly, a study in Canada confirmed a higher prevalence of anxiety and depression in nurses during the pandemic, caused by fear and work overload.[24] Nurses particularly feel anxious when caring for children because they are asymptomatic when infected with SARS-CoV-2; therefore, this condition combined with work overload enhances the adversities faced during child care.[25,26]

As for working conditions and overload, two aspects emerge from both issues. First, it is important to emphasize that knowledge of the elements that contribute to the increase or reduction of work overload cannot always contribute to strengthening the positive aspects of work and minimizing the negative aspects. The finding that children are less or minimally susceptible to COVID-19, when compared to adults, does not necessarily mean that they will not have medium and long-term implications. Although children are less susceptible to COVID-19, this study showed important negative impacts on care, which, above all, makes children even more vulnerable, and may lead to situations of IV.

This study was limited by the use of only one postgraduate program for data collection, which indicates the need to expand studies on this topic.

Conclusion

The study presented the challenges for exercising advocacy in the health of hospitalized children during the COVID-19 pandemic. The challenges were described in two categories: impacts of the pandemic for pediatric care and existing barriers that were aggravated by the health crisis. Among the impacts, participants highlighted that children were placed in the background (evidenced by the reduction in the offer of pediatric care and care) and child isolation (due to the application of visitation restrictions policies), which led to violations of children's rights and aggravated the scenario of difficulties in offering pediatric services. As for the barriers that worsened with the health crisis, it was identified that the overload of professionals, hospital structure precariousness and difficulty in working conditions increased the challenge for health teams and made the exercise of health advocacy in pediatric care even more difficult. The study revealed a scenario of difficulties for the exercise of health advocacy in the field of pediatrics. In this study, it was possible to perceive that, despite the pandemic having highlighted the limitations of professionals in the exercise of health advocacy, this problem already existed before, and may persist in the post-pandemic period, as children's needs still remain invisible to most of those involved in pediatric care. In this regard, health advocacy discussions in pediatric care contribute to giving visibility to the topic and to equip health

professionals to carry out their professional practice free of violations. It is necessary to rethink and adjust access policies to health care during and after the COVID-19 pandemic to ensure that child care is not restricted. It is necessary to invest in training the nursing team as well as to expand multidisciplinary collaboration in the formation of teams to protect children in health services so that children's rights are no longer violated.

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Collaborations

Santos ACPO, Vargas MAO, Camargo CL, Forte ECN, Nepomuceno CMA and Ventura CAA declare that they contributed to project design, data analysis and interpretation, relevant critical review of intellectual content and approval of the version to be published.

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