



# CHILDREN AND YOUTH WITH SPECIAL HEALTHCARE NEEDS: (DIS) CONTINUITY OF CARE

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#### ABSTRACT

**Objective:** to investigate the follow-up and characteristics of children and youth with special healthcare needs within Primary Health Care services located in a city in the State of São Paulo, Brazil.

**Method:** this qualitative study was supported by the Primary Health Care framework, and interviews were held with 37 health workers from the primary health care units located in the interior of São Paulo. Data were collected from May to December 2018 and treated with inductive thematic analysis.

**Results:** from the perspective of the health workers, the characteristics of these children and youth are centered on the dependence of specific care such as to promote psychomotor development, and dependence on technology and pharmacological treatments. They reported the difficulty to access health services while the primary health care services do not implement systematic follow-up.

**Conclusion:** these children and youth demand continuous and longitudinal care, which, however, is not provided by primary health care services, considering the discontinuity of care and a lack of networked follow-up. Therefore, health services need to be reorganized to keep up with changes in the child and youth morbidity and mortality to ensure continuous, integral, and networked follow-up to this population.

DESCRIPTORS: Chronic disease. Health personnel. Primary health care. Child health. Pediatric nursing.

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# CRIANÇAS E ADOLESCENTES COM NECESSIDADES ESPECIAIS DE SAÚDE: (DES)CONTINUIDADE DO CUIDADO

#### RESUMO

**Objetivo:** investigar o acompanhamento e as características de crianças e adolescentes com necessidades especiais de saúde nos serviços de Atenção Primária à Saúde em um município do Estado de São Paulo. **Método:** estudo de abordagem qualitativa, apoiado no quadro teórico da Atenção Primária à Saúde, desenvolvido por meio de entrevista com 37 profissionais de saúde de unidades de atenção primária de um município do interior do Estado de São Paulo. Os dados coletados entre os meses de maio e dezembro de 2018 foram submetidos à análise temática indutiva.

**Resultados:** para os profissionais de saúde, as características dessas crianças e adolescentes centraram-se na dependência de cuidados específicos como cuidados para o desenvolvimento psicomotor, tecnológico e medicamentoso. Eles relataram a dificuldade de acesso aos serviços de saúde e a falta de acompanhamento sistemático pelos serviços de atenção primária.

**Conclusão:** essas crianças e adolescentes demandam um cuidado contínuo e longitudinal, o qual não foi sustentado pelos serviços de atenção primária, tendo em vista a descontinuidade do cuidado e a ausência do cuidado em rede. Dessa forma, faz-se necessário reorganizar os serviços de saúde para acompanhar as mudanças no perfil de morbimortalidade infantojuvenil, de modo a assegurar o acompanhamento contínuo, integral e em rede desta população.

**DESCRITORES:** Doenças crônicas. Profissionais de saúde. Atenção primária à saúde. Saúde da criança. Enfermagem pediatrica.

# NIÑOS Y ADOLESCENTES COM NECESIDADES ESPECIALES DE SALUD: (DIS) CONTINUIDAD DEL CUIDADO

#### RESUMEN

**Objetivo:** investigar el acompañamiento y las características de niños y adolescentes con necesidades especiales de salud, en los servicios de Atención Primaria a la Salud, en un municipio del Estado de Sao Paulo.

**Método:** estudio de abordaje cualitativo, apoyado en el cuadro teórico de la Atención Primaria a la Salud, desarrollado por medio de entrevistas con 37 profesionales de la salud, de unidades de atención primaria, de un municipio del interior del estado de Sao Paulo. Los datos recogidos, entre los meses de mayo y diciembre de 2018, fueron sometidos al análisis temático inductivo.

**Resultados:** para los profesionales de la salud, las características de esos niños y adolescentes se enfocaron en la dependencia de cuidados específicos, como los cuidados para el desarrollo psicomotor, tecnológico y medicamentoso. Ellos relataron la dificultad de acceso a esa clientela a los servicios de salud y la falta de acompañamiento sistemático por los servicios de atención primaria.

**Conclusión:** esos niños y adolescentes demandan un cuidado continuo y longitudinal, el cual no fue sustentado por los servicios de atención primaria, teniendo en consideración la discontinuidad del cuidado y la ausencia del cuidado en red. De esa forma, es necesario reorganizar los servicios de salud para acompañar los cambios en el perfil de morbilidad y mortalidad infantojuvenil, de modo a asegurar el acompañamiento continuo, integral y en red de esta población.

**DESCRIPTORES:** Enfermedad crónica. Personal de salud. Atención primaria de salud. Salud del niño. Enfermería Pediátrica.



### INTRODUCTION

The literature has recently reported changes in the morbidity and mortality rates of children and youth in Brazil. These changes are caused by a set of factors such as a decreased number of infectious diseases, improved basic sanitation, greater access to health services, and preventive measures to fight child mortality. Recent medical-technological advancements have also favored higher survival rates among those with prognoses that life-threatening illnesses, especially chronic conditions. Survival, however, may be accompanied by some degree of dependency throughout life.<sup>1</sup>

This vast and heterogeneous group of chronic conditions<sup>2</sup> comprises a subgroup called Children with Special Health Care Needs (CSHCN). This group has one aspect in common, the need for continuous and long-term healthcare, educational or social assistance of a type or amount beyond that required by children at the same age.<sup>3</sup>

There are many denominations in the literature to classify this group of children. The first researchers who identified and characterized this group of patients in the United States called them Children With Special Health Care Needs. These researchers state that these children and youth are at increased risk for physical (behavioral or emotional) developmental conditions that presented more healthcare needs than children in general.<sup>3</sup> Another classification for this group was based on the typology of care demands such as: medication; development; modified usual care; technological; or mixed, when more than of these was present.<sup>4</sup> Other classifications were more recently proposed, such as medically fragile children, children with medical complexity<sup>5</sup> and children with a life-threatening illness.<sup>6</sup> From this perspective, children are classified according to their care needs rather than by their medical diagnosis.

The fragile health of this population requires frequent hospitalizations, during which a multiprofessional team provides continuous and complex care. However, with the children's improved clinical condition and hospital discharge, many of these care actions are transferred to the home under the family's responsibility. Hence, these children's families also need to be assisted by the Primary Health Care service nearest to their homes.<sup>5</sup>

Considering the Primary Health Care's (PHC) potential problem-solving capacity and its impact on people and the community's health when bonds are established to ensure longitudinal care,<sup>7</sup> PHC is an essential ally of the families of children and youth with special healthcare needs in the pursuit of integral care. Primary Health Care is the entrance door to the health system and is, therefore, the basis for continued monitoring of health care.<sup>8</sup> However, even though PHC services have high problem-solving potential, studies show that most hospitalizations and re-hospitalizations of children with one or more chronic conditions are unnecessary and could be prevented at other levels of the healthcare system, such as PHC.<sup>5,9</sup>

Therefore, the following question is asked: how are these children and youth monitored within Primary Health Care units? and what are the characteristics of these children and youth from the perspective of health workers? This study's objective was to investigate the follow-up and characteristics of children and youth with special healthcare needs cared for by the PHC services located in a city in São Paulo, Brazil.



### METHOD

This qualitative study,<sup>10</sup> was based on the Primary Health Care theoretical framework and addressed 37 PHC health workers from a city located in the interior of São Paulo using inductive thematic analysis.<sup>11</sup>

The data presented in this study originated from a Master's dissertation developed from a multicenter study carried out in three Brazilian municipalities (References are not included here to ensure blind peer review).

Data collected in the multicenter study included nine health units (statistical division of the city's heath units) subdivided into Primary Healthcare Units and Family Health Strategy units. Workers from different professions were individually invited to participate in this study. Five health units, out of the nine included in the original study, were randomly selected according to the services' and workers' availability. Inclusion criteria were workers with a minimum experience of 12 months in the city's health network, while those absent at the time of data collection, from May to December 2018, were excluded.

Data were collected using semi-structured interviews recorded and conducted by the Master's student as a primary researcher in a private room in the units' premises. The interviews lasted 16 minutes on average and addressed the workers' experiences with the care provided to children and youth with special healthcare needs (children's characteristics, access, follow-up, network cooperation). A form was used to characterize the participants (sex, age, education, profession/occupation). Data collection ceased with the participation of 37 workers from five health units when the primary researcher verified that information became redundant, and the empirical material already enabled understanding of the phenomenon, that is, the objectives had been achieved.<sup>12</sup>

The empirical material was analyzed using inductive content analysis,<sup>11</sup> based on six stages: transcription of data; coding; grouping and establishment of themes; refinement and exclusion of provisional codes; establishment of the title of each meaning unit, and selection of representative excerpts; and interpretation of data based on the literature. Two units of meanings emerged: characteristics of children and youth with special healthcare needs and Providing care to children and youth with special healthcare needs within PHC.

The reports were edited during the transcription process to correct colloquial terms, language vices, and grammatical errors. Punctuation marks were also standardized: quotation marks and ellipsis between parentheses were used at the beginning and at the end of the phrases to indicate the report was interrupted; ellipsis in the middle of phrases indicated a pause in the participants' reports; and a report between square brackets signalizes the researchers' comments. In order to ensure confidentiality of the participants' identities, the reports are identified with the letter/acronym that corresponded to the professions, followed by a number corresponding to the order in which the interviews were held. Hence, the first nurse is identified as N1, the first physician from the Family Strategy team is identified as PF1, and Community Health Agents as CHA1, for instance.

This study was approved by the Research Project Assessment Committee of the city's Health Department and the Institutional Review Board at the hosting university. This study was conducted according to the guidelines for qualitative research provided by COREQ (Consolidated Criteria for Reporting Qualitative Research).



### RESULTS

Thirty-seven health workers from three Family Health Strategy units and two Primary Care units participated in this study: 13 community health agents, six nursing one general practitioner, three dentists, six nurses, one pharmacist, three family physicians, one nutritionist, and three pediatricians aged 45.8 years old on average; 29 women and eight men. Of the 37 participants, 23 reported a bachelor's degree, including five community health agents with a degree in fields other than the health field (business administration, physical education, pedagogy); 19 attended degree or non-degree graduate programs, eight in more than a modality: residency (nine), Master's (six), and doctoral program (two). Five of the remaining workers attended vocational high school; five attended regular high school; and one had incomplete high school studies. Regarding the workers' experience in the city's health network, 10 had an experience of more than ten years.

The two meaning units are presented below:

### Characteristics of children and youth with special healthcare needs

The health workers characterized these children based on their dependence on specific care related to psychomotor development and technological and pharmacological support. They also mentioned that the health staff provided differentiated care that goes beyond the childcare protocol:

[...] I understand that these children require differentiated care when compared to children with typical development. One example is children with cleft palate who need one type of care or a deaf or mute or physically disabled child who requires other types of care (NA1).

[...] they are children with greater dependence, who require a different type of care compared to other children and need more attention and differentiated treatment, a treatment that needs to consider their needs (CHA3).

Are those who demand care that is not common... demand extra care (Pe2).

The participants also reported that these children have a diagnosis of a chronic disease even though they depended on a pharmacological care or some technology:

[...] children, who besides the disease, have some other comorbidity [...] sometimes children with cystic fibrosis come here [...]; children with an acute illness come here in the unit and also with this other comorbidity, which is the chronic disease (Ph1).

*I believe that these children have a pathology that requires special equipment, both for seizures or to breathe, like a BIPap* [machine that supplies pressurized air] *or a feeding tube* (N2).

*I think, many types, sometimes a diabetic, hypertensive child, I have children with emotional problems,* [...] *not only people with physical or mental problems who are special, but there are also others* (CHA12).

Some workers also considered special health needs included social vulnerability and the use of illegal drugs:

[...] there is also this child who I consider [with special healthcare needs] whose father is imprisoned, the mother has left and the child is with the grandmother, and is pretty young, so this child is special (N4).

[...] I had a 10-year old boy who was hanging around a drug house, and we had to call the Guardian Council help his aunt, you know? [...] I consider it to be a special need (CHA6).

Even though the definitions of children and youth with special healthcare needs reported in the literature do not include the use of illegal drugs, it does not mean these children do not require special care. A child consuming narcotic substances may develop a mental illness in the future or become socially vulnerable as a result.



### Providing care to children and youth with special healthcare needs within PHC

The participants reported that the parents had difficulties accessing the health unit when children presented physical disabilities. They complained that these children and youth were not systematically monitored in the health unit:

[...] the health unit is far away. Access is difficult for the parents, you know, to bring this child [...] so, I guess that the distance influences a lot, because it is challenging to get a child on a wheelchair or carry on your lap, or even using those special strollers [...] (CHA7).

[...] we don't have many of these children. Generally, they receive treatment in another unit or at the HC [Hospital das Clinicas] or in a specific clinic... (NA3).

We virtually do not provide this type of care [children and youth with special needs]; it's more of an emergency care where we deal with this type of thing (Pe1).

We have the case of a mother whose child's follow-up is in the HC [Hospital das Clínicas], and she actually hadn't understood what the child's condition was. So, if she comes to talk, we can explain; obviously, the secondary [care level] can explain it with much more detail and explain the situation better than us [Primary Health Care]. Still, I suppose that the bond we established here makes this family seek us, and I guess that this is how we help (N1).

The participants reported that the possibility of Family Health Strategy units to make home visits was an aspect that differentiated them. They asserted that these visits enabled closer monitoring of these children and youth, though, in practice, these visits were not performed as regularly as they should:

[...] besides the care provided within the unit for those with some walking problem, or some visual or cognitive condition that prevents them from commuting to the health unit, we perform home visits. So, this is another mechanism that facilitates access (PD3).

*I won't lie, we don't manage visiting all the homes, or all these families every month. The closer we can do making one visit every two months* (CHA2).

Usually, [follow-up] happens during consultations. Still, we also have home visits to know how the consultations are going, how they are taking the medications, whether there is any problem or any intercurrences during a given period. We visit a little more frequently to see what the unit [health unit] is doing, what it can offer, or what the multi-professional team can do to complement care (CHA3).

The difficulty of these children and families to access the health units compromises the establishment of bonds with the services. The workers reported how difficult it was to work together with the other services and how long it took to refer these patients to other services:

[...] we need to prioritize the referrals too... we give them priority but the final decision, whether a case is a priority or not, belongs to the regulator complex. This is another issue that is not under our power (D1).

[...] I guess these services should communicate with the primary health care service, I think it would improve the connection, communication, what they write, how the consultations are going [...] we don't have this direct communication [...] (N3).

The greatest problem we currently have here is the network. The health network is not organized [laugh]. It is not well connected... you see something here but cannot move on; if you send it forward, you have no response. Many things come up in social service, and we don't even know what is happening. Then, suddenly we find out that social service is doing many things that we don't even know about (FP2).

From the workers' perspective, the follow-up of this group of patients within the primary health care service is weak, which directly results in the families seeking other health care services in the



search for a solution, considering that these children's health condition may become acute at any time if there is no proper and continuous follow-up.

### DISCUSSION

This study's main findings reveal some characteristics of these children and youth with special healthcare needs and enabled understanding of how this population is monitored by the health services from the perspective of the PHC workers.

The results show that the main characteristic of these children and youth with special healthcare needs is their dependence on specific care, though some participants mentioned having a medical diagnosis of a chronic condition to be the main defining factor. The definition provided in the literature for children and youth with special healthcare needs is comprehensive, encompassing various subgroups: children and youth with a specific chronic illness, a physical, behavioral, or emotional impairment, and children and youth dependent on technology or pharmacological treatment.<sup>3-4</sup> All these children, however, require full-time monitoring to prevent the condition from aggravating or becoming acute.

One study describing the continuous use of medication by children with chronic conditions identified a demand for health care five times greater than among children the same age but with no special care needs.<sup>13</sup> Another study investigating the mortality of children and youth with chronic diseases caused by sepsis<sup>14</sup> analyzed 16,387 hospitalizations and found that 14,243 (86.9%) developed sepsis; most (68.6%) of these children had at least one chronic condition, and 5.1% of the deaths occurred among patients with chronic conditions.

One international study intended to characterize the outcomes of hospitalizations of technologydependent children in Pediatric Intensive Care Units (PICU) reports that 19.7% of the children admitted in PICU depended on technology; 20% of these specifically depended on feeding and/or breathing devices. Of the technology-dependent children, 3.7% died, 4.05% developed other comorbidities, and 3.0% improved and were discharged.<sup>15</sup> These studies show that the fragility of this group is a factor that contributes to frequent hospitalizations. After these children had their clinical condition improved, the care previously provided by a multi-professional team at the hospital is transferred to the home and becomes a responsibility of the family, especially the primary caregiver, mostly mothers.

One descriptive study intended to identify the challenges faced by the caregivers of children with special healthcare needs<sup>16</sup> reports that the families emphasized their lack of preparedness to deal with the care required by their children at home, as they consider little information is provided at the hospital discharge. A similar situation was reported by one of the participants in this study in which the family of a child sought information at the service for not having received proper guidance at the secondary level of care.

Lack of information leads parents to face considerable challenges, including difficulty providing care, fear, and aspirations experienced while providing daily care to their children. Usually, the need to assume this responsibility arises abruptly and unexpectedly, which can be overwhelming.<sup>17–18</sup>

Social vulnerability allied with the use of illegal drugs was reported as one of the characteristics of children and youth with special healthcare needs. Even though this situation is not described in the literature, it is essential to consider this possibility to expand discussions in which social care is under medical complexity because both may be interconnected. Social determinants of health may make care more complex, even when such complexity is not directly linked to a biomedical profile.<sup>19</sup> In other words, the fact that a child does not demand clinical medical care does not mean she/he does not have a complex health need. Hence, a child with a social need is also considered a child or adolescent with special healthcare needs as she/he has needs that should be heeded by health, social, or school services, thus, requiring care actions that go beyond that provided to children in general.



Additionally, the use of narcotic substances by youth may favor the development of mental illnesses, especially anxiety, depression, schizophrenia, or bipolar disorder, which is often triggered by drug use.<sup>20</sup>

Data from the National Survey of School Health (PeNSE) 2015 conducted by the Brazilian Institute of Geography and Statistics addressing 9<sup>th</sup> year students draw attention to this situation. According to the survey, 18.4% of the interviewees had already smoked cigarettes, and 55.5% consumed alcohol.<sup>21</sup> Keep in mind that the average age of these students is 14 years old. Another study addressing school violence and its association with the use of alcohol or other drugs among 12 to 18-year-old individuals reports an expressive consumption of alcohol (16.5%), tobacco (15.7%), and illegal drugs (6.8%), which corroborate the discussions concerning the need of providing specialized care to this population.<sup>22</sup>

Regarding psychosocial care, one study characterized the patients cared for by a Child Psychosocial Support Center located in Santa Catarina, Brazil, and identified that the primary motivations for these individuals to seek the service included learning difficulties, followed by anxiety and aggressiveness. Only 22.75% of the 444 medical records analyzed reported the outcomes: 8.78% were referred to a PHC service, and the remaining did not need to be referred to other services.<sup>23</sup>

These studies suggest a lack of cooperation and counter referral between mental health and PHC services, though both these services should monitor these children regardless of whether the cases were resolved within the scope of the Child Psychosocial Support Center. The workers addressed in this study also reported that the lack of communication with other health services was a factor that hindered follow-up/continuity within PHC.

In terms of the access of these children, youth, and families to health services, this study's findings reveal they face difficulties because of the distance of the services and the slowness in which health problems are resolved. Other studies<sup>13,24</sup> conducted with health workers also report difficulties faced by the parents of children and youth with special healthcare needs because of the distance of their homes from the health units, a lack of adapted transportation, and the unit's improper infrastructure to receive this population. Note that these factors may directly interfere with which health services families seek.

Regarding the lack of follow-up and delay in specialists' care, studies highlight difficulties accessing PHC units, mainly because the chronic conditions of children and youth with special care needs became acute. Additionally, they concluded that the ordeal up to establishing a diagnosis also reveals barriers to the access of this population to health services.<sup>17,24</sup>

These situations need to be discussed because PHC is the health system's entrance door, the guiding and coordinating basis of the Health Care Network (RAS). Hence, workers in these services should be prepared to meet this demand and prevent many avoidable hospitalizations.<sup>25</sup> Otherwise, the PHC workers' lack of preparedness, slowness, and the long ordeal families have to face to obtain the diagnosis will continue to favor discontinuity in the care provided by the health network.

One study<sup>1</sup> addressing the families of children with special care needs characterized this group's social network using a Speaking Map and verified that hospital services are the starting point of care delivery. For this reason, caregivers consider these services to have adequate problemsolving capacity rather than PHC services, reinforcing the lack of cooperation between the services at different levels of complexity.



Another study addressing the access of children with special care needs to the healthcare network, delay in establishment diagnoses, and slowness in referring patients to specialty services also reports that family caregivers consider these to be obstacles that aggravate the already low operative functionality of the healthcare network.<sup>26</sup> A lack of cooperation among services was also found in this study. The participants report that it takes too long for these children to be referred to a specialty service, as well as a lack of communication among the services.

Home visits are a tool used to monitor these patients and support family caregivers. In this study's context, though, only the Family Health Strategy adopted this tool, and even in this case, its use could be improved. According to the participants, the visits were predominantly performed by community health agents, and even though the visits to children and youth with special care needs were prioritized, the number of personnel was much lower than the number of families that needed to be visited.

A proposal to improve the care provided at home to these children and youth is the Home Care Service, characterized by longitudinal care provided to patients with chronic diseases through actions that encompass from health promotion to health rehabilitation. Under Decree No.825, from April 25th, 2016, a qualified multi-professional team provides the care within this service.<sup>27</sup> This service is divided into three levels: Home care 1 (AD1), Home care 2 (AD2), and Home care 3 (AD3). The first level is under the responsibility of PHC services, and only individuals presenting a low complex condition, whose problems are under control, or who have some level of difficulty accessing the health services but can receive less frequent visits, are classified under Home care 1. The second level covers individuals who require domiciliary and intensive and sequential care, including degenerative-chronic diseases, palliative care, and those who demand minimum weekly care. The third level covers patients with previous needs and also dependent on technology, requiring more complex procedures and daily visits.

One study conducted in cities in the southern region of Brazil, intending to describe the care provided by the Home Care Service to children and youth with special care needs, verified that most of the care provided to these patients was under AD2 and AD3 modalities. The authors reported that the protocols were not standardized, and communication between this service and other services composing the healthcare network, especially with the PHC network, was insufficient.<sup>28</sup>

The slow service and lack of communication among the health services is understandable, considering that the health system has not systematically kept up with epidemiological transitions (decreasing acute illnesses and increased chronic conditions). The health services' organization remains fragmented since its inception, without cooperation among the different services. In this context, difficulty in managing chronic conditions may lead these to become acute more frequently, and, as a consequence, the system ends up working more intensively with acute conditions. It is worth noting that even though the fragmented system has been able to, at least partially, resolve acute conditions in the past, it is unsustainable for the current increased number of chronic conditions.<sup>7</sup>

This lack of cooperation was also reported in this study, mainly when the participants reported the presence of children and youth with special health needs in emergence services, under the care of specialists or even only in large-sized hospitals, without being able to identify these children in the units where they worked.

This study's limitation refers to the fact that only the workers of some Primary Health Services from only city in the interior of São Paulo were included. However, the results presented here can encourage other studies asking the same questions in other contexts or exploring other professionals' point of view, contributing to the advancement of this subject.



### CONCLUSION

The follow-up of children and youth with special healthcare needs from the perspective of the health workers from Primary Health Care services is not continued at this care level. The participants report that this group is not monitored in the units where they work because these children were already monitored at other levels of the health care system, such as large-sized hospitals and specialty outpatient clinics.

The workers characterized these children and youth as patients demanding care beyond regular childcare, such as pharmacological treatment, technological assistance, or needs that required close monitoring within the social work sphere. They also highlighted social vulnerability associated with the use of narcotics, including these individuals in the subgroup of children and youth with special healthcare needs.

The absence of networking was another aspect the participants reported. The participants stated that lack of communication among the different services, delay in referring a patient to a given medical specialty, and not having a response from the services kept these patients disconnected from the network.

In summary, to ensure that appropriate care is provided to these children and youth within the PHC sphere requires rethinking the health system, updating health workers regarding the new morbidity and mortality profile, replacing the biomedical-centered care, mainly focused on the diagnosis and medical-center treatment, and strengthening Primary Health Care so it can truly function as the coordinator of the health network. If PHC does not assume its problem-solving role and deals with the numerous existing health needs, the demands presented by the children and youth addressed here will remain unheeded, and unnecessary hospitalizations will continue to occur.

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### NOTES

### **ORIGIN OF THE ARTICLE**

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### **CONTRIBUTION OF AUTHORITY**

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### **CONFLICT OF INTEREST**

There is no conflict of interest.

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