



Challenges and proposals for the care of patients with immune and allergic diseases within the Brazilian Unified Health System: The Maceió Charter

Desafios e propostas para a assistência aos pacientes com doenças imunoalérgicas no Sistema Único de Saúde brasileiro – Carta de Maceió

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ABSTRACT

The Maceió Charter was based on discussions held at the 3rd Unified Health System Forum (*Fórum SUS*) of the Brazilian Association of Allergy and Immunology (ASBAI). This document highlights challenges and proposals to improve care for patients with immune and allergic diseases within the Brazilian Unified Health System (SUS). Such conditions, often chronic and debilitating, affect millions of Brazilians and require an integrated approach from primary health through to specialty care. The need for improved management of referrals and counter-referrals,

RESUMO

A Carta de Maceió foi elaborada com base nas discussões do 3º Fórum SUS da Associação Brasileira de Alergia e Imunologia (ASBAI). O documento destaca os desafios e propostas para aprimorar a assistência a pacientes com doenças imunoalérgicas no Sistema Único de Saúde (SUS) do Brasil. Tais condições, frequentemente crônicas e debilitantes, afetam milhões de brasileiros e exigem uma abordagem integrada, desde a atenção primária à saúde até a atenção especializada. Foram discutidos a necessidade de aprimorar a gestão de referência e contrarreferência, a

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the urgency of overcoming the shortage of specialists, and the challenge represented by limited access to proper diagnosis and treatment alike were discussed. Rare diseases, including inborn errors of immunity (IEI), pose an additional challenge, requiring access to high-cost technologies for diagnosis and treatment as well as multidisciplinary care. Several proposals emerged from the Forum, such as securing sufficient funding for health, strengthening early diagnosis, integrating management, continuing education for health professionals, and implementation of telemedicine. These proposed interventions seek a more inclusive, efficient, and humanized healthcare system which meets the needs of patients with immune and allergic diseases.

Keywords: Allergy and immunology, Unified Health System, health policy, rare diseases.

urgência na superação da carência de especialistas e o desafio representado pelo limitado acesso tanto a diagnóstico quanto a tratamento adequados. As doenças raras, incluindo os erros inatos da imunidade (EII), apresentam um desafio adicional, exigindo acesso a tecnologias de alto custo para diagnóstico e tratamento e cuidado multidisciplinar. Do fórum emergiram propostas como o financiamento adequado da saúde, o fortalecimento do diagnóstico precoce, a gestão integrada de cuidados, a educação continuada dos profissionais de saúde e a implementação de telemedicina. Essas ações visam um sistema de saúde mais inclusivo, eficiente e humanizado, atendendo às necessidades dos pacientes com doenças imunológicas.

Descritores: Alergia e imunologia, Sistema Único de Saúde, política de saúde, doenças raras.

Introduction

The Brazilian Unified Health System (*Sistema Único de Saúde*, SUS) faces significant challenges in the care of patients with immune and allergic diseases, mostly chronic conditions that affect millions and demand an integrated and effective approach in the SUS. The care of patients with immune and allergic diseases should cover everything from diseases that are very prevalent in the population, such as rhinitis and asthma, to rare and complex diseases classified as inborn errors of immunity (IEI). Health care demands for these diseases require access to specialists, follow-up due to chronicity, and care provided by multiprofessional teams. In addition, access to diagnostic technologies and some therapies required to treat these diseases is often not available on the SUS.

In view of the current scenario of care for these patients in Brazil, the Brazilian Association of Allergy and Immunology (*Associação Brasileira de Alergia e Imunologia*, ASBAI) has brought this debate to specialists over the last few years and, since 2021, has held an annual forum, seeking to bring proposals to improve care for Brazilian patients suffering from these chronic, often debilitating conditions that generate high costs for families and the entire health system if not addressed properly.¹⁻⁵ Thus, the III ASBAI SUS Forum, held on November 17, 2023 in the city Maceió, state of Alagoas, represented a crucial moment for dialogue and proposing improvements in health policies and clinical practice relating to these diseases, addressing key issues involving comprehensive and ongoing care for patients, from primary health care (PHC) to specialized care (Figure 1).

III ASBAI SUS Forum

Opening

Fábio Chigres Kuschnir (ASBAI President)

Module 1 - Primary Health Care

Moderator: Norma de Paula Motta Rubini (ASBAI)

- Immune and allergic diseases in PHC - Luane Marques de Mello (ASBAI)
- Immune and allergic diseases in PHC from the perspective of the manager - Kátia Betina Rios Silveira (Council of Municipal Health Secretaries - COSEMS Alagoas)

Module 2 - Specialized Care

Moderator: Eduardo Costa de Freitas Silva (ASBAI)

- Allergology and immunology in specialized care: the Brazilian context - Faradiba Sarquis Serpa (ASBAI)
- Rede de Atenção à Saúde (Health Care Network): is it possible to expand access to allergology and immunology procedures? - Emanuel Sarinho (ASBAI)
- The specialty of immunology in the context of Health Policies for Rare Diseases - Natan Monsores de Sá (Brazilian Ministry of Health - General Coordination of Rare Diseases)

Figure 1

Program of the III ASBAI SUS Forum

Immune and allergic diseases in primary health care

PHC is the preferred gateway for patients with immune and allergic diseases on the SUS. Some studies, such as the one conducted by Gusso in 2009, have already indicated the high prevalence of

asthma and allergic rhinitis, placing them among the most frequent conditions treated in PHC in various locations in Brazil.⁶ This reality still holds true, as shown by recent data on the global burden of asthma in 204 countries, ranking Brazil as the fourth country with the highest incidence of asthma after India, China, and the United States.⁷

PHC approaches to immune and allergic conditions can help change this reality, requiring not only qualified management, but also adequate and sufficient resources for diagnosis, treatment, and longitudinal follow-up.

In this context, the lines of care developed from the perspective of the current Brazilian public health scenario, in which PHC acts as the coordinator of the health care network (*Rede de Atenção à Saúde*, RAS) and the coordinator of health care, are aimed at systematizing care flows, favoring the quality of health care for patients with chronic diseases.⁸ Figure 2 shows the lines of care for different diseases that have been drawn up and are currently available, and asthma is the only immune and allergic disease covered.⁸ However, there are concerns as to whether this line of care has been implemented or whether it has been able to achieve its goals to organize and improve care through organizing pathways and communication among RAS teams, services, and users. Considering that several allergic manifestations commonly coexist in the same individual, it might be more appropriate to implement a line of care for the person with allergy.

The gap between the need for resources and their availability leads to financial and logistical problems in PHC. The discussion on health care funding highlights the lack of resources to meet the growing demand for pharmaceutical care and diagnostic tests, a scenario that challenges the sustainability and efficiency of the SUS in responding to patients' needs.⁹

It is essential to discuss health care funding to improve care for immune and allergic diseases in PHC. It is also important to promote early diagnosis and integrated care management through effective partnerships between the different levels of health care. Fundamental measures include implementing evidence-based practices, increasing access to essential medications, and providing continuing education for health professionals. Furthermore, the use of telemedicine can serve as a valuable support resource, especially in regions underserved with specialists. We believe that actions like these will result in better control of immune and allergic

diseases, not to mention reduced hospitalizations for ambulatory care sensitive conditions (ACSCs).¹⁰ A partnership between the PHC/SUS and the ASBAI, through their local offices, could help organize and deliver continuing education activities both in person and via telehealth.

Allergology and immunology in specialized care

The transition from PHC to specialized care in allergology and immunology has significant challenges. Considerable barriers include the geographical size of Brazil, shortage of specialists, and limited access to diagnostic and therapeutic procedures. Although some progress has been made, the uneven distribution of specialized services throughout the country perpetuates the difficulties in the adequate management of these diseases.^{4,5}

It is imperative to develop health policies that encourage the training and equitable distribution of

- Stroke in adults
- Asthma
- Breast cancer
- Depression in adults
- Type 2 Diabetes Mellitus (first version)
- Chronic Obstructive Pulmonary Disease (COPD)
- Chronic Kidney Disease (CKD) in adults
- Low back pain
- Chest pain
- Viral hepatitis
- Systemic Arterial Hypertension (SAH) in adults
- HIV/AIDS in adults
- Acute Myocardial Infarction (AMI)
- Heart failure (HF) in adults
- Obesity in adults
- People with dementia
- Childcare and Adolescent health
- Smoking
- Anxiety disorders in adults
- Alcohol use disorders in adults
- Autism Spectrum Disorder (ASD) in children
- Congenital Zika virus infection syndrome (CZS)

Figure 2

Lines of care in primary health care

Source: Brazilian Ministry of Health.⁸

specialists in allergology and immunology. Expanding access to advanced diagnostic procedures and treatments, including biological therapies and immunotherapies, is essential for the provision of quality specialized care. Investments in research and development in technology are also necessary to adapt scientific innovations to the context of the SUS. Moreover, efficient management is needed to expand access to specialized services, including the regulation of referrals and counter-referrals.¹¹

Health care for patients with rare diseases

The management of rare diseases, including IEI, poses a major challenge within the SUS. Diagnosis is often complex and time-consuming, aggravated by the lack of specific knowledge among health care professionals and the scarcity of specialized diagnostic resources.

In 2014, the Brazilian Ministry of Health instituted the National Policy on Comprehensive Health Care for People with Rare Diseases and approved the Guidelines on Comprehensive Health Care for People with Rare Diseases within the SUS through Ordinance GM/MS No. 199 of January 30, 2014 (consolidated in Annex XXXVIII of Consolidating Ordinance No. 2 of September 28, 2017).^{12,13}

The policy has a transversal scope in the RAS and seeks to reduce mortality, contribute to reducing morbimortality, secondary manifestations, and provide opportunities to improve people's quality of life through promotion, prevention, early detection, timely treatment, disability reduction, and palliative care actions.¹⁴

The Brazilian Ministry of Health has so far authorized 31 referral or health care services for patients with rare diseases. However, these services are located in only 13 Brazilian states, mostly in the Southeast, and few treat patients with IEI¹⁵ (Table 1).

In this context, it is necessary to encourage health care services for patients with rare diseases to apply for qualification as a reference or health care service for rare diseases.

The introduction of newborn screening programs and access to innovative and personalized treatments, guaranteeing more effective and humanized care, are also measures that are awaited. Multidisciplinary care and ongoing monitoring are essential to guarantee a better prognosis for these patients, creating the

need for an integrated and accessible support network. Additionally, the training of health care professionals in PHC and specialized care, as well as the strengthening of specific public policies for these conditions, are necessary measures as access to these services is guaranteed.

Recommendations

Strategic recommendations emerged from the SUS Forum with the aim of improving care for patients with immune and allergic diseases within the SUS, ranging from funding and strengthening PHC, through training health care professionals, to expanding access to diagnostic and therapeutic procedures in specialized care.

Table 2 shows the barriers and proposed solutions for the comprehensive and continuous care of patients with immune and allergic diseases in PHC, specialized care, and for rare diseases.

Conclusion

Immune and allergic diseases require specialized, comprehensive, and continuous care, given their chronic nature and high impact on the quality of life of individuals. In addition, the management of these diseases is challenging and potentially costly, requiring well-defined and coordinated health care policies and strategies.

The Maceió Charter is a call for action for health managers and professionals, highlighting the urgency of moving forward in building a more inclusive, efficient, and humanized health system that also meets the needs of patients with immune and allergic diseases.

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Table 1

Centers for Rare Disease authorized by the Brazilian Ministry of Health between 2016 and 2023

Region	State	Municipality	Centers for Rare Disease	Type of accreditation	Year of accreditation
Midwest	GO	Anápolis	Associação de Pais e Amigos dos Excepcionais - APAE de Anápolis	SRDR ^a	2016
Midwest	DF	Brasília	Hospital de Apoio de Brasília	SRDR ^a	2016
Midwest	DF	Brasília	Hospital Materno Infantil de Brasília - HMIB	SRDR ^a	2019
Midwest	GO	Goiânia	Hospital Estadual de Geral de Goiânia “Dr. Alberto Rassi”	SRDR ^a	2022
Northeast	BA	Salvador	Associação de Pais e Amigos dos Excepcionais - APAE	SRDR ^a	2018
Northeast	BA	Salvador	Hospital Universitário Professor Edgard Santos - HUPES	SRDR ^a	2019
Northeast	CE	Fortaleza	Hospital Infantil Albert Sabin	SRDR ^a	2019
Northeast	CE	Fortaleza	Hospital Universitário Walter Cantídio	SRDR ^a	
Northeast	PE	Recife	Instituto de Medicina Integral Professor Fernando Figueira - IMIP	SAEDR ^b	2019
Northeast	PE	Recife	Instituto de Medicina Integral Professor Fernando Figueira - IMIP	SRDR ^a	2021
Northeast	CE	Fortaleza	Hospital Geral de Fortaleza - HGF	SAEDR ^b	2023
Northeast	PE	Recife	Hospital Maria Lucinda	SRDR ^a	2023
North	PA	Belém	Hospital Universitário Bettina Ferro - Universidade Federal do Pará	SRDR ^a	2023
Southeast	RJ	Rio de Janeiro	Instituto Federal Fluminense	SRDR ^a	2016
Southeast	SP	Santo André	Ambulatório de Especialidade da Faculdade de Medicina do ABC	SRDR ^a	2016
Southeast	ES	Vitória	Hospital Santa Casa de Misericórdia de Vitória	SAEDR ^b	2019
Southeast	MG	Belo Horizonte	Hospital Infantil João Paulo II	SRDR ^a	2019
Southeast	SP	Campinas	Hospital de Clínicas da Universidade de Campinas - UNICAMP	SRDR ^a	2019
Southeast	SP	Ribeirão Preto	Hospital de Clínicas de Ribeirão Preto	SRDR ^a	2019
Southeast	SP	São José do Rio Preto	Hospital de Base de São José do Rio Preto	SRDR ^a	2020
Southeast	MG	Juiz de Fora	Hospital Universitário da Universidade Federal de Juiz de Fora	SRDR ^a	2021
Southeast	MG	Belo Horizonte	Hospital das Clínicas da Universidade Federal de Minas Gerais	SRDR ^a	2022
Southeast	MG	Bom Despacho	Centro de Especialidades Multiprofissionais Dr. Gê	SAEDR ^b	2023
Southeast	MG	Belo Horizonte	Hospital Julia Kubitschek	SAEDR ^b	2023
Southeast	RJ	Rio de Janeiro	Instituto de Puericultura e Pediatria Martagão Gesteira da Universidade Federal do Rio de Janeiro - UFRJ	SRDR ^a	2023
South	PR	Curitiba	Hospital Pequeno Príncipe de Curitiba	SRDR ^a	2016
South	RS	Porto Alegre	Hospital de Clínicas de Porto Alegre	SRDR ^a	2016
South	SC	Florianópolis	Hospital Infantil Joana de Gusmão	SRDR ^a	2019
South	PR	Curitiba	Complexo Hospital de Clínicas da Universidade Federal do Paraná - UFPR	SAEDR ^b	2020
South	RS	Santa Maria	Hospital Universitário de Santa Maria - HUSM	SRDR ^a	2021
South	PR	Curitiba	Hospital Erasto Gaertner	SRDR ^a	2023
South	SC	Blumenau	Associação Renal Vida	SAEDR ^b	2023

^a SRDR *Serviço de Referência em Doenças Raras* (Reference Service for Rare Diseases),^b SAEDR *Serviço de Atenção Especializada em Doenças Raras* (Specialized Care Service for Rare Diseases).Source: Brazilian Ministry of Health.¹⁵

Table 2

Barriers and proposed solutions for the comprehensive and continuous health care of patients with immune and allergic diseases in the Unified Health System

	Barriers	Proposed solution
Primary health care	<p>Delay in diagnosis and access to appropriate treatment, either due to unfamiliarity with the disease or inadequate access to diagnostic screening tests and essential drugs.</p> <p>No integration with specialized care, which could reduce excessive referrals of mild cases and shorten waiting time for moderate and severe cases.</p>	<p>Implement evidence-based practices;</p> <p>Encourage in-person and telehealth continuing medical education in allergic diseases and inborn errors of immunity through a partnership with the ASBAI Regional Offices;</p> <p>Implement a Line of Care for persons with allergies;</p> <p>Include telemedicine in daily clinical practice, facilitating access and strengthening partnerships with specialized care;</p> <p>Ensuring access to essential medication.</p>
Specialized care	<p>Unequal distribution of specialized professionals and centers across the country;</p> <p>Difficulties and delays in referring patients to specialized care centers;</p> <p>Difficulty in accessing specialized diagnostic and therapeutic procedures in allergology and immunology.</p>	<p>Encourage training and equitable distribution of specialists in the SUS network through policies to encourage people management and the implementation of specialized care in regional centers in areas in need of the specialty;</p> <p>Ensure more efficient management of the RAS, including regulation of referrals and counter-referrals;</p> <p>Update outdated clinical protocols and therapeutic guidelines;</p> <p>Introduce clinical and therapeutic protocols for chronic diseases requiring high-cost diagnostic and/or therapeutic procedures.</p>
Rare diseases	<p>Complex and time-consuming diagnosis, aggravated due to the lack of specific knowledge of health care professionals;</p> <p>Shortage of specialized diagnostic resources;</p> <p>Deficiency of an integrated and accessible multidisciplinary support network.</p>	<p>Train health care professionals in PHC and specialized care through partnerships with the ASBAI Regional Offices;</p> <p>Implement newborn screening programs;</p> <p>Expand access to diagnostic methods to investigate inborn errors of immunity and innovative high-cost treatments;</p> <p>Ensure multidisciplinary care through professional development policies and fostering and supporting new reference centers in underprivileged regions of the country;</p> <p>Ensure access to medicines from the specialized component of pharmaceutical assistance already incorporated into the SUS.</p>

ASBAI: Associação Brasileira de Alergia e Imunologia (Brazilian Association of Allergy and Immunology).

RAS: Redes de Atenção à Saúde (health care network).

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