


# Oral health care for patients with hereditary coagulopathies: the students' contribution to the re-structuring of health care


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**Abstract** Due to their increased risk of bleeding during dental procedures, patients diagnosed with hereditary coagulopathies or thrombopathies often have difficulty in accessing dental care in primary health care. Some centres specialised in the treatment of these diseases have a dentist as part of the multidisciplinary team, making most patients undergo dental follow-up in such services. This study aims to report the experience of undergraduate and graduate students in dentistry at the Federal University of Paraná in the re-opening of the dental outpatient clinic for patients with hereditary coagulopathies and thrombopathies in the State of Paraná. With the retirement of the dentist accounting for local dental care, the patients were left unattended. To meet the repressed demand, the dental outpatient clinic was re-opened as an extramural activity for undergraduate and postgraduate courses in dentistry. This fact made it possible to improve the students' care for patients with systemic impairment, in addition to resuming dental care for patients with predisposition to haemorrhage. The re-opening of a highly complex clinic as a field of academic practice is atypical, as the process commonly takes place in reverse order, that is, with the student entering well-established service. In the present experience, the students played a fundamental role in the re-establishment of dental care at the blood centre.

**Descriptors:** Public Health Dentistry. Blood Coagulation Disorders. Students, Dental.

## Atención de salud bucal para pacientes con coagulopatías hereditarias: la contribución de los estudiantes a la reestructuración de la atención

**Resumen** Debido a su mayor riesgo de hemorragia durante los procedimientos dentales, los pacientes diagnosticados con coagulopatías o trombopatías hereditarias a menudo tienen dificultades para acceder a la atención dental en la Atención Primaria de Salud. Algunos centros especializados en el tratamiento de estas enfermedades cuentan con el odontólogo como parte del equipo multidisciplinario, haciendo que la mayoría de los pacientes se sometan a un seguimiento odontológico en dichos servicios. Este estudio tiene como objetivo reportar la experiencia de estudiantes de pre y posgrado en Odontología de la Universidade Federal do Paraná en la reapertura de la consulta externa de odontología para pacientes con coagulopatías y trombopatías hereditarias en el estado. Con la jubilación del profesional responsable de la atención odontológica de este servicio, los pacientes quedaron desatendidos. Para atender la demanda reprimida, se reabrió el ambulatorio como actividad extramuros para los cursos de grado y posgrado en Odontología. Este hecho permitió, además de la reanudación de la atención odontológica de los pacientes con predisposición a la hemorragia, la mejora de los estudiantes en la atención de los pacientes con deterioro sistémico. La reapertura de una clínica de salud de alta complejidad como campo de práctica académica es atípica, ya que el proceso comúnmente se da a la inversa: el estudiante ingresa a un servicio bien establecido. En la experiencia actual, los estudiantes tuvieron un papel fundamental en el restablecimiento de la atención de la salud por parte de la consulta externa de Odontología del Hemocentro.

**Descriptores:** Odontología en Salud Pública. Trastornos de la Coagulación Sanguínea. Estudiantes de Odontología.

## Atenção à saúde bucal de pacientes com coagulopatias hereditárias: a contribuição discente na reestruturação da assistência

**Resumo** Por apresentarem maior risco de sangramento durante a realização de procedimentos odontológicos, pacientes diagnosticados com coagulopatias ou



trombopatias hereditárias apresentam, frequentemente, dificuldade de acesso à assistência odontológica na Atenção Primária em Saúde. Alguns centros especializados no tratamento dessas doenças contam com o cirurgião-dentista como parte da equipe multiprofissional, permitindo que a maioria dos pacientes realizem o acompanhamento odontológico em tais serviços. Este estudo tem como objetivo relatar a experiência dos discentes de graduação e pós-graduação em Odontologia da Universidade Federal do Paraná na reabertura do ambulatório odontológico de assistência à pacientes com coagulopatias e trombopatias hereditárias do estado. Com a aposentadoria da profissional responsável pelos atendimentos odontológicos deste serviço, os pacientes ficaram desassistidos. Para suprir a demanda reprimida, o ambulatório foi reaberto como atividade extramuros da graduação e pós-graduação em Odontologia. Este fato possibilitou, além da retomada ao cuidado odontológico de pacientes com predisposição a hemorragias, o aprimoramento dos alunos no atendimento de pacientes com comprometimento sistêmico. A reabertura de um ambulatório de alta complexidade em saúde como campo de prática acadêmico é atípico, uma vez que comumente o processo se dá de forma inversa: o discente ingressando em um serviço bem estabelecido. Na presente experiência, os discentes tiveram atuação fundamental no restabelecimento da assistência à saúde pelo ambulatório de Odontologia do hemocentro.

**Descritores:** Odontologia em Saúde Pública. Transtornos da Coagulação Sanguínea. Estudantes de Odontologia.

## INTRODUCTION

Hereditary coagulopathies are diseases resulting from the quantitative and/or qualitative deficiency of platelets or coagulation factors<sup>1</sup>. They are characterised by the occurrence of haemorrhage of varying severity, which can be spontaneous or post-traumatic, causing these patients to often require replacement of blood components or derivatives<sup>1,2</sup>. The treatment of coagulopathies resulting from the deficiency of coagulation factors is carried out with infusion of the absent factor. This can be performed whenever necessary, such as in situations involving episodes of bleeding (episodic or on-demand therapy) or prevention (prophylactic therapy)<sup>1,2</sup>. In the Brazilian National Health System (*SUS*), the Program for People with Haemophilia and other Hereditary Haemorrhagic Disorders has been seeking to improve the care for these patients since its creation in the 1980s<sup>1-3</sup>.

In 2009 a partnership with the *SUS* Department of Informatics was established for improvement of the processes of health care management in this scenario, the Hemovida Web Coagulopathies. The objectives of this system are to record, store and process data from patients with coagulopathies, thus allowing systematisation, analysis and availability of information reported by the Profile of Hereditary Coagulopathies in Brazil<sup>3</sup>. In its latest version, published in 2018 (data consolidated until 2016), the number of patients with hereditary coagulopathies in Brazil was 24,228, with approximately 43% corresponding to haemophilia A, 8% to haemophilia B, 32% to von Willebrand disease, 7% to rare coagulopathies and 10% to other hereditary coagulopathies and other haemorrhagic disorders<sup>3</sup>. The south-eastern region of Brazil concentrates approximately half of the cases of coagulopathies (46.21%), with the state of São Paulo accounting for 20.13% of all cases in the country. The southern region of Brazil, from where the case was reported, concentrates 18% of all cases of coagulopathies, in which the state of Paraná accounts for 7% of the cases, with 667 patients diagnosed with haemophilia A and 651 patients diagnosed with von Willebrand disease. Age distribution shows a higher prevalence of coagulopathies in individuals aged between 20-29 years old, which corresponds to 22% of all cases in the country. With regard to gender, 67% of all blood dyscrasias affect male individuals. Due to its recessive inheritance characteristics, approximately 98% of patients with haemophilia A and 97% of those with haemophilia B are male<sup>3</sup>. On the other hand, von Willebrand disease (66%), rare hereditary coagulopathies (51%) and other coagulopathies and other haemorrhagic disorders (64%) affect females in the majority of the cases<sup>3</sup>.

Although patients with hereditary coagulopathies and thrombopathies are often diagnosed in the primary health care (PHC), they are usually referred to specialised centres for continuity of care, which is dependent of highly-moderately complex services (e.g. blood centres, reference hospitals and emergency services)<sup>4,5</sup>. Such a practice occurs mainly due to the lack of both service structure and qualification of human resources, which makes it difficult to have access to

health care on an integral basis and compromises the universality of health care as well as the establishment and strengthening of ties with local healthcare teams<sup>5</sup>.

Socio-economic characteristics have also influenced the severity of the direct and indirect consequences of the coagulopathies. Unassisted children living in environments with higher risk of accidents, both at home and at school, who are not educated for self-care and are inserted in a context of unprepared family and community, will suffer repeated bleeding events more precociously and with greater severity, thus impacting directly the medical costs and their quality of life. Among adults, one can highlight occupational risks, unemployment and lack of adherence to the treatment<sup>6,7</sup>.

The need of follow-up is reinforced by the fact that patients diagnosed with hereditary coagulopathies and thrombopathies often present haemarthrosis, which when not treated or poorly treated, can result in permanent damage to the articulations, thus disabling the affected individuals. In this way, the greater and better the access to healthcare services for patients with hereditary coagulopathies and thrombopathies, the better the prevention of these and other irreversible sequels<sup>8-10</sup>.

In the dental context, patients diagnosed with hereditary coagulopathies and thrombopathies have a higher risk of oral bleeding, mainly after surgical procedures or oral mucosal trauma<sup>2,4-5</sup>.

In Brazil, the participation of dental surgeons in multidisciplinary teams has allowed outpatient dental treatment to be provided to patients with hereditary coagulopathies and thrombopathies<sup>4,5,8</sup>. With the improvement of local haemostatic techniques, replacement of coagulation factors should be reserved for procedures which are judiciously required and indicated<sup>5</sup>. Nevertheless, the access to dental treatment for these services is not a guarantee as many healthcare centres have no dental surgeon in their multiprofessional team<sup>8</sup>. This fact, added to the difficult access to public health service, causes the oral condition of individuals diagnosed with hereditary coagulopathies and other haemorrhagic disorders to be in risk of being neglected. This further complicates the already-difficult journey of these individuals in the healthcare network, such as referral to other blood centres, university clinics, hospitals or private clinics<sup>8-10</sup>.

A research performed by the Curitiba Coordinating Blood Centre investigated the major barriers to access care faced by patients diagnosed with haemorrhagic disorders and hereditary hemoglobin diseases. A total of 131 patients participated in the study and 29.1% reported that they had already been denied dental care, 64.6% felt anxious for visiting dental surgeons of their communities because of their health condition and 38.4% had already needed dental treatment, but they could not afford it or did not manage to schedule a dental visit in the public sector<sup>9</sup>.

According to a resolution determining the national curriculum guidelines for undergraduate courses of dentistry (CNE/CES number 3, June 2021), the graduation of a dental surgeon should include the national health system (*SUS*) as part of the curriculum in terms of professional practice and learning<sup>11</sup>. The graduation of a dentist should have as objective the integral attention to healthcare by taking into consideration the system of reference and counter-reference<sup>11</sup>. The same document traces the profile of the former dental students who, among other characteristics, should be capable to work as a team on an inter-professional, inter-disciplinary and trans-disciplinary basis and practise dentistry in all levels of healthcare<sup>11</sup>.

Therefore, the highly-moderately complex outpatient clinics of the Brazilian blood centres are an important scenario of complementary and integrative practices for a professional graduation in dentistry.

## EXPERIENCE REPORT

The Curitiba Coordinating Blood Centre is a public institution providing services for the state secretary of health, being a reference in haemotherapy and haematology in the state of Paraná<sup>11,12</sup>. The network of blood centres (*HemoRede*) accounts for collection, storage, processing, transfusion and distribution of blood for 384 hospitals in all regions of the state of Paraná. Today, the *HemoRede* consists of 24 blood centres which are strategically located throughout the state of Paraná<sup>11,12</sup>. In Curitiba, the Hemepar blood centre is where the reported experience took place.

The institution is accounted for providing haemotherapeutic and haematological services to patients with coagulopathies, thrombopathies, sickle cell disease and thalassemia<sup>12,13</sup>. Dental office is part of the outpatient facilities of the Hemepar blood centre, but because of the retirement of the dental surgeon of the team, the service remained closed since then as no new professional was hired and there is no selective process or public competitive examination either. Consequently, great part of the haematological patients seeking dental care were then without the service.

The re-opening of dental outpatient clinic occurred after the Hemepar executive board submitted a request based on the repressed demand for dental treatment, which was impaired due to the closed service. The institution's outpatient dental clinic was re-structured by the eight dental undergraduate students, four residents of the multiprofessional hospital care in the oncology and haematology program of a public hospital and four post-graduate students in dentistry, all supervised by a tutor professor.

The Hemepar outpatient dental clinic was re-structured with the aim to provide primary oral healthcare services to prevent acute and chronic odonto-stomatological complications in patients diagnosed with hereditary coagulopathies and thrombopathies who were being followed up at the clinic. A service charter was developed according to the dental procedures offered in the primary health care and in accordance with the Portfolio of Primary Healthcare Services<sup>14</sup>, namely, preventive procedures and promotion of oral health, emergency care, and restorative, surgical and periodontal treatments.

Dental care is covered by the National Health System and is provided in a shift work schedule every week, in which about five patients are seen a day. The patients are booked appointments according to spontaneous demand or demand induced by the healthcare team for emergency procedures. In order to integrate all the students involved in the project, weekly rotation was organised to allow their full participation and avoid turmoil, thus preserving the outpatient environment.

In the first 20 months of functioning of the outpatient dental clinic, 205 patients were assisted and approximately 300 procedures were performed, such as initial evaluation and re-evaluations, self-care orientations, plaque removal, periodontal curettage, endodontic emergency and tooth extractions. Early haemostatic planning for each patient and necessary dental procedures were discussed by the participants together with the tutor professor and professionals of the institution's multiprofessional team. Underlying pathology, haematological conditions, difficulties, type of dental procedure were all taken into consideration before deciding which haemostatic manoeuvres were the most adequate for each situation. In this way, replacement of deficient or altered coagulation factor was necessary for some patients, whereas others required anti-fibrinolytic medications and local haemostatic manoeuvres only. The discussion on the dental cases with other health professionals was fundamental for an interaction between students and multiprofessional team, which allowed relationships to be built, improved communication and provided integral and individualised care to the patients.

The most commonly identified diseases in the group of patients treated by the dental participants were haemophilia A, von Willebrand disease and sickle cell anemia, in addition to patients undergoing diagnostic process. Patients needing procedures not offered by the outpatient dental clinic, such as extraction of third molars, confection of prosthesis and imaging examination, are referred to other services (e.g. dental clinic of the Federal University of Paraná) in order to ensure continuity of the assistance by the National Health System. Whenever possible, the patient is referred to the Hemepar outpatient clinic for dental treatment by the undergraduate students participating in the project, which allows relationships to be built and longitudinal follow-up of each case. The students are also trained in treatment supervision, matrix support and improvement of inter-professional communication, thus helping the user navigate through the public healthcare network and use, if available and convenient, private services.

In addition to dental services, four master's dissertations in the areas of stomatopathology and paediatric dentistry were carried out in the service, thus providing assistance in association with scientific research.

The repressed demand for dental services in the Hemepar outpatient dental clinic has been solved with weekly visits, despite being still present. Dental care is improving over time as visit schedule, equipment, instruments and materials are better organised and both dental and multiprofessional teams are prepared, which will allow a greater number of services to be provided with more dental procedures, resulting consequently in more cases solved. Moreover, the return of dental services has allowed patients diagnosed with hereditary coagulopathies and thrombopathies to have a referenced outpatient dental clinic for dental follow-up. In this way, they can seek dental care whenever necessary, thus preventing impairment of the oral conditions, which was experienced during the period when the dental services were closed. Another contribution to be highlighted is the matrix support provided by the team of dental professionals from the public and private sectors in situations of clinical care and intervention which can be performed in cities nearer to the places of origin of the patients<sup>15,16</sup>.

For the undergraduate students, the experience acquired with supervised practice in this outpatient dental clinic represents the possibility of becoming a generalist professional who is accurate and decisive in the context of coagulopathies, thus attenuating stigmas regarding the care of complex patients and stimulating the professional qualification of this segment of healthcare practitioners and their insertion in the National Health System.

## FINAL CONSIDERATIONS

The re-opening of a highly complex outpatient clinic for academic practice is an atypical event. Students participate routinely in a well-established service programs. In the case of Hemepar, the students played a fundamental role in the re-structuring of the oral healthcare, which contributed to integrity of the service.

The performance of the dental students in a highly complex outpatient environment allows them to better handle the clinical interventions, as in the case of the patients diagnosed with hereditary coagulopathies and thrombopathies, and thus become professionals capable of increasing the access of this group of patients to public and/or private services.

In addition, the professional training with multiprofessional health teams will prepare the students to better communicate with them, thus resulting in improvement of the quality of life and care of the patients.

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