Oral cancer care in the "Metropolitan I" health region in the state of Rio de Janeiro, Brazil: enabling and constraining factors

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Abstract *The aim was to identify constraining and enabling factors related to the organization of health care networks that influence access to oral cancer diagnosis and treatment. A case study in the "Metropolitan I" health region using data collected from health information systems and 26 semi-structured interviews with health managers and professionals. The data were analyzed using descriptive statistics and strategic conduct analysis, drawing on the theory of structuration proposed by Giddens. The findings reveal that coverage of oral health care in primary care services is generally low and prioritizes specific groups and urgent cases, hampering access to oral cancer diagnosis. While the presence of a network of secondary care services in the municipalities that make up the health region facilitates diagnosis, there are major barriers to treatment. Informal partnerships established with dental schools play an important role in diagnosis, but do not receive funding. The regulation of appointments for diagnosis was not restrictive. In contrast, the regulation of referrals for treatment lacked transparency, was subject to long delays, and shortage of places. Despite advances, constraining factors related to structure and the actions of agents involved in the care process persist, hampering the timely diagnosis and treatment of oral cancer.*

Key words *Neoplasms of Mouth, Health Policy, Oral Health Services*

Introduction

The National Oral Health Policy (PNSB)[1] and National Cancer Prevention and Control Policy (PNPCC)[2] provide that primary health care services are responsible for the detection of suspicious oral lesions and referral to confirm diagnosis.

Preferentially, diagnosis should be performed in specialist outpatient services, including specialist dental centers (CEOs). All CEOs should perform oral diagnosis[3] and be equipped with the necessary structure and facilities to carry out clinical examinations, biopsies, and referral for analysis in pathology laboratories, which serve as a support system[2].

After oral cancer diagnosis, the patient is referred to a specialist hospital unit for treatment, preferably to a High-Complexity Cancer Care Unit (UNACON), which delivers radiotherapy treatment, or High-Complexity Cancer Care Center (CACON)[4]. This process should be set out in regional plans that include regulatory mechanisms designed to optimize the organization of service delivery and promote equity[2].

However, in the everyday practice of health services, the rules and regulations are not necessarily implemented in the form envisaged by the PNPCC and PNSB. This happens as the roles and responsibilities of each institution involved in the process are not always clearly defined and, despite being limited by the rules and regulations and underfunding of the country's public health system, the *Sistema Único de Saúde* (SUS) or Unified Health System, the agents involved in the process tend to innovate and seek alternatives, straining established forms of organization[5].

It is estimated that there were 15,190 cases of oral cancer in Brazil in 2021[6] and 6,192 deaths due to the disease in 2020[7]. The high number of oral cancer cases and deaths is associated with late diagnosis, despite the fact that this type of cancer occurs in places that are accessible to visual inspection[8]. Despite regulations and increased funding, the oral cancer mortality rate rose between 2003 and 2012[9,10].

The multiple factors that have led to this increase need to be better understood. While other studies have investigated access to oral cancer care, this article is innovative insofar as it examines access considering the reality of the different components of the care network from the perspective of different agents involved in this process. The objective of this study was to identify enabling and constraining factors related to the organization of the health care network that influence access to the diagnosis and treatment of oral cancer in the Metropolitan I health region in the state of Rio de Janeiro.

Methodology

We conducted an analytical case study using data from multiple sources to obtain a holistic understanding of the problem[11]. The data were collected in the second semester of 2019. We selected the Metropolitan I health region because it is the health region with the highest population and concentration of oral cancer care services in the state. The region has a population of 9 million and is made up of 12 municipalities: Belford Roxo, Duque de Caxias, Itaguaí, Japeri, Magé, Mesquita, Nilópolis, Nova Iguaçu, Queimados, Rio de Janeiro, São João de Meriti, and Seropédica.

The primary health care services were characterized according to variations in coverage of primary oral health care in 2009, 2014 and 2019 and considering the registry of family health professionals, health posts, health centers, primary care units, consulting rooms, and mobile clinics, using criteria and data from the primary care data platform eGestor (https://egestorab.saude.gov.br/). These years were selected to enable the observation of alterations over a 10-year period with an interval in the fifth year.

Data from the SUS's Outpatient Information System (SIA/SUS) were analyzed using TABWIN to identify facilities that performed oral biopsies in 2019. These facilities were classified according to their accreditation status in the National Register of Health Facilities (CNES). We included all procedures entered under codes 0201010232 (salivary gland biopsies), 0201010372 (skin and soft-tissue biopsies), and 0201010526 (oral soft-tissue biopsies), which are indicated for the following ICD-10 codes: C00 (Malignant neoplasm of lip); C01 (Malignant neoplasm of base of tongue); C02 (Malignant neoplasm of other and unspecified parts of tongue); C03 (Malignant neoplasm of gum); C04 (Malignant neoplasm of floor of mouth); C05 (Malignant neoplasm of palate); C06 (Malignant neoplasm of other and unspecified parts of mouth); C07 (Malignant neoplasm of parotid gland); C08 (Malignant neoplasm of other and unspecified major salivary glands); C09 (Malignant neoplasm of tonsil); C10 (Malignant neoplasm of oropharynx); D10 (Benign neoplasm of mouth and pharynx); K00 (Disorders of tooth development and eruption);

K01 (Embedded and impacted teeth); K02 (Dental carries); K03 (Other diseases of hard tissues of teeth); K04 (Diseases of pulp and periapical tissues); K05 (Gingivitis and periodontal diseases); K06 (Other disorders of gingiva and edentulous alveolar ridge); K07 (Dentofacial anomalies [including malocclusion]); K08 (Other disorders of teeth and supporting structures); K09 (Cysts of oral region, not elsewhere classified); K10 (Other diseases of jaws); K11 (Diseases of salivary glands); K12 (Stomatitis and related lesions); K13 (Other diseases of lip and oral mucosa); and K14 (Diseases of tongue).

We used data from the Hospital Information System (SIH/SUS) to determine the number of oral cancer surgeries (code 0416) for the ICD-10 codes C00-C10 and map the municipalities responsible for oral cancer treatment in the Metropolitan I health region in 2019.

To understand oral cancer care management mechanisms, we interviewed 26 people: three members of the technical team of the state department of health's (SES/RJ) Office for the Coordination of Oral Health Care; five municipal oral health managers; and 19 dental surgeons from five different municipalities – 12 working in oral health teams (eSBs), which are part of the family health strategy (eSF), and six responsible for oral cancer diagnosis in CEOs. All interviewees had worked for at least one year in the services. The selection of the municipalities was based on population size: one with over one million; two with between 500,000 and one million; and two with less than 500,000.

The number of interviews was considered adequate by the authors based the concept of "information power", which is a substitute for the saturation method proposed by grounded theory[12]. The interviewers did not know the participants. The latter were contacted by telephone to schedule the interview, when they were explained the purpose and procedures of the study. There were no refusals to participate in the study.

We used strategic conduct analysis as a frame of reference, drawing on the theory of structuration proposed by Giddens[13], which focuses on the discursive consciousness of agents to elucidate the meanings they assign to their actions and reveal constraining and enabling factors affecting access to oral cancer diagnosis and treatment on the SUS. This type of analysis advocates the integration of qualitative and quantitative approaches, albeit giving more emphasis to the former[13].

The theory of structuration offers a framework for analyzing public policies structured around the intentionality of governments and the concrete actions of agents in the implementation of these policies[14]. It is based on the "duality of structure", where the structural properties of social systems are both medium and outcomes of the practices they recursively organize[13]. This understanding of the relationship between structure and action suggests that social systems (including health systems) are a balance between the influence of society on the individual (constraining structure) and the freedom of the individual to act and influence society (freedom of action). Structure and action are therefore inextricably linked, mutually influencing each other[13,14].

We conducted semi-structured interviews using a guide containing questions about the organization of oral care and everyday reality of services, which varied depending on the profile of the participant and work setting. Additional questions were asked depending on the interviewees' answers to the questions contained in the guide[15,16]. The questions about the everyday reality of services were designed to directly or indirectly reveal constraining and enabling factors related to structures (laws, funding and physical resources) and the role played by the agents in oral cancer diagnosis, as suggested by the theory of structuration[13]. Structural factors and agents' actions positively related to achieving the objectives defined by people and services are considered enabling factors, while factors that hamper or make fulfilling these objectives impossible are understood to be constraining factors[13].

All interviews were conducted by the same researcher, who had prior experience in qualitative research. The interviews were conducted in the interviewee's workplace, recorded, transcribed, and analyzed using NVivo®. It was not necessary to repeat the interviews. The researcher also took field notes during the interviews, which were used to help understand the interview data.

The interview data were analyzed using thematic analysis. The results and discussion section is structured around the following categories[17] based on the core components of the care network set out in the PNPCC: primary care; specialist care; and support systems and regulation of appointment scheduling and referrals. This article follows the consolidated criteria for reporting qualitative research (the COREQ checklist)[18].

All participants signed an informed consent form and are identified using acronyms and random numbers: municipal oral health manager (CMSB); dental surgeon responsible for diagnosis (CDD); family health dental surgeon (CDeSF);

and member of the state Office for the Coordination Oral Health technical team (CESB).

The study protocol was approved by the research ethics committees (references CAAE 82201418.0.3001.5279 and 82201418.0.0000.5240).

Results and discussion

The constraining and enabling factors related to structural conditions and the actions developed by agents to tackle oral cancer are synthesized in Chart 1 and discussed below. Given the importance of the Metropolitan I health region at state and national level, this set of factors can serve as a proxy for discussing and understanding this problem in other health regions.

Primary care

Primary oral health care coverage in the health region is the lowest in the state. The highest and lowest rates in 2019 were 63.81%, in Seropédica, and 6.90%, in Belford Roxo. Primary care services expanded between 2009 and 2014, followed by a contraction between 2014 and 2019, following general patterns of coverage in the state (Table 1). Overall coverage in the health region (22.12%) was considered low by the interviewees.

The interviewees suggested that the region's low coverage rates were a constraining factor for access to oral cancer diagnosis and treatment and related to the large size of the municipalities, lack of funding, and the fact that the health region has been historically underserved. Despite the expansion of oral care in primary care services after the PNSB came into force, the historic debt of social exclusion meant that the results of this expansion have been limited[10].

Low coverage has a direct effect on oral cancer care, considering that the presence of eSBs in the eSF has a positive impact on actions such as campaigns, follow-up, referral to specialists, and the recording of suspected cases[19], which in turn contributes to the reduction in mouth and oropharyngeal cancer mortality rates in Brazil[20].

The low coverage and consequential overburdening of the health system help explain the forms of organization of primary care in the region described by the interviewees. According to the interviewees, there are different forms of organization of access to oral health care in primary care services: individual and family waiting lists; unscheduled consultations; referral by a multiprofessional team; active screening in schools and homes; and operative groups. According to the interviewees, waiting times for the first routine appointment were between three and 12 months. The findings clearly show that oral health care health services in the region are overburdened. The interviewees mentioned that, while the catchment population of a health facility is technically covered by one eSB, in practice access to services is limited, as this eSB is often allocated to four or more eSF teams (covering 10,000 to 15,000 service users). This situation is not unique to our study, with studies showing overburdening and the centralization of unscheduled consultations[21].

Overburdening has resulted in the prioritization of individual appointments to the detriment of collective activities. Difficulties developing health promotion and disease prevention activities have contributed to the high demand for individual treatment:

They are trying to bring it closer to the old health center, when patients were treated on arrival. First because urgent care clinics are being dismantled and can't meet the demand they used to meet, which is left to us, overwhelming [the facility] here. In fact, it is and always has been overwhelmed (CDeSF6).

The interviewees suggested that the old model before the adoption of the eSF focusing on unscheduled consultations was a stop gap measure and screening for potentially malignant disorders[22] ended up being neglected by overworked professionals who did not pay due attention to the soft tissues in the mouth during examinations. While recognizing the advantages of the new model over the old one, the interviewees mentioned difficulties related to this change, especially those due to low primary care coverage and the buildup of demand for individual appointments:

Dentists have to perform 20 appointments a day (to meet the target), so they often have to speed up and things end up getting missed. The positive side is that they perform more appointments and meet the demand of that region. The downside is the attention you give to each patient. So we don't do good patient anamneses (CMSB3).

According to the participants, the fact that the catchment population is beyond the team's capacity means that they have to prioritize certain groups, such as pregnant women, children, and people with diabetes, resulting in the unintended exclusion of other groups, like men aged over 40, alcoholics and smokers, who are less

Chart 1. Constraining and enabling factors relating to structural conditions and actions developed by agents to tackle oral cancer by care component.

Component	Structure		Agent	
	Enabling factors	Constraining factors	Enabling factors	Constraining factors
Primary care	- National primary health care and national oral health policies - Funding - Expansion of oral health care in primary services	- Low primary care coverage - Extremely low coverage of oral health care in primary care services - Economic crisis and funding shortages	- Stop smoking support groups - Contact between health managers to share supplies between municipalities	- Limitations of oral examination campaigns - Prioritization of specific groups - Prioritization of individual treatment the detriment of collective actions - Centralization of unscheduled consultations - Passivity in case screening
Specialist care	- National oral health and cancer prevention and control policies - Funding of specialist dental centers in all municipalities in the health region - Mandatory oral diagnosis services in specialist dental centers - Expansion of the hospital network for treatment	- Lack of funding for the National Cancer Prevention and Control Policy - Shortage of stomatologists in services - Lack of specific targets for oral diagnosis in specialist dental centers - Shortage of treatment facilities Services concentrated in the capital	- Unscheduled appointments for direct referral for diagnosis	- Profession responsible for diagnosis is not a specialist
Support system and regulation	- University pathology laboratories - State and municipal regulation systems - No waiting lists for diagnosis - State controls regulation for treatment - Online waiting lists more convenient for patients	- University pathology laboratories - State and municipal regulation systems - No waiting lists for diagnosis - State controls regulation for treatment - Online waiting lists more convenient for patients	- Provision of training for health professionals by universities - Informal arrangements to ensure access - State encourages the use of university laboratories - Multiple ways of facilitating access to diagnosis	- Informal and personal nature of the biopsy specimen referral process - Informal nature of diagnosis regulation process - Limited role of the regulator

Source: Authors.

likely to seek services and are at greater risk of oral cancer[23]:

Pregnant women, people with diabetes, children under 12 months, and the bedridden are a priority. Each month one team treats 20 new preg-nant women and the other 12. How much time is left over for those who are not a priority? Priority is almost exclusive access (CDeSF6).

The passive nature of health services was observed by an evaluation conducted under

Table 1. Coverage of oral health care in primary care services in the Metropolitan I health region in the state of Rio de Janeiro in 2009, 2014, and 2019.

Location	2009	2014	2019
State of Rio de Janeiro	29.23%	36.91%	32.53%
Metropolitan I	17.53%	25.77%	22.12%
Belford Roxo	11.26%	10.27%	6.90%
Duque de Caxias	17.56%	16.29%	18.77%
Itaguaí	47.96%	42.97%	27.76%
Japeri	10.49%	25.00%	9.96%
Magé	68.98%	66.80%	22.65%
Mesquita	18.91%	17.72%	20.31%
Nilópolis	9.43%	27.01%	33.37%
Nova Iguaçu	9.94%	21.96%	23.85%
Queimados	4.35%	12.80%	14.87%
Rio de Janeiro	17.66%	28.22%	24.03%
São João de Meriti	4.48%	7.52%	7.44%
Seropédica	56.04%	63.13%	63.81%

Source: eGestor. Accessed 24/02/2020.

the National Program for Improving Primary Care Access and Quality (PMAQ-AB) in 2012, which showed that only 62.1% of eSBs in the health region reported recording and following up suspected cases of mouth cancer referred for diagnosis and that only half (51.6%) were able to prove that they had recorded the cases[24].

According to the interviewees, the overburdening of eSBs became even worse after 2014 due to the country's political and economic situation, which affected coverage and services, as shown by the literature[25]. The funding crisis faced by municipalities led to an overall reduction in coverage in the state of Rio de Janeiro and in the Metropolitan I health region, with major differences across municipalities (Table 1).

According to the interviewees, in 2016, services were interrupted due to staff dismissals, delays in salary payments, strikes, lack of maintenance of broken equipment, lack of supplies, and infrastructure problems. Thus low coverage rates were further aggravated by poorly or nonfunctioning health facilities:

The working conditions of health posts are extremely precarious, and the majority are not functioning properly. Many posts are paralyzed because the compressor was either stolen, is broken, or doesn't work properly, or lighting is poor, or the air-conditioning in the consultation rooms is broken (CDD6).

One of the ways adopted by some managers to tackle the funding crisis was sharing supplies

with other municipalities. Although an important for solving specific problems, this strategy is unlikely to meet the long-term needs of health facilities due to the informal and personal nature of arrangements.

In addition, in response to widespread shortages, health managers were forced to establish criteria to prioritize services for the distribution supplies, with primary care often becoming a secondary priority:

Everything was affected. Today, for example, do we have enough supplies for all dentists? No. When anesthetics arrive, hospitals and CEOs are prioritized (CMSB2).

As a result of the funding crisis, oral health became a secondary priority and restrictive measures had a negative impact on access to care among disadvantaged groups[25], which are at greater risk of oral cancer:

You lose focus on prevention. We cannot let primary care be dismantled this way (CDD5).

In response to poor access, eSB professionals use different strategies to amplify the reach of their actions, including oral examination campaigns.

In 2012, 65.5% of the eSBs in the region reported promoting oral lesion detection campaigns[24]. Despite the importance of improving access to oral examinations, these campaigns are generally piecemeal and sporadic and tend to target audiences that already use the health facility and are therefore not high-risk groups[26].

There is little reflection on campaign results. None of the interviewees were able to say how many people were examined and the number of examinations performed or lesions identified. Neither could they describe the profile of participants and results of the examinations or confirm whether cases were referred for diagnosis. In addition, the local community tend to question the campaigns:

Oral assessment task forces to identify mouth cancer. Where it comes up against problems. [The community] complains to us: "Are you only going to look? What about the hole in my tooth, are you not going to look at it?". How can I solve everybody's problem? I can't (CDeSF6).

Another strategy is examinations for the health facility's stop smoking support groups. The interviewees mentioned that that this group has been weakened due to lack of demand and high staff turnover rates. This is an important action because it targets a group of people who are exposed to a key risk factor for oral cancer[27] and should therefore be stimulated. However, some

interviewees highlighted that the group is made up of people who want to stop smoking and already visit the health center and are therefore less at risk than hardline smokers who only use the center for emergencies. This very high-risk group requires complementary strategies and improvement in access to primary care.

Specialist care

Specialist care facilities include CEOs, UNACONs and CACONs[1,2].

CEOs perform biopsies and oral cancer diagnosis[1]. The interviewees highlighted that federal funding was a key factor determining the implementation of these services. While each municipality in the health region has a CEO, the expansion of primary care has led to an increase in demand for secondary services, which have not grown at the same pace[10].

Studies have highlighted that although there have been advances in secondary oral health care, services are mainly concentrated in large municipalities and CEOs tend to be located in municipalities with better social indicators[28]. A possible solution to this problem suggested by members of the technical team is the creation of regional services integrating various municipalities; however, there are a number of challenges involving patient transport:

We have always thought about a regional CEO, but it's very difficult. What they claim, and rightly so, is that patients from my municipality can't afford to travel to another municipality. A lot of small municipalities request a CEO, but we know that it won't be able to meet the targets (CESB1).

Despite limitations, in 2019, CEOs accounted for the largest share of biopsies for oral cancer diagnosis in the state and health region investigated by this study. The data from the SIA/SUS show that primary care centers did not perform biopsies (Table 2). These findings confirm the situation described by the interviewees, in which the role of primary care services is to identify lesions and refer patients for diagnosis. There are no major barriers to diagnosis as each municipality in the region has a CEO.

Table 2 shows that some municipalities did not enter biopsies into the SIA/SUS during the year in question. It is understood that the lack of data is due more to the lack of availability of procedures and deficiencies in recording procedures in the SIA/SUS than to lack of demand for biopsies. It is important to highlight that there are no agreed indicators for monitoring the oral

diagnosis services provided by CEO[1], despite the fact that these services are mandatory. The resulting lack of data may be a limiting factor for decision-making, as managers are not able to base decisions on trends in demand in the catchment area.

The interviewees reported that there are long waiting lists for all CEO services (up to six months), except oral diagnosis, where average waiting time is 10 days. Data from an evaluation conducted under the PMAQ-AB in 2012 show that it took an average of 14 days to schedule an appointment with a specialist in the capital and 50 days in other municipalities[24].

The specialist hospital component of the PNPCC, responsible for providing cancer treatment, consists of UNACONs and CACONs. Seventeen of the 32 accredited cancer centers in the state are located in the Metropolitan I health region. Fourteen of these are public services, differentiating the region form other health regions in the state and across the country[4]. The health managers interviewed in this study considered this to be an enabling factor in the negotiation process, despite the fact that it can also be a constraining factor when the political context is not conducive to collaborative negotiation between the public organizations involved in the care process.

According to data from the SIH/SUS, of the 303 surgeries for oral cancer undertaken in the state in 2019, 211 (69.8%) were performed in the Metropolitan I health region, 44 of which (20.8%) on patients from other health regions. These findings illustrate the key role played by the region in meeting demand for oral cancer treatment in the state. The expansion and decentralization of this service, considering the scale and scope criteria set out in the PNPCC[2] could contribute to a reduction in the treatment waiting list in the region.

Despite the limitations of hospital services mentioned above, it is important to recognize advances. It is known that a new reality for cancer control in the country has been structured in a short period of time. While funding remains a constraining factor for tertiary care, these services have witnessed expansion, which may be an enabling factor for access to treatment[29].

Support system and regulation

Pathology laboratories are part of the support system outlined in the PNPCC[2]. Despite the vital role these facilities play in diagnosis, the PNSB[1]

Table 2. Number and percentage of biopsies performed in the Metropolitan I health region in the state of Rio de Janeiro in 2019 according to facility accreditation status and municipality.

Location	CEO	General Hospital	UNACON	Total
Metropolitan I	670 (81.2)	130 (15.8)	25 (3.0)	825 (100.0)
Rio de Janeiro	600 (79.8)	127 (16.9)	25 (3.3)	752 (100.0)
Itaguaí	26 (96.3)	1 (3.7)	0	27 (100.0)
Japeri	19 (100.0)	0	0	19 (100.0)
Magé	11 (100.0)	0	0	11 (100.0)
Seropédica	6 (100.0)	0	0	6 (100.0)
Queimados	6 (100.0)	0	0	6 (100.0)
São João de Meriti	2 (100.0)	0	0	2 (100.0)
Nova Iguaçu	0	2 (100.0)	0	2 (100.0)
Belford Roxo	0	0	0	0
Duque de Caxias	0	0	0	0
Mesquita	0	0	0	0
Nilópolis	0	0	0	0

Key: CEO: Specialist Dental Center; UNACON: High-Complexity Cancer Care Unit.

Source: Outpatient Information System (SIA/SUS) and National Register of Health Facilities (CNES). Accessed 24/02/2020.

does not provide for the funding of the structuring of these services.

The interviewees highlighted that municipalities recently reorganized diagnosis, with some sending material to pathology laboratories that diagnose other types of lesions. This was viewed as a problem by the interviewees:

A major issue is the quality of the [lab] report, not only for determining the diagnosis but also in terms of the time gained when you have a highly qualified professional for slide analysis (CDD6).

University pathology laboratories have gained prominence as, according to the interviewees, they provide rapid, free, and high-quality diagnoses. This type of collaboration has been witnessed in other settings[30] and has been shown to improve the effectiveness of the care network and care delivery:

The first biopsies showed dysplasia, but no cancer. I took a photo of the lesion and sent it to the pathology professor. He said "do another [biopsy], because there's an abnormal area". We redid the biopsy and it was malignant (CDD6).

Given the difficulties faced with outsourced laboratory services and the positive experience with university laboratories, the members of the technical team reported that they encourage municipalities to use the latter as pathology reports are made available within 5 to 10 days. However, according to the interviewees, the informal nature of the process has resulted in the lack of

allocation of funding to the universities. There is therefore an urgent need to rethink the financial sustainability of this process, as demand is increasing and possible cuts in university funding could jeopardize this partnership and directly affect waiting time for cancer diagnosis.

With regard to the appointment and referral regulation process, the interviewees highlighted differences in the regulation of oral cancer diagnosis and treatment. First, diagnosis is regulated by the municipality, mainly via the National Regulation System (SISREG), while treatment is the responsibility of the SES/RJ and undertaken via the State Regulation System (SER).

Access to diagnosis is uneven, even within the same municipality. Generally, referral to CEOs is the responsibility of the eSB. However, other forms of referral were identified during the interviews, such as referral by emergency departments or urgent care centers and even via unscheduled appointments. This aspect illustrates the understanding that the formal regulation of referral via complex regulators is just one of the multiple ways of accessing health services[5]:

There is a consensus that stomatology requires unscheduled appointments. Because if a patient has a mouth lesion and doesn't know what it is, he/she needs to have access to a professional who is qualified to diagnose it (CDD1).

State control of the regulation of treatment was viewed positively by the interviewees be-

cause it means that patients from other municipalities are able to access treatment in care facilities located in the capital and facilitates follow-up by the SES/RJ technical team:

Before, SISREG was responsible for regulation and the municipality of Rio held control. For other municipalities to get access, it was that crazy process of requesting places in the middle of the night. Today it's much fairer (CESB1).

Another difference highlighted by the interviewees is waiting time for diagnosis and treatment. Waiting time for diagnosis is up to a week, compared to between four and six months for initiation of treatment. It is well-known that the time interval between diagnosis and treatment is critical for prognosis, with longer intervals being associated with a reduction in survival and increase in recurrence[31].-

Long treatment waiting lists mean that it is essential that the tertiary care facility clearly defines its own rules, with regulators having little autonomy for innovation. The interviewees highlighted that the small number of accredited cancer treatment centers in the state and high demand for treatment were key constraining factors for access to treatment. A nationwide study showed that the number of CEOs with hospitals that they could refer cases of oral cancer to fell by 18.3% between 2014 and 2018[32].

Long wait times in health facilities have now been replaced by online waiting lists via the SER. While this situation is more convenient for patients, it reduces potential political embarrassment for health managers as it decreases the visibility of the problem. In addition, the lack of transparency highlighted in the interviews raises doubts about the different factors influencing the regulation process[5] and is inconsistent with the PNPCC, which states the need to ensure transparency and equity in access to health care[2].

In contrast, the informal and personal nature of regulation processes was a key feature of referrals for diagnosis. The reason for this given by the agents is to facilitate patient access as much as possible in order to reduce waiting times. The absence of queues has loosened formal requirements, unlike the state treatment system:

When it is something that needs to be done really quickly, I use WhatsApp. I ask where it [the service] is quickest and they say "enter it in the system and I'll authorize it right away". In 10 minutes the place is approved (CDeSF8).

While informal referral may meet immediate demands, this process can create weaknesses in the coordination of the care pathway, such as the absence of records of referrals in patient records and consequent difficulties in monitoring referred cases and outcomes[33].

Final considerations

Through the lens of the theory of structuration, this study identified constraining and enabling factors that have influenced access to oral cancer diagnosis and treatment in the Metropolitan I health region in the state of Rio de Janeiro. Despite expansion after the introduction of the PNSB, the coverage of oral health care in primary care services remains low, resulting in the overburdening of the system and difficulties in accessing care, especially among non-priority groups. The fact that each municipality in the health region has a CEO and the regulation process has facilitated access to biopsies. While partnerships with dental schools have been an enabling factor for diagnosis, the lack of funding for these actions casts doubt on the long-term sustainability of this collaboration. Access to treatment is hampered by the small number of tertiary care facilities in the state, resulting in a more rigid and lengthy regulation process.

Main study limitations include the limited geographical scope of the health region investigated and the fact that we did not include patients in the study sample. However, the multiple sources of data used in this study provide valuable insights, stimulating reflection on how to address the current challenges facing oral cancer services.

Collaborations

FLT Lima participated in study conception and design, data collection and analysis, and in drafting this article. G O'Dwyer participated in study design and data analysis, and revised the final version of the article.

References

1. Brasil. Ministério da Saúde (MS). Coordenação Nacional de Saúde Bucal, Departamento de Atenção Básica, Secretaria de Atenção à Saúde. *Diretrizes da Política Nacional de Saúde Bucal*. Brasília: MS; 2004.

2. Brasil. Ministério da Saúde (MS). Anexo IX da Portaria de Consolidação nº 2, de 28 de setembro de 2017. Política Nacional para Prevenção e Controle do Câncer. *Diário Oficial da União* 2017; 3 out.

3. Brasil. Ministério da Saúde (MS). Portaria nº 599, de 23 de março de 2006. Define a implantação de Especialidades Odontológicas (CEO) e de Laboratórios Regionais de Próteses Dentárias (LRPD) e estabelece critérios, normas e requisitos para seu credenciamento. *Diário Oficial da União* 2006; 24 mar.

4. Brasil. Ministério da Saúde (MS). Portaria nº 1.399, de 17 de dezembro de 2019. Redefine os critérios e parâmetros referenciais para a habilitação de estabelecimentos de saúde na alta complexidade em oncologia no âmbito do SUS. *Diário Oficial da União* 2019; 19 fev.

5. Cecilio LCO. Escolhas para inovarmos na produção do cuidado, das práticas e do conhecimento: como não fazermos "mais do mesmo". *Saude Soc* 2012; 21(2):280-289.

6. Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA). *Estimativa 2020: incidência de câncer no Brasil*. Rio de Janeiro: INCA; 2019.

7. Instituto Nacional de Câncer José Alencar Gomes da Silva (INCA). *Atlas on-line da mortalidade* [Internet]. [acessado 24 fev 2020]. Disponível em: https://mortalidade.inca.gov.br/MortalidadeWeb/.

8. Torres-Pereira CC, Angelim-Dias A, Melo NS, Lemos-Jr CA, Oliveira EMF. Abordagem do câncer da boca: uma estratégia para os níveis primário e secundário de atenção em saúde. *Cad Saude Publica* 2012; 28(Supl. l):S30-S39.

9. Rocha TAH, Thomaz EBAF, Silva NCS, Queiroz RCS, Souza MR, Barbosa ACQ, Thumé E, Rocha VCM, Alvares V, Almeida DG, Vissoci JRN, Staton CA, Facchini LA. Oral primary care: an analysis of its impact on the incidence and mortality rates of oral cancer. *BMC Cancer* 2017; 17(1):706.

10. Lima FLT, O'Dwyer G. Políticas de Prevenção e Controle do Câncer Bucal à luz da Teoria da Estruturação de Giddens. *Cien Saude Colet* 2020; 25(8):3201-3213.

11. Creswell JW. *Investigação Qualitativa & Projeto de Pesquisa*: escolhendo entre cinco abordagens. Porto Alegre: Penso; 2014.

12. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qual Health Res* 2016; 26(13):1753-1760.

13. Giddens A. *A constituição da sociedade*. São Paulo: Martins Fontes; 2003.

14. O'Dwyer G. Estudos de políticas e a Teoria da Estruturação de Giddens. In: Baptista TWF, Azevedo CS, Machado CV, organizadores. *Políticas, Planejamento e Gestão em Saúde: abordagens e métodos de pesquisa*. Rio de Janeiro: Editora Fiocruz; 2015. p.173-192.

15. Gray DE. *Pesquisa o mundo real*. Porto Alegre: Penso; 2009.

16. Yin RK. *Pesquisa qualitativa do início ao fim*. Porto Alegre: Penso; 2016.

17. Bardin L. *Análise de Conteúdo*. São Paulo: Edições 70; 2011.

18. Tong A, Sainsbury P, Craig J, Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19(6):349-357.

19. Galante ML, Silva DPD, Gabriel M, Michel-Crosato E, Pucca Junior GA, Biazevic MGH, Carrer FCA. Brazilian Oral health teams in primary care and oral cancer: Results of a national evaluation. *Braz Oral Res.* 2021; 35:e116.

20. Cunha ARD, Prass TS, Hugo FN. Mortality from oral and oropharyngeal cancer in Brazil: impact of the National Oral Health Policy. *Cad Saude Publica* 2019; 35(12):e00014319.

21. Warmling CM, Baldisserotto J, Rocha ET. Acolhimento & acesso de necessidades de saúde bucal e o agir profissional na Atenção Primária à Saúde. *Interface (Botucatu)* 2019; 23:e180398.

22. Van Der Waal I. Potentially malignant disorders of the oral and oropharyngeal mucosa: present concepts of management. *Oral Oncol* 2010; 46(6):423-425.

23. Kumar M, Nanavati R, Modi TG, Dobariya C. Oral cancer: Etiology and risk factors: A review. *J Cancer Res Ther* 2016; 12(2):458-463.

24. Casotti E, Monteiro ABF, Castro-Filho EL, Santos MP. Organização dos serviços públicos de saúde bucal para diagnóstico precoce de desordens com potencial de malignização do estado do Rio de Janeiro, Brasil. *Cien Saude Colet* 2016; 21(5):1573-1582.

25. Probst LF, Pucca-Junior GA, Pereira, AC, Carli AD. Impacto das crises financeiras sobre os indicadores de saúde bucal: revisão integrativa da literatura. *Cien Saude Colet* 2019; 24(12):4437-4448.

26. Nemoto RP, Victorino AA, Pessoa GB, Cunha LLG, Silva JAR, Kanda JL, Matos LL. Oral cancer preventive campaigns: are we reaching the real target? *Braz J Otorhinolaryngol* 2015; 81(1):44-49.

27. Andrade MAC. *Busca ativa de lesões malignas e desordens potencialmente malignas da cavidade bucal em quatro unidades de saúde da família (USF) na cidade de Piracicaba* [dissertação]. Campinas: Universidade Estadual de Campinas; 2010.

28. Frazão P, Narvai PC. Saúde bucal no Sistema Único de Saúde: 20 anos de lutas por uma política pública. *Saude Debate* 2009; 33(81):64-71.

29. Silva MJS, Lima, FLT, O'Dwyer G, Osório-De-Castro CGS. Política de Atenção ao Câncer no Brasil após a Criação do Sistema Único de Saúde. *R Bras Canc* 2017; 63(3):177-187.

30. Fonte DCB, Siqueira RA, Castro JFL, Perez DEC, Carvalho EJA. Padrão das biópsias e fichas de solicitação de exame histopatológico encaminhados para o laboratório de patologia oral da Universidade Federal de Pernambuco. *Odontol Clín-Cient* 2015; 14(1):575-578.

31. Liao DZ, Schlecht NF, Rosenblatt G, Kinkhabwala CM, Leonard JA, Ference RS, Prystowsky MB, Ow TJ, Schiff BA, Smith RV, Mehta V. Association of Delayed Time to Treatment Initiation with Overall Survival and Recurrence Among Patients With Head and Neck Squamous Cell Carcinoma in an Underserved Urban Population. *JAMA Otolaryngol Head Neck Surg* 2019; 145(11):1001-1009.

32. Thomaz EBAF, Costa EM, Queiroz RCS, Emmi DT, Ribeiro AGA, Silva NCD, Hugo FN, Figueiredo N. Advances and weaknesses of the work process of the oral cancer care network in Brazil: A latent class transition analysis. *Community Dent Oral Epidemiol* 2022; 50(1):38-47.

33. Casotti E. Rede de cuidado ao paciente com câncer de boca na Cidade do Rio de Janeiro. *Diversitates Int J* 2019; 11(2):33-48.