

Participatory institutions and their effects on public policies: a study of the *Comitê de Mortalidade por AIDS*, in Porto Alegre, Brazil

Instituições participativas e seus efeitos nas políticas públicas: estudo do Comitê de Mortalidade por AIDS de Porto Alegre

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Abstract

This study is part of the discussions on the effects of participatory institutions on public policies. The objective was to understand the perception of the members of the *Comitê Municipal de Mortalidade por AIDS* (Municipal AIDS Mortality Committee) in Porto Alegre, Brazil, on the effects of this institution on the improvement of care for people living with HIV/AIDS. This is a qualitative research performed as a case study, conducted with 17 members of this committee. We attended their monthly meetings; data was collected with ethnographic observation and in-depth interviews using a semi-structured interview guide. We used the Theory of Institutions as the theoretical framework. We identified that the committee can diagnose several problems in the health system of the city and point the frailties of the services. However, the institution is still incapable of guaranteeing that the suggested proposals will be implemented to solve the problems identified and, therefore, improve the quality of the services for people with HIV/AIDS.

Keywords: Comitê de Mortalidade por Aids; Participatory Institutions; Public Health Policies.

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Resumo

Este estudo se insere no contexto das discussões sobre os efeitos das instituições participativas sobre políticas públicas. O objetivo foi conhecer a percepção dos membros do Comitê Municipal de Mortalidade por Aids de Porto Alegre sobre como essa instituição participativa tem consequências na melhoria do atendimento às pessoas que vivem com HIV/aids. Trata-se de pesquisa qualitativa, com método de estudo de caso, realizada com 17 membros do referido comitê. Suas reuniões mensais foram acompanhadas, quando se realizou observação de cunho etnográfico; realizou-se, também, entrevistas a partir de um roteiro semiestruturado, empregando-se o referencial da Teoria das Instituições Participativas. Identificou-se que o comitê é capaz de diagnosticar inúmeros problemas no sistema de saúde da cidade e apontar as fragilidades dos serviços de atendimento. Todavia, ainda não consegue assegurar que as propostas sugeridas sejam implementadas nos serviços a fim de resolver os problemas identificados e, por conseguinte, melhorar a qualidade dos serviços de atendimento às pessoas com HIV/aids.

Palavras-chave: Comitê de Mortalidade por Aids; Instituições Participativas; Políticas Públicas de Saúde.

Introduction

The Brazilian Federal Constitution of 1988 expanded forms of social participation and widened the spaces for direct participation. Since the early 1990s, the area of health in Brazil always featured participation mechanisms such as health boards, bipartite and tripartite committees, and decentralized management (Côrtes, 2009). Social participation is guaranteed by law no. 8.142/1990 as a guideline of the Brazilian Unified Health System (UHS), having health councils as the regulatory instances. Participation mechanisms are designed with the double goal of promoting community participation in the decision-making processes of public policies and of expanding the process of democratization, which promotes greater effectiveness and optimization of the resources (Lotta; Vaz, 2015).

In addition to health councils, Maternal, Child and Fetal Mortality Committees have existed for several decades and also rely on social participation, including representatives of the feminist movement, since their creation in Brazil (Fordyce, 2014; Mathias, 2008; Rodrigues; Siqueira, 2003; Soares; Martins, 2006; Venâncio; Paiva, 2010). In Brazil, the first Maternal Mortality Study Committees were created in São Paulo in 1988, therefore, a little before the creation of the UHS (Rodrigues; Siqueira, 2003). The objective of these first Maternal Mortality Committees was to improve the reporting system of this type of mortality and to have a dialogue with health services to implement better care for pregnant women and during puerperium (Venâncio; Paiva, 2010).

The focus of literature on Mortality Committees is mostly on maternal mortality and on the issues related to the creation of this type of organization, either providing context for the funding of international and national events (Soares; Martins, 2006; Vorpapel, 2008), or presenting the creation of local specific committees (Rodrigues; Siqueira, 2003). Some studies on Child and Maternal Mortality Committees analyze the functioning of the institution (Alencar Júnior, 2006; Mathias, 2008; Venâncio; Paiva, 2010). Other studies focus on maternal, child and fetal mortality rates from data

produced by Mortality Committees (Alencar Júnior, 2006; Barbieri et al., 2013; Hasegawa et al., 2016; Main et al., 2015; Morton, 2014; Vega et al., 2017). The only study we found about mortality committees with an anthropological approach analyzes the moral discourse formed within a committee, which ultimately assigns the responsibility to mothers due to the outcome of the cases (Fordyce, 2014). We found no studies on mortality committees as participatory institutions, focus of this paper.

In Brazil, all participatory organizations in health, such as mortality committees, are composed by government officials, health professionals, users and community representatives. Given the challenges presented by the new institutional arrangements of public policies in Brazil, it is important to observe and analyze the effects participatory institutions have on policies.

We highlight that Galvão (2000) claims that, since the start of the epidemic of HIV/AIDS in Brazil, social movements demanded the State, calling for quality care services to meet the population needs. Thus, the existence of institutional spaces in which the civil society, health professionals and State agents are combined must be understood as part of a larger configuration which includes the very opening of the Brazilian State to social participation and the specificity of the AIDS epidemic as a theme, which always had social support.

According to the epidemiological bulletin from the Ministry of Health (Brasil, 2017), the state of Rio Grande do Sul, as well as its capital, Porto Alegre, presents the highest rates of incidence, prevalence and mortality by AIDS, and these rates have been steady for over a decade. Given this context, the first *Comitê Municipal de Mortalidade por AIDS* was created in the city of Porto Alegre, in 2011. The institutional design characteristics of the Committee are similar to maternal, infant and fetal mortality committees of the country: tripartite composition, monthly meetings dedicated to discussing cases of death by AIDS that occurred in the city and the prerogative of, from the analysis of death cases, proposing improvements to health services to prevent deaths by similar causes to those analyzed. Besides the local government, employer, and worker representatives, the Committee has a representative

of the Ministry of Health and a representative of the *Superintendência de Serviços Penitenciários* (Superintendency of Penitentiary Services) of the state of Rio Grande do Sul.

To understand the effects of a new institutional arrangement with a participatory organization on the problem faced, we analyzed the process of consolidation of the role of the committee over the years, from the elements pointed by literature on the theme (Lotta; Favareto, 2016; Lotta; Vaz, 2015; Pires, 2011; Pires; Gomide, 2015; Santos; Gugliano, 2015; Wampler, 2011). We highlight that the Committee is part of a larger institutional structure, the Municipal Secretariat of Health (SMS/POA), and of all policies that are developed on the subject for many years throughout the country. Thus, this study will use the perception that the social actors have of the Committee, always considering the institutional structure around it.

Research method

This is a case study, based on a qualitative approach, with participant observation and in-depth interviews from a semi-structured guide of the first committee of this kind in the country (Fordyce, 2014; Lui, 2016; Yin, 2015). Data collection occurred from June 2014 to December 2015. Initially, we approached the public administrator of HIV/AIDS, who is a member of the Committee coordination, and presented the research project. The Committee coordinating commission authorized and supported the project, providing access to the monthly meetings and to the documents that the researchers needed, such as minutes. On the first meeting of the Committee the researchers were introduced to all members present, explaining the objectives of the research, as well as the ethnographic method involving the observation of the meetings. After actively participating in the Committee meetings for almost a year, with prior authorization from the administrators, the researchers invited each of the members of the Committee for individual interviews.

During field work, approximately 25 members were present at each meeting of the Committee; we interviewed in-depth 17 of them. Among the interviewees, six worked in medium complexity

services (AIDS Specialized Care, Center for HIV Testing and Counseling, Emergency Unit), three in public hospitals, two are community representatives, and one was a researcher from a university; we interviewed the four founding members, and a representative of the Ministry of Health. Each in-depth interview was scheduled according to the place and time of preference stated by participants, having lasted, on average, an hour and a half; all interviews were recorded with permission of those involved, who also signed an Informed Consent Form. At the end of the study, the researchers presented the main results to the Committee, at a meeting which specifically included such feedback in its agenda.

The members of the Committee knew about the research throughout the whole process, including the meeting observations, and the commitment of the researchers to confidentiality of the data regarding the deaths discussed by the Committee. The identity of the participants was not made secret, since their names are listed in documents that can be looked up, such as minutes of the meetings. The Committee was in activity for four years when we collected data for this study, thus allowing us to question the members on their perception regarding the solutions for, and the impacts on, the problems faced.

Social participation and the effects of participatory institutions

A premise of social participation in literature is that expanding the forms of political participation is fundamental to solidifying democratic regimes (Pires, 2011). Social participation contributes to forums, councils, committees and public inquiries by providing greater transparency of the actions developed by the State, and by granting greater rationality and efficiency to the public administration. Studies on participatory institutions emerged in Brazil in a certain sense since the end of the Military Dictatorship in 1985 (Abers; Jorge, 2005; Almeida; Tatagiba, 2012; Avritzer, 2011; Borba, 2011; Côrtes, 2009, 2011). In the beginning, such studies emphasized with great enthusiasm the emergence of participation as a phenomenon. More recently, have shifted to a concern in understanding the institutional environment in which participatory

institutions are present, and their impacts, or even if they have any effect at all. Côrtes (2011) underlines that by studying people's perceptions, one can identify the effects caused by these institutions.

Literature focuses on two issues: the working and the outcomes of participatory institutions (Almeida; Tatagiba, 2012; Lavallo; Voigt; Serafim, 2016; Wampler, 2011). Almeida and Tatagiba (2012) developed an argument regarding the problem faced by participatory institutions for decades in Brazil. According to these authors, this model is important for the participation of civil society; however, this model is frailly anchored institutionally since communication between these institutions and decision-making spheres in public administration is still difficult. Thus, there are no guarantees that the policy decision sphere will comply with the decisions made within the participatory forum. Wampler (2011) is even more skeptical of the effectiveness of participatory institutions in Brazil: there is little empirical evidence showing systematically how committees and other participatory institutions affect the results of public policies, i.e., there is little evidence that the presence of these organizations makes the State provide better quality services.

According to the epidemiological bulletin, the coefficient of mortality (per 100,000 inhabitants) in Porto Alegre, Brazil, in 2011, was 27.1 cases, having dropped to 22.4 in 2016 (Brasil, 2017). This is still, however, the Brazilian capital with the greatest AIDS mortality coefficient in the country. We cannot measure in this study the impact the Mortality Committee may have had on this decline, since there are many factors contributing to this reduction. We can, based on research and the data collected, discuss the perception that members of the Committee have about how it may have contributed to the reduction of AIDS mortality in the city in recent years.

Results and discussion: the Committee as a participatory instance

The Committee was created under the SMS/POA as a response to the pressure and questionings made by the civil society and other government agencies, regarding the high rates of the AIDS epidemic, to the municipal health management. Created in 2011, and

institutionalized by the Municipal law no. 11.425, of April 22, 2013 (Porto Alegre, 2013), the Committee is linked to the SMS/POA. This organization is classified as an interinstitutional collegiate body, whose nature is that of counseling, research and regulation. Its stated objectives are to investigate cases of death by AIDS in the city, to contribute to the knowledge of indicators of such deaths and to divulge associated risk factors.

The interviewees mentioned that when the SMS created the Committee, they asked for two representatives from each health service focused on the care of HIV/AIDS patients (specialized services, centers for HIV testing and counseling, and hospitals) to participate in the new body. In addition to the representatives from the SMS, they invited members of the State Secretariat of Health (SES/RS), of the Superintendency of Penitentiary Services of the state of Rio Grande do Sul, of the Municipal Health Council of Porto Alegre and representatives of the HIV/AIDS social movements. The concept behind such invitations was the creation of a plural group, who would collectively observe the paths followed by patients who died due to AIDS in the capital, seeking information from different types of services that these patients could have used or come in contact with.

The Committee intends to develop measures which may impact the AIDS death toll, focusing on deaths that could have been prevented. The meetings occur monthly, and each one includes the discussion of three AIDS cases, focusing on the patients' trajectory, from their diagnosis to their death, seeking to identify the factors that contributed to case's outcome. The activities assume the collaboration of the members (health professionals in the area, activists from social movements, and government agents) to investigate the cases of death due to AIDS. The investigation depends on sharing information about the patient and about the therapeutic procedures adopted, including medical records.

The creation of the Committee is associated by most interviewees to the appointment of the new coordinator of the Technical Area of STD/AIDS of the SMS/POA in 2011. Historically involved with the fight against the AIDS epidemic, he participated

in the creation of the first AIDS NGO in the city, the *Grupo de Apoio à Prevenção da AIDS* (GAPA-RS - Support Group for the Prevention of AIDS) at the end of the 1980s. He went on to occupy the then recently created position of municipal AIDS policies coordinator between 1993 and 1998. His appointment in 2011 meant he was reoccupying that position, when he founded, with others, the Mortality Committee. The exchange of leaders among Non-Governmental Organizations (NGOs) and official State agents/positions is very present in the study of Galvão (2000), who identifies how the leaders of NGOs performed both in State positions, implementing policies against the epidemic, and in activists positions, demanding better services be provided by the State for those living with the virus.

Initially, the Committee was planned by four people: the then Coordinator of the STD/AIDS Technical Area; two employees of the Health Surveillance General Coordination; and a university professor and researcher with experience in management and research in HIV/AIDS. These four people already had more than 15 years of experience in the health field and/or were involved with the AIDS epidemic. Three of them had been Coordinators of the STD/AIDS Technical Area of the SMS/POA. Only one of these four had not overseen the coordination of this organ, and this person had considerable experience on the Maternal Mortality Committee of the city, providing fundamental references to the recently created AIDS Mortality Committee. During our fieldwork, the four founding members were coordinators of the Committee.

Through the resources, experience and expertise that these four people could summon, the Committee was created, health services and the community representatives were convened and the dynamics for the Committee's operation were established. When talking about the reasons for the creation of the Committee, the founding members mention that it was created due to the high rates of AIDS mortality in the city, to pressures from the civil society and government bodies, and also due to the lack of epidemiological data on the AIDS epidemic in the city to guide policies.

People involved in the creation of the Committee also criticize the lack of epidemiological information

about the state of Rio Grande do Sul and the metropolitan region of Porto Alegre. One of the respondents harshly criticized the inertia of the state in producing epidemiological information on HIV/AIDS, once not knowing the magnitude of the epidemic and the profile of the population infected, the formulation of appropriate policies is very difficult. Thus, the role of the Committee was to collect data on mortality so members gain more knowledge about the reality of the city.

In addition to the monthly meetings, some members of the Committee created a smaller work group in 2015. This group met weekly to review all reported cases in detail, discussing if those deaths were preventable or not, in order to make recommendations to health services. This group is not composed by any representatives from social movements; these representatives, therefore, do not take part in the formulation of written recommendations made to health services. Government officials, health professionals and civil society representatives participate in the monthly meeting to discuss three death cases previously selected by the coordination of the Committee, collectively discussing recommendations for the services. Venâncio and Paiva (2010) studied child mortality committees in São Paulo, Brazil. They identified that while some committees investigate all death cases, others applied some selection criteria for the investigation. The elevated number of deaths per month is the main reason the AIDS Mortality Committee previously selects three cases for discussion. All members are aware of the Committee's case selection criteria (Lui, 2016).

The founding members' goal with the creation of the Committee was to create a venue where the paths trailed by patients could be understood, from their diagnosis of HIV infection up to their death. This would help trace the patients' itinerary, revealing the main frailties of the health services, the causes of death and the comorbidities associated with the HIV infection. To produce knowledge of itineraries, collaboration from professionals working in different health services is needed: health professionals must be willing to share information on the patients as to take part in the case discussions at the Committee. The analysis

and discussion of patient itinerary requires, beyond health professionals' participation, the criticism and questioning brought forth by representatives of social movements, who demand the Committee be proactive in discussing how to improve the quality of health services.

Different from what literature suggests about Mortality Committees in Brazil, regarding how this type of organization works (Mathias, 2008; Rodrigues; Siqueira, 2003; Venâncio; Paiva, 2010), we highlight that the Porto Alegre AIDS Mortality Committee presents a clear organization and has an established routine of meetings. However, the Committee is still incapable of instituting a more productive dialogue with the decision-making spheres of public policies, such as municipal and state government representatives, or agents of the SMS/POA or of the SES/RS.

A number of the Committee members who were interviewed expressed a view of the organization as extremely important and positive, due to it being a place for discussion about the AIDS mortality problem. The existence of a committee exclusively focused on the analysis of deaths caused by AIDS is considered by some members as politically important for placing the problem in the agenda. Despite identifying positive aspects, the members also understand that the Committee has little capacity for proposing improvements to the state and municipal decision-making spheres; consequently, these members believe the Committee stands little chance at making any impact on the social reality. We observed a discrepancy regarding what members expect from the Committee and what they perceive it actually does. The members' positions reveal they expect the Committee will produce immediate responses that will in turn make AIDS mortality rates drop.

One of the creators of the Committee explained that the initial concern focused on institutionalizing a routine of activities, making health professionals become used to attending the meetings and to discussing cases together with community members, other health professionals and officials from the SMS/POA. The interviewee referred mostly to Medical professionals in this particular case. Medical professionals were presented as resistant or fearful about the idea of the Committee, since

they believed that it would serve as a punitive and supervisory mechanism of their professional conduct. The interview reported that the initial discussion regarding if the Aids deaths could have been prevented raised conflicts within the group in meetings, and for this reason this topic was left for a later moment.

It is important to understand how a group that shares inter-dependencies may organize itself, construing an institutional structure that maintains the shared production of continuous benefits at the same time avoiding that its members feel attracted to the negative externalities of cooperation processes (Abrucio; Filippim; Dieguez, 2013; Ostrom, 2000). According to the Committee coordinators, group members learned to trust each other in a process that took years to be established. The Committee's institutional structure, set by a municipal law, had an important part in assuring the the group's existence; however, its activities were maintained throughout the years specially due to the group members' shared feeling that the epidemiological situation of the city was very serious. The process of establishing trust between the members who were initially resistant to the idea of the Committee is associated with the ability of the its founding members to present the work of the Committee and its emphasis on improving health services. These four founding members have always highlighted that the Committee would be of a punitive character regarding the medical performances, since its focus was on the health services that cared for patients living with HIV.

The discussions of the Committee are dynamic and critical, especially regarding the analysis of how the existing health services in the city are organized, considering the effective demand for such services. This occurs mainly due to the presence of a representative from the civil society in the Committee who is a frequent participant since its creation. This participant presents a critical view during the meetings as in our interview, demanding improvements in the quality of care. This person has been living with HIV for almost 30 years and takes part of organized social movements since 2005. During the discussion of cases by the Committee, the during which medical records are presented by the medics and agents of the SMS/POA, this representative from civil society makes constant

interruptions to question the procedures adopted, inquiring about the factors which contributed to the death. Some members are visibly upset during several moments of the meetings, feeling questioned about their practices due to these questions. During these moments, the state agents assume a position as mediators, coordinating the debate.

Other members are also critical of how the death cases are discussed. The founders and the citizen representative understand that the role of the latter in the Committee is to challenge the discussions and to ask for accountability. Activists in social movements have been demanding better services and assistance from the State since the start of the epidemic (Galvão, 2000). This community representative who is a Committee member explained during our interview that the discussions carried out in meetings are usually very technical and restricted to those who dominate medical terms; he calls himself "annoying", saying he "bugs" everyone, constantly provoking and questioning about the cases. During the interview he admitted he disliked being always so critical, but he felt "he has to do it", for that is his role there: these questionings and criticism set the standards of accountability. Another regular member of the Committee who is also a community representative is a member of the *Conselho Municipal de Saúde* (CMS - Municipal Council of Health); however, he rarely joins the discussions, mostly observing them. Since the beginning of the activities, he has been responsible for recording the meetings and for writing the minute - shared after the meeting through email. Other civil society representatives are not regular participants at meetings of the Committee. The interviewee who participates the most (both attending and speaking) takes these absences to represent the weakening of the social and political movements for AIDS.

We asked the coordinator of the Committee, in our interview, about the capacity this organization could have of influencing public policies; we also inquired about the possibility that a recommendation formulated by the Committee would reach higher decision-making levels, such as the Brazilian Ministry of Health, the SES/RS and the SMS/POA. The coordinator explained that the Committee's main

interest was not to think about public policies on a macrostructural level, but rather to analyze the health services' routines and the work processes. He expressed concern in establishing a dialogue with the institutions and health services that could affect their daily routines. He was not concerned with discussing with them in any other instances or levels. In his view, the AIDS epidemic would be fought in the city by negotiating with the local institutions. According to the interviewee, having health services representatives on the Committee would eventually change these health professionals' view, promoting a more qualified understanding of the epidemic.

For the most part, Committee members have been working in health services for over 10 years, thus, all claimed to be aware of the AIDS epidemic before the creation of this organization. When questioned whether taking part in the Committee had allowed them to gain a deeper understanding of the issues related to the epidemic in the city, the responses were varied. Some claimed that the Committee promoted increased awareness amongst their working teams and had brought up AIDS mortality discussions again. However, other interviewees claimed that their participation did not add any more in-depth knowledge about the epidemic, since they already knew how the services operated and what the profile of the patients was.

The situation of the epidemic in the cities of the metropolitan region of Porto Alegre is a recurring subject both on the discussions of the Committee and on the interviews. The epidemiological bulletin of the Ministry of Health records that many cities located in this region also have high incidence, prevalence and mortality rates of HIV/AIDS cases, specially Viamão and Alvorada, both adjacent to Porto Alegre, the capital. As we mentioned, the Committee is part of a larger institutional framework, involving institutions from every level of government, from the Ministry of Health to the Municipal Secretariat of Health. Any claim that the Committee is not effective, or that the Committee has little impact on the problem, therefore misses the fact that it cannot be isolated from the institutional context in which it is situated.

There is consensus among the Committee members regarding the complexity of the AIDS problem, and its multiple causes. Most participants

stress how important it is to have such a place where AIDS patients itineraries are discussed, focusing those who have died in local health services. Certain interviewees, mainly health professionals, do not expect the Committee to resolve the shortcomings and frailties of the services where they work, nor those of the health services network and organization. In many instances, health professionals stressed that many of the AIDS patients who die are drug users, pointing to the need to include representatives from the mental health services in the AIDS Mortality Committee. Many of those participating in the meetings showed familiarity with the theoretical framework of vulnerability and human rights used by scholars in the field of AIDS, such as Parker and Camargo Júnior (2000) and Paiva, Ayres and Buchalla (2012), having identified the complexity of the problem in its multiple dimensions. As one of the founders of the Committee said during the interview, the Committee allows them to understand the factors that contributed to the death of the patient more in-depth, focusing on the patients' vulnerabilities. Knowledge of these factors are the basis for the recommendations issued by the Committee and sent to health services.

A health care professional reported that the hospital where he works does not have a laboratory equipped for routine tests required for the treatment of people living with HIV/AIDS; the samples collected there are forwarded to another public health service in the city to be examined. In addition, the hospital pharmacy where he works does not have all medicines he needs to prescribe to his patients. At the time of his interview, it was impossible for his service to provide antiretroviral drugs to patients under his care. Many interviewees, when taking into account all these factors, do not see how the Committee could solve these issues. The Committee, however, can be described as an important locus where demands and frailties of the health services are brought to the forefront and exposed to State and community representatives .

Santos and Gugliano (2015) note that, to observe the effectiveness of participatory institutions means one also pays attention to the exogenous factors that interfere in its performance. In our study, such factors translate into the health services' physical structure and its human resources . Once the

Committee is a place where information is shared, deepening the knowledge of the city epidemics, and recommendations are formulated, the Committee has, by definition, limited capacity to promote changes - specially because many problems reported there are due to the lack of structure and financial resources. On the other hand, regarding the impact of the Committee by endogenous factors, participants reported changes on the professional practices with AIDS patients, including increased awareness and commitment on the active search for patients who abandoned treatment, as improvements in the health services' first contact with newly discovered HIV-positive patients.

The existing institutional problems between the state and the city regarding referrals and counter-referrals of patients with HIV/AIDS by health services were emphasized during several moments of our research. A health professional reported that state services do not have access to the computerized system for scheduling appointments within the municipal health services network (*Sistema AGHOS*). Another study on HIV/AIDS state services in Porto Alegre registered the same problem (Haag; Gonçalves; Barcellos, 2013). This problem, whereby state services do not have access to the scheduling system of appointments, tests and hospitalizations within the municipal network, already lasts for years. Once this is the result of an institutional conflict, the Committee members do not think this organization can help with it.

Several health professionals demanded, in more than one Committee meeting, that the Secretary of Health effectively take part in the process of sending the recommendations for improvements to the health services and institutions. All the members seemed to agree that the Committee should elaborate recommendations to the health services. The health professionals who are members of the Committee explain that the institutions they represent are resistant to changes; as employees who are subordinate to the health service, they could hardly influence the process of implementing recommendations that involve routine or institutional changes in the service. These Committee members propose the Municipal Secretary of Health be actively engaged in the process of sending the recommendations to the services, so

these suggestions may have concrete effects. One of the founding members of the Committee was emphatic in saying that the Secretary of Health is the health authority of the municipality, and that it is his or her responsibility to perform an effective intermediation between the Committee and the health services.

While the Committee produces knowledge of AIDS by studying death cases and formulates recommendations to the health services, the Committee has no institutional power to solve the problems reported by its members. Thus, there is no direct perception of how this participatory institution can be effective in solving the AIDS mortality problem and in improving the quality of the health care. We did identify that the Committee allowed for an exchange between the health professionals, State agents and community representatives, in addition to giving greater visibility to the mortality problem in the city.

Civil society has a cross-participation in the Committee. Since the beginning of the epidemic, AIDS NGOs have been engaged in formulating the Brazilian response to the epidemic, through projects of their own and in partnership with the State. Throughout the 1990's, many of these activists went from actively engaging in social movements to taking a place in different administrative spheres, was an offset named as a transit of administrators by Galvão (2000). In the case of the Committee, we identified one person who has a history acting in both social movements and the State, who was able to draw upon personal, human and technical resources to create the first AIDS Mortality Committee in Brazil. The coordinator of the Technical Area of HIV/AIDS is one of the Committee's founding members, and he can perform as both a government agent and as a member of social movements concerned who demand better quality health services from the state. The Committee members intend on discussing with health services which aspects could be changed in their patient care, in order improve on the quality of their services.

Thus, turning to the discussion raised by the literature on which effects are produced by participatory institutions (Almeida; Tatagiba, 2012; Avritzer, 2011; Borba, 2011; Côrtes, 2009; Lavalle; Voigt; Serafim, 2016; Pires, 2011; Wampler, 2011), we can say that the Committee meets one of its objectives:

to analyze and produce recommendations to health services. However, the problems identified by the Committee are complex, and in many instances their possible solutions are beyond the reach of the Committee. The participatory institution here analyzed, the Committee, may be incapable of solving the problems identified by its members because of exogenous issues such as the infrastructure of the services and the lack of resources.

Conclusion

The Committee opened a channel for discussion among the health services and representatives of the public administration. In particular, public health services at the state level that care for people living with HIV/AIDS and are located in Porto Alegre now can communicate directly with representatives of the municipal administration. After five years of activities, the Committee has established a routine of surveying data on death cases by promoting the cooperation of its members to share the information from medical records, especially from the health professionals who work in these services.

The AIDS Committee members report that AIDS mortality usually occurs due to multicausal factors, related to different situations where the patient presents vulnerability in all of its dimensions: individual, social, and institutional, including structural deficiencies of health services. The vulnerabilities identified in the institutional or programmatic dimension demand an action plan and investments that are well beyond the capacity of the Committee. As for the health services' operation and organization, the Committee has begun formulating recommendations that are forwarded to the services in 2015, despite having no guarantees that such will be implemented.

Regarding the problems identified by the members, it is important to remember that the Committee represents a recent experience in public administration. Vaz and Pires (2011) claim that durability is an important factor regarding the effectiveness of participatory institutions, i.e., over time and considering the trajectory and consolidation, these organizations become more influential, coordinated and efficient as to producing effects on

the public administration and in the development of public policies. Thus, we believe that the Committee may follow this path in the next few years.

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Authors' contribution

Lui and Leal conceived the study, formulated the data collection instruments, interpreted and analyzed the data and contributed to the writing of the article. Lui performed the data collection.

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