Participatory governance in the context of local health councils: interviews with six local health council presidents in Northeastern Brazil[1]

Governança participativa no âmbito dos conselhos de saúde locais: entrevistas com seis presidentes de conselhos de saúde locais no nordeste do Brasil

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Abstract

The aim of this study was to describe the challenges and opportunities faced by local health council presidents in their practice of participatory governance. In-depth interviews were conducted with six presidents at health posts at six neighborhoods located in a single region in a peripheral neighborhood in Fortaleza. The interviews were complemented by participant observation of local health council meetings conducted over a three-year period (2015-2017), and interviews with presidents of the municipal, regional and state health councils, as well as with more than twenty actors from government agencies and local associations. The data were analyzed with the help of Atlas.ti, and resulted in the identification of four core topics: the weakness of community representation, the generation of new health initiatives, the concern with the physical and material infrastructure of the councils, and the linkages between council Presidents and the historical network of community-based organizations (*Associações Voluntárias*) in the region in which the health posts were situated. The local health councils included in this study faced similar challenges to those documented by prior scholars, but also demonstrated the potential to cultivate local ideas for new health initiatives.

Keywords: Local Health Councils; Participatory Democracy; Voluntary Associations; Challenges; Accomplishments.

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Resumo

O objetivo deste estudo foi descrever os desafios e oportunidades enfrentadas pelos presidentes de conselhos de saúde locais em executar governança participativa. Foram realizadas entrevistas a fundo com seis presidentes de postos de saúde em seis bairros localizados em uma única região em um bairro da periferia de Fortaleza. As entrevistas foram complementadas por observação participante de reuniões de cada conselho de saúde local, realizado durante um período de três anos (2015-2017), e entrevistas com os presidentes dos conselhos de saúde municipais, regionais e estaduais, bem como com mais de vinte atores de agências governamentais e associações locais. Os dados foram analisados usando o Atlas.ti, resultando na identificação de quatro temas principais: a fragilidade de representação da comunidade, a criação de novas iniciativas de saúde, a preocupação com a infra-estrutura física e material dos conselhos, e os vínculos entre presidentes de conselho e a histórica rede de organizações de base comunitária (Associações Voluntárias) na região em que os postos de saúde se localizavam. Os conselhos de saúde locais incluídos neste estudo enfrentaram desafios semelhantes àqueles documentadas pelos estudiosos anteriores, mas também demonstraram potencial para cultivar ideias locais para novas iniciativas de saúde.

Palavras-chave: Conselhos de Saúde Locais; Democracia Participativa; Associações Voluntárias; Desafios; Conquistas.

Introduction

The ideal of participatory governance achieved through neighborhood-based deliberation about health care has energized activists and politicians throughout Brazil and produced a voluminous scholarly literature both national and international (See for example, Carvalho; Teixeira, 2000; Coelho, 2004, 2013, 2014; Elias; Cohn, 2003; Escorel; Moreira, 2009; Martinez; Kohler, 2016; Santos, 2000). As a system that devolves substantial power to citizens and their act of participation, health care councils in Brazil stand apart from more vaguely defined forms of "participatory reforms" found throughout Latin America (Baiocchi; Heller; Silva, 2011). Nowhere does the possibility of seeing 'ordinary citizens' come together to raise concerns and voice demands seem to hold more promise than in the context of the council system's most basic unit: the local health councils formed at each of the community health posts found throughout Brazil's municipalities.

Local health councils (LHCs) are deliberative bodies convened at neighborhood health posts (*Unidades Básicas de Saúde* – UBSs) on a monthly basis to inspect public health accounts, demand accountability for services, and exert influence over how public health resources are spent. According to the by-laws of the Brazilian National Health System (SUS – *Sistema Único de Saúde*), federal transfers of public money for local health systems depend upon budget verification by local health councils. LHCs are thus one of the most important policy tools for providing resources for local health systems.

Despite a subset of literature devoted to LHCs (Brasil; Capella, 2016; Coelho, 2013; Durán; Gerschman, 2014; Martins; Santos, 2012; Miwa; Serapioni; Ventura, 2017), there has been relatively little qualitative evidence gathered about the perceptions and understandings of the actors who animate these local participatory spaces. The aim of this article is to contribute an 'emic' or insider point of view about the challenges and opportunities faced by leaders of local health councils to a literature that has largely relied on more quantitative methodologies to evaluate the success of participatory governance at the local level. The article presents the results of six semi-structured

in-depth interviews with health council presidents at health posts in six neighborhoods located in a single region in a peripheral neighborhood in Fortaleza. The interviews are complemented by participant observation of local health council meetings conducted over a three-year period (2015-2017), and interviews with presidents of the municipal, regional and state health councils, as well as with more than twenty actors from government agencies and local associations.

Prior articles about LHCs tend to be dubious about their effectiveness as a tool of participatory governance, citing for example the invisibility of local councils, the lack of representativeness of their members, and the paucity of evidence suggesting that council discussions are making a difference in the health policy process (Coelho, 2014; Miwa; Serapioni; Ventura, 2017). Acutely expressing this pessimism, the Brazilian scholar Vera Coelho writes, "Their [participatory mechanisms] contributions to the development of a robust form of accountability is shy, citizens remain only weakly involved and policy impacts are few" (Coelho, 2014, p. 2).

While this study corroborates some of the challenges that have been previously documented for LHCs, such as insufficient training and operational budgets, as well as lack of adequate representation among community-patient representatives (*usuários*),[2] the in-depth interviews with local council presidents also showed new insights about how local health councils function, including: the often negative effect of health post coordinators on the community-patient representatives' willingness in participating in meetings; several examples of health initiatives that came directly from residents and were brought to fruition by presidents of the posts; and dense linkages between council presidents and the historical network of community-based organizations (*Associações Voluntárias*) of the area. These insights suggest new directions for future research, and a reevaluation of the pessimism that has accompanied much of the scholarship on local health councils.

Study setting and methodology

Data for this article was collected in the city of Fortaleza during three residencies that lasted six weeks (June-July 2015, July-August 2016, and October-November 2017). Fortaleza is divided into six regions, which maintain the social services of the areas, including social security, food aid, and family assistance (*Assistência Social*, *Cesta Básica* and *Bolsa Família*). Region A is characterized by working class and impoverished communities located on the periphery of the city, and was selected for this study due to the relative socioeconomic homogeneity of its population. I have conducted research in this region over the past two decades, and therefore was able to situate the politics and actions of the local health posts within a history I have already documented (Jerome, 2015).

In order to select specific UBSs for further research, I first visited all eleven of the community health posts located in Region A.[3] All eleven posts agreed to participate in the study, and seven of them were selected for inclusion. The remaining four posts in Region A were reported by residents to be potentially unsafe for non-residents to visit on a regular basis and were therefore excluded from the study.

At each post, with the exception of UBS 6, which did not maintain a health council, I conducted a semi-structured interview with the council president (see Appendix A for the interview guide), sometimes in the presence of community-patient representatives who would also comment on the questions. During these interviews I also solicited a history of the individual posts. Health council meetings were typically held monthly at the local posts, and I attended as many of these as I could during my

2 There is no American English equivalent of the Brazilian Portuguese term *usuário*. The United States maintains few community health clinics, and community representation at such clinics is rare. Terms such as "patient" or "community-representative" do not capture the salient fact that *usuários* are both patients *and* live in the community area where the UBSs are located. Therefore I have chosen to use the more cumbersome term, "community-patient representative".

3 The names of all local health posts as well as the Region where they are located have been changed to protect the privacy of the individuals and institutions in this study. The numbers 1-7 are used to signify the individual posts and their corresponding president. All quotations attributed to a specific president are identified by their health post number (e.g., President of UBS 1).

research trips. See Tables 1, 2 and 3 for a schematic presentation of these findings.

Concurrent to these interviews, I visited and held informational interviews with administrators at the Region A headquarters, the Municipal Headquarters, and the State Health Council offices, as well as attended regional, municipal and state health council meetings that took place during my research. I also interviewed the president of both the Municipal Council and the State Council. All interviews were transcribed and analyzed using ATLAS.ti, a software program for qualitative data analysis and research.

Finally, I lived in Region A throughout my fieldwork and was therefore able to follow up on the linkages that health council presidents described between the posts and the community-based organizations. Three trips over three years allowed me to capture a longitudinal portrait of the councils and to trace thematic patterns as they emerged over time. I hope that this perspective adds depth to the assertions presented by studies that have primarily focused on the councils at a single point in time.

The research was approved by the Institutional Review Board of my home institution, DePaul University with the protocol JJ052615CSH, as well as by the Health Research Ethics Committee of the Municipal Health Secretariat (*Secretaria Municipal de Saúde*) of Fortaleza with the protocol P920157.

Results and discussion

General characteristics of UBSs, health councils and health council presidents

All seven neighborhood health posts visited for this study maintained at least one dentist and an on-site pharmacy, as well as what were described by council presidents as "the latest modernization efforts": flat screen TVs in the patients' waiting areas, and an electronic medical record system. Despite a widespread concern among council presidents and community-patient representatives on administrative personal changes, only two of the seven UBSs appointed new administrators (*coordenadores*) during the duration of the study (Table 1).

Table 1 – General descriptive features of Unidades Básicas de Saúde (UBS)

UBS	Year opened	Originally opened under pressure from community activism?	UBS has on-site dentist?	UBS has on-site pharmacy?	UBS has flat screen TVs and electronic records?	Has the coordinator changed over the 3-year research period?
UBS #1	1982	Yes	Yes	Yes	Yes	Yes
UBS #2	1983	Yes	Yes	Yes	Yes	No
UBS #3	1995	Yes	Yes	Yes	Yes	No
UBS #4	2007	Yes	Yes	Yes	Yes	No
UBS #5	1992	Yes	Yes	Yes	Yes	No
UBS #6	2012	No	No	No	No	No
UBS #7	1990	Yes	Yes	Yes	Yes	Yes

Six out of the seven UBSs in the study stated that they had an active health council, and all six of these posts held at least one health council meeting during each of the three periods of six weeks of the study (Table 2). With regard to health council representation, at only two of the UBS council meetings that I attended did a person was identified as a "new attendee", a finding that was confirmed and amplified by health council presidents during their interviews. All of the local health council meetings I attended had twelve or fewer participants (including myself and the health council president), and roughly half of them had fewer than five people present.

Table 2 – Description of Health Council Activity at Unidade Básica de Saúde (UBS)

UBS	Does UBS have an active Health Council?	Did the council meet during all 3 years of research study?	Is there a dedicated room for Health Council meetings?	Was there ever more than 3 *usuários* present at meeting?	Was there ever someone present at a meeting from the "health professionals" constituency
UBS #1	Yes	Yes	No	No	No
UBS #2	Yes	Yes	Yes	No	Yes
UBS #3	Yes	Yes	No	No	No
UBS #4	Yes	Yes	Yes	Yes	Yes
UBS #5	Yes	Yes	Yes	Yes	No
UBS #6	No	No	No	No	No
UBS #7	Yes	Yes	Yes	Yes	Yes

The demographic characteristics of the six health council presidents (Table 3) show a wide range of ages, an even number of men and women, and high school as the most commonly completed level of education. All six health council presidents grew up in the neighborhoods their health post was located and resided in them. One of the presidents' most striking similarities, which I discuss in greater detail below, is that five out of six of them were members of past and/or current community-based organizations and described active participation within the broader community's historical struggle to establish civic, social and legal rights within the city. Based on my interviews with six health council presidents, as well as an analysis of the local health council meetings I attended, I also identified three leading concerns addressed during health council meetings, including missing medications and staffing problems; faulty infrastructure to carry out the work of the health council; and lack of adequate representation at health council meetings.

Table 3 – Demographic characteristics of Health Council presidents

UBS	Approximate age of Council president	Gender	Level of education attained	Lives in UBS neighborhood	Was actively involved in community's *Associações Voluntárias*?
UBS #1	35-45	Female	High school	Yes	Yes
UBS #2	65-75	Male	Primary school	Yes	Yes
UBS #3	45-55	Male	2 years of University	Yes	Yes
UBS #4	25-35	Female	High school, attending University	Yes	No
UBS #5	35-45	Female	High school	Yes	Yes
UBS #6	N/A	N/A	N/A	N/A	N/A
UBS# 7	55-65	Male	High school	Yes	Yes

During my interviews with health council presidents, four interrelated themes emerged, which are presented and discussed below.

Theme I: Community Representation in LHCs

By law, LHCs are composed of community-patient representatives (50%), health professionals, as the doctors or nurses who work at the posts (25%), and administrative representatives, as the coordinator (top administrator of the post) (25%). A quick glance at Table 2 will reveal that for the posts included in this study, this compositional ideal was hardly ever met. More frequently, the president of the council would attend the meeting with a few community-patient representatives and the coordinator. Health professionals might drop in, but were often unable to attend the meetings for their entire duration, and were more likely to be informed of what was discussed at a later point. Community-patient representatives' attendance was also sporadic, but in the LHC meetings I attended, I rarely saw a health council meeting commence without the presence of the coordinator of the post.

In their interviews, presidents frequently discussed the difficulty of getting an adequate number of community-patient representatives to attend the health council meetings. The president of UBS 5 remarked, "Nowadays you have to do more than just put up a flyer to get people to come to a meeting, there has to be food, or games – something free! People won't just come to talk about health. I mean, maybe if it were about tourism, or surfing! But health? People just aren't interested!"

To educate more generally the public about the importance of health councils and social control (*controle social*) is an idea that has been taken very seriously by municipal and state government agencies in Fortaleza. At many of the interviews I conducted with state health officials, they would finish by offering me colorful booklets and thick workbooks devoted to the elaboration of social control and its role within SUS. Pamphlets, as "Between Wheels and Networks: the trajectory of social control in the SUS (*Entre Rodas e Redes: a trajetória do controle social do SUS*)", were products of a collaboration between the Ministry of Health (*Ministério da Saúde*), and the Secretary of Health, Government of Ceará (*Secretaria da Saúde, Governo do Estado do Ceará*), and detailed in simple language the necessity of getting representatives from the entire population to participate in decisions about health care.

In June 2016, I also attended a three-day workshop in Fortaleza, entitled "Experiences of Social Control (*Experiências de Controle Social*)", led by a member of the National Health Council to train presidents of local and municipal health councils all over Ceará about how to get more residents to participate in health councils and what methods could be used to increase communication between health councils across the state in order to share on-going concerns regarding their posts. "The problem is," stated the workshop leader, "the citizen is already a capitalist, so they don't always want to be part of the social system. But if you can get the people to the meetings, and they help planning what goes on at the health posts, then they begin to see that this is how you create a better system. Not a system of experts, but a system of people who are using the posts, learning and creating something new!"

But local health council presidents almost always attributed the difficulties that the local posts had in cultivating a broader reception and interest in the health posts not to residents' lack of education regarding social control, but rather to the requirement for administrative representation of councils. How could community-patient representatives be expected to speak freely, many local presidents asked, when they saw post administrators sitting right there? "This is a big problem at the local health councils," explained the President of UBS 1. "The coordinator is put in place by whatever administration is in power – these are political appointments! They show up in the meetings, and you're not going to come to a meeting and denounce what the administration – what the post is doing! You need them to be your friend, to do you favors, to help you get the care you need."

The President of UBS 2 asserted that, "For the majority of the councilors here, it's a joke, they do exactly what they're supposed to do, and what the management (*gestão*) says they should: they shut their eyes, their mouths and cover their ears... because they don't want to know. But that's

not how it's supposed to be, community-patient representatives are supposed to denounce! Instead they are simply talking about the price of doctors, their salaries, the medications, and things that aren't really about health. We need to be talking about how to move forward, and about what we lack!"

Presidents' concerns about the relative silence and even absence of community-patient-representatives at council meetings corroborates the work of scholars who have documented patterns of inadequate representation and participation in health councils at municipal and state levels (Coelho, 2004; Moreira; Escorel, 2009; Oliveira, 2004; Shimizu; Moura, 2015). However, the presidents' attribution of this absence to the presence of post coordinators at meetings suggests that prior scholars' and, indeed, state agencies' suggestions of increased education on the importance of social control may not be enough. Their remarks instead imply that the lack of adequate representation from community-patient representatives might be generated by the formal requirement that health councils include representation of administrators.

The requirement of LHCs that an administrative member of the health post attends the councils, and its specific instantiation in Region A of having the coordinator of the health post attending the councils, guarantee that in Region A the meetings will have at least one person who is *not* from the community. In Region A, this distinction was further heightened by the slightly more formal outfits the coordinators would wear to work, the cars they would drive to the posts (as opposed to community-patient representatives who would generally walk or take buses) and the more advanced educational degrees they held. These semiotic differences, which set the administration apart from other council members, were noticeable at every post and health council meeting I attended.

The sociologist Pierre Bourdieu has proposed that it is precisely these semiotic distinctions which can be understood as forms of cultural, social or economic capital, that enable certain groups of people to participate more effectively in civil society than others (Bourdieu, 1984). According to Bourdieu, the ability to speak equally, the very premise of a participatory mechanism such as the health councils, is a fiction that is unlikely to be corrected through education. Linguistic competence in his view is not merely a matter of technical expertise (something that could for example be learned at the type of training I attended, organized by the National Health Council Association) but rather embedded in individual habits and life histories. While the LHCs that I observed were almost entirely composed of people from the same humble backgrounds, it appears that the presence of even one member who had professional authority and was of a higher social class, was perceived by presidents as shutting down conversation and debate, and perhaps more importantly, as keeping residents away from attending health council meetings in the first place.

As one particularly cynical ex-health council president observed, "The councils are really just for show. Look, these councils have to be composed of fifty percent community members, but also fifty percent administrators and doctors. But what does this even mean? It's ridiculous. These councils are not for the people. I would never do it again, I just don't want to be a slave to the administration". Statements such as this and others like it that I heard throughout my research challenge the repeated urgings of scholars and activists to simply increase education about the importance of social control, and suggest that urban LHCs may need to reexamine the impact of the administrative representatives on the social dynamics of their meetings.

Theme II: Presidential Accomplishments

All six presidents responded enthusiastically and with detailed examples to the question of what they had accomplished at their posts during their tenure as president. Several presidents began by explaining that they viewed one of their roles as being an advocate for residents who use their post. For example, the President of UBS 7 explained, "What happens is, someone will come to the post and say - hey, I'm having this or that problem with something, I need to get a surgery sooner, or I need to get this medicine and we don't have it here. What we can do as part of the local council is to advocate on their behalf - sometimes all the way up to the Secretary of Health. We'll take their forms, along

with all the documentation and make enough noise so that something gets done."

Almost all of the presidents also included a description of what they had done to maintain the physical building of the post as part of their list of accomplishments. For example, the President of UBS 3 related how he had gotten several new windows placed in the downstairs portion of the post in order to have sufficient air coming in from that side of the building. As he explained, "We had pregnant women coming to the post who almost fainted while they were waiting to be seen because it was so stifling. I went to the regional [health council] president and told them, 'You put millions of *reais* into building these posts, and you can't even put in a window in the right place now?' It took a while, but eventually we got the funds." The President of UBS 5 related how he had pushed hard to secure funds to build an additional floor onto their post to provide a room for their community health agents, and build an additional bathroom onto the post.

Besides advocating for residents and looking after the physical structure of their posts, several presidents described examples of initiatives they had implemented based on suggestions made by community-patient representatives at local health council meetings. For example, the President of UBS 5 described how community-patient representatives had been complaining for several consecutive meetings about the lack of security at their health post. "We have a guard that watches over the post from 7 a.m. (when the post opens) until 4 p.m. But residents thought that there should be someone posted until the post closed (at 7 p.m.), and that they should offer to walk some of the older neighborhood residents home, if they needed it." The President then went on to explain that oftentimes older, sicker community-patient representatives would not come to the post at all if they were worried about safety on the walk to or from the post. "This was a problem for their health, so we knew we had to fix it!" he concluded. The post now maintains a security guard on site from seven in the morning until seven at night, and allows the guard to walk elderly patients home when necessary.

Another example of a resident-driven initiative was provided by the President of UBS 2, who described the story of a community-patient representative that had come to a council meeting because she was concerned about the lack of a sidewalk around the perimeter of her daughter's school. She was nervous because there were all these children milling around in front of the school, sometimes playing ball, sometimes just chatting, but never paying attention to the traffic on what was a fairly busy road. Often cars would come perilously close to the children who were waiting for their school to open. "At first I was dismissive of her concern," related the President of UBS 2, "it didn't seem like something the health post should deal with. But then I realized that this *was* a health issue, it was an issue of health and safety in our community, and we needed to do something about it." In response, the President of UBS 2 said he had gone to a local politician to ask about building a wider concrete perimeter around the school so that kids could wait out of the way of oncoming traffic and, after several months, the perimeter had been built. He stated that he also intended to bring the issue up at the next regional health council meeting because he thought that the problem existed at other schools in the Region.

The most substantial example of a resident-driven initiative was provided by the President of UBS 4, who described how an idea for facilitating pharmacy pickups that was suggested by residents during health council meetings at UBS 4, eventually led to the creation of a citywide program for prescription pickups at bus terminals. The President of UBS 4 explained the origins of the program in this way: she had been bothered for a long time by the medication orders that sat at the pharmacy of the post, waiting to be picked up by residents. She thought about the possibility of creating some sort of home delivery service, but then at one of the council meetings a community-patient representative brought up the idea of having small pharmacies located in Fortaleza's largest bus terminals. Most of the residents of Region A pass through these terminals on their way to or from work, and could conveniently pick up their medications as they transited through the terminals, rather than having to try to visit their local health post before or after work. Other residents who had been present at that meeting agreed that picking up prescriptions at bus terminals would facilitate adherence to

medications, simply by building in access to them into residents' daily routines.

The President of UBS 4 further explained that she had first brought this idea to a health council meeting of Region A, where it was greeted with enthusiasm, and then to a municipal health council meeting, where the members also responded with enthusiasm. At that point, several municipal health council members discussed the idea with the Secretary of Health. Months later, it was one of the ideas picked up by the Mayor of Fortaleza, Roberto Cláudio, to improve pharmaceutical access in the city. He eventually implemented the program in August 2017 (Madeira, 2017).

Although the President of UBS 4 acknowledged that it was rare to see an idea that had first been suggested by local community members to influence the citywide policy, and that it required the support of citywide health councils, as well as politicians, she was adamant that allowing local ideas about health care to impact citywide health initiatives was emblematic of the democratic process that the health councils were trying to facilitate.

Prior scholarship on LHCs has found that the councils have little impact on healthcare policy or innovation (Coelho, 2013; Martinez; Kohler, 2016). Indeed, most of the accomplishments that presidents in this study described had more to do with day-to-day improvements at their health posts, or with improving the care of specific individuals. However, two examples (that of building a safety perimeter around a school, and creating pharmaceutical outposts at bus terminals) raise the possibility that local health councils can become spaces where local citizens voice their concerns, suggest innovations to improve the health of their communities, and see their ideas materialized through the work of the council.

It is also notable that UBS 4, the post in which the most substantial example of a resident-driven initiative was undertaken, both the president of the post, and several community-patient representatives reported that the coordinator of the post worked exceptionally well with the Council, and was always extremely supportive of community suggestions. Participant observation of several council meetings confirmed these remarks. This finding, as well as the finding in the prior section about the influence of coordinators on the willingness of community-patient representatives to actively participate in the councils, suggest that the role and individual persona of the coordinator may have an even greater influence on the success of particular LHCs to facilitate resident-driven health initiatives than a president of a health council.

Theme III: Presidential concerns

One of the leading concerns of health council presidents expressed during my interviews was not having appropriate building infrastructure, space or material resources for their meetings. Physical space to hold meetings was a source of particular concern. The three health council presidents whose posts had only a small office reserved for the council (on days when it was not been used for multiple other purposes) repeatedly spoke of their fears that their meeting rooms would be allocated to a different use by future coordinators. The presidents of the three UBSs that had a room dedicated for health council meetings all recounted in great detail how they or a prior president had fought hard to get money to build a stand-alone building that could be used for council and other post-related meetings. When addressing the importance of such a space, the President of UBS 1 commented, "If we don't have a dedicated space for meetings, it's much less likely that extensive conversations will take place."

But even more mundane resources such as transportation funds for community-patient representatives to attend meetings, computers, printers and even pens and paper were frequently discussed as lacking by health council presidents and thereby undermined the potential of the councils. "How do they expect us to take notes, when they don't even provide us with paper?" asked the President of UBS 5 right before the beginning of a meeting. My field notes from participant observation of health council meetings also indicate that the meetings often began with a struggle to get functioning air conditioning going in the often small and hot rooms in which they took place.

The intensity of debate over local council infrastructure, and the degree to which presidents and community-patient representatives noticed, focused on, and tried to improve the material conditions

in which they performed their work, may appear to be a trivial problem for health council members to spend their time on. As one community-patient representative commented in exasperation after a prolonged discussion over refunding transportation costs, "We need to move on, the SUS is broken and people are dying!" And indeed it is health innovations, such as the ones discussed in the previous section, not complaints about infrastructure, or arguments over meeting protocols, that have tended to be seen by scholars and activists as the key to measure the success of health councils. However, several scholars have been careful to draw attention to other signs of participatory democracy that merit consideration here.

Andrea Cornwall, for example, describing the style of deliberation in a municipal council in Pernambuco argues that, "The enactment of democracy in the council (*conselho*) consists as much in arguments over laws, rules and procedures as substantive deliberation over health policies, which are more rarely the source of controversy or even debate. This needs to be understood as not just quibbling about the rules, but redefining the very boundaries of the procedural and the political." (Cornwall, 2008, p. 527).

The attention to and concern for the material circumstances of health councils sets contemporary political participation in Fortaleza apart from city activism of the 1970s and 80s. As I discuss below, almost all of the health council presidents were involved in local activism in prior decades, and were members of community-based associations that were early models of participatory governance in action. During that period, many of these same people fought for the very existence of health posts, as well as increased resources and healthcare providers to staff them.

While it is tempting to view earlier struggles to increase, for example, the number of health posts in Region A as "real politics", my interviews with all six presidents, as well as my own observations of council meetings, suggest that in contemporary Fortaleza, the "political" itself is being reframed and extended to include the material conditions in which meetings are held. By arguing for a dedicated room for meetings, for the presence of air conditioning, even for pens and papers, council members redefine 'politics' as something that must be done according to policy and procedure rather than in the organic and unpredictable manner that activism proceeded in the 1970s and 80s. As the President of UBS 4 asserted, when asking for the air conditioning to be turned on before starting the health council meeting of the post, and complaining that her computer had stopped working again, "The Constitution guarantees us the right to meet about these issues. We need to be taken seriously, and show that we treat these meetings with respect!" Articulating demands for even seemingly mundane items such as air conditioning can be understood as a way of differentiating contemporary political engagement, with its attention to formal rules, processes and appropriate conditions, from the kind of activism that preceded it, and can thus also be seen as a way of sustaining rather than undermining the democratic potential of health councils.

Theme IV: Linkages with the Past

The interviews with council presidents, as well as the participant observation I conducted during the years of this study revealed a dense assemblage of linkages between presidents' personal histories, local voluntary associations, and the history of activism in their community. The older presidents included in this study often went out of their way to emphasize that a version of the health councils had existed before the emergence of the SUS. As explained by the President of UBS 7, "SUS wasn't hard to set up because we had talked about it before; in fact, things like the health councils existed a long time ago. We'd been working for many years to get health services in our neighborhood." This assertion was amplified by several older community-patient representatives. "We did this all the time," one woman explained to me, "getting together, trying to get the city to give us space for a health post, to give us some access to basic services, just to recognize us. Going to meetings like this was the way you got things done." Table 1 confirms that the majority of the health posts arose out of direct community activism, as well as the relative age of the posts: of the seven UBSs chosen for inclusion in this study, all but one (UBS 6) were opened under what was described by health council presidents as "community activism and pressure". Two UBSs

were opened well before the SUS was inaugurated in Brazil (in 1982 and 1983, respectively), and three were opened in the early years of the implementation of such health care system in Fortaleza (1990, 1992 and 1995, respectively).

All of the health council presidents I interviewed also reported being personally involved in the struggle for civic and legal rights led by peripheral neighborhoods around Fortaleza during the 1970s and 80s. And all but one president had been an active member of one or more of their community's voluntary associations. The only president who had not been involved in these struggles had been born too late to participate in the uprisings of her parents' generation.

Voluntary associations flourished in peripheral neighborhoods throughout Fortaleza during the 1970s, 80s and early 90s. According to a census conducted in 1986, there were 97 self-identified community-based organizations in Region A alone (Gonçalves da Costa, 1995). These organizations, which ranged from groups of women selling handcrafted products, to Samba groups, to children's fishing groups, to housing material cooperatives, to day care centers, were central to the character of the community. Presidents described belonging to multiple associations and using them to nurture social relationships, as well as to organize campaigns to secure more resources from city politicians.

Their history of involvement with the voluntary associations in their community had multiple effects on their work at the current LHCs. For example, the President of UBS 5 emphasized how deeply connected he felt to the residents in his community, and how he used this knowledge to assess the potential of public health proposals presented at the health post. He explained, "When the city comes to us [the council] and proposes a scheme about the health agents going door to door for, let's suppose, a new campaign to lower blood pressure, I know whether it will work or not." The President of UBS 2 asserted that, "I know how they'll respond to a new coordinator and I can kind of ward off problems between him and the residents before the communication breaks down."

Presidents also stressed the importance of having personally witnessed and worked for the implementation of the health posts of whose councils they were now president. "We came together from the beginning," explained the President of UBS 3. "I can remember when this was just a field, and we all came together for many weeks and months in order to make sure that this post would be built. This post may go through bad times," he continued, "where we don't have enough money or medications, but I remind people that there used to be a time, not so long ago, when there was nothing here at all!"

All six presidents I interviewed also described their personal trajectory (having been a citizen of a poor, peripheral neighborhood in Regional A, becoming a community-patient representative, and then being elected health council president) as one that flowed naturally out of a long-standing preoccupation with bettering their community. "I can't explain exactly why," said the President of UBS 3, "but I've always been interested in trying to organize people to come together. I believe something like health, that's our right, and we have to take it! That's what I'm trying to do here [as council president]." The President of UBS 5 asserted, "This work is just a continuation of what I've always done in the community: organize, educate and protest."

A key concern of scholarship about participatory governance is how independent it is from the influence of dominant political parties. Several studies of Brazilian health councils have found that the councils simply extend the hegemonic power of government representatives rather than increasing the number and diversity of social actors in improving access to health care (Coelho, 2004; Elias; Cohn, 2003).

In contrast, interviews with the presidents in this study suggest that at least at the local health council level, ties with past community-based organizations, may exert more influence on presidents than do political affiliations. While presidents spoke with great enthusiasm about the way that their community connections facilitated their current work, and attributed their passion for their work as president to their history of political activism, these findings also underscore the necessity for future scholarship to investigate the broad range of networks that might exist between local health

councils and community organizations, as well as to understand how older forms of civil society, such as voluntary associations, have shaped the expectations and priorities of current LHCs.

Limitations

This study is limited first by its reliance on a small number of interviews to describe the attitudes and experiences of health council presidents. The findings should thus be examined in a larger number of LHCs in additional cities, before wide generalizations are derived from this study. The study is also limited by the potential for bias in the presidents' responses to interview questions. Particularly around the issues of contributions and accomplishments, there may have been a tendency for presidents to report their achievements more favorably due to a concern for their legacy. Every effort was made to verify the specific accomplishments that presidents reported with other community members, but the possibility of bias still exists. As a small qualitative study, one of its most important goals is to provide direction for future research, which I outline below.

Final considerations

This study documents the existence of six functioning, active health councils in one of the poorest regions of Fortaleza during a time of great national political turmoil and local unease about the ability of politicians in continuing to secure funding for the SUS. Six out of the seven UBSs I surveyed had convened a health council that met regularly and was represented by a president who was from the local community. Although my interviews and observations of LHCs confirmed some of the findings of prior scholars who found insufficient training and operational budgets at LHCs, as well as inadequate representation of community-patient representatives, they also revealed new insights about how local health councils function.

Presidents' reports about the impact of health post coordinators on the willingness of community residents to participate in council meetings challenge the repeated urgings of scholars and activists to simply increase education about the importance of social control, and suggest that urban LHCs may need to reexamine the impact of coordinators on the social dynamics of their meetings. The necessity for future scholarship on LHCs to look more closely at the role of the coordinator was also suggested by the finding that the most innovative resident-driven health initiative (creating pharmaceutical outposts at bus terminals) came from a UBS where the coordinator had been at the post for many years and was well liked and integrated into its day-to-day activities. The success of this particular health council at promoting community-patient representatives' ideas raises the possibility that local health councils *can* become spaces where local citizens see their ideas about health materialized but also indicates that coordinators can play at least as an important a role in furthering those ideas as do council presidents.

Finally, this study uncovered deep relationships between health council presidents and the historical network of community-based organizations (*Associações Voluntárias*) that had flourished in the neighborhoods surrounding the UBSs. Almost all of the health council presidents interviewed for this study had been involved in local activism in prior decades, and were prominent members of local community-based organizations. While it is tempting to view the forms of activism of the 1970s and 80s as more organic and concerned with more substantial issues than current mechanisms of participatory governance, the presidents' attention to and concern for the material circumstances of the health councils suggest that the very definition of 'politics' has been expanded in contemporary Fortaleza to encompass something that must be done according to policy and procedure. The documented success of Region A in maintaining local health councils and its attempts to open up formation and management of health policies to citizen participation is a sliver of optimism in Brazil's ongoing struggle to sustain effective participatory institutions.

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Appendix A – Semi structured interview guide for Health Council Presidents

Demographic

1. Please state your approximate age (pick from a list of decades).

2. Please state your gender.

3. What is the last grade level that you attended?

4. Do you currently live in the neighborhood of your health post?

Interest in Becoming a Council President

5. How did you become involved in the health councils?

6. What was your motivation for becoming President?

7. Did you participate (or do you currently) in any of the community groups in your neighborhood such as *Associações Voluntárias*?

Effectiveness of the Local Health Councils and History of Your Post

8. What are the common discussion topics of the Health Council meetings?

9. Can you describe the history of the opening of your UBS?

10. Can you describe some of your accomplishments as Council President?

11. Do you work with the health councils at the regional, municipal and state level in Fortaleza?

12. Does your health council represent the interests of the community as a whole? If not, why, in your view, is this?