

Specialized care services for children with congenital zika virus syndrome in Rio de Janeiro, Brazil: a social network analysis

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Abstract *In 2015 the correlation between increasing numbers of cases of microcephaly and a zika virus outbreak led to recognition of an epidemic of congenital zika virus syndrome (CZVS), highlighting well-known weaknesses in health care measures. This article examines the network of virtual information available on health service provision for children suffering from CZVS in Rio de Janeiro. Using social media analysis, data on information about services and care institutions were collected from virtual sources using the Google search engine, so as to assess relations among these actors in 2018. The results revealed a fragmented network centred on virtual sources and secondary and tertiary public care services, with striking proximity of press sources to public services. Also salient was the isolation of private services and the lack of dialogue between philanthropic and public services. Moreover, the information offered was found to be insufficient and superficial, despite the gaps in the formal rehabilitation network. The evidence thus suggested the importance of a well-established health care service network and the necessity of fostering communication through virtual media.*

Key words *Zika virus, Microcephaly, Social networking, Access to information, Health service accessibility*

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Introduction

In 2015 incidence of cases of microcephaly increased in a number of countries simultaneously with the Zika virus (ZikaV) outbreak. Confirmation of that correlation led to the recognition of an epidemic of Congenital Zika Virus Syndrome (CZVS). Given a Public Health Emergency of National Concern (PHENC) and a Public Health Emergency of International Concern (PHEIC), the Ministry of Health (MoH) introduced the National Plan to Combat Microcephaly (*Plano Nacional de Enfrentamento da Microcefalia*). This contemplated measures for surveillance of microcephaly and Zika cases, vector control, health care organisation to monitor and provide care to expectant mothers and children, organisation of a rehabilitation network and early stimulation of newborns¹ – all of which pointed to gaps and difficulties pre-dating the CZVS epidemic.

In order for access to diagnostic services and treatment to secure the greatest gains in functionality for children presenting with disability, the health care system (HCS) must offer comprehensive care and collaboration among primary health care (PHC) and specialised health care (SHC) services. Brazil's HCS embodies the national comprehensive children's health care policy (*Política Nacional de Atenção Integral à Saúde da Criança*, PNAISC), the national health policy for people with disability (*Política Nacional de Saúde da Pessoa com Deficiência*) and the health care network for people with disability (*Rede de Cuidados à Saúde da Pessoa com Deficiência*, RCPD) and the national primary health care policy (*Política Nacional de Atenção Básica*, PNAB)².

Although PHC is regarded as organising the system, specialised care for mothers and their newborn babies was not satisfactorily connected with primary care. In addition, care was lacking in peripheral urban areas, as was known to be the case prior to the Zika epidemic, but worsened as the number of SCZV cases increased³. From 2015 to 2019 MoH epidemiological bulletins confirmed 3,474 cases in Brazil, of which 2,121 (71.4%) received some kind of care in the health system. Of these latter, 1,860 (62.6%) received PHC and 1,805 (60.8%), SHC⁴. Despite the MoH's efforts to expand rehabilitation services, a considerable portion of the children had no access to such services and nor was it possible to measure the quality of these facilities or the frequency and conditions of families' access to them.

One of the characteristics of health service (HS) provision is access, which can be defined

as the possibility of using HSs appropriately when necessary. It comprises several dimensions including availability, ability to pay and information. Many authors consider the latter to be key to the equity debate⁵. The information dimension can be evaluated by the "information sources" indicator pointing to the possibility of reaching the HS, which depends both on the individual's attitude to the disease and to the characteristics of care provision. Difficulty in accessing the HS, rehabilitation and early stimulation contributes to impaired quality of life, increased carer stress, delayed definitive diagnosis and appropriate treatment, as well as to the travel and costs entailed^{5,6}.

The concept of regulation instituted by Brazil's National Regulation Policy in 2008 was introduced in reductionist form, basing provision on available services and resources. However, regulation of access, planning and care organisation came to be based on the population's health needs rather than on available supply. Municipalities where SHC services are concentrated receive local users, plus others from the local region catchment area and still others whose private health insurance offers only partial coverage and who thus resort to the national health system (SUS) for the more costly procedures⁷. Analysis of information distribution among health system actors is one tool to elucidate and improve communication processes by identifying asymmetries. Missing or deficient information on the real options available in the health context limits users' perceptions and possible choices⁵.

Araújo and Cardoso (2007)⁸ address disputes among discourses and practices in the health communication process, which produces social meanings over and beyond its content. They show that "communication is associated with politics and the right to citizenship, to health and to the principles of the SUS". Accordingly, this entails affording the population access to various communications media; contemplating socioeconomic and cultural differences, so as to prevent harm being caused by difficulties in accessing information and health care; fostering participation in local decisions by strengthening communication channels; and encouraging greater involvement by state and municipal governments in SUS communication⁸.

The ease with which a variety of information sources can be set up to enter into an endless number of topics has made the Internet an instrument for spreading information and conducting countless searches in the health field. It

is fundamentally important to understand better the metrics or patterns of online searches for health information, given that Internet users can be exposed to a great deal of dubious and poor quality information. It is difficult to arrive at reliable information, because the quantity of data makes it hard to locate reliable sources^{9,10}.

CZVS accentuated the urgency of the right of access to health, as well as highlighting limitations and discrepancies between health policy organisation and the related legislation. Studies have mapped people's origins and destinations for the purpose of identifying the real situation of health care, with its shortcomings and/or successes^{6,11}.

Social network analysis (SNA) has been used in Brazilian and international studies in the collective health field to identify and understand information flows and the roles of the various actors involved in the networks. Those studies can contribute to more effective policymaking for access to public health services (PHSs) that meet real needs^{6,11-13}. SNA is an appropriately structured instrument for this study into SHC service provision in relation to CZVS. Drawing on information from Internet search sites, it has the ability to identify the underlying structure of the social system, bringing out regularities in actors behaviours and exchanges of resources, which point to how they are interdependent and influence one another¹⁰. To the authors' knowledge, this is the first time that SNA theory has been applied to understanding this issue in relation to obtaining care for CZVS. It is important to note the differences among the terms SNA theory, social media networks and health care networks.

Even with regulation in place, large numbers of patients still enter flows at variance with those recommended⁶. Given that their efforts to find information on rehabilitation services are not facilitated, an SNA approach to the issue would seem to be an effective methodological strategy, because it allows the actors and their relationships to be visualised, making it a practical tool for planning and management.

Rio de Janeiro (RJ), an area affected by the epidemic, has a population with multiple demands and an insufficient and underused health care system in which many difficulties arise daily between planned HS availability and actual use. As a result, demand is ultimately conditional on the pattern of existing supply^{11,14,15}. Accordingly, this study examined the virtual information network regarding provision of health services for children with CZVS in RJ.

Method

The frame of reference for this study involves the exploratory network analysis model¹⁶, which features four stages: network specification; network data treatment; determination of structural characteristics; and visual inspection. Their goal is to identify and interpret social patterns in relations among network actors. Therefore, this study focusses on analysing connections between virtual sources and care sites mentioned by those sources. Note that the visual inspection is a key stage, because it allows relationship patterns to be mapped and displayed more easily and visibly, in addition to supporting the definition of network structural characteristics and an improved understanding of results¹⁷.

Here it was proposed to construct and analyse the virtual information network relating to provision of SHC services for CZVS in RJ, with reference to the outbreak that occurred in 2016. However, data were collected in 2018 (6 June 2018), as they resulted from a research project begun in 2017. In this method, the data collected always refer to a specific date, thus providing a panorama of the moment, which is necessary in order to visualise the network graph. In some cases, data collection may be repeated so as to examine how relations change over time¹².

Information was collected from the virtual sources (VSs) of care services and institutions. Data were collected by the simple Google search mechanism, so as to simulate a search by an ordinary citizen seeking virtual information on care for CZVS. Google has been Brazilians' main source of information and an important search channel on questions relating to diseases and treatments. It was chosen for data collection because of its high prevalence in searches for medical treatment (60%), general information on diseases (52%), causes and symptoms (48%), information on medicines (40%), potential consequences of treatments (39%), searches for specialists (39%), disease diagnosis (28%) and topics including nutrition, diet, physical condition and child health¹⁸. Also, the search strategy via simple search engines (Google, Yahoo etc.) is now being used as the primary source of health information¹⁶. Accordingly, for this study, the Google digital channel was chosen to perform the Internet field research, because it is one of the most powerful virtual search tools available.

It was necessary to test that search engine with a set of terms on different computers and at different times, so as to avoid the invisible filter

that prevents total access to the Internet¹⁹. The combination of words that specified the search terms was [in Portuguese] “Health care for children with microcephaly in Rio de Janeiro” and “Rehabilitation for children with microcephaly in Rio de Janeiro”, with no use of additional tools and without quotes. For now, the study was not intended to explore other possible combinations of terms¹¹.

The term “microcephaly” was chosen for being the most widespread and well-known among the public at that time, besides being a common worry among parents concerned with the sequela and no longer with the virus. The major media mentioned only the term microcephaly and by 2020 it was already being used by the Rio de Janeiro state health department (*Secretaria Estadual de Saúde do Rio de Janeiro*, SES/RJ) website devoted to the campaign against the ZikaV²⁰. Also corroborating the specification of the term, Fleischer (2017)²¹ showed that mothers identified children with microcephaly rather than with CZVS. In addition, searching with the term “CZVS” returned hits comprising scientific articles and thus reflecting more academic environments.

Although the study focused on rehabilitation services, it is important to acknowledge the importance of the HCS to providing effective care and to consider the interfaces with other facilities in the territory, as well as social assistance and education services. For that reason, it was decided to record all the services mentioned by the VSs encountered, with no restrictions, because the presence or absence of such services also points to how the rehabilitation network is organised (e.g., when, for lack or insufficiency of rehabilitation services, demand for rehabilitation care is absorbed by tertiary services)²².

In the digital humanities, one area of interest is developments in new ways of visualising information. Many software options exist for analysing networks of both institutional and personal interrelationships, and offer the possibility of processing and organising large amounts of information and displaying network measurements, which are selected in advance to reflect the characteristics of interest to the analysis¹³. These include degree centrality (which measures which element has most interconnections with others) and density (to what extent all possible connections in a network are used)²³. One much used tool for manipulating sociograms (graphs resulting from interactions) is the collaborative freeware, Gephi. This is an interactive platform

for structuring and visualising networks. Its flexible architecture and multi-tasking offer new opportunities for working with complex datasets and producing valuable visual results²⁴ and it has been useful in evaluating health programmes and services^{6,11}.

The network metrics presented in this study were calculated using Gephi version 0.9.2. The data collected were recorded on Excel spreadsheets containing the name of the information source, the type of VS (government, press, third sector or private) and then the names of the care facilities mentioned by each VS and the type of service (public, private and philanthropic). Chart 1 shows a summary of the meanings of the metrics used. Gephi organises information into tables or matrices. The table format used comprised a Source column containing the VS (represented by node numbering from 1 to 41); a Target column indicating the services (actors, numbered from 42 to 122) mentioned by informants; a Type column giving the linkage type (directed or undirected) of the edges, i.e., the links between nodes; and a Weight column with measures of the strength of the link between two nodes. Layout by Fruchterman and Reingolde and Rotate algorithms was selected, with visual parameters set to colour-code the service types, represent actors’ degree centrality by their size in the network and indicate edge weights by line thickness.

The attributes table generated by Gephi showed nodes in columns with codes (LABEL), name, node type (virtual source or service), VS classification (government, press, third sector or private). Other attributes identified included a classification of the services mentioned (public, philanthropic or private), VS publication date (identifying the CZVS health emergency period), the state and municipality of the service mentioned, type of health care and specialities offered by the services. The edges table identified the links between the respective nodes for direct relations between VSs and services. Services mentioned by a VS outside the municipality and state of RJ were also recorded.

Given that each metric serves a purpose, the classic structural measurements “degree centrality” and “betweenness centrality” were used to analyse the sociogram, because they met the study objective²³. Degree centrality measures a node, representing one of the persons or institutions which are the elements that participate in the network and are linked by connections called edges. It measures the node’s importance within

Chart 1. Definitions and meanings of the social network analysis metrics used in this study.

Metrics	Definition	Meaning in this study
Degree centrality (average degree)	A measure of nodes. The sum of all connections made by a given node in a network, demonstrating its level of activity in the network; the greater a node's degree centrality, the greater its popularity in the network	<u>Virtual source</u> – represents the virtual source with the largest list of care services (F4) <u>Care service</u> – represents the health service most mentioned by virtual sources (IEC) Degree centrality adds more control and power
Degree of betweenness	A measure of the extent to which a node can control or mediate the information flow, given its position in the network; nodes with strong intermediation centrality can be considered coordinators of the network flow. Weak values indicate a fragmented network	<u>Figure 08</u> – the actor that most mediated information <u>Virtual source</u> – Government 5 (SES/RJ) Care services – IEC
Density	Density is the links in the network as a percentage of the total possible links. A density of one means a dense network where everyone is related to everyone else, using 100% of its potential. A density of zero is a total lack of links: no-one knows anyone else, no relationships are established, a network does not exist. It is calculated by dividing the number of existing relationships (X) by the number of possible relationships (n x n-1). The resulting value is multiplied by 100 to obtain a percentage density, which can reach 100%.	Percentage of links (when a service is mentioned) existing between virtual sources and health services in the total possible links. A network density of one is equivalent to a situation in which all virtual sources mention all care services existing in the virtual network
Low modularity Cliques (<i>clusters</i>)	Algorithm to detect communities Number of groupings (of at least three nodes) that form subgroups within the network.	Virtual sources and services mentioned divided by colours corresponding to their area of activity: public, philanthropic, private or press Service facilities that interrelate through links with a virtual source, forming closed groups.
Network centralisation	A measure of the network (the network is centralised or is not).	Network centralised on a few services
Indegree and outdegree	The connection between target nodes and source nodes	How often the service was mentioned (indegree). How often the source made mentions (outdegree)

Source: Borgatti (2005); Vaz (2009); McCarty (2010). Table based on Rossi et al. (2018).

the network, which is quantified as the number of direct links established by any given node or actor⁶. As the links (edges) of this network are directed, i.e., go towards another node, it is possible to calculate any node's "indegree" and "outdegree", i.e., how much a source node mentioned some other node is its outdegree and how much the service node was mentioned is its indegree.

Average degree is measure of the node; in this network, the average degree metric (overall panorama) returned a value of 1.303, indicating a lack of centrality among the HSs mentioned. Modularity, a network metric involving an algorithm used to observe the number of communities in a given sociogram, shows whether or not the network is fragmented to form groups

or small nuclei also known as cliques or clusters. When the actors (or nodes) are strongly interconnected, there are large flows between them, which fosters strong cohesion. In this network, the high value of the modularity metric, which identifies groups, points to how particulate the network is, as corroborated by the nodes' lack of centrality even within the groups involved. In this study, modularity of 0.698 indicated that the network was fragmented²⁵.

To return to the connections between nodes, these can be of two kinds, i.e., connections between target and source nodes can be unilateral or bilateral. In the network analysed in this study, services mentioned are linked with VSs, which requires that the direction of the relationship be differentiated to show that it is oriented from the virtual source to the service mentioned. In the graph, arrows indicate the direction of the relationship (who is providing information about whom), thus characterising the relationship between nodes (Sociogram A). When the informant (VS) mentions a service, providing information about the care network, the actor mentioned will be represented in the network as an institutional node.

As regards ethical concerns, this study used free-access, virtual information in the public domain and, as such, under National Health Council Resolution No. 466/2012 and ethical principles it contains, was not required to be submitted for evaluation by the research ethics committee, because it did not involve human subjects.

Results

The Google search returned 81 public, philanthropic or private services, mentioned by 40 government, press, third sector or private VSs. From these data, seven sociograms were generated: (a) a panorama of the network of virtual information on care for CZVS in Rio de Janeiro, which provided the basis for the others; (b) the same, but by modularity and degree of betweenness; (c) focusing on the type of service; (d) focusing on the home states of the services mentioned; (e) showing the period of the CZVS public health emergency; (f) showing the type of health care offered by the services mentioned; and (g) showing the type of specialities offered by the services mentioned.

The network (a) comprised 122 nodes (actors), representing the VSs and the services mentioned. The edges, meanwhile, described 159

connections between actors. In all, 41 VSs were studied, 15 of them government, 16 press, 6 third sector and 4 private. These VSs mentioned 81 services: 30 public, 26 philanthropic and 25 private. Network density was 1.1% of all possible relationships, fostering extremely few links.

The Paulo Niemeyer State Brain Institute (*Instituto Estadual do Cérebro Paulo Niemeyer*, IEC) returned highest indegree, i.e., it was mentioned by 17 different VSs, followed by the services of the Specialised Rehabilitation Centres (*Centros Especializados de Reabilitação*, CERs), Family Health Support Nucleus (*Núcleo de Apoio à Saúde da Família*, NASF), Fernandes Figueira Institute (*Instituto Fernandes Figueira*, IFF) and PHC facilities. The VS with the highest outdegree was the Down Movement NGO (*Movimento Down*) (TS4), which mentioned 23 private services, and displayed a degree of isolation, because there were no connections with other care sites nor indications of other private services by other VSs (a). Note that the Rio de Janeiro state health department (SES/RJ) (GA5) mentioned 21 services.

The community representing most actors belonged to the PHSs grouping and government VSs (about 37%), then the group of third sector VSs and philanthropic services (26%), then private VSs and private services (24%). The smallest grouping was the press VSs, because it only indicated services, most of them public (13%) (Figure 1).

The second VS to stand out for its degree centrality was the SES/RJ (Figure 1), which mentioned 21 services, 3 of them national in scope, 1 offering tertiary care (IEC), 17 in the RCPD disability care network (five public and 12 philanthropic institutions). The philanthropic and public VSs – respectively, OCA (F3) and Mesquita municipal government (PM) – formed clusters: the former mentioned two public hospitals (tertiary care) and one philanthropic institution, while the PM mentioned the services available in its municipal area and was the only source to mention psycho-pedagogical care in a municipal school. Degree of betweenness can be observed in the groups of public, philanthropic, private and press actors, constituting modularity. The size of each node in the network graph reflects its degree of betweenness: the larger the node, the greater its betweenness.

In the third graph (c), the PHSs mentioned predominate: of the 81 services, 30 were public (37%), 26 were philanthropic (32%) and 25 were private (31%). The VSs were found to mention PHSs recurrently, producing more links and a

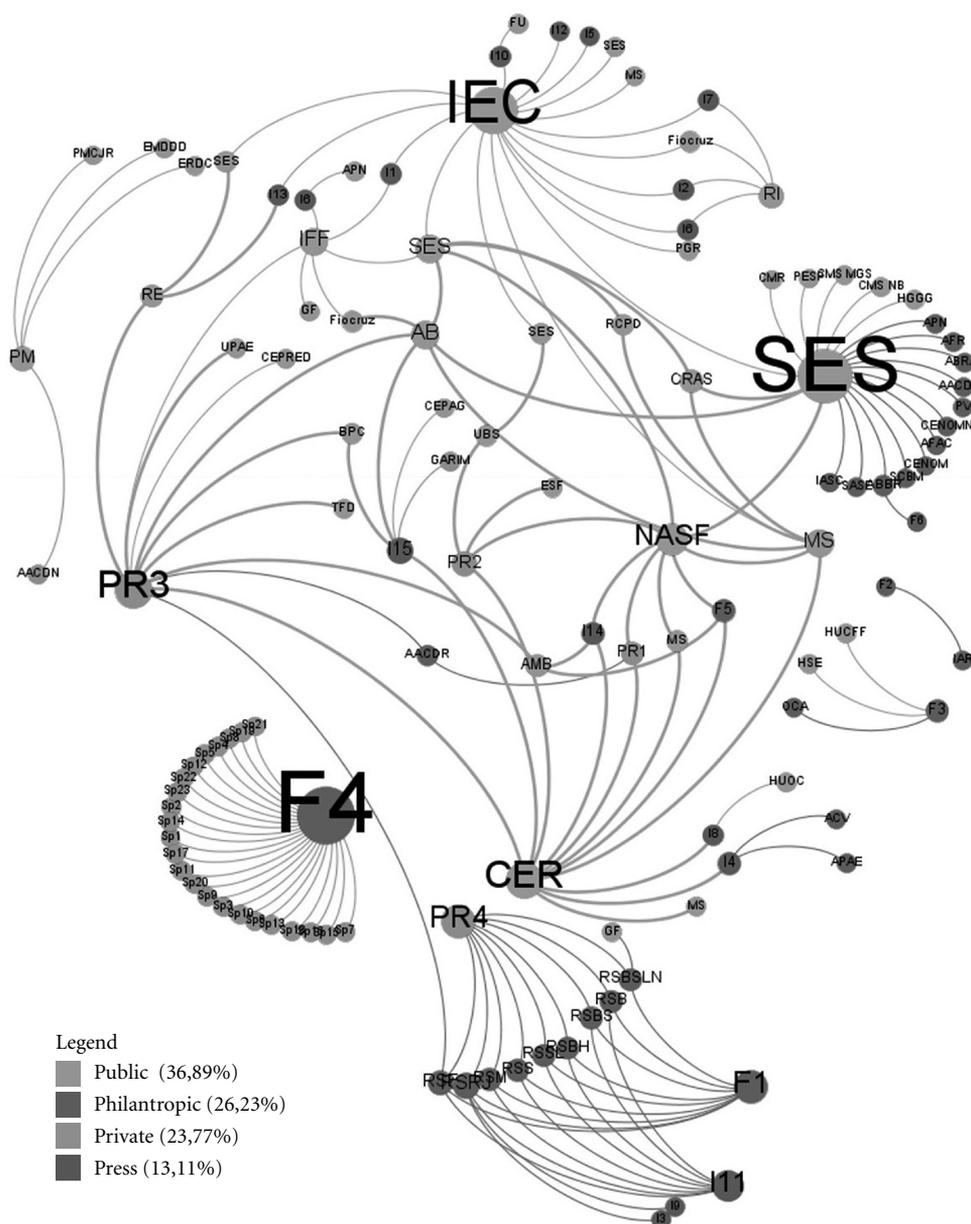


Figure 1. Sociogram of case (b), representing the network of virtual information on care for CZVS in Rio de Janeiro, by modularity and degree of betweenness.

Source: Gephi software, modified by authors.

fuller network. In case (d), showing the relationships encountered during the period of the public health emergency, about 70% of the network is made up of municipalities in RJ state, which is to be expected, and particularly the capital (38%). VSs also mentioned services in municipalities of other states, particularly in the northeast re-

gion, the worst affected by the CZVS epidemic. As the press is one of the VSs that appeared most, it contributed CZVS-related information beyond Rio de Janeiro. Most VSs of private institutions (3 of 4) also mentioned services outside RJ. Table 1 shows the network composition by municipalities mentioned by the various VSs.

The websites that most mentioned services in RJ originated with government, philanthropic institutions and the press. However, while there were 15 press VSs, only 6 corresponded to philanthropic institutions and one of those alone accounted for 23 mentions of services. The press VSs were an important means of circulating information. The case (e) sociogram (Figure 2) depicts that situation.

Of the total of 41 VSs, 66% returned a publication date during the public health emergency: 41% during the PHEIC and 22% during the PHENC. Only two philanthropic sites (5%) (Down Movement and ABBR) publicised services prior to the CZVS (PREM). The case (e) sociogram (Figure 2) shows that the sites mentioned care services most during the period of the PHEIC, followed by mentions by VSs following the emergency (PEM).

The services most mentioned by VSs were those offering secondary care (SC) (75%); of these 57 services, some were mentioned more than once. Also mentioned were services offering tertiary care (20%), PHC (5%), social assistance (2.5%) and education (0.5%). The IEC was mentioned 17 times, 10 by government sites and 7 by press sites. The CER was mentioned 11 times (by 4 press, 3 private, 3 public and 1 philanthropic VSs).

In case (g), by type of speciality offered by the services mentioned, half (40) did not give that information. Most of those that did mentioned care by health professionals (60%), particularly speech therapy (27) and physiotherapy

(23). There were 41 records relating to diagnostic testing and 36 indicating the type of disability for which care was offered. The numbers of mentions in the Therapies (23), Social Assistance (21) and PHC (16) categories were similar, while Education was mentioned nine times.

Discussion

From the networks, centralisation was found in VSs and PHSs relating to secondary and tertiary care, featuring particularly close relations between press sources and PHSs. The degree centrality of the IEC, in case (b), makes it one of the highest-visibility nodes in terms of potential for communication among actors in the network. This can be explained by its having been the health centre chosen by the SES/RJ to receive children with microcephaly in RJ, as was made public on 29 February 2016, shortly after the WHO declared the PHEIC. In this period, the topic was prominent in the press, which – together with government sources – reported that care was offered at the IEC. In case (e), about 40% (17 of 41) of the VSs that appear in the study refer to the PHEIC. Practically all the VSs identified tertiary care centres and many described what types of services were offered.

Rehabilitation requires constancy in care at short intervals and, accordingly, the graph shows a positive result, in that VSs concentrated on SC services. In case (f), this can be seen to indicate

Table 1. Municipalities of the services mentioned by virtual sources.

Municipalities in RJ State				Municipalities in other states			
	State	Total	%		State	Total	%
Rio de Janeiro	RJ	31	38%	Belém	PA	1	1,2%
Niterói	RJ	8	10%	Belo Horizonte	MG	1	1,2%
Mesquita	RJ	3	3,7%	Brasília	DF	2	2,4%
Nova Iguaçu	RJ	3	3,7%	Fortaleza	CE	1	1,2%
Volta Redonda	RJ	1	1,2%	Macapá	AP	1	1,2%
Teresópolis	RJ	1	1,2%	Salvador	BA	2	2,4%
Duque de Caxias	RJ	3	1,2%	São Luiz	MA	1	1,2%
Barra Mansa	RJ	1	1,2%	São Paulo	SP	1	1,2%
Campos dos Goytacazes	RJ	1	1,2%	Recife	PE	2	2,4%
Natividade	RJ	1	1,2%	Ouricuri	PE	1	1,2%
São Gonçalo	RJ	1	1,2%	Natal	RN	2	2,4%
Três Rios	RJ	1	1,2%	Nacional	BR	11	13,5%
Mentions by municipalities in RJ state		55	67%	Mentions by other states and nationally		26	33%
Total						81	100%

Source: Authors.

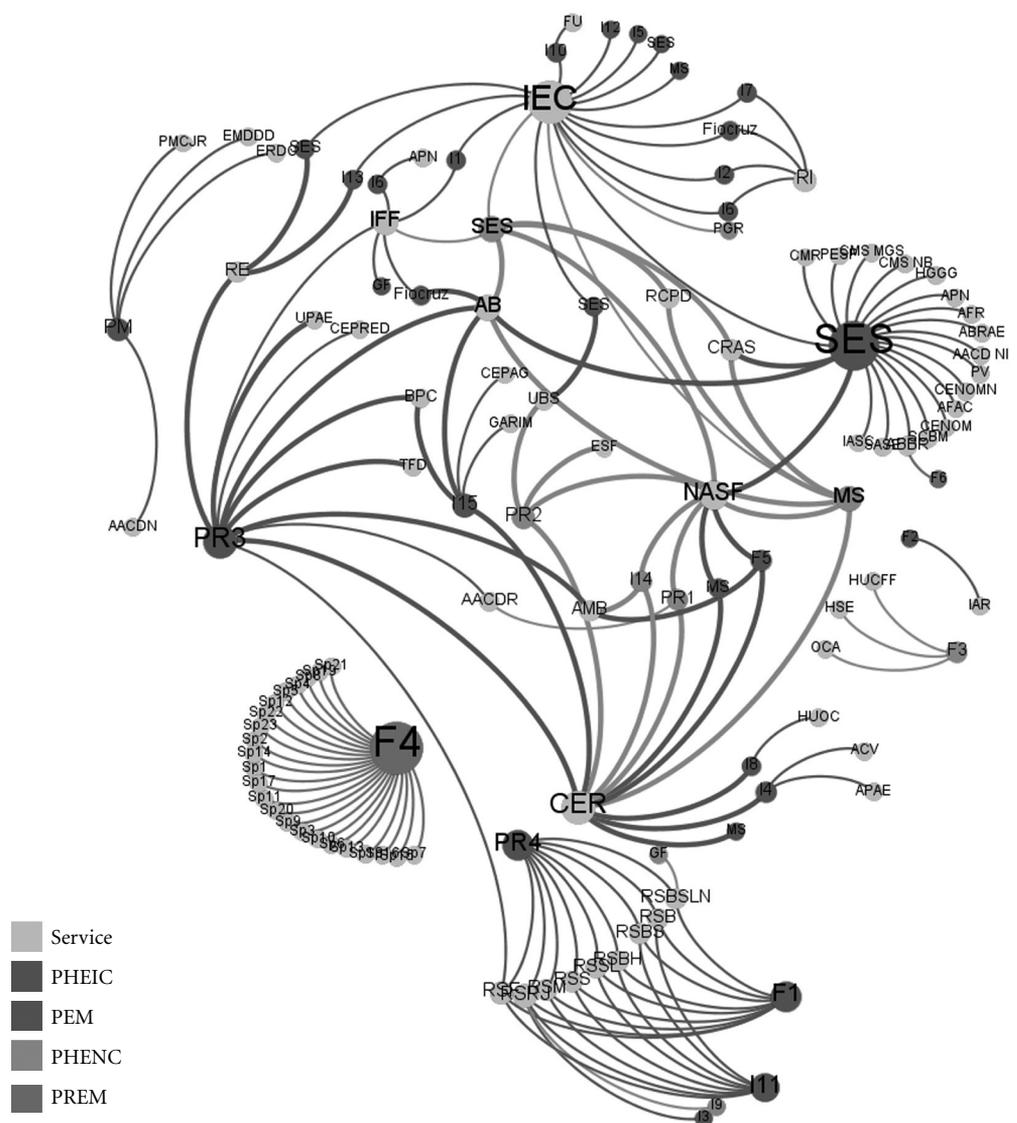


Figure 2. Sociogram of case (e), representing the network of virtual information on care for CZVS in Rio de Janeiro, focusing on the period of the CZVS public health emergency.

Source: Gephi software, modified by authors.

that there was an awareness in the network of their importance to treatment and a recognition of the need for access. However, although 81 services were mentioned, social network analysis suggested that the information provided on these institutions was superficial and insufficient.

In case (c), nearly all the government VSs contain information on some or all of the services, but using nomenclature that does not direct to specific institutions. That information

presented with so many omissions points to the quality of the information offered. Only one VS of the SES/RJ mentioned the CERs, giving the name and centre where they operated, but in an annex to the SEASDH/SES-RJ Joint Technical Note No. 01, which would require in-depth reading of the document in order to encounter that information. One exception that should be highlighted is the Mesquita municipal government, which identified all the services it mentioned.

This means that all families of children with CZVS had to search using personal resources, such as the Internet, in order to find institutions for continuous care. A study addressing the social implications of CZVS showed that the mothers interviewed searched randomly for referral centres. The following excerpt stands out: “For lack of a previously structured flow, the Internet and the experience of other mothers encountered in health centre corridors figured as the main sources of information and guidance as regards treatment” (Mendes et al., 2019)²⁶. The Internet is a complex virtual universe with no territorial base, but that does not entail people’s distancing themselves from their everyday experience (their “traditional socialities”) nor that there is any single pattern of connections on the Internet¹³.

The modularity metric suggests that users organised informally in their personal networks, despite the gaps in the formal rehabilitation network. That weakness was evident in the network’s small flow of connectivity and in the absence of referral and counter-referral by health personnel at the time of the epidemic²². Actors’ positions determine control over information about resources, and greater or lesser porosity in the network structure depends on how that information is circulated among them. Studies corroborating these data^{14,15,26} point to difficulties in accessing services: of 50 children in rehabilitation monitored by the IFF, 22 did not have full access to a rehabilitation service²⁶; and in 2016 a spatial analysis of notified microcephaly cases, by municipality in RJ and by rehabilitation centre, indicated difficulties in access to a specialised health service in areas more distant from the state capital. This demonstrates that it is important to ascertain what care flows are established and to examine trajectories to obtaining care and ease and difficulty of access¹⁴. This situation was also described by a SES/RJ report¹⁵, which highlighted the 13 CERs and their locations in RJ state (7 are in the state capital). It found that, in the territories, measures are still disjointed and that this hinders the construction of care flows¹⁵.

Relations of centrality in the network and how information on resources flows produce more open or closed patterns of interaction among actors. Such mentions can be instrumentalised in a health communication process and thus indicate opportunities for building effective information on access^{8,13}. The recently structured SUS Rehabilitation Network (*Rede de Reabilitação*, RR) comprises facilities offering services managed totally by the public sector or by phil-

anthropic institutions under agreements with the MoH²⁷. Design of the RR did not proceed as quickly as necessary. Press portals encountered by this study reported that the MoH website failed to specify either these services’ capacity or where new facilities were being installed²⁸. Brazil had no infrastructure even for existing cases of severe cerebral palsy, far less for those that were emerging²⁹. The political and economic scenario in Brazil was critical and a history of low investments in health care was further impacted by a constitutional amendment capping public spending, which will limit growth in State expenditures for the next 20 years. While it was already difficult to use funding during the Zika epidemic, the prospect is now that the spending freeze will worsen the scrapping of PHSs. The measure overburdens the states and municipalities with financial responsibilities and they will now have to provide access to information and services in a restrictive context, which may have more severe impacts on the poorer members of the population^{30,31}.

In the graph for this study, the configuration of the SES VS reporting the SEASDH/SES-RJ Joint Technical Note No. 01 suggests a cluster regarding the services mentioned that make up the RCPD, because it is the only source to mention them. However, in the network structure, it is also an actor that bridges to other services and can contribute to “optimising relationships and maximising contacts”, “facilitating the flow of information”, which indicates some degree of betweenness²⁵.

In practice, this means that the nodes representing the RCPD are isolated, with no potential to intermediate among network components. It can be inferred that RCPD services did not receive information originating from most of the VSs, were not points of reference on the graph and did not display information centrality, suggesting that they would have had difficulty absorbing the kind of demand addressed by the health policy in question. The modularity of 0.698 identifies a lack of centrality and a fragmented network, which is at odds with the MoH policy. This finding shows the importance of the proposal for referral and counter-referral³². The difficulty of accessing and providing information on SHC facilities and the lack of referrals from diagnostic facilities to SHC are serious obstacles to effective treatment and entail enormous public health risks²⁶.

The third sector VSs do not foster information flows among their philanthropic services,

particularly among the institutions that form part of the RCPD in RJ, as can be seen in case (c). Thus, despite the number of philanthropic services found in the search (26), it seems to be a challenge to obtain information on care for CZVS from third sector VSs established and organised by civil society for people with disability (and the NGOs do not mention PHSs). Case (f) shows scant information on social assistance and education policy in the search for care (Figure 3). Although the mentions are superficial, their very presence signals the importance of interdiscipli-

narity, because guaranteeing health in its broadest sense entails collaboration and coordination with social policies.

The VSs with most interconnections are those pertaining to press (16) and government (15). These seem to exert a considerable influence on the virtual information flows, at the same time as they can be seen to be insufficient; see Figure 1, relating to sociogram (b). That fact suggests a direction relationship with being in the midst of an epidemic of interest to the media: the items news dated mostly from the period from 2016 to 2017;

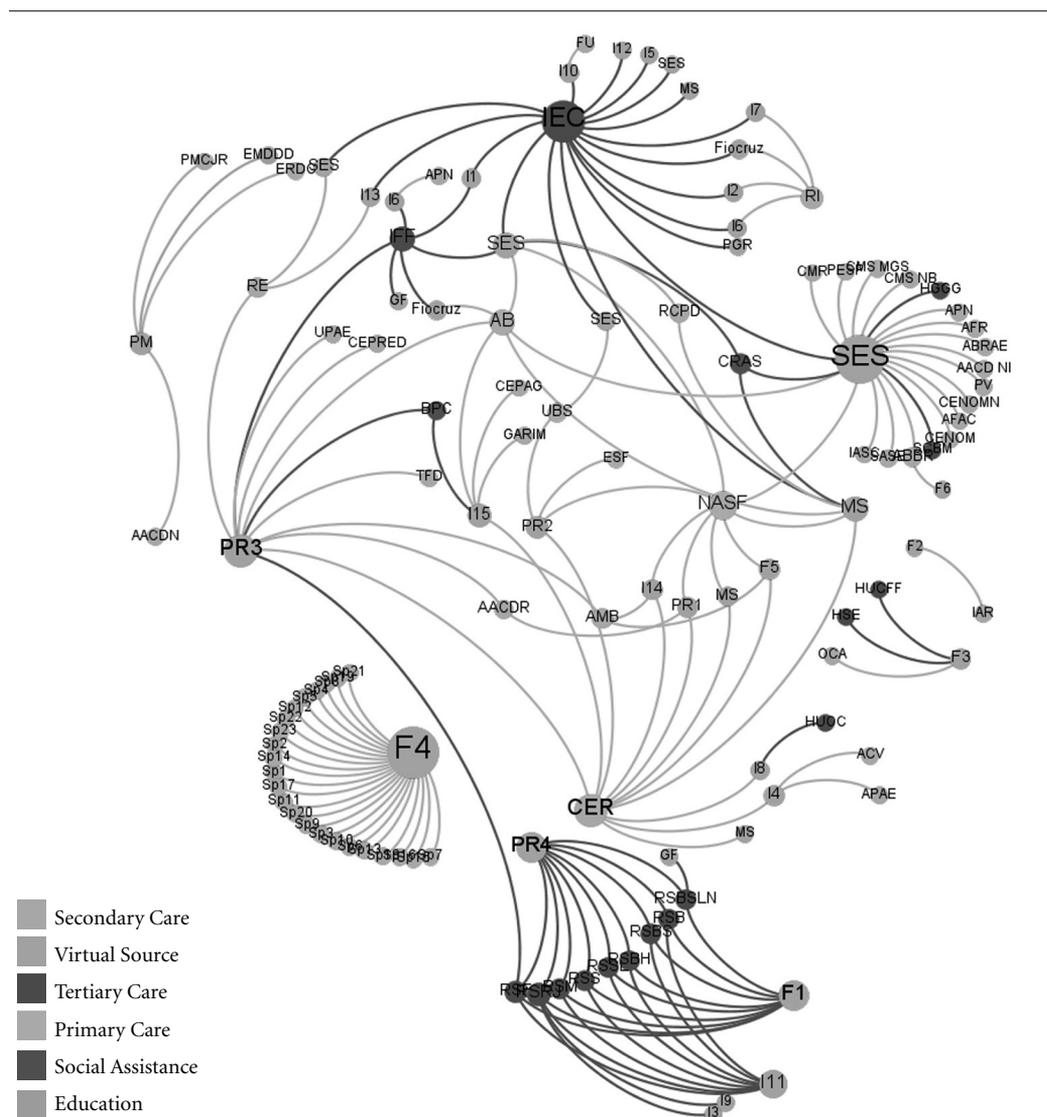


Figure 3. Sociogram of case (f), representing the network of virtual information on care for CZVS in Rio de Janeiro, focusing on the type of care offered by the services mentioned.

Source: Gephi software, modified by authors.

see Figure 2, relating to sociogram (e). Rossi et al. (2018), investigating services offering care for autistic children in RJ, found only two VSs originating with the press¹¹. In the study reported here, meanwhile, all the 15 press VSs mentioned services in RJ or at the national level, pointing emphatically to difficulties and gaps in this network of services. In 2020 the SES/RJ's Shoo Zika (*Xô Zika*)²⁰ portal, which focused on the campaign to combat the ZikaV, continued to lag: information was out of date or missing.

The Internet is a particularly advantageous medium for spreading information. Government websites should use easy language and tools that are intuitive to lay persons, a diversity of electronic formats and be constantly updated. Information dissemination in a service network should consider local contexts, different realities and obstacles to access to education, to means of communication and to technology. It is important to identify specific needs, increase the proactive publication of important documents and proceed with making those resources public³³.

The manner in which the virtual pathways of the SES/RJ emerge in a search for information on care signal difficulties in the process. The Google search did not return any of the SES/RJ information websites. This suggests that effective communication among managers is lacking and that practice developed without sufficient interaction in order for it to be publicised and shared. The SES/RJ reference sites on the mosquito (*Rio Against the Dengue/Rio contra a dengue*)³⁴ and Zika and microcephaly (*Shoo Zika/Xô Zika*)²⁰ did not point to other portals with information on the care network, such as the site that can be consulted for information on health care centres and its web page on RCPD resources, which contains the addresses of all the institutions. That

lack of connectedness seems to have contributed to the overall worsening of the scenario of disinformation on the epidemic.

Final considerations

It can be concluded that information about PHSs from public VSs predominated, with particular emphasis on one diagnostic facility, reflected in its centrality, its power of intermediation and information quality, although most of the mentions were of SC services. Private services were conspicuously isolated and philanthropic services did not dialogue among themselves or with PHSs. Press VSs appeared directly related to indications of PHSs, particularly during the PHEIC period.

SNA allowed a panorama of existing conditions to be visualised, revealing difficulty accessing virtual information on specialised rehabilitation services in RJ, especially those of the RCPD, in addition to pointing to the insufficiency and superficiality of the information offered at the time. SNA showed how relations occurred between actors and also afforded a better understanding of the flow of virtual information about services in the study period. Even though further studies are needed to generalise about the situation encountered here, these initial findings themselves already indicate the importance of establishing the health service network more firmly. They also threw light on paths to be taken towards implementing related policy, so as to offer citizens timely access to therapeutic resources and thus to health promotion. Although gaps were found to exist, the evidence points to the importance of fostering communication by virtual means.

Collaborations

DLS Gouvêa worked on the conception, design, collection, analysis, interpretation of data, and paper writing. GM Lovisi and MS Gomide worked on the conception, design, analysis, interpretation of data, paper writing, critical review and approved the version to be published.

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