Knowledge and risk perception of vulnerable women on Zika virus infection at primary health care level in Brazil

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ABSTRACT
Vulnerable low-income groups were most affected by Zika virus (ZIKV)-related neurologic syndrome during the 2014–2016 outbreak in Brazil. Major ZIKV infection response took place in Primary Health Care (PHC), including prevention strategies and risk communication. We aimed to detect knowledge and beliefs, as well as knowledge gaps among vulnerable women at the PHC level. A cross-sectional study was carried out in two low-income urban community settings: a small municipality with few ZIKV infection cases and a large municipality hard-hit by the epidemic. An open-ended data collection instrument centred on ZIKV infection knowledge, sources of information, possible causes, symptoms, risk perception, consequences for pregnant women and PHC point-of-care communication was developed. Interviews were recorded, transcribed and content coded for thematic analysis. Most of the seventy-nine respondents had some knowledge of the disease, acknowledging the vector as the source of infection and associating microcephaly with the disease, but distanced themselves from possible ZIKV infection and related risk. PHC services in both communities did not adequately communicate risk for women and children. In an uncertain future scenario as to disease re-emergence, awareness may be diminished and acquired knowledge lost, configuring a public health challenge that must be overcome.

ARTICLE HISTORY
Received 24 February 2021
Accepted 23 June 2021

KEYWORDS
Zika virus; preparedness; health risk; health knowledge; attitudes and practice

Introduction
The Zika virus (ZIKV) infection outbreak in Brazil surged from late 2014–2016, peaking in 2015. Poverty-stricken population groups were the most affected by Zika. Most cases of ZIKV-related neurologic syndrome, with microcephaly, were detected among newborns coming from this type of environment. The most affected country region was the Northeast, but states in the Southeast were also affected by the epidemic, due to a large number of cases in the poor, low-income communities of major cities (Ministério da Saúde, 2017).

A disaster may be perceived as a consequence of socially structured risks (Rabby et al., 2019). This is true for ZIKV infection, a neglected disease with climate-sensitive vectors, spreading initially, and unchecked, in poor and remote communities (Jamrozik & Selgelid, 2018). While the disaster itself brings new risk situations for the exposed, especially the most vulnerable, socio-economic vulnerability is a factor that favours the occurrence of a disaster and should be considered in the public health context (Diderichsen et al., 2019).

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Lack of information and inadequate perception of disease risk by vulnerable groups may impede prevention and health promotion measures for this population. Risk perception should include a variety of aspects, such as cultural and social factors regarding the disease and its consequences. This is especially relevant in the ZIKV context, considering the possibility of recurrent outbreaks (Singer, 2017). Zika cases are still being notified in 2020 (Ministério da Saúde, 2020a) and in 2021 (Ministério da Saúde, 2021). From 2015 to November 2020, there were 3,563 confirmed cases of Zika Neurologic Syndrome in Brazil, twenty-seven in 2020 (Ministério da Saúde, 2020b).

In Brazil municipalities are responsible for Primary Health Care (PHC), and this setting was the effector of prevention and care during the ZIKV epidemic (Garcia, 2018). This study was based on two assumptions – that vulnerable groups (in this case, poor and low-income women) are especially susceptible to health emergencies and disasters (Kawasaki et al., 2019), and that PHC is the setting where care and prevention strategies should be implemented to effectively approach risk communication and risk reduction.

Several studies have been done to surmise the 'knowns and unknowns' regarding Zika, at the peak of the epidemic, and later on (Osorio-de-Castro et al., 2017; Kelly et al., 2020). However, it is interesting to note that in the perspective of health system preparedness, that is, of measures and actions that must be in-place for a future health emergency, two large gaps remain regarding women vulnerable to the disease and its consequences: risk perception at the point-of-care – in this case, PHC facilities in two different contexts, and the overall knowledge and knowledge gaps in this group. If a specific point-of-care makes a difference, looking at at-risk groups in different communities may bring new light to the best strategies for health system preparedness (Pepe et al., 2020).

Although risk perception has been studied among pregnant women and mothers of affected children (Mouchtouri et al., 2017; de Sousa et al., 2018; Marbán-Castro et al., 2020; Passos et al., 2020; Lima & Iriart, 2021), no previous work has been done to specifically study these issues among vulnerable women in different settings and in non-epidemic seasons.

The overall aim of this study is to help detect knowledge and risk perception at PHC level, as well as important knowledge gaps of women vulnerable to ZIKV and its consequences, in order to better prepare the health system to deal with future public health emergencies. To approach our goals, our queries were: (a) What are the perceptions of risk among vulnerable women that seek care in PHC level, in non-epidemic seasons? (b) What are their basic knowledge and perceptions regarding ZIKV? What are the knowledge gaps among these women? (c) Were there differences in knowledge and perceptions among women from different regional settings?

Methods

This was a cross-sectional study, carried out in two different low-income urban community settings in Brazil. A small municipality in Central-West Brazilian state (codified as CW), where ZIKV infection cases were few (1,719), was visited in April 2018. From July to September 2018, a large municipality in the state of Southeast Brazil (codified as SE) was studied. In it, the number of ZIKV infection cases were many (68,542) and the toll in microcephaly and ZIKA Neurologic Syndrome was high (Ministério da Saúde, 2017).

Preliminary analytical categories were established: knowledge, communication about ZIKV at PHC facility and risk perception, based on known causes and consequences of ZIKV infection, risk communication and risk perception literature (Glik, 2007) and The WHO Resource Pack (World Health Organization, 2016) which can be used in communities with ZIKV transmission or those at risk. It is a structured survey instrument and deals with the entire scope of Knowledge, Attitudes and Practices (KAP) about ZIKV, being perceived as a means to gather valuable information.

A data collection instrument was developed, based on aspects of the WHO questionnaire and on the Brazilian ZIKV epidemic history and characteristics and risk communication strategies for patients at PHC level. Interviewee profile, containing questions on issues describing vulnerabilities
was placed last since at the end of the interview participants tend to be more at ease. The questionnaire aimed to guide the interview with the help of key open-ended questions while eliciting the information free from the interviewees. Participants were asked to tell all they knew – or remembered – about ZIKV, possible causes, symptoms, sources of information on the disease, possible consequences for pregnant women, risk perception and risk factors, communication and information received at the PHC facility. In the knowledge investigation section of the instrument there was also an itemised question for which the interviewer would mark all answers given by the interviewee, without the need of actively questioning them or offering alternatives. The instrument was pre-tested for possible inconsistencies, manifested by initial difficulties in understanding questions and making interviewees on edge by the syntax. These were overcome by changing the order of key questions (to give better cadence) and rephrasing some questions so as to ‘invite’ the participant to answer rather than asking outright for them to tell all they knew.

The two researched areas are different in respect to demographic dimensions and social environment. The population in the large urban municipality totalled 6,718,903 inhabitants in 2019 (second in the country) and the women came from an urban slum (favela), in which social exclusion and urban violence are recognised characteristics. The population in the smaller municipality in Brazil’s heartland totalled 57,665 inhabitants in 2019, ranking 717th in population among 5570 Brazilian municipalities (IBGE, 2019). Women were mostly poor but were not exposed to the same external factors as the women from the large municipality. A pilot study was conducted with ten women at a health facility in a resource-restricted setting of another urban area.

Authorisation to interview women patients at the PHC facilities was sought and given by the managers. Sampling was purposive. The interviewers approached women who were in the consultation waiting room, explained what the study was about and asked them to participate. If the woman gave acceptance at this first approach, the Term of Consent Statement was read and any doubts as to participation were addressed, according to Brazilian ethical guidelines (Ministério da Saúde & Conselho Nacional de Saúde, 2012).

The number of possible interviewees was provisionally set at around forty for each center, considering the variety of investigated aspects. Data saturation was achieved very close to that number when all aspects of the instrument were clarified, and answers to queries became repetitive in content. In the Central-West municipality, thirty-nine adult women at all eight urban PHC centres were interviewed. In the Southeast, forty adult women attending a large PHC, were interviewed. No censorship regarding age distribution in adult population or other demographic characteristics were applied.

Vulnerability of interviewees was characterised by membership in Brazilian government income supplementation programs. Poor families with children or teenagers (characterised by monthly income between 16.61 and 33.23 USD), and extremely poor families (characterised by maximum monthly income of 16.61 USD) are candidates to receive government funds (Caixa, 2021). Other characteristics to add to the description were number of children, number of persons in household and number of employed persons in household.

Interviews took on average 10 min, were conducted face-to-face, in confidentiality and recorded. Field notes were taken and later cross-checked with transcribed recordings. From this corpus, content analysis was performed. After in-depth reading of interviews, coding was carried out manually by three researchers, with the help of a coding tree, and detection of key expressions and central ideas ensued. The preliminary characteristics were revised, and new categories emerged. The women’s speech was analysed regarding principal categories and sub-categories and highlighted by issues on risk perception and knowledge in ZIKV literature.

COREQ guidelines were employed in study execution, to improve rigor, comprehensiveness, and credibility. Final reporting was reviewed to assure completeness and transparency (Tong et al., 2007).

The study was sanctioned by the Sergio Arouca National School of Public Health Ethics Review Board under CAAE 67311617.8.0000.5240 (review number 2.180.892) on July 20th, 2017.
Results

Final principal categories were (1) general knowledge, information sources and communication (2) specific knowledge about the disease (3) risk perception (4) perceived consequences for pregnant women. Information on PHC point-of-care communication was spread mostly inside the first category and analysis was unable to sever this and present it as an individual category, as initially planned.

Participant characteristics

All women who were asked to participate accepted and gave informed consent. All completed the interview. Many were eager to talk and exchange information.

Regarding demographic characteristics, Table 1 summarises findings.

Most interviewees were in reproductive age, from 21 to 50 years. Number of children per family as number of people per household were 2.1 and 4.0 in the Southeast (SE), and 2.7 and 3.8 in the Central-West (CW), respectively. This is to be expected since the municipality in the SE is a large urban center and the CW one is a small town in a rural setting. More women from small municipalities were recipients of income supplementation, but differences between groups were not marked (333% in the SE and 41% in CW), which denotes similar vulnerability.

General knowledge, information sources and communication, and specific knowledge about the disease

Table 2 presents results for the first two categories, with sub-categories.

Except for two women in the smaller municipality, all others had some or any knowledge of ZIKV or had heard about the disease.

As to general knowledge, a highlight was the response to sources of information on ZIKV infection. Many interviewees pointed towards the media as a main source of information:

‘What I know (...) and I’m into what they say on TV, right? Always only [about] microcephaly’. (CW 37)

‘So, I know [about the disease] from TV, right?’ (CW 1)

When asked if they got any information from health workers, many responded with a simple ‘no’. Information from health workers centred on elimination of mosquito breeding grounds:

[on information from health workers] ‘No, only to forewarn us, right, about zika. I can’t remember [much] Ahhh from what I know, it’s about plants, right? Watering plants, accumulating water, accumulated water in [discarded] tires right? This is what I know, right?’ (CW 20).

Table 1. Demographic characteristics of interviewees. Vulnerable women in Brazilian urban centers, 2018.

| Brazilian Urban Center/Region | Southeast (SE) | Center West (CW) |
|------------------------------|---------------|-----------------|
| Total number of interviewees | 40<sup>a</sup> | 39              |
| Age distribution<sup>c</sup>  |               |                 |
| <21                          | 3             | 0               |
| 21–30                        | 12            | 11              |
| 31–40                        | 8             | 5               |
| 41–50                        | 7             | 11              |
| 51–60                        | 6             | 7               |
| >60                          | 3             | 5               |
| Average number of children   | 2.1           | 2.7             |
| Average number of people in household | 4.0          | 3.8             |
| Average number of people with income in household | 1.7<sup>b</sup> | 1.4             |
| Number of recipients of income supplementation<sup>c</sup> | 13            | 16              |

<sup>a</sup>Demographic data for thirty-nine interviewees; <sup>b</sup>Data from thirty-six interviewees; <sup>c</sup>Number of women.
Yes, you have to try to close down places where there are mosquito breeding grounds. (SE 03)

Some mentioned that Zika had been ‘forgotten’:

‘Something very sad, something that will remain forever, and I don’t know what became of it [the disease] right, because nobody comments on it anymore’ (CW 31).

Association to mosquitos as vectors was present in the discourse of women, and more women in the Southeast associated Zika with mosquitoes:

‘The cause [of ZIKV infection] is the mosquito, isn’t it?’ (SE 1)

‘They’re always talking (…) about the mosquito, right? What it’s causing, right? About zika, the disease (…)’ (CW 1)

Confusion was present with respect to the symptoms of the disease. The interviewer prompted the women in case they needed reminding that the focus of the questions was Zika:

‘They say it’s not like dengue, but it was. When it is going to rain your bones ache’ (CW 21)

‘It brings [with it] a lot of body ache, from the disease; it [the disease] causes lots of things, right? Body ache, a lot of fever; It even feels like the flu, right? In the beginning, it feels like a flu, but after it ends up more intense. Like malaria, right?’ (CW 1)

**Risk perception around ZIKV infection and disease**

Women mentioned factors associated with ZIKV infection. Table 3 summarises distribution of answers by category and sub-categories.

Several responders associated ZIKV with problems with sanitation, lack of garbage collection and ‘unclean’ water. Most of all, the risk was perceived as coming from outside, promoted by others:

‘Oh, I think it’s [ZIKV infection strikes] where there is less sanitation, people that do not clean their backyards, they don’t worry. You can see that many people do not care at all’. (CW 7)

‘If everyone takes care, care for your backyard, and all that must be clean, I don’t think you can [catch ZIKV infection]’. (CW 10)

Some were critical of their communities:

‘(…) you take care of your home, but others do not. You’re squeaky clean, everything is spotless, but not everyone is. In [neighbourhood] everything is very dirty. You clean but others don’t. Alleys are filthy, garbage, trash, lots of stuff. Sewage in the open. It [the filth]) attracts, understand? Some people don’t like to clean their own environment. It’s difficult.’ (SE 37)
Table 3. Factors associated with ZIKV infection risk perception. Vulnerable women in two Brazilian urban centers, 2018.

| Urban Center/Region | Southeast (SE) | Central-West (CW) |
|---------------------|----------------|-------------------|
| Total number of interviewees | 40 | 39 |
|_factors associated with risk of ZIKV infection cited by women^a_ | Environment (garbage, lack of sanitation, presence of mosquito) 21 | 22 |
| Health status | 4 | 4 |
| Low immunity | 9 | 8 |
| Chronic diseases | – | 5 |
| Poverty | – | 1 |
| Childhood | 6 | 14 |
| Old age | 5 | 9 |
| Cites that does not know^a_ | 8 | 9 |

^aNumber of women in each PHC center. Total number of answers exceed number of interviewees – some women cited more than one aspect.

‘Beats me, I think people are untidy with their neighbourhoods, there’s a lot of garbage. Lots of garbage, lots of, how do you say it? ‘Contaminated’, right? Those contaminated things, do you get it? And when the garbage collector comes and takes it away, people go and throw more. Then come the flies, the blowflies. All that.’ (SE 9)

Health status was a possible contributor to risk for ZIKV infection, especially regarding low immunity status:

‘(…) from my point of view it depends on the person’s health state. (…) if the person’s health is fragile, I don’t know, zika might be more serious than in a normal person, with normal health, I don’t know. To me it can vary from person to person’ (SE 14)

‘It depends on the body, right? On the person’s immunity, I think, if it’s very low, right? If for pregnant women, immunity is low, I think there is more risk.’ (CW 19)

Pre-existent chronic diseases were also mentioned as a risk for ZIKV infection:

‘Someone that has, I don’t know, diabetes or some heart problem or hypertension (…). I suppose one thing drags the other’ (CW 33)

‘Oh, they [source of information] said whoever has a chronic disease, something. I imagine those [are more at risk]’ (CW 21)

Poverty (seen as an impediment for private, costly care) was reported by only one respondent:

‘Oh, surely the poor population, right? If you have the means to go to private physicians and others you can care better for your child. And those that are poorer can’t because public health services are so deficient’ (CW 9)

Finally, age – old or young – were factors associated with risk. A connection to low immunity and frailty underlies the discourse:

‘I think elderly people are more prone to trouble, right? Because of low immunity, right?’ (CW 16)

‘Children and the elderly, I suppose, that are more sensitive, immunity is lower.’ (CW 33)

‘And the elderly (…) they are more prone because they are weaker, right?’ (SE 19)

Perceived consequences of ZIKV infection for pregnant women

This last category is a specific part of our results for risk perception. The issue of pregnancy among the interviewees was not in the study focus. Despite this, most women were of childbearing age, and thus theoretically at risk for ZIKV infection during pregnancy. This sub-category surged with some prominence in the discourse.

In both groups, only three among seventy-nine women associated Zika with abortion or miscarriage (Table 4):
Table 4. Perceived consequences for pregnant women. Vulnerable women in two Brazilian urban centers, 2018.

| Problems associated with ZIKV infection during pregnancy cited by women<sup>a</sup> | Brazilian Urban Center/Region |
|---|---|
| | Southeast (SE) | Central-West (CW) |
| Total number of interviewees | 40 | 39 |
| Abortion | 1 | 2 |
| Non-specific problems in fetal development | 13 | 11 |
| Deformities, malformation, Microcephaly | 18 | 16 |
| Cited that does not know<sup>a</sup> | 8 | 6 |

<sup>a</sup>Number of women in each PHC center. Total number of answers exceed number of interviewees – some women cited more than one aspect.

‘My little granddaughter, my daughter was pregnant, and she lost [the baby] right, her little girl because of this disease. Last year’. (CW 10)

‘It causes trouble, right, for the child, right? I don’t know what can happen. I think she [the pregnant woman] can lose the child, something like that.’ (CW 16)

‘[On what can happen] From an abortion, right, to a cephalic problem, right?’ (SE 20)

Non-specific problems with fetal development and the association of Zika infection in pregnancy with birth defects and microcephaly were abundantly mentioned:

‘There are problems with the fetus.’ (SE 04)

‘It’s because I saw cases of pregnant women (…) that had zika and babies were born with microcephaly’ (CW 17)

‘Well, what I know is that my daughter-in-law got pregnant, right? We were really worried about this because the child could be born with a deformity’. (SE 16)

‘What’s the name of the condition? Mic … I don’t know … [babies] are born with a small head.’ (CW 37)

Women reproduced various degrees of knowledge from misinformation to accurate knowledge:

‘So, until the first three months [of pregnancy] she [the pregnant woman] is at risk for the fetus to be born with microcephaly, right? Or some problem with the fetus.’ (CW 13)

‘Yes, everything goes to the baby, right? Everything there will go to the baby because it [the virus] can pass through the placental barrier.’ (CW 30)

Some women were suspicious as to the occurrence of Zika and its related consequences. A 28-year-old woman with two small children volunteered that zika had been a ‘lie’:

‘(…) that children are born with problems. I don’t know, I think it’s a lie (…) they are blaming this disease, but it [really] was an expired vaccine, something the pregnant woman took. I’ve heard so many stories I don’t know anything anymore’. (SE 01)

Another questioned the information she received from the media:

‘I heard about it on television, I don’t know if it’s true, but [it is] microcephaly, right?’ (CW 36)

Some suspected causes for microcephaly other than a mosquito-borne viral infection, as relayed by one interviewee:

‘I think it’s not the poor mosquito that is responsible, right, for incidence of cases (…). Not all places have [mosquitoes]. Various friends had babies during this period, of this epidemic, zika epidemic, but it was very limited. I think something else caused it, right? Some drug for which the mothers produced an antibody and the child ended up with microcephaly.’ (CW 09)

Women also cited preventive measures, and the content of the discourse is clear:
Including information, right? What the person can (do) at home (…) she decreases the chances by [adequate] habits, covering the water tank, these things we hear around (…). Always more hygiene in everything helps. (SE 17)

Discussion

Main results of this study presented general and specific knowledge, and perceptions on ZIKV infection, associated factors and consequences among vulnerable women in two distinct Brazilian regions, one in which a number of Zika cases had been moderate and one in which cases were much higher in number. From 2016 to 2018, the total number of cases in the Central-West was 42,275 (17.49% of the total number of cases in the country), while in the Southeast they totaled 98,139 (40.62%). (Ministério da Saúde, 2017; Ministério da Saúde, 2019)

Other qualitative studies have assessed knowledge, attitudes and practices of pregnant women at risk for ZIKV infection in Brazil, and of those actually infected by ZIKV and their offspring (de Sousa et al., 2018; Passos et al., 2020). To our knowledge, however, this is the first study that approaches vulnerable women as a group, assuming that the socio-economic vulnerabilities are important factors underlying knowledge and risk perceptions. We assumed that differences in regional incidence and in direct contact with the Zika epidemic and its consequences, such as microcephaly, might return different perceptions among women with similar backgrounds (Guedes et al., 2018). Moreover, the epidemic has waned in the last three years, and it is worthwhile to explore which knowledge has survived and whether knowledge and perceptions of risk remain in vulnerable groups.

Demographic characteristics of both groups show some similarity, in respect to age distribution. Most women were of reproductive age (World Health Organization, 2019). This characterises an adequate at-risk group for ZIKV infection during pregnancy. Older women, past reproductive age, may reproduce views in respect to pregnancy risk. Due to seniority, older women continue to shoulder responsibilities in their social groups and may translate broader perceptions (Mudege & Ezeh, 2009). Older women may also be sexually active, but this source of risk (sexual transmission) (Santos et al., 2018) was not explored in this study.

The number of children per household reflects fertility rates for both regions in 2018: 1.70 in the Southeast and 1.87 in the Central-West (IBGE, 2018). Differences were small. The risk to a child in a given household may be more linked to mothers’ or caregivers’ risk perceptions. Smaller children may be especially at risk because they are possibly kept at home with mothers or caregivers most of the time (Santos et al., 2018).

The average number of persons per household was similar between the urban centers, but variation between each participant was considerable – in the large urban center, 1–8 people lived in the household, while in the smaller urban center, 1–18 people. Nonetheless, earnings came from very few contributors in households. Poor families with a large number of children are more socially vulnerable and this characteristic holds for both settings in this study. Fewer women from the larger municipality were recipients of income supplementation – an indicator which characterises poverty-stricken households in Brazil – but proportions were similar (36% versus 41%, respectively) and both groups are socially vulnerable (Bolin & Kurtz, 2007).

The characterisation of the vulnerable women interviewed in this study was anchored in income and household composition. It is noteworthy that poverty entails more than the lack of income. Living conditions and limitations as to education, self-care, basic services, empowerment, and decision-making also depict a poverty-stricken setting (United Nations, 2021) and may contribute to their standing knowledge and risk perceptions (Lima & Iriart, 2021).

Discussing the theory of ‘affect heuristics’ Richard Eiser et al. (2012) point out that a positive (or not negative) experience will lead one to make a more relaxed judgement in respect to risk prevention. Poverty is certainly a main factor associated with ZIKV infection and consequences for the unborn child (Lesser & Kitron, 2016). However, among the respondents, poverty in itself was
not seen as a factor associated with Zika. Poverty is, for this population, not a negative, but a natural state, and no other is known. Income at over one USD a day is the reality of the households were part of the participants come from. The only factor perceived as an impediment, and associated with being poor, was the fact that private health care would be impossible. If most women do not view poverty as a basic threat to their lives, an evaluation of any future occurrence related to ZIKV infection, and its consequences will not be viewed as poverty dependent by this group.

In their approach to affect heuristics, Slovic et al. (2007) argue that proximity to the event and personal experience may modulate decision-making, this theory also helped guide methodologic choices considering (i) the study group – a close experience with pregnancy during the event might bring about very different perceptions; we did not focus on pregnant women and the women’s pregnancy status was not asked, leaving open the possibility and preserving variety; (ii) the study setting – vulnerable women in two distinct communities – one that was hard-hit by the epidemic, and another where cases where few and sparse, in order to understand if close experience to ZIKV infection might change risk perceptions.

Work related to ZIKV knowledge among pregnant women in Southern European countries varied in approach (Mouchtouri et al., 2017; Marbán-Castro et al., 2020). Mouchtouri et al. (2017) studied pregnant Greek women’s knowledge and found it lacking in respect to risks of sexual transmission and to risks for fetus. Marbán-Castro et al. (2020), approached migrant women workers from South and Central America, positive for ZIKV during pregnancy. This study focused on perceptions and revealed that there was awareness of mosquitoes as transmiters, but little perception of risk related to sexual transmission. In these aspects, they were similar to study subjects in Brazil, even at perhaps higher socio-economic stature. However, as expressed by the subjects in Spain, the perceptions of risk changed with pregnancy. In this regard, it is difficult to relate to Brazilian subjects, as their pregnancy status was not investigated.

Given that seventy-seven of seventy-nine interviewees mentioned some knowledge of Zika, it would be prudent to say that these groups had heard about the infection at some point in time, and the media, especially television, is perceived as the main source of information. Paradoxically, health workers and health professionals were not regarded as a source of information from most women. In the large urban center, in fact, where many cases occurred and where the PHC personnel had most probably had some experience with diagnostics and effects, many respondents gave a straightforward ‘no’ when asked if they had received information from health professionals at the point-of-care. In the smaller municipality, a woman pointed out that Zika had been forgotten. Both situations may point to the health system possibly abandoning an important task in risk reduction – neglecting information dissemination and communication (Burke, 2016). There was some expectation of differences between settings, given the number of cases, the possible exposure to experiences with the disease and its consequences and preparedness of health professionals. However, no differences were found in respect to communication, indicating there may not have been a concerted strategy at the PHC level for ZIKV risk reduction.

However, would this in any way be useful for a resurgence of the disease in the future? Would preparedness profit from lessons learned about Zika and its consequences? Koenig and colleagues argue that ‘lessons learned’ are not a valid scientific output in public health and disaster research (Koenig et al., 2017) and that this term should be discarded. However, the role of information dissemination in disaster preparedness is more than proven (Liu et al., 2017) and there is no way to condone the health system in both settings from falling short of their responsibilities.

While on one hand there was a lack of comprehensive information from the health system, on the other the presence of at least three other endemic arboviruses in the country (dengue, chikungunya and yellow fever) and a number of other endemic diseases (such as malaria, which came up in the discourse) led to a lot of confusion in regard to symptoms (Liu et al., 2017). The actual consequences of this were not investigated but may reflect on inappropriate care-seeking behaviour, which might enhance risk.
As to transmission (‘cause’) of ZIKV infection, more women from the large urban center associated it with mosquitoes, having had greater contact with the epidemic and its consequences. Also, most information coming from health workers centered only on that aspect. In Brazil, vector control has been the mainstay in Zika awareness campaigns, and there has been wide criticism of the narrow range of risk reduction strategies available to the population that lives in squalid conditions, with inadequate sanitation, water supply or garbage collection (Possas et al., 2017). The interviewees were more than aware of this risk factor and it was prominent in the discourse, also acknowledged in Spain (Marbán-Castro et al., 2020).

Most women felt that they did their ‘bit’ in preventing the occurrence of mosquito breeding grounds while their neighbours did not. Women did not condition sanitation to government action. This may be viewed as positive – if regarded as empowerment – but in these cases, since government action was basically null, the population overestimated its role – actually more of a burden – in preventing disease. This is an important aspect of social representations of the ZIKV epidemic (Guedes et al., 2018). This contrasts with women interviewed in Spain, who presented a much more passive posture towards their personal capacity in implementing individual preventive measures to avoid infection (Marbán-Castro et al., 2020).

Other health factors, such as perceived low immunity and chronic illnesses were expressed as possibly associated with risk, but from few respondents in both groups. Age – young or old – was also an issue to some, but always related in the discourse to low immunity or frailty. It is noteworthy to point out, however, that there is evidence that young children (<4 years) are three times more susceptible to ZIKV infection than adult men, possibly because of daily exposure inside the household (Santos et al., 2018).

Health status of the interviewees was not investigated, but aspects that were mentioned are present in the general population, and these aspects are perceived as ‘risky’ conditions in common knowledge (Guedes et al., 2018). Moreover, women interviewed in this study were not themselves affected by ZIKV infection. The ability to discern and interpret greater or lesser risk in ZIKV infection with any factor may be jeopardised by lack of personal experience; deciding what is risky or not risky involves the ability to accurately discriminate (Richard Eiser et al., 2012). For example, some mentioned immunity, but none mentioned vaccination as a non-specific health measure. This has significance at this moment, as Brazil has been undergoing a measles outbreak and there is new evidence that measles may enhance susceptibility to other infectious diseases (Mina et al., 2019). Protection from vaccination may be a health issue unperceived by these women.

Problems associated with Zika infection during pregnancy brought up abortion, problems in fetal development, and deformities and microcephaly. Overall, most women mentioned one or more of these aspects. However, 20% of women from a high-risk municipality and 15.4% of women at a low-risk site answered that they did not know anything about these issues. This shows an important gap in knowledge of the disease and its consequences among the most at-risk population for ZIKV infection (Santos et al., 2018).

Only one in forty and two in thirty-nine women mentioned abortion, perhaps out of fear. Women possibly never viewed abortion as a possible option in case of ZIKV infection. Abortion is illegal in Brazil, and as such was never mentioned as a ‘secondary’ prevention strategy (Nazer, 2004), but only as a consequence of ZIKV infection. Contraception, on the other hand, was shown to have increased as a result of the ZIKV epidemic. In 2013, before ZIKV, the prevalence of contraceptive measures was around 75% (Hodge et al., 2016), increasing, in 2018, to 81.1% among 15–19-year-old non-pregnant women in Brazil’s largest city (Olsen et al., 2018).

Problems with fetal development and sequelae related to ZIKV infection during pregnancy dominated the answers, with 77.5% of women from the larger municipality and 69.2% of women from the smaller one voicing that concern. Microcephaly was the dominant part of the discourse. Although information on ZIKV consequences has focused on microcephaly,
Zika Neurologic Syndrome (ZNS), oftentimes accompanied by microcephaly, but not always so, was not mentioned. Congenital ZIKV infection produces several abnormalities in neurodevelopment and may not be apparent at birth, either because it is not recognisable or because diagnosis may depend on unavailable technologies. This is more so in the smaller community, where access to highly complex care is certainly not as easy, but women from the larger at-risk group did not speak about it either. Findings apparent at birth may resolve in time, or children with this problem may only have their condition asserted later in age, or even after entering school (Muller & Mulkey, 2019). This may explain why women did not mention ZNS. If no ‘problem’ is apparent, no problem exists. However, most will probably never receive accurate diagnosis and lower developmental scores presented by these children may be mistaken for any other dysfunction. Moreover, when these women do not express concern over this, they will not actively seek care for their children.

Among the interviewees, there was some other misinformation and inaccurate assumptions regarding pregnancy risk restricted to the first trimester, and a supposed relation to the placental barrier as a cause for infection. Otherwise created in the media and other reliable sources as to information received from other topics, some women were suspicious of the consequences and causes of ZIKV infection. Suspicions may be related to the excess of available information and from the ‘fake news’ epidemic faced by many societies—fabricated news, manipulated news, advertisements and irrelevant news, which contrast to ‘sufficient’ news, usually evidence-based and true, but which may not be adequately valued (Waszak et al., 2018). This is a big challenge for health professionals to approach and clear, and for risk reduction strategies to reduce, which couples with the fact that few women cited preventive measures for ZIKV infection.

Our questionnaire proved worthy of providing information regarding knowledge and knowledge gaps, information sources and communication at PHC point-of-care and women’s overall perceptions regarding ZIKV infection. The pre-test was important in enhancing understanding of questions and the pilot study instrumental in mimicking actual interview situations. As the Zika emergency in Brazil targeted vulnerable populations, the instrument was designed for this segment and may not be adequate for other settings.

Despite our understanding that the interviewed women from both municipalities are part of the same context and share vulnerabilities, subtle differences were not definable, and may exist. As some interviewees were not very forthcoming with their opinions and had to be gently prodded for details, we might have some distortions as to perceptions. In contrast, our findings as to lack of knowledge and lack of health service involvement in dissemination of information and communication are corroborated by previous work among infected pregnant women in Brazil (de Sousa et al., 2018). In 2018, at the beginning of field research, the epidemic was still a ‘fresh’ subject to many women and there was talk of an augmented risk for the 2018–2019 summer months in Brazil, which may have given the subject a perceived sense of importance. As that forecast fortunately did not hold, and because there is little evidence for the future path of this disease, other investigations in this vulnerable population may produce different results. In a future scenario with less information on the infection, its causes and consequences, we propose that awareness will be certainly diminished and acquired knowledge lost.

Conclusion

Apart from a slight difference in knowledge of vector transmission and pregnancy risks by women in the SE, an important aspect to note is that there were no other substantial differences between the two study settings. Although we did not investigate women in higher socio-economic strata and thus cannot pinpoint whether specific vulnerabilities disrupted knowledge uptake or risk perception, vulnerable groups in both settings showed similar gaps, which steers the focus to the reduction of vulnerabilities, or to better health care interventions by the health system for these groups in order to bridge the gaps and enhance better response.
Key findings of this study show that all respondents had some knowledge of the disease, its causes, and consequences. They acknowledged the vector as the source of infection and associated microcephaly with the disease.

Participants in both settings distanced themselves from the causes and consequences of the disease, referring to other actors as responsible for enhancing risk. Women did not refer to health professionals as those responsible for risk communication and information, which shows that health services in both communities did not contribute to risk reduction for ZIKV by effectively communicating risk for women and children, according to the interviewee’s responses. This is a great public health challenge that must be overcome.

Disaster and health emergencies are enhanced by social disparities and in order to overcome inequities, measures inside the system should be taken to give vulnerable populations sufficient awareness and information. One way of understanding outcomes of the health system’s preparedness efforts was brought by the women’s discourse in both settings. The ZIKV emergency did not effectively count on health professionals’ involvement in risk communication. Preparedness for future public health emergencies such as ZIKV must involve active risk communication strategies at PHC level, which was made responsible for prevention and risk reduction, targeting vulnerable groups. Health professionals and workers must receive training and constant reminders of their roles in health emergency response. Policymakers must provide for the PHC setting, as a key intervention and observation site for prevention strategies in ZIKV response and managers have a responsibility to acknowledge the importance and feasibility of implementing risk communication and risk reduction measures effectively.

However, it is possible that this may not be a ‘ZIKV problem’ at all, but an overreaching one, and in this case, must be dealt with by structural measures related to communities, in order to enhance resilience and response. Recognition of risk and risk-prevention measures must be disseminated. Adverse context, poverty and poor health conditions are overwhelming determinants for risk.

The story of ZIKV infection in Brazil is a known entity – an emerging disease, sensitive to climate change, burdening areas already presenting important inequities and environmental disparities. And, in this case, putting vulnerable women and children at greater, unacceptable, risk.

What have we learned from the ZIKV outbreak? No one knows whether, when or how ZIKV might be returning. But it is still with us as may be other emerging and re-emerging diseases. Vulnerable groups in the country are not protected. If risk reduction measures are not implemented a new health emergency of magnitude may be around the corner.

Acknowledgements
The Authors gratefully thank the Municipal Health Secretariats of both cities in which the investigation took place, for their help and entry into the PHC units.

Disclosure statement
No potential conflict of interest was reported by the author(s).

Funding
This work was supported by CNPq: [grant number 304975/2016-8]; Horizon 2020 Framework Programme: [grant number ZIKAlliance Grant Agreement no. 734548].

Funding sources
This work was partially supported by the European Union’s Horizon 2020 Research and Innovation Programme under ZIKAlliance Grant Agreement no. 734548, by the Brazilian National Research
and Development Council (CNPq, grant number 304975/2016-8). No funding source participated in planning, analyses or discussion of results.

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