Experiencing Zika

A qualitative interview study of Brazilian nurses

Att uppleva Zika
En kvalitativ intervjustudie med brasilianska sjuksköterskor

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ABSTRACT

Background: Zika virus was discovered in the 1950’s in the Zikaforest in Uganda, it is a vector borne flavivirus and its main carrier is the Aedes Aegypti mosquito. In 2015 ZIKV reached Brazil and from Brazil it has spread to 26 countries in the Americas. ZIKV is most known for its ties with Microcephaly, but the ZIKV has been linked to several neurological conditions including Guillain-Barré Syndrome. Very limited treatment is currently available for the complications and prevention is the most used method to combat the infection. Aim: The aim of this study is to describe the experience of Brazilian registered nurses in regards to Zika virus and its complications. Method: An Empirical qualitative approach was used, and the data was retrieved through semi-structured interviews. The method used for analysing was a Qualitative content analysis. Results: The findings resulted in two categories: 1. The many faces of uncertainty and, 2. Spreading and attaining knowledge. In addition 10 sub-categories were identified. Conclusion: The suffering that was expressed was related to the uncertainty of the disease. By providing information and educating patients, the health literacy may strengthen. Increasing health literacy can empower the people and lead to sound health decisions.
SAMMANFATTNING

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INTRODUCTION
Since the first picture of babies born with small heads caught the media’s attention, it also caught the interest of the authors. The condition was called microcephaly and it was a new virus causing it. This new virus was called Zika and it had just hit Brazil. The consequences of the virus could be severe, and new pictures of mothers holding their newborn babies with the microcephaly condition were circulating. Much information about the different consequences that the virus was causing was spread. But the lack of information on the nurse’s experiences was obvious to the authors. Questions about how the nurses tackle these consequences arose, and the authors were keen to gain a greater understanding of the nurses’ experiences in regards to the Zika virus and its complications.
BACKGROUND

Zika Virus, an historical overview

Zika virus (ZIKV) is a mosquito-borne disease that has been linked to Guillian-Barre´ syndrome and microcephaly (Malone et al., 2016). It is a single-stranded Ribonucleic acid (RNA) virus of the Flavivirus genus and it is closely related to Dengue, Japanese encephalitis, yellow fever and West Nile viruses (Rabe et al., 2016). The incubation period for the infection has been estimated to range from 3 to 12 days after being contaminated by the virus (Charrel et al, 2016). ZIKV is as other sexually transmittable diseases (STD) often asymptomatic and carried unknowingly. The virus has been isolated in blood, semen, saliva, amniotic fluid, breast milk, and cerebrospinal fluid in humans (Gebre, Forbes and Gebre, 2016.). Those who get symptoms, about one in five, quickly develop fever and a rash, arthralgia, conjunctivitis, and headaches (Lupton, 2016).

The first human case of ZIKV dates back to 1947, during routine surveillance for yellow fever in the Zikaforest in Uganda. The virus was isolated in samples taken from a captive sentinel rhesus monkey (Kindhauser, Allen, Frank, Santhana, & Dye 2016). The ZIKV was recovered from the mosquito Aedes africanus in 1948 (a mosquito of the Aedes genus which is common in the Zikaforest), infection experiments in mice revealed the virus as neurotropic (ibid). In 1952 the first human cases diagnosed as ZIKV were observed in Uganda and Tanzania, and the same year the virus was found in humans in India (ibid). Throughout the 1950’s the virus was identified using serological surveys, in Egypt, Nigeria, Mozambique, the Philippines and Vietnam, and the presence of neutralizing antibodies were confirmed (ibid). Between 1960 to 2006 ZIKV was successfully isolated in over 20 different mosquito species, predominantly of the Aedes genus. The main vector for the disease is the Aedes Aegypti mosquitoes (Orsborne., et al. 2016). Occasional human cases were identified using serological methods, however, the sickness was deemed benign and no deaths or even hospitalizations were reported. By 1983 the virus had spread to equatorial Asia, Indonesia, Malaysia and Pakistan. The virus expanded from Asia and Africa to the Pacific Island of Yap where the first large outbreak of ZIKV in humans was reported in 2007 (Kindhauser, et al. 2016). A survey conducted on 200 out of 1276 possible households on the Island of Yap revealed 49 confirmed cases and 59 probable cases. Before the outbreak, only 16 cases of ZIKV disease in humans had been reported. The aggressive behaviour showed by the ZIKV during the
outbreak on the Island of Yap could be explained by viral mutations, however, there is not enough data to support this. (ibid)

Three other explanations for the outbreak, and why there had been no previous outbreaks, are listed by Kindhauser, Allen, Frank, Santhana, & Dye (2016), the first concerning the possible lack of immunity in the Island’s population, as in Asia and Africa the population had been exposed regularly to the virus and developed antibodies which most likely halted an outbreak in those regions. The second explanation is that the disease might have been misdiagnosed as similar illnesses like chikungunya, dengue or even malaria. And the third explanation is underreporting due to the benign nature of the disease and lack of proper surveillance (ibid). Sporadic cases continued between 2007 and 2014 with travellers returning home from Thailand, Indonesia and Maldives with ZIKV infection (ibid). Outbreaks were confirmed on four different Pacific Islands: Isla de Pascua, the Cook Islands, New Caledonia and French Polynesia. The outbreak in French Polynesia generated thousands of suspected infections and was investigated thoroughly, the investigations provided extensive information to the WHO in November 2015 and January 2016 (ibid). Transmission of ZIKV was first reported in Brazil in May 2015, after this the disease spread rapidly through Brazil and the Americas and has since been reported in 26 countries in the Americas (Petersen et al., 2016).

Complications of Zika virus
In 2015, the prevalence of children born with microcephaly was amplified in Brazil. Many of the mothers reported rashes during their pregnancy, and they had not been exposed to any substances that are known to be harmful to foetuses. The incidence increased even more in 2016. WHO declared the ZIKV epidemic as a public health emergency of global concern in February 2016. (Teixeira, Costa, de Oliveira, Nunes and Rodrigues, 2016).

The Virus has gained much attention from media, perhaps mostly because of its connections with microcephaly. Microcephaly is an unusual multifactorial condition in which the most common symptoms are hearing impairment, severe mental retardation, developmental difficulties, cerebral palsy and seizure disorder. Neonatal deaths related to the conditions are also occurring. Microcephaly is characterized by an abnormally small head and it is a condition called Zika fetal syndrome because of its ties to the ZIKV. There is no cure for microcephaly, but there’s a lot that can be done to cope with the different disabilities (Malone et al., 2016). Guillian-Barré syndrome (GBS) is a syndrome of various autoimmune
etiológies. The syndrome will by unknown cause damage the peripheral nerves, which leads to acute flaccid paralysis. The symptoms are pain, numbness and feeling weak in the limbs (Charrel et al, 2016). The main characteristics are the two-sided symmetrical weakness of the limbs that quickly get worsened. The cranial and respiratory nerve-innervated muscles can also be affected. Both of these diagnoses linked to ZIKV have had a higher prevalence in the current epidemic regions and have also been retrospectively identified in the French Polynesia outbreak (ibid).

**The Brazilian Healthcare system**
The majority of the Brazilians annually consult with health professionals regarding their health issues. Most of them use a combination of both public and private care. The Brazilian public health system is called Sistema unico de saúde (SUS), which translates to unique health system. The federal state and the municipalities are together funding the system. This system is in the larger cities often relatively well developed, with well trained staff and access to new technology. Long waiting lists exist, and a lot of people who seek treatment do not get it because it does not have the capacity to help all. It is also greatly underfunded, this affects the poorest part of the population the hardest and is also an indication of the inequity that exists. The Brazilian private care is considered to be of high standard, however care of this kind is very expensive and beyond reach for the large majority. (Paim, Travassos, Almeida, Bahia and Macinko, 2011).

**Major Obstacles**
According to Tronosco (2016) the people living in the countries affected by ZIKV are dependent on the state to control the mosquitoes. Tronosco continues to explain that these countries have seen a negative trend, the governments have a tendency to promise results they cannot accomplish. When fighting the spread of the ZIKV a goal has been to implement countermeasures. Sadly, by the decision makers working in the public health sector, and their failure to launch strategies in a long and medium long term has worked in favour for the spread of the Aedes Aegypti (ibid). Previous interventions such as the use of insecticides have been proved to work well for preventing the spread of malaria. Unfortunately, these methods have not been successful for the Aedes Aegypti mosquito (ibid). The fumigation made by airplanes and lorries has proven only to have a very limited effect on these mosquitoes because the fumes do not make their way into buildings where mosquitoes are often present.
The government with the knowledge of the limited effectiveness of these fumigation programs often goes through with them anyways as “a visible symbol of government action”. (ibid).

The mosquitoes can breed almost everywhere, every container with a potential to carry water can work as a breeding site. This is problematic due to the unequal distribution of running water in many of the countries in the Americas, which forces people to store large amounts of water (ibid). The mosquitoes stay indoors, in people’s homes mostly. A good way to reduce the risk of ZIKV is to throw away items with the potential to accumulate water, and change water in vases and containers that animals drink from. To remove breeding sites has a huge impact on the spread of the virus. But one must consider the history of social disadvantages present in these areas. The scarcity of drinkable water and the inadequate sanitary situation has created reservoirs that are perfect for mosquitoes to breed (ibid.). The northeast region in Brazil is where most microcephaly cases have been reported. More than a quarter of its population is utilizing open sewers which are perfect breeding spots for the mosquito. Kadri (2016) points out that social and environmental conditions must be improved to eradicate the mosquito breeding sites.

**Treatment, support and prevention**

Today there is no special treatment available for the ZIKV disease. Therefore, the nurses are treating the symptoms. This supportive care consists of resting, antipyretics, analgesics, Intravenous fluids and oxygen if it is needed, this while monitoring the vital signs. It is also important to watch for symptoms of coagulation problems and/or multi organ failure. Because the ZIKV has very similar symptoms to chikungunya and dengue fever exams should be done to rule out the other possibilities. The use of non-steroidal anti-inflammatory drugs (NSAID) and acetylsalicylic acid (ASA) should be put on hold until dengue can be ruled out as a differential diagnose due to the risk of haemorrhagic complications. Pregnant patients should also avoid these drugs (Shuaib, Stanazai, Abazid & Mattar., 2016). Additionally if rashes develop as a cutaneous manifestation, antihistamines could be used. Even though it is very rare, signs of sepsis or multi-organ failure, a rising fever, hypotension, renal and liver dysfunction and neurological complications can manifest in the patient. If these signs are visible, intensive care is needed (Sikka et al., 2016). ZIKV is challenging in many ways. The nursing care meets a lot of obstacles when facing the virus and its complications.
Kadri (2016) points out that the problem is not only the acute damages of the ZIKV that is taking a toll on the health care, but also the long-term monitoring of the children affected by these complications. It is recommended that the babies of mothers who potentially are infected by ZIKV should under their first year be given special attention. This is due to the possibility of neurological symptoms appearing during this time (ibid).

Apart from surveillance, WHO (2016) underlines that the complications of ZIKV should be treated with psychological support. The nurse has many opportunities to give this support, which consists of giving accurate information, providing basic psychosocial support, supportive communication and strengthening social support (ibid). Midwives may find it especially challenging to help support women who are pregnant or planning pregnancy, since so little can be done except take the necessary steps to prevent it (Turienzo & Brown 2016). Prevention is the most effective way to protect yourself from the ZIKV infection, and it is crucial that information that prevents further exposure to the mosquito is shared with all patients (Frazer & Hussey 2016). Insecticide-treated bed nets, insect repellent and protecting your skin from exposure are all examples of good preventative measures. However, a particularly hard challenge is to find and destroy the water sources where mosquito larvae thrive, usually near houses (Blood-Siegfried et al 2015).

**The nurse’s role and health literacy**

The International Council of Nurses (2012) outlines the four fundamentals of nursing as preventing illness, restoring health, alleviating suffering and promoting health. It also states that retrieving and distributing the right information at the right time is one of the key aspects of the nurse’s work. ZIKV can be battled by prevention, and prevention is essentially information that can be distributed. Just distributing information is however not enough, since it has become apparent that many people have a hard time translating the information they receive into good healthy choices for their lives (Ringberg 2009). The aspect of health literacy needs to be discussed in these matters. Health literacy has two different components and both should be reflected upon in the context of ZIKV. Firstly, Individual health literacy is the capacity of a person to use and acquire information to make decision and take appropriate actions about health and health care. Secondly, there is the health literacy environment which consists of infrastructure, policies, material, people and relationships that make up the health
system (Johnson 2015). To facilitate good health literacy Johnson (2015) states that nurses need to organise, present and communicate information in an effective manner, both interpersonally and with the patients. One of the most common complaints about health care is communication failure, and health professionals needs to communicate with patients to strengthen health literacy which in turn would improve health outcomes (ibid). In the context of ZIKV, a lack of health literacy could mean that very few preventative measures are taken to avoid the infection. Here lies one of the nurses’ biggest roles, namely to educate the patient. The patients have a right to receive education that is individually tailored, to help them take responsibility regarding their own well-being and the treatment they are receiving. Often when nurses give out information, the patients need to practically apply the information to their daily lives. For this to happen, the nurse must have conveyed the importance of the information (Tingström 2009).

PROBLEM STATEMENT
History shows us that the ZIKV, when first discovered, was a relatively benign disease and no cause for drastic measures. Now the status has changed and there is currently scientific consensus in regards to ZIKV direct link to microcephaly and Guillain-Barré syndrome. As more studies are being conducted on the subject, the more knowledge is being distributed. Although there is a great amount of medical research regarding ZIKV in circulation there is a definite lack of caring science research on the topic. Since the treatment options are limited, especially in regards to complications of ZIKV, the focus lies mostly on prevention and halting the infection before it spreads more. The absence of research highlighting registered nurses’ experiences of ZIKV was the motivation to undertake this study.

METHOD

AIM
The aim of this study is to describe the experience of Brazilian registered nurses in regards to Zika virus and its complications.

Design
For this study, a qualitative empirical approach based on semi-structured interviews was used. To understand people’s lived experience of a situation, qualitative interviews is a suggested method. (Danielsson, 2012)
Sample
Before the study started, a contact in Brazil was established who was a trained nurse and worked for the government in Goiás. She had a lot of insight into how nurses worked with ZIKV, and therefore she became a gatekeeper for the study. The contact person was informed regarding the study’s purpose and that the authors needed nurses to interview. The contact person then referred us to another Brazilian nurse who was living in Sweden, whom the authors met and discussed with prior to travelling to Brazil. Both of these contacts provided the authors with a big variety of different contacts including doctors, biomedical engineers and nurses. The inclusion criteria was Brazilian registered nurses who had experience treating patients affected by the ZIKV. The exclusion criteria were participants who were not able to provide informed consent and participants who did not fit in the aim of the study. See table 1 for the characteristics of the participants. Contacts were informed with the inclusion criteria’s and kept as contacts throughout the study, since most of them were able to contact more nurses with ZIKV experience.

Table 1. Participants.
Interview
Semi-structured interviews were chosen as the method to facilitate the data collection. In accordance with Danielsson (2013) an interview guide with open-ended questions was prepared, tied to the open questions were additional keywords the authors believed to be of importance to the data collection. Neither the questions, nor the keywords had any specific order they were supposed to be asked in. Instead the contents revealed in the actual interviews guided which questions were used. The authors needed to direct the consciousness and attention of the informers to subject being researched (Friberg & Öhlen, 2013). This was done through the initial open question; could you please tell us about your experiences with the ZIKV. The first question was designed to make the informants focus on their own experiences of treating ZIKV. The keywords were then used to continue the interview when discussion stagnated, or when the authors felt the information had been inadequate.

After the consent was signed, the recording started and the interview leader continued by asking the questions to the informants on Skype©, the interpreter would translate the question to Portuguese, and then translate the answer that was given in English. Both of the authors were present during all five of the interviews, but they had different roles. One was the interview leader, leading the semi structured interviews with the interview guide as a tool to help facilitate the discussion. The other one had the responsibility to record the interview, using a free program called Amolto Skype Recorder©. The one not leading the interviews also took supplementary notes, and had the interview guide on screen to make sure they did not miss anything of importance. The roles of the authors were switched every other interview so author 1 (RK) lead the interviews three times, and author 2 (JT) led the remaining two interviews. The interviews were held via Skype© (a free online program that enables online communication) with an interpreter present due to the language barrier.

Data analysis
Because the authors wanted to describe registered nurses’ experiences of treating ZIKV and its complications in Brazil, they chose a qualitative content analysis as the method of analysing.

After each interview the author who did not conduct the interview started transcribing the text. After the data had been transcribed, both of the authors read the text in its entirety several times. This was done to establish an understanding of the text, as well as finding meaning in the context (Polit & Beck, 2014). Because an inductive approach was used, the
content of the transcribed text was the base of the analysis (Danielsson, 2013). During the initial read through both authors individually marked the transcribed texts to underline what was important in relation to the studies aim. These findings were then discussed between the authors to decide what should be included into the study. The texts that were agreed upon were then included in the study and became the meaning units. During this time it was important to develop a category scheme to make the important parts of the data easier to access.

The manifest content of the text was analysed by condensing the meaning units. To understand how the condensed meaning units was correlated with each other, sub-categories was developed. See table 2 for visual example of the condensing process and the categories.

Table 2. Example of condensed meaning units and category scheme

<table>
<thead>
<tr>
<th>Meaning units</th>
<th>Condensed meaning units</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>We can’t know if the pregnancy will go to the end, and if it does, what is going to happen?</td>
<td>Not knowing the pregnancies outcome</td>
<td>Uncertainty</td>
</tr>
<tr>
<td>We do also feel insecure in these moment as it’s a disease that we don’t know much about.</td>
<td>lack of knowledge leads to insecurity</td>
<td>Lack of knowledge</td>
</tr>
</tbody>
</table>

Ethical considerations

Ethical considerations involve the freedom, integrity, confidentiality and anonymity of the individuals taking part in a study (Bryman, 2011). Prior to the interviews The Swedish Red Cross University College approved the ethical conditions of the study. Bryman (2011) lists four ethical principles that are of importance while conducting research on this level. The first consideration is the information requirements all participants of the study have a right to take part of. The informants should be informed with the aims of the study, they need to know that their involvement is not obligatory and that they can end the interviews whenever they want
to. The second consideration is the requirement of consent. All participants in the study have the right to decide if they want to be involved (ibid). Both consent and information regarding the study was summarized in an information letter which was given out prior to the interviews, the aim of the study was stated in the letter and written consent was collected by the informant at the time of the interview. If consent was not given, the authors would not conduct the interview.

The third consideration regards confidentiality, every participant should be treated with the highest possible confidentiality, and personal information must be treated with care and should not fall in the hands of individuals not involved (ibid). To facilitate this, the authors coded all names of the informants and kept all data at a safe location. The data was at no point shared on an open network or distributed to anyone except the authors themselves.

The fourth consideration explained by Bryman (2011) is the requirement of utilization. Utilization in this context means that the information gathered by the informants can be used for aims of the ongoing study only, it must not be used for anything else or be kept for future studies.

Skype© was used and it is important that the interviews were held to the same ethical standard as regular interviews (Janghorban, 2014). During the interviews, the authors first explained the above mentioned ethical considerations, which were also handed to them in an information letter prior to the interview. The information letter also contained information regarding consent, and the interviewees got the option to turn in their written consent. This was either mailed or scanned to the authors after each interview.

**RESULTS**
The aim was to describe the informant’s experiences in regards to the ZIKV. 10 subcategories were formed and linked to the two main categories.
THE MANY FACES OF UNCERTAINTY
The sub-categories related to this categories are; Experiences of feeling powerless, experiencing lack of knowledge, perceptions of ZIKV complications, giving psychological support, recognizing emotional burden. The feeling of uncertainty was expressed by all of the participants. The lack of knowledge, and the uncertainty the disease brings has sometimes lead the nurses and their patients to feel emotionally burdened and powerless to the situation. When these feelings appear in the patient the best tool according to the participants, has been the psychological support.
**Experiences of feeling powerless**

The participants repeatedly spoke of feeling powerless to different situations. They expressed that they felt limited to what they could achieve.

“We don’t know how to prevent it for the baby, when the infection has spread to the foetus it is irreversible and that makes me feel powerless.” (Participant 1)

Other factors that have made the participants feel powerless has been the unpredictable power of nature, such as the hot climate in Brazil as well as the rainy seasons. Rain that accumulates and creates ideal breeding sites for the mosquitoes is something many participants expressed.

”And as this year was not a normal year, we had much rain this year and because of that the cases have grown exponentially, not only for Zika but also Chikungunya.” (Participant 2)

People that got stung by the mosquitoes and contracted the virus tend to blame themselves for being infected. This invokes a feeling of not being in power of the situation, something the participants outlined as a common problem.

“While feeling guilty, at the same time they are feeling powerless of what they could do to feel better. And they don’t know how to avoid Microcephaly.” (Participant 4)

There are situations when no alternative is a preferable one, and none of the consequences will turn out ideally. In this situation, the patient's feeling of powerlessness was evident.

“We advised her to get an abortion, because it was dangerous. But she didn’t accept it, she wanted to have the baby. Then, when she was 33 weeks pregnant, the amniotic fluid levels were dangerously high and she had to have the abortion.” (Participant 1)
Experiencing lack of knowledge
Participants described that in the beginning of the outbreak in Brazil, hardly anyone knew anything about the virus and the complications it brings.

“From 2014-15 the disease was poorly known, not many people knew it at the time.”
(Participant 2)

Although more is now known about the ZIKV since 2014, this lack of knowledge seemed to be a constant companion of the disease. It is not only in the beginning of the outbreak that the lack of knowledge was highlighted. Also, when the nurses were trying to explain to patients what the disease is, the knowledge gaps were evident.

“We try to explain that it’s like Dengue but worse, but we still don’t know what makes it worse. What is it that makes ZIKV become microcephaly, GBS and those different things?”
(Participant 3)

If you as a health professional don’t fully understand the disease and what complications it may lead to, it is very hard to try to communicate this to the patients. This is what the participants have experienced as one of the most difficult things to handle.

“The biggest obstacle for health care professionals is not knowing what we’re dealing with.”
(Participant 1)

The lack of knowledge has been very frustrating for the participants and they have all spoken about the importance of trying to decrease the knowledge gaps. Although this has proven hard and it was expressed as one of the biggest obstacles facing the disease, and caring for the patients infected.
Experiencing patients with ZIKV complications

Much of the uncertainty and the suffering regarding ZIKV are related to the complications that might occur. While treating patients with GBS, not much can be said that is reassuring. One participant said:

“They all get very worried about the treatment and it takes a while. There’s also not that much we can give them as insurance that everything’s going to be all right. We don’t know.” (Participant 3)

Microcephaly is seen as the main complication according to the participants. They don’t know what the future has in store for these children. When asked about the fears of the virus, the participants once again highlighted Microcephaly and the fears connected to the complication.

“I have no big fears about the ZIKV itself, but Microcephaly is another story altogether, it is the biggest fear that we have. Every time a woman has been infected with ZIKV, we fear that her children might develop microcephaly.” (Participant 3)

These fears make the nurse’s supportive work much harder, and some participants described a lack of confidence while communicating with the patients. They simply did not have any means to reassure the patients because of the severe complications. One participant worked specifically with the parents of the babies that had developed microcephaly, this nurse had concerns that stretched into unknown grounds.

“And we also discovered that it is not only microcephaly that the Zika virus can cause in children. Because we had some cases were the babies had smaller complications in their brains and nobody knows how many untested children might develop further complications in the future.” (Participant 5)

When there is not much to do in ways of comforting patients and relatives, one can still try to manage a supportive relationship with the patient. The ICN code says that it lies in our core to prevent illness, when Illness can’t be prevented the nurse still needs to alleviate suffering and promote health.
Giving psychological support
Since it was common for the patients to blame themselves for being infected, the importance of being able to comfort the patient was vital. One participant had a strategy where the patients got explanations regarding the different ways one might get infected. And that the community wasn’t prepared for this kind of infection, especially not the amount of afflicted.

“So I try to tell them about all the other perspectives regarding how you can get infected, and I try to calm them down...And I am trying to explain to them that this is no one’s fault, this is the communities fault.” (Participant 4)

The fact that open sewers and the garbage system is not optimal is increasing the number of mosquitoes. To explain that it is a structural problem is something the nurse used as a way of calming the patients. The nurses working with patients that has GBS as a result of the ZIKV infection expressed the importance of the psychological support.

“The patients can’t move but they still feel a lot of pain. They need somehow to be more calm and relaxed about it, so psychological support is the most important work for those patients...they are incredibly worried about not being able to move, that’s their absolute biggest concern.” (Participant 3)

These patients often express their fear for losing feeling and strength in the limbs. They also spoke of the anxiety about the treatment.

“The most important thing with my work with these patients, must be psychological support actually. Because that is what makes possible for the patients to get better, and not to feel so worried about the treatment.” (Participant 3)

Because of the lack of a cure to the complications, psychological support remains a vital part of the treatment

Recognizing emotional burden
When caring for patients and trying your best with the means you have, it is always hard for nurses when things won’t work out. This often takes a toll on the nurses and a feeling of being inadequate was something that was apparent when talking to the participants. One of the participants was talking about when a parent to a child born with microcephaly was moving to another city, she feared that same treatment probably wouldn’t be available.
“The nurses in this new place won’t know her entire history. So she lost her opportunity to receive good treatment. I feel anxious because it’s hard to see some of our patients just leaving their treatment with such a dangerous disease... I’m very sorry that I wasn’t able to help this patient, it’s a failure.” (Participant 5).

The participant further explained that she felt sorry that she was not able to help that family and she personally described it as a failure on her part. This feeling of guilt was also very clear when the participants spoke of the parents of the children born with microcephaly. Many of the mothers blamed themselves for not following the recommendations and they felt responsible for the damage the virus had caused the babies.

“The patients are feeling very responsible for having been infected. They even remind themselves of days when they haven’t used mosquito repellent or when they weren’t wearing long clothes to protect themselves” (participant 4).

This way of self-blame was said to be common and it was hard for the patients and the participant to tackle these feelings.

SPREADING AND ATTAINING KNOWLEDGE
This category was formed out of five sub-categories: The importance of educating the patient, giving community education, the nurse’s own knowledge, health literacy and conveying preventative measures. The nurses interviewed during the study were unanimous regarding the importance of knowledge. The nurses expressed a need to educate their patients about prevention and the dangers of the disease’s complications. They also discussed the need to update their own knowledge consistently as new information became available.

The importance of educating the patient
Since ZIKV and its complications are a relatively new concept in Brazil, the population still aren’t fully aware of how ZIKV can affect them. There is no cure for ZIKV disease and the treatment consists mainly of treating the symptoms. One of the participants underlined that it is during this instance that the nurse has a good opportunity to educate the patient.

“...while doing the treatment always try to make the person understand the gravity of the situation.” (Participant 5)
There seems to be a need of conveying the gravity of the ZIKV, since many people haven’t fully grasped the severity of the disease and the complications it can cause. The same participant had recently treated a pregnant woman infected with ZIKV.

“The patient didn’t show any big concerns or take any precautions, I believe she wasn’t aware of what the consequences could be.” (participant 5)

Pregnancy makes ZIKV much worse because of the inherent risk of microcephaly. According to our informers the best suited profession to convey this knowledge to the patient is the nurse, because they are the ones that usually meets and communicates with the patients during treatment.

“During the treatment, we are there to support the patients by teaching them about the treatment and what we know about the disease.” (Participant 1).

All the interviewed nurses did agree that the most important part of patient education was teaching the patients about prevention, since it’s still the most effective way to combat the ZIKV. When a participant was asked what she believed to be the most important to teach, she answered:

“Prevention more than anything, we are the ones that can teach people better how to prevent themselves from the mosquito” (Participant 1).

**Giving community education**

There are a couple different ways the nurses help educate the community. There’s available literature that they hand out for free which they believed to have had an impact.

“Chikungunya, dengue and Zika are all transmitted by the same mosquito. So, we actually have a pamphlet where we teach how to avoid all the three diseases by prevention.” (Participant 1)

Having something available for the patients to read have helped make the community more aware of the disease. Since most of the participants addressed a lack of understanding of what ZIKV actually could do in the community, many of the nurses saw a solution in educating the community. The pamphlets had surely helped people understand how to effectively prevent
themselves from infection, but everyone did not understand exactly why they had to protect themselves from ZIKV. The participants conveyed a need for the community to know the full picture, and one participant stressed that the government is partly responsible for the current lack of understanding.

“The government can also be blamed and should feel guilt in this situation. Their programs aren’t working as well as they should and could.” (Participant 4)

Seeing as the government has taken actions, the community believes that they’re being taken care of and are therefore in no need to do any efforts by themselves. There are however programs where they teach the communities about mosquito prevention.

“We have community agents, their work is to go into each house that is a potential mosquito breeding site, to search for the places where the mosquitoes can reproduce.” (Participant 2).

Teaching the community how they can prevent being infected is a high priority, but the community needs resources to facilitate the needs of its inhabitants and government action is encouraged.

**The Nurses’ own Knowledge**

Another aspect that became apparent during the interviews was the need for the nurses to update their own knowledge about the ZIKV and its complications. Seeing as it’s still a relatively new disease for the health care professionals in Brazil, a lot of research is currently being done and the nurses need to keep informed to give the best available care. A majority of the nurses also expressed that there is much to learn from treating the patients.

“For each patient that we have, the problems get a little bit clearer. We are starting to get to know the disease, and we hope treatment gets better as time goes.” (Participant 2)

This participant sounded particularly hopeful while discussing this topic, and continued by describing how much harder it had been when the mosquito’s different diseases were hard to differentiate.
“It wasn’t until 2015 that we could perceive the difference between the Zika virus and the dengue, which are transmitted by the same mosquito, you know. Now that has become much easier.” (Participant 2)

This participant believed they had already come a long way, but that there was still a lot to learn, especially about Microcephaly and Guillain-Barré syndrome. Participants was all talking about the value of learning by experience. To be supported by the workplace to gain new experience was said to encourage the nurses to be updated on the latest research to help the better understand the disease.

“The hospital works with the nurses and wants us to always be studying new cases and the latest treatments... We still don’t know enough.” (Participant 3)

All nurses did in some way explain that there isn’t enough information yet to properly treat the complications of the ZIKV. There is however still much useful knowledge that the nurses can attain regarding how to treat the symptoms, how to emotionally support the patients and more effective ways to prevent the disease.

**Perceived health literacy**
Seeing as the disease itself is fairly benign it becomes much more important to promote health literacy in the patients so they learn to understand how serious the complications can be. Many of the nurses had encountered patients who didn’t take the necessary steps to prevent the disease, and now those patients felt incredibly responsible for not taking those actions. Even though most people now have heard about the disease, there seems to be some confusion regarding how it can affect them.

“I believe that people are not conscious about the gravity of the disease because they haven’t seen the consequences with their own eyes.” (Participant 5)

Some patients thought that the mild nature of the symptoms meant that ZIKV was no cause to take precautionary steps. They had understood that it was not anything serious. This way of thinking was common, and the participants felt frustrated and wanted a change in people’s understanding of the disease.
“I haven’t seen people too worried about being affected by the virus... People feel that it’s no problem, they believe the disease stays for a week and then it’s gone, and that’s it.”

(Participant 5)

According to the same participant, some parts of the population aren’t worried enough, and since they aren’t taking the necessary steps to prevent it, it will be harder to halt the infection. The same thoughts were expressed by other participants.

“This patient was from a lower income area, as I normally have. And the patient didn’t show any big concerns or take any precaution, I believe she wasn’t aware of what the consequences could be.” (Participant 1)

All participants in the study had a similar story, where they had experienced a patient at risk for ZIKV not taking precautions to prevent an infection. This lack of health literacy scared many of the participants in the study, and individually tailored education for the patients was seen as the solution.

**Conveying preventative measures**

Prevention work was highlighted by all participants as one of the most important tools at the nurse’s disposal;

the most important part of our work is the education to the community and the early prevention of this (participant 2).

Mosquito prevention is something the Brazilian nurses are accustomed too, since the country has many other infectious diseases carried by mosquitoes. Both Dengue and Chikungunya are carried by the same mosquito that carries ZIKV, hence the prevention methods are the same. However, the participants described a sense of responsibility attached to the prevention work;

as a nurse doing the treatment, I feel responsible to orient people on prevention and on treatment (Participant 4).
This participant in particular took prevention very seriously and conveyed confidence in her abilities to do so. Having this confidence in your own abilities correlates well with abolishing uncertainty, and is definitely a good characteristic of a nurse. Having an attitude like this, or similar to this, was also something the nurses discussed as important to achieve good prevention work;

*if you just tell them that they need to do it and act superior, I don’t think they understand as well.. You can’t force it* (Participant 1)

The authors had a good pre-understanding of prevention before conducting this study, it was bound to be a big part of the result since it is one of the most effective ways to combat the infection. One participant did however express a different perspective;

*so, at the same time as prevention is our biggest responsibility it is also a big obstacle, because it is the only thing we can do to the people* (Participant 2).

This participant discussed a lack of faith in the community and their ability to handle prevention by themselves, he did nonetheless express that prevention work is very much a necessity.
DISCUSSION

Discussion of methods
Because the authors wanted to get greater understanding for the nurses’ experience in regards to the Zika virus, a qualitative empirical approach based on semi-structured interviews was used. Danielsson (2012) is saying that it is a suitable method if you want to understand peoples experience of a situation. Because all interviews were started with the same open question “could you please tell me about your experiences with the ZIKV”, the authors let the participants tell their own story and therefore the entire study is based on their experiences. Since the study’s aim was to describe the participants’ experiences the authors agree that the method of choice was right.

When writing the background of the study the authors only choose peer reviewed articles from the databases EBSCO and CINAHL in accordance with Henricson (2012) to strengthen the validity. The most of the articles that been used in this paper have only been a couple of years old, with some exceptions. This increased the validity and strengthened the study. Sometimes the authors read articles separately Henricson (2012) is stating that doing so lowers the reliability, and therefore this has been a limitation.

When participants were chosen our contact person helped us getting in contact with the participants. This is a weakness of the study. Seidman (1998) is suggesting not relying on a third party to contact participants, because the interviewing relationships start the moment a partaker hears of the study. Although it was necessary in this case due to the language barrier. The authors tried to build a relationship with the informants by what means were possible. Mails, phone calls, messages and the interviews were different arenas where the relationships were built.

When the authors choose the participants a variety in experience and working years as a nurse was sought. Granheim and Lundman (2003) are pointing out a strength with the study. They are stating that, choosing participants with different experiences is shedding a broader light on the research problems. Therefore, the fluctuations in the working experience and the different focus the participants had increased the credibility of this study (See table 1). During the interview the authors wanted a description of registered nurses experience of working with ZIKV, so the questions were open and the interview was semi structured. The authors was very clear to let the participants speak of their own experiences and not to be biased by the
thoughts of the author. Regarding credibility, all participants was introduced to the authors before the interview. After the introduction the informed consent was went through, thereby the ethical considerations was taken into account. To further strengthen credibility the interview phase of the study was characterized by a constant dialogue between the authors.

Discussion is a way for the researcher’s vision to be widened (Shenton, 2004)

Granheim and Lundman (2003) explains that dependability is dependent on the authors ability to question the same questions to all participants, but also to be aware that interviewing is an developing process, so follow up questions may be needed. During the interview the authors followed the interview guide to be consistent with the questions. Some variations in the follow up questions have therefore been changing which could be a limitation.

Because the interviews were translated from Portuguese to English some of the sentences might not have been translated correctly. But a thorough translation process has been conducted and therefore the authors don’t believe this has influenced the result or the credibility. As the interviews were on Skype© the participants themselves chose were the interview should take place, most chose to be at home. This made the participants feel more at home and made the interview feel more like a conversation. Janghorban (2014) is pointing out that nonverbal communication is possible in Skype© interviews, and that they can have the same authenticity level as to face to face interviews. It allows the same opportunity to interpret the nonverbal communication. Because of the translation the authors have not been able to analyse the data on a latent level but in accordance with Olsson and Sörrenson (2011) explain that data can be analysed on a manifest level. The content analysis focuses on the text in its entirety and describes what is important about the text.

Another way of increasing the credibility of the data is by not choosing long sentences as meaning units nor too short meaning units, since this can lead to fragmentation. In line with Granheim and Lundman (2003) the authors chose to show how the meaning units was condensed and later abstracted with a model of how the abstraction process was managed. Please see table 2.

Polit & Beck (2014) is arguing that the data in qualitative studies may be disputed. When one reads qualitative research data, only a small amount of the data is available for the readers. Therefore for authors to gain credibility the reader needs to trust the authors’ honesty when recognizing the limitations of the study. Using triangulation methods for validating the results
is a tool for increasing the credibility (ibid). The authors therefore suggest this to be done with future studies. Polit & Beck (2014) argues that to be able to make meaning of qualitative data the researcher needs to be close to the text, therefore all the material was read through several times to get an understanding for the data as a whole. This increased the credibility in the analysing process as well as the writing process.

The authors believe that this study cannot be generalized because the findings might not be transferable to other participants in another setting. The participants were too few, therefore the result should not be able to generalize. All aspects of the experiences of working with ZIKV cannot be described in such a short study. But according to Polit and Beck (2014) the generazibility is not the only strive when conducting qualitative research, instead an objective can be to generate knowledge that can be applied in different situation.

**Discussion of results**

A total of ten sub-categories formed the two main categories. Many of the sub-categories were intertwined and not necessarily fully explained by themselves, rather they overlapped and together formed a whole.

**Supporting uncertainty**

Uncertainty was a feeling the informants many times spoke vividly of and it was described to often be accompanied by sadness or guilt. The experience of feeling uncertain is omnipresent in human existence (Penrod, 2001). When an individual is faced with something unexpected, such as a serious disease or many other events, the feeling of uncertainty is evident. Penrod (2001) explains that uncertainty is a state where the individual has a goal, but cannot find the way to achieve it. Even though options are available, the person is incapable to determine the effectiveness of the options. An individual living in uncertainty exists in the present but is not capable to perceive the future as a reality. Hope does not survive in the wake of uncertainty, and the essential cause of uncertainty is described to be lack of knowledge. Penrod (2001) explains that uncertainty is managed by feelings of confidence and control. The participants who worked with the GBS patients witnessed that the fear of losing the feelings in limbs in a way is the opposite of control. Sharshar, Polito, Porcher, Merhbene, Blanc, Antona & Marcadet (2012) did a qualitative study where they did an assessment of anxiety of GBS patients and they found out that the most stressful aspect was the uncertainty of how the
disease would progress. Because GBS patients are terrified and feeling conscious of the need of people to care for them, Drummond (1990) says that these patients most importantly need much psychological support. This supports the description the participants gave. Although the psychological support necessary for these patients, one cannot stress the importance of the medical treatment that is vital for the patients to survive. In lack of better treatment or cure the psychological support is currently the best solution for alleviating suffering.

It is not only the GBS patients that feel the psychological toll of the ZIKV, dos Santos Oliveira, Gurgel, Melo, Reinheimer, Santos & Martins-Filho (2016) writes about the increased anxiety levels and the psychological suffering that infected pregnant women might feel. This was something the participants expressed as well. The feeling of self-guilt by getting infected was described, and remembering days when they didn’t use repellent was something many had felt. The best help when those feelings were experienced was to tell the patient about all the other perspectives regarding how to get infected. This was a method that a participant had used. She had given the patient the knowledge of the mosquitoes’ different ways of transmission, and by doing so the patient could cope with her self-guilt in a healthier manner. When the participants described their experience of working with ZIKV the uncertainty was something that came up time after time and all the categories the authors developed are in some way descriptions linked to uncertainty. Hansen, Rørtveit, Leiknes, Morken, Testad & Severinsson (2012) described uncertainty as something that brings an incredible emotional burden to individuals, and they argue that nurses need to better understand uncertainty and enhance patient education. To recognize what it means to live with the uncertainty of diseases when no cure can be offered is of great importance to nurses and healthcare professionals (Ibid).

**Educating the patient to fill the knowledge gaps**

Hansen et al. (2012), Penrod (2001) and Dos Santos Oliveira et al. (2016) all discussed, that promotion of the use of evidence based knowledge and practice is of great importance. And to clearly be able to communicate this to patients and the relatives is vital to reduce uncertainty. This statement is further backed by our participants who spoke highly of always being updated. They did highlight a hopeful tone regarding the future, and that they get better for each new case they have. Also, the hospitals that encourage their nurses to update themselves on the most recent research take further steps to nullify uncertainty. When new knowledge has been obtained, both from interactions with patients and from contemporary research, an
opportunity to teach arises, and the nurse needs to utilize these opportunities to educate both
patients and peers. Clarke (1991) implies that it lies in the nurse’s nature to acquire new
knowledge and distribute it. She further explains that information giving and assisting
understanding are traditional areas of the nurse (ibid). The authors believe that these traits
make them ideal for educating patients, and in the context of ZIKV the nurses can do much
needed work to fill the patients’ knowledge gaps.

The participants were unanimous when discussing the importance of prevention, everyone
believed it to be one of the most important aspects of their current work with ZIKV. However,
the prevention work has been hard because of environmental factors and the perceived low
understanding of ZIKV and its complications. The authors identified this low understanding
in the community as a lack of health literacy, and many participants discussed troubles they
have had while trying to convey just how serious a ZIKV infection can be. Lacking health
literacy has proven to have adverse effects on infectious diseases and multifactorial
interventions are needed to take care of the problem (Castro-Sánchez, Chang, Vila-Candel,
Escobedo & Holmes 2016). WHO (2016) states that citizens need a foundation where they are
enabled to be actively improve their own health, this should ideally be provided in the
communities by their respective governments. They continue by identifying health literacy as
a way to instil empowerment in the patients. Furthermore, one should not try to assess a
patient’s certain level of health literacy each time, instead the healthcare system should ensure
that everyone, regardless of abilities, are able to use the information and opportunities
available to make good decisions regarding their health. For this to be a reality, the public
needs to receive adequate information (Castro-Sánchez et al, 2016). While discussing
adequate information, the nurse’s role as an educator should be taken into account.

Since the problem the authors identified lies in the lack of knowledge, which in turn can be
improved greatly by an increase in health literacy. Friberg, Granum & Bergh (2012) outlined
factors for patient education in their literary review, and many studies has shown that nurses
regard patient education as a significant part of their daily practise. Further it has been proven
that nurses with more responsibility perform educational activities more often (ibid). The
participants of the study all pointed out that education was key in combating the ZIKV, and
all of them identified their roles as educators. However, Macdonald, Rogers, Blakeman, &
Bower (2008) emphasise that there is a need for more training, education and skill to
thoroughly tackle patient education. This might be true, but it should not halt the nurse from
providing the patients with at least some education to help them achieve a higher level of health literacy. Another survey by Lewis (2005) show that many nurses feel that they are competent enough to give out education, but that it differs a lot depending on where you search. Seeing as the hearth of the problem lies with lack of knowledge, the nurse can be utilized to educate patients. The participants interviewed for this study characterized the nurse as the results have reflected; as an educator that is there to support when there’s nothing to do, and a provider of information that ultimately gives the patients the freedom to help themselves.

**Conclusion**
The findings in this study concludes that much suffering while treating ZIKV is caused because of the uncertainties connected to the virus. Uncertainty is a state where both patients and nurses get halted in their hopes for good healthcare, and when a previously benign disease resurfaces with new complications it has been hard to convey the severity to the patients. The root of uncertainty has been identified to be anchored in a lack of knowledge, and therefore the authors firmly believe that the nurse can ease the feelings of uncertainty by providing necessary information and educating the patient. By doing this the patient’s health literacy can be strengthened which in turn empowers them to make good health decisions by themselves. Since education is the key, and nurses with more responsibility tend to give more education, one can argue that if the nurse is given more responsibility they will become better educators. However, further research is needed to strengthen this claim. Also, further research on how to practically implement health literacy is needed.

**Clinical significance**
This study offers an insight in the nurses´ experience when caring for patients with ZIKV related complications. It also brings a nuanced understanding of the difficulties with uncertainty. The study also serves as a reminder to nurses of their role as an educator, and should be used to motivate nurses to at least reflect on the subject of health literacy.

**Suggestion for further research**
To the authors knowledge there is very limited research found on the nurses´ experience on the ZIKV therefore the authors recommendation is that further research regarding nurses experience when caring for patients infected by ZIKV or related diseases is needed. Especially the authors call for more treatment alternatives for Microcephaly and Guillian-Barré syndrome, since psychological support is the only available treatment the nurses can
give at the moment. Seeing as health literacy is a strong point the authors are making, further research that explains how health literacy could be implemented practically is also needed.

**Authors contribution**
Both authors have been mutually active throughout the study. Articles have been sought out in unison with discussions to facilitate doubt. Some segments of the texts have been written individually, but all text have been read and revised by both authors throughout the entire study.
REFERENCES


APPENDIX I

Information letter/Consent form

Dear participants.

We, Robin Kristoffersson and Jonas Tillman, would like to begin with thanking you for participating in our bachelor-thesis. We are both students at the Red Cross University College in Stockholm, Sweden. The study you are taking part in aims to explore nurses’ experiences of the Zika phenomenon currently active in Brazil.

If you chose to consent to our study, you will participate in an individual interview with the researchers that will last approximately 20-40 minutes. The researchers’ role will be to guide you through the interview by asking a few open questions focusing on the subject of nurses’ experiences of working with the Zika virus. We want to know how you have experienced the Zika virus and what your thoughts are after having treated it. The interview will be held outside the workplace (mainly through Skype), and if needed an interpreter will be present that’s fluent in Portuguese, English and Swedish. It will be recorded and later transcribed and all data collected will be stored in a safe place and be accessible only to the researchers. We ensure that all data will be anonymous so that in the unlikely event of a security breach your identity remains hidden. Every recording and transcription will be erased after the study’s completion, and the information gathered from the interviews will only be used to complete this study. You have the right to refuse to participate or withdraw from the study at any time, if you chose to withdraw during an interview, the information gathered will not be used for the study and the data will be terminated.

If you have any further questions regarding the study, please contact our lecturers at the Swedish Red Cross University College, Mia Kraft and Stephanie Paillard-Borg, who can be reached on these emails: riam@rkh.se and pais@rkh.se (only English)

If you have any further questions to us regarding the study, you may contact us on these emails: Robin Kristoffersson – Robin.kristoffersson@hotmail.se or Jonas Tillman – Jonas.tillman@hotmail.se

If you want to take part of the completed study in its written form, you can write down your email on the line and you will be notified when it gets published.
I have read and understood the information given to me as a participant of this study. I’ve been given the opportunity to ask the researchers any questions prior to the interview.

Please tick the boxes if you have understood that:

☐ I can withdraw from the study when I want to

☐ I will remain anonymous during the study

☐ The interview will be recorded and later erased

☐ Participation is voluntary

Sign here: ______________________________________________________
APPENDIX II

Interview guide
The interview will be structured as follows.

First, we had a short presentation of our study and its aim and then we moved on to a semi structured interview with the questions below provided as background. Only one open question was chosen, and attached to it were keywords that could help guide the interviewee if the conversation stagnated.

Trivia:
How old are you?
How long have you been working as a nurse?
Where are you currently working?
Could you tell me a little bit about your work?

Actual Interview:
1. Could you please tell us about your experiences with the Zika-virus?
   - Work
   - The media
   - Perceptions of patients
   - Patient’s perceptions
   - Prevention

2. Could you tell me your thoughts about and/or feelings during that situation?