

Managing Uncertainty: Using Social Media for Risk Assessment during a Public Health Crisis

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ABSTRACT

Recently, diseases like H1N1 influenza, Ebola, and Zika virus have created severe crises, requiring public resources and personal behavior adaptation. Crisis Informatics literature examines interconnections of people, organizations, and IT during crisis events. However, how people use technology to cope with disease crises (outbreaks, epidemics, and pandemics) remains understudied. We investigate how individuals used social media in response to the outbreak of Zika, focusing on travel-related decisions. We found that extreme uncertainty and ambiguity characterized the Zika virus crisis. To cope, people turned to social media for information gathering and social learning geared towards personal risk assessment and modifying decisions when dealing with partial and conflicting information about Zika. In particular, individuals sought local information and used socially informed logical reasoning to deduce the risk at a specific locale. We conclude with implications for designing information systems to support individual risk assessment and decision-making when faced with uncertainty and ambiguity during public health crises.

Author Keywords

Crisis Informatics; decision-making; information seeking; online forums; risk assessment; social media; uncertainty reduction; public health; Zika virus.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g. HCI); Miscellaneous; J.3 Life and Medical Sciences, Health, Medical Information Systems.

INTRODUCTION

In the last two decades, multiple severe public health crises have centered on diseases, including the SARS epidemic in 2003, H1N1 influenza pandemic in 2009, and Ebola virus epidemic of 2013 to 2016. These public health crises

affected large populations, some at a global scale (those reaching pandemic status), and caused huge rates of morbidity and mortality in affected populations. Ebola, for example, killed an estimated 11,000 people, and H1N1 killed an estimated 8,000-18,000 people. However, during such crisis, there is often considerable ambiguity regarding the disease itself, its affected geographical scope, risks posed by a disease for an individual, and appropriate preventative strategies [21]. Disease crises typically do not occur with as much regularity as other types of crises, such as floods and hurricanes. Information is often partial and conflicting, especially in the early stages of the crisis. Yet, individuals have to make fast decisions of high consequence to themselves, their families, and the general public under these conditions, using uncertain and ambiguous information [68].

A rich stream of research in HCI and related areas examines crisis informatics, which is concerned with the interconnections between people, organizations, and Information and Communication Technology (ICTs) during a wide variety of crisis events [46]. Much work has focused on how people utilized ICTs in response to natural disasters including floods (e.g., [66]) and hurricanes (e.g., [49]), and human-induced crisis such as bombing (e.g., [29]) and mass violence (e.g., [11,28,40]). These studies have shown that ICTs provided local community members a means to connect with each other and communicate community-relevant information during some crises [25,49,58]. ICTs, especially social media platforms such as Twitter and Facebook, helped individuals seek assistance, develop situational awareness, and recover from disruption [29,57,60,66].

However, there is a dearth of research on how individual citizens use ICTs to cope with public health crises such as disease outbreaks. Information needs are quite different in a public health crisis than in other kinds of crises [34]; weather events and terrorist attacks may lead to different ICT use patterns [20]. Given the impact of public health crises, there is a pressing need for research on these crises both to illuminate how crisis informatics can support individual and collective responses to disease outbreaks and to inform crisis informatics literature more broadly through exploring an additional crisis area.

In this paper, we investigate how individuals leveraged social media in response to the Zika virus crisis, with a

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CHI 2017, May 06 - 11, 2017, Denver, CO, USA

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ACM 978-1-4503-4655-9/17/05...\$15.00

DOI: <http://dx.doi.org/10.1145/3025453.3025891>

particular focus on their travel-related decision-making. We analyzed people's conversations about making travel decisions in response to the Zika virus crisis on three online forums: Reddit, BabyCenter, and TripAdvisor. We found that people on these forums encountered many difficulties in making sense of the Zika virus crisis because of the limited amount of credible information. Complicating the situation, information from authorities was often unreliable. Online forums became a place where people gathered and exchanged critical information that was missing from news media and formal channels. We also observed social learning that took place around personal risk assessment and decision-making when people attempted to comprehend partial and conflicting information. Local information shared by previous travelers and local residents played a particularly important role in risk assessment. Based on obtained information, people used socially informed logical reasoning to calculate the risk at a specific locale. We conclude with implications for designing information systems to support individual sensemaking when faced with uncertainty and ambiguity during public health crises.

BACKGROUND

Zika virus was first discovered in Uganda in 1947, at which time much was unknown about the virus. Until recently Zika had not been associated with any severe public health events [17,19,68] and thus was understudied. Zika became a public health emergency after an unprecedented rise in the number of newborns with microcephaly (newborns with much smaller heads compared with other babies of the same age and sex) was observed and reported in Brazil in 2015 [68]. Zika was later pinpointed as the likely cause of these microcephaly cases, and on February 1, 2016, the World Health Organization (WHO) declared the Zika outbreak a public health emergency of international concern [69].

So far, evidence shows that Zika virus can be transmitted in multiple ways, including the bite of a particular species of mosquito carrying the virus, pregnancy, sexual intercourse, blood transfusion, and laboratory exposure [4]. While Zika can affect anyone, current research finds it has severe consequences in unborn fetuses [3]. The outbreak of Zika is geographically dispersed in multiple countries and territories globally. To prevent the transmission and spread of Zika, Public health authorities such as the World Health Organization (WHO) and the Centers for Disease Control and Prevention (CDC) of the United States have been advising pregnant women, women trying to become pregnant, and their partners not to travel to areas where Zika virus cases have been reported [5,69]. As of September, 13, 2016, 70 countries and territories have reported cases of Zika virus transmission [69]. Zika is perceived to be an especially egregious public health crisis because of the risk it poses to newborns [68].

Despite known risks, vulnerable individuals (particularly women of child bearing age and their partners) face

difficulty in avoiding travel to Zika affected areas. Would-be travelers must make crucial decisions about whether to travel into affected areas and about what procedures they should follow during and after traveling. Numerous circumstances make avoiding travel difficult; some people have to relocate to impacted areas because of circumstances beyond their control, some have made expensive, non-refundable travel plans before a local outbreak, and some people have traveled to an area before cases were reported.

When making consequential decisions and planning travel during a disease crisis, people need high quality information to weigh the potential risks and benefits of travel to affected areas and take precautions to mitigate risk. People experience deep uncertainty when public health information is unavailable or inconsistent, and details of the situation are ambiguous, unpredictable, and probabilistic [2]. Uncertainty surrounding Zika virus is increasingly evident [26]. At the time of writing there is no effective vaccine to prevent transmission and no effective treatment [3]. About 80% of infected people are asymptomatic and may recover without ever knowing they were infected [3,68]. Even diagnosis is fraught at this time, making it difficult to determine conclusively that an individual carries the virus. The CDC admits that there is still "a lot" they "do not know about the virus and how to interpret test results," thus available tests may not be accurate [6]. Consequently, it is difficult to know whether all cases have been identified and reported, thus accurately determine the extent of the outbreak in a given location. Identification and effects of Zika-related complications are also subtle [13]. The linkage between Zika virus and microcephaly is still under study. Temporality adds additional complexity, as the risk of infection from mosquito-borne diseases changes seasonally. It is very challenging for health authorities to mount an appropriate response to Zika virus and provide more complete information to the public, since authorities themselves still know very little about it [17].

RELATED WORK

Health Information Seeking and Decision Making

Previous healthcare studies have focused on patients' information needs regarding their diagnoses, treatment, alternative plans, unanswered questions during clinical visits, and diet and exercise regimens [36,53,64,65]. Studies show that patients sought information from various informal sources such as the internet, newspapers, family, friends, and coworkers in addition to formal channels [1,16,65]. While Cutilli's review of previous studies shows that the most common and trusted information source is healthcare professionals, individuals use multiple informal sources to supplement formal clinical channels [16].

Online health communities have enjoyed explosive popularity in recent years. These online communities are playing a vital role in meeting patients' health information needs. Individuals receive information from peers and moderators [33]. A study of an online diabetes community

found that the community members often constructed shared meaning through discussions, negotiations, and reconciling conflicting opinions [39]. Despite their utility, some of the information accessed in online communities has been found to be incorrect and misleading [36].

Much research on healthcare information practices has focused on shared decision-making. Shared decision-making refers to a collaborative decision-making process in which patients and physicians share information and build a consensus about the preferred treatment to be undertaken [8]. Shared decision-making has long been highlighted as a beneficial model for improving the quality of medical care [8]. Past research [e.g., 35,42] found that it is particularly suited to chronic illness care, where patients tend to take an active role in carrying out care decisions. Chronic care also offers ample opportunity for clinicians and patients to review the results of treatments decisions-- revisiting, adjusting, and sometimes even reversing treatment plans. Acute care decisions, which often take place under urgent circumstances and may be irreversible, are more likely to involve minimal patient participation. Counterintuitively, studies have shown that not all patients would like to participate in decision-making, and many factors affect their preferences for involvement [56]. Patients who are willing to participate in decision-making need to harness complex information regarding treatment options to reduce decisional conflict [59].

Social Media and Public Health

A burgeoning body of research in public health has demonstrated the potential of mining social media data for public health surveillance. Munro et al. [44] used natural language processing strategies to analyze social media data to detect some of the early outbreak-related reports of epidemics. A linguistic analysis [15] of Twitter activity found Twitter-derived statistics can improve predictive accuracy for some health-related statistics at county level. User-provided and machine-generated geo-tags of images from Instagram can also be used to infer a county's health statistics, such as obesity statistics [22]. Paul & Dredze [48] applied a topic model to health-related tweets and discovered quantitative correlations with public health data.

Surveillance is one promising application of social media for public health, but communication is also crucial during public health crises and social media has a large role to play. Public health research has emphasized the importance of social media in disseminating disease outbreak-related information [10,43]. An analysis [47] of 142 videos related to the H1N1 flu pandemic showed that YouTube videos had a substantial amount of useful information, yet also had a fair amount of misleading information. CDC-uploaded videos had a significant viewership and were shared often as a source of authoritative information about the disease. A content analysis of Tweets during the same outbreak showed that Twitter was also used to disseminate information, and news websites were the most popular

sources of Tweets [9]. Another potential use for social media comes from monitoring affective responses during crises. Studies such as De Choudhury et al.'s study [11] on affective dimensions of Twitter data during the Mexican drug war violence demonstrates how Twitter data may be useful in helping healthcare policy makers and agencies to associate affective responses to circumstances people face in prolonged violent crises. Public health agencies also used social media for risk communication. For example, during the H1N1 flu epidemic, governmental institutions such as CDC and the United States Department of Health & Human Services (HHS) used social media and websites to disseminate information to the public, although their use of social media was still very limited [18].

ICTs and Crisis Response

A rich and growing body of literature on Crisis Informatics has examined how acutely affected populations, the general public, and professional emergency responders used ICTs in response to natural and human-induced crises.

Amidst crisis, ICTs such as blogs and online forums provided community members a means to connect with each other, communicate community-relevant information, build community resources, and sustain geographic community ties when populations became geographically dispersed during wildfires and hurricanes [37,38,49,58]. Communication needs during crises are often hyper-local, relating to locations of hazards, individuals, and key resources; social media has driven a revolution in communication during crises. For example, in response to Hurricane Sandy, those who were in high-impact areas commonly retweeted tweets from local people with locally-useful information [37] which supported nearby residents in making informed decisions. ICTs can enhance situational awareness, defined as "all knowledge that is accessible and can be integrated into a coherent picture, when required, to assess and cope with a situation" [55];" such effects have been shown during crises including the Oklahoma grass fires and the Red River flood [66].

Furthermore, ICTs help affected populations and the general public collectively make sense of and respond to crises. ICTs provide both functional and emotional support. In China, people used Microblogging services and online forums to disseminate information, express opinions, offer emotional support and coordinate resident-to-resident assistance in response to earthquakes [50,51]. In the aftermath of the April 16, 2007 Virginia Tech shooting, the public collectively discovered the names of victims using online sites such as Facebook [67]. Researchers have chronicled how individuals' communication on Twitter helped people make sense of violent crises on US college campuses in 2010 and 2011 [28]. Citizens living in Iraq during the Gulf War used ICTs to reconfigure social networks, create self-reliant communities, self-organize alternative resources, and repair trust in news as previously government-controlled single voice communication was

replaced with a range of media [41]. Social media helped people return to normalcy after crisis [40], including maintaining and developing new social norms [57].

Another body of research examines the complex micro-practices through which people seek and share local information online during crises. Starbird et al. found that the public used and relied on official sources and information from believable eyewitness accounts, and actively manipulated information to make it locally useful [61]. Physical and emotional proximity plays a role in information-seeking activities. In the aftermath of the 2013 Boston Marathon Bombings, for example, hyper-local and real-time information were necessary for people who lived locally or had friends near the affected areas [29]. Rumors proliferated as people faced uncertainty [29,63].

Another strand of research focuses on how emergency response professionals use ICTs. One focus is how emergency response professionals coordinate and collaborate in response to crises. Goggins et al. [23] investigated how the US Navy and NGOs coordinated and shared information in an online forum after the 2010 Haiti earthquake. Sarcevic et al. [54] examined emergency medical response teams' Twitter usage in the immediate aftermath of the 2010 Haiti Earthquake to understand the coordination challenges faced by personnel. Hellmann et al. [27] studied relief practitioners' collaborative data management and analysis during the Ebola crisis in West Africa in 2014. Social media expanded the information pathways between emergency management organizations and the public from one-way communication to two-way communication [31]. For example, during Hurricane Sandy some (although not many) fire and police departments used online media for public communication in 2012 [30].

Research also examines how social media, as a crisis-reporting platform, can serve the needs of professional emergency responders. Agencies face multiple challenges when using social media: roles and responsibilities, concerns with liability, data overload, trustworthiness of citizen-generated data, reliability of social media networks, and lack of information access faced by some members of the public [32]. For instance, although citizen-reported data on Twitter is a potential data source for emergency responders [62], the data are so abundant that they require intense information processing operations such as filtering and extracting [34]. Emergency response professionals and digital volunteers have to collaboratively filter and process social media data into usable resources during crisis events [12], which can be time and resource intensive.

While studies of health information seeking and decision-making mainly concern patients' needs, our research focuses on a more general population--not necessarily patients, our sample differ along a variety of aspects such as health condition and purpose of information seeking. Different from research on media and public health that attends to ICTs' role in public health surveillance,

information dissemination, and risk communication, we examined individuals' use of ICTs for risk assessment and decision-making. Compared to crisis informatics work that focuses on how ICTs could support mass communication, we pay close attention to risk assessment and decision-making behaviors at the individual level in a public health crisis. Our work aims to extend these research strands by using deep qualitative analysis to elucidate how people seek information, ascertain risks despite partial and conflicting information, and make complex and weighty personal decisions about behavior during the Zika virus crisis.

METHODS

To meet these research aims, we utilized a grounded theory research design [14] with the primary data collection being qualitative content analysis of social media. We chose this research method for multiple reasons. First, it is not realistic to look for participants in real life because those concerned with Zika are geographically dispersed in the world. Second, there is not a particular offline community where potential participants gather. Third, although the crisis affects all women who might become pregnant and travel overseas—thus the total number might be huge—it would be difficult to identify participants through transitional channels (such as an obstetrician's office or social networking sites). Therefore, we turned to online forums where individuals engaged in collective communication about Zika. Our goal was to identify cases of personal risk assessment and decision-making related to Zika.

Data Sources

To identify forums, we did a broad search using search engines such as Google and Bing, as well as popular social media sites such as Facebook and Twitter. Due to our language competency, we only searched in English and might have missed information in Spanish or Portuguese, the primary languages in Latin America. We found that many sites only covered official information as well as Zika-related news, and lacked information sourced from laypeople. User posts on Twitter were too short to reveal personal decision-making processes. This pre-screening eventually led us to choose three sites (Reddit, TripAdvisor, and BabyCenter) that contained rich data about risk assessment and decision-making in response to Zika. We chose these sites because Reddit has been the largest online forum for the general public in terms of internet traffic, TripAdvisor has been the largest travel-related website in terms of visitor numbers, and BabyCenter is the most popular online venue for pregnant women, the group most affected by Zika virus. We focused on forum discussions that took place between January 1st, 2016 and August 20th, 2016, the period during which Zika surfaced as an international news topic. We collected and analyzed both initial posts and follow-up responses in a thread.

Search Strategy

Each of these three forums provides an in-site search function supporting keyword-based search of forum discussions. Our data collection relied on the search

function. Initially we only used “Zika” as the keyword to find all discussions mentioning Zika. In July, 2016, two authors read discussions on the forums and acquired a sense of how people talked about Zika and the important keywords that people referenced in discussion. In this process of initial reading, the two authors collected 58 Reddit threads, 32 threads from TripAdvisor, and 51 threads from BabyCenter. Through analysis of this initial dataset, the two authors generated a list of keywords that people frequently mentioned when talking about travel decisions. The keywords were {“Zika” AND [“trip” OR “travel” OR “flight” OR “cruise” OR “vacation”]}. On August 20, 2016, two authors used this search condition to search threads from these forums. In total the search returned 594 Reddit threads, 411 BabyCenter threads, and 1722 TripAdvisor threads. Two authors sampled 100 threads from each forum, with a total of 300 threads. They then conducted an initial round of double coding to find themes about how people assessed risks and made travel decisions in response to Zika virus. The initial coding generated three recurring themes that impacted people’s decision-making processes: 1) problems with authoritative information; 2) what information people needed to make decisions; and 3) what people obtained from forum discussions. With these themes in mind, we kept analyzing more threads from these three sources until we reached what Glaser and Strauss call “theoretical saturation [14].” At that point, we had coded 300 Reddit threads, 500 TripAdvisor threads, and 300 BabyCenter threads. The entire data collection process is illustrated in Figure 1.

Data Analysis

We first coded factual information in the threads, such as types of travel decisions, personal health conditions, travel destinations, questions, and concerns. Through the data analysis, we found that the Zika virus affected a large and highly diverse population, including not only pregnant women and women who are planning for pregnancy, but also men who have female partners, single young women, family members of young women (pregnant or not), and family members of someone planning to travel. People seeking information were not limited to those who started the initial posts. In many threads, we observed those who left comments were also looking for similar information regarding a particular location. People had to consider traveling to Zika affected countries and territories in the face of warnings about Zika virus outbreak, due to work demands, job changes, travel plans that could not be cancelled or refunded, and personal issues.

To explore the processes through which people made risk assessments about Zika, we again utilized a grounded theory approach [14] to analyze our data, in which researchers inductively build theory that is directly grounded in the data. Our analysis included forum conversations, including both posts and comments. Using the three main themes we generated during data collection, two authors read through data, coding data according to our

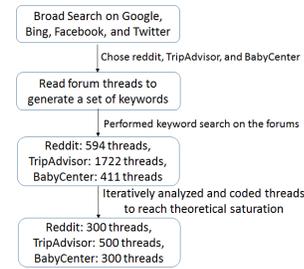


Figure 1. Flow of Research Methods.

themes and comparing new data to themes we had already identified. We continued examining relevant data to generate sub-themes under the three major themes. Through several rounds of reading, coding, and comparing emerging data to existing themes, we generated several sub-themes to describe the weaknesses that people revealed in authoritative information, the types of information they came to online forums to look for, and the types of help they obtained from the online forums.

FINDINGS

In general, people who participated in the online forums studied felt uncertain when making decisions regarding where to travel, whether to travel to affected areas, what to do during travel to prevent infection, and what to do after traveling back. In this section, we report three themes that emerged from our analysis of forum discussions. We first discuss the challenges people perceived when using information from authoritative resources. We then report the types of information that people were seeking in online forums. Lastly, we discuss several concrete ways in which forum discussions helped people to make travel decisions.

Problems of Authoritative Information

People frequently shared links to Zika-related information published by authorities, such as public health agencies (particularly CDC and WHO), and news media. Many of forum participants, especially pregnant women, also discussed asking their doctors for advice (see Table 1 for the rounded percentages of threads discussing each source).

However, many perceived authoritative information to be incomplete, inaccurate, and insufficient for them to make travel decisions. Our analysis reveals major issues that people identified with authoritative information from three types of authorities: disease control agencies, doctors, and media. We identified six types of issues people repeatedly

	Agencies	Healthcare Providers	News Media
Reddit	73%	60%	32%
TripAdvisor	61%	26%	22%
BabyCenter	76%	57%	81%

Table 1. Percentages of threads discussing each type of authoritative information. One thread might discuss multiple sources.

raised when discussing information from these sources, described below.

Inaccurate Scope: In posts regarding the CDC, people often complained about the inaccurate scope of the CDC's information. The CDC website maintained a detailed map of Zika cases reported in the U.S. However, regarding other countries and territories, oftentimes entire countries were listed as risky destinations on the CDC watchlist without detailing certain high-risk geographic areas. The CDC also provides elevation maps of some affected countries to facilitate decision-making, since mosquitoes that spread Zika usually do not live at elevations above 2000 meters. However, the CDC also noted that these maps did not indicate absolute risk, the maps did not depict elevation accurately, and travelers to high elevations could still be infected with Zika from human-induced transmission.

Nevertheless, people who planned to travel were often only interested in a specific city or area rather than the entire country. It was also challenging for some people to limit their itineraries to areas of low elevation. Thus, they desired more detailed information about specific areas. The following post shows a Reddit thread expressing dissatisfaction with the CDC's official information:

All I keep hearing is Zika and Brazil in the same sentence. But Brazil is a big country... I never hear what areas of Brazil is being affected...How big of a concern is it in Sao Paulo area?

In this post, the author expressed dissatisfaction with the CDC marking the whole country of Brazil 'risky,' while they require city-specific information.

Questionable Information Sources: Many questioned how public health agencies assessed the situation in all countries listed. They were unable to find information about methods on agency websites. For example, here is a comment from TripAdvisor:

That is the reason the CDC/PAHO/WHO does not have true and accurate data on where and how wide spread the disease is. With only 20% of infected people having symptoms that leaves 80% with no symptoms at all...I have emailed the CDC questioning the validity of their list of countries with known zika activity...

This post exemplifies questions that were raised regarding agencies' accuracy and lack of reporting information specific to local areas. It also points to transparency issues that plagued some individuals' trust in these agencies.

Information Delay: Many posts indicated that individuals believed that public health agencies could not gather information about new cases quickly enough to provide accurate, up-to-date information to the public. These individuals perceived a time delay between when a case occurred, when it was reported, and when it was listed online. For example, a BabyCenter user discussed her concern about the CDC's information.

So far no locally transmitted cases in Florida but who knows how this will change... My issue with the "locally transmitted cases" stat is the fact that typically they only find out that cases are being locally transmitted a month or so after the fact.

People observed that authoritative information was slow amidst a time-intensive public health crisis. Temporality became a critical dimension in determining information's usefulness.

Overgeneralized Recommendations: Some considered the CDC's recommendations too broad and uncertain for them to follow. For example, a woman who was trying to conceive posted on Reddit:

Our plan was to...go full-force into fertility mode. Vacation is supposed to be in 2 weeks. Now there's a CDC notice that our destination has reported zika cases, and they're saying that anyone trying to get pregnant shouldn't travel there. They don't know anything about how long it can remain in sperm...I'm seeing things like "if you are pregnant and your partner traveled somewhere with zika, don't have sex for the entire pregnancy" - which obviously...isn't going to happen.

In this case, the CDC's recommendation was very conservative, but individuals felt it was untenable and overly general. Online forum users voiced a need for more scientific details to make better decisions.

Distrust towards the agencies: Some individuals went so far as to voice distrust in the CDC's reporting of facts, based largely on past perceptions of the CDC. For example, a Reddit conversation between two users:

User 1: The CDC lost major credibility for me when they came out and said that no women of childbearing age who were not actively trying to prevent pregnancy should be drinking... [that is] LAZY.

User 2: Yeah, it's important for folks to remember that they're a politicized body, not just scientific...That level of nannying and borderline slut shaming, though... gah.

In this case, two users observed that the CDC's past warning to young women to avoid all alcohol was (in their opinion) overly conservative and not based purely on scientific evidence. This perception bled into their assessment of the CDC's guidelines regarding Zika, which they judged to be overly general and politically biased.

Inconsistent Information from Healthcare Providers: Many posts relayed information gleaned from consulting medical professionals. However, doctors seemed to have varied knowledge and risk evaluation of Zika and offered multiple, often confusing, suggestions. Sharing information on the forums further revealed that medical advice was sometimes conflicting. The following user reported encountering physicians with little knowledge of the virus:

I personally found the doctors in Canada to be very uninformed about mosquito-borne viruses. I contracted

dengue and when I showed up in Emergency in Toronto they had no idea what to do. In my opinion, the doctors are actually better equipped to deal with it in Mexico... where they see cases of it more often.

In some posts, we found that fearful individuals reported requesting information from multiple doctors and receiving conflicting suggestions. Here is a post from Reddit:

My boyfriend booked us a cruise to Mexico months ago for my birthday and we were so excited to go! I got the ok from my doctor (I'm 16 weeks) and thought I was in the clear. I went to get my papers signed off on a couple days ago and another doctor...said he won't sign off because of the risk of the zika virus.

Some people even received conflicting advice from the same doctor, as shown in the BabyCenter post below:

Anyone planning a warm trip this winter...thoughts on if it's safe to go to Florida? My Dr. told me "on the record" he wouldn't go..."off the record" the % that you would contract Zika is so so so minuscule that he doesn't see an issue.

The “on/off record” binary in the doctors’ advice reveals an underlying motivation centered on liability. The “on record” recommendation is in line with the CDC’s suggestions that typically advise the most conservative measures possible to limit exposure, yet this patient received mixed messages from their physician making it hard to arrive at a decision.

Exaggerated Media Reports: People suspected that the media tried to attract the public’s attention by exaggerating the influence of Zika without providing sufficient information. For example, a Reddit user wrote:

Disease outbreaks are treated very dramatically by American media... How worried should I actually be about Zika?

Similarly, in a BabyCenter thread, a person wrote:

Just wear bug spray and long clothes...you'll be fine. The media is making a bigger deal out of this than it needs to be, just like every year whether it's west Nile, mad cow disease, the bird flu or some other "epidemic"... I wouldn't cancel if I were you.

People were concerned that media was not reporting the risks posed by the Zika crisis in an objective manner. This fear muddied available information and made it harder to ascertain which information was accurate.

Desired Information about Zika

Feeling that authoritative information was insufficient as a

	Local info.	Alternative info.
Reddit	58%	5%
TripAdvisor	84%	1%
BabyCenter	44%	23%

Table 2. Percentages of threads seeking other information.

basis for travel-related decision making, people turned to online forums to seek information that they could not obtain from authoritative sources, including local information and alternative authoritative information (see Table 2 for detailed rounded percentages).

Local and hyper-local information

People sought information about specific locations. They preferred to hear such information from individuals with first-hand experience, including previous travelers and locals. To get local information, people often posted on location-focused or topic-focused sub-forums. For example, a pregnant woman who had planned a vacation to Grand Cayman before the Zika outbreak posted on the Grand Cayman Travel Forum, a sub-forum of TripAdvisor:

I know the island is not currently on the CDC restricted site. But I'm wondering how robust the testing is and if there's any information anyone here could provide?... I was looking for advice about the mosquito load or an "inside scoop" on the zika virus from people who have actually been there.

The information that this user and others were seeking concerned specific conditions in a specific locale, information that was completely lacking from authoritative sources. Sometimes, self-identified local residents would answer these questions and provide many details. For example, on Reddit, a couple who were planning their honeymoon asked on May 05, 2016, “Are there Zika cases known by locals on the island?” A local person replied as an eyewitness of a Zika case, “I am not aware of any outbreaks as such, but there have been cases. My gf's mom got it a few weeks back...”

Another form of hyper-local information sought by users focused on the specific preventative measures that local hotels were taking against zika. For example, a user asked about the hygiene standards of local hotels on a regional travel sub-forum on TripAdvisor:

Has anybody been in Jan/16 in [region] & seen anything unusual regarding mosquitos & zika virus in that area? Im pregnant & traveling to [city] Feb 6th. But i'd like to know if the hotels are doing something to protect tourist...

Knowing that mosquitos were a major vector for transmission, many people asked about mosquito conditions during specific timeframes. For instance, on one sub-forum of TripAdvisor, a person inquired about likely mosquito conditions during a specific season near a specific hotel:

How is [city] in March when it comes to mosquitoes? I know it is dry season, does that mean their should not be too many mosquitoes because the chance of rain is slim? I am booked at [hotel name] and was wondering if it is close to the jungle or in an area with lots of vegetation. I was just wondering if this is a big issue in the Riviera Maya area or more in other areas in Mexico...

Seeking Alternative Authoritative Information

People who posted on forums also asked for others' obstetricians' (OBs) opinions. For example, one post stated that the user's OB told them to cancel a trip scheduled for the next week because of Zika. The user asked whether others had had similar experiences, and what others were being told by their doctors. Another Reddit user asked,

I'm wondering if other women have gotten advice this extreme about US-based travel?... Anyone else getting feedback this anxiety-inducing from OBs? ...

Although each individual had different conditions to contend with, much discussion on all three forums centered on sharing physician advice and comparing the advice they were receiving from their respective OBs. By comparing their situations and medical advice, they were receiving access to additional authoritative information, and seeking a second opinion by proxy.

Risk Assessment and Decision-making

In this section, we examine the extent to which people's questions were answered and how responses on the forums shaped the decision-making process of users. We found that people did not just provide information and share experiences. They also analyzed available information from informal online interaction to generate new knowledge amidst a crisis situation characterized by partial, ambiguous, and conflicting information.

Decision-making Based on Local Information

Most posts asking for local information received replies from previous travelers or local people in the user's intended destination. Besides offering local information, respondents often provided local knowledge that potential travelers might otherwise not think of. For example, in the following Reddit conversation posted in August 2016, a man asked about traveling to Florida in a few weeks with his wife. A local resident raised a key issue that might otherwise have gone unnoticed:

Rainy season has started here, which means more water and more mosquitoes. My personal belief is that it will not stay confined to [city]. I live in the vicinity that you are traveling to, and all I can say personally is that I have no intention of getting pregnant until we really understand the impact of Zika in our area.

The upcoming rainy season was confirmed by another person in the same post, who replied:

Rainy season is the key here. I completely agree with you. I'm shocked by the number of people like, "Oh, it's isolated to one neighborhood (one that's already decently moving inland), so you totes don't have to worry!" Like... Why would you even risk this?

In this thread, new local information such as how local weather patterns may affect future pervasiveness of Zika in the area during a specific timeframe were added to the existing body of the user's knowledge.

Similarly, when a TripAdvisor user asked for some local information in a large city in South America, she got a response from a local person:

None yet detected in [country] due to comprehensive ongoing mosquito eradication to combat malaria and dengue, incidences of both decreasing each yr. But, assume if its in the area and all the way up in the US, no one can offer assurances here or up there.

After consulting the forum, the original post's author eventually decided to cancel her trip:

Thank you everyone for your thoughts. After much consideration, we are cancelling our trip. We can always make it back there another time!

In each of these cases, local residents' information and opinions helped people to make decisions based on more nuanced information about the destination, including local weather patterns and other factors that were likely to effect the Zika risk in the present and during specific times of future travel.

Reasoning from Known Information

People often needed to deduce a certain piece of information that was lacking in authoritative information. In the following example, a person attempted to build a logical link between a country's Zika condition and its neighboring countries' Zika condition.

User 1: Can't find any recent reports of Zika within [beach city] has anyone visited recently that can give some further insight?

User 2...My point was quite simply that if you are surrounded by countries and large swaths of land through which the Zika Virus has spread, that there are no "safe places" since the way the virus spreads is how I described. Since most cases of Zika are mild and testing is actually very rare and expensive, then lack of "reports" means absolutely nothing!

Besides using geographical proximity as a way to infer risk level and make suggestions, people also reasoned about Zika risks based on weather in different months. For example, in the following thread posted on BabyCenter on July 11, 2016, people deduced the risk based on time.

User 1: My husband has his annual work cruise coming up at the end of September to the Bahamas (3 day cruise I will be 18w). I have done some research and the CDC has not mentioned the Bahamas as a Zika location. However, there are several countries surrounding the Bahamas that are on the list. I am not sure if we should go this year. What are your thoughts?...

User 2. I am not planning to travel anywhere near zika... From what I've read, zika might intensify as summer takes hold...

User 3: ...I may consider if Bahamas is not on the CDC list, yet. Since the cruise is in September, things maybe different though...

On August 23, 2016, CDC posted a Zika virus travel alert for this particular destination, as local transmission of Zika had been reported [7]. Those people's reasoning and prediction of the Zika risk in this locale proved to be correct.

Pondering Probabilities and Calculating Costs and Benefits
Because authoritative information was insufficient and key information was missing, people were unsure whether it was safe to travel to certain destinations. Therefore, they did not speak about decisions and suggestions in absolute terms. Rather, they talked about possibilities. When they weighed personal costs and benefits of making different travel related decisions, they considered individual differences such as current pregnancy status and whether or not travel arrangements were booked and refundable. The following thread exemplifies this mode of engagement. Advice was not given in an absolute manner, instead, he or she emphasized that each individual had to make their own risk calculations because of individual differences.

The problem is places are not either "safe" or "unsafe." It is just not binary, unfortunately. Instead, there is a spectrum of risk. ... So you have to figure out how much you want to go, and what your risk tolerance is. If you do not want to take ANY chance at all of zika, you should not go - because the odds are more than zero percent that you will get it. For me, I have decided to go. I am not pregnant or immunocompromised and I plan to use mosquito spray. If I were pregnant or immunocompromised, or could not afford mosquito spray, I might make a different decision. But we each have to make our own risk calculations.

The following quote further illustrates how people took a situated, probabilistic approach to assessing risk:

Maybe check with your airline and insurance, and see what the time limits are for cancelling or re-booking without penalties (or with minor ones) and wait it out a bit. You're still 6 months away, a lot could happen in that time.

Some people shared their risk calculation process to inform others. For example, when a Reddit user asked for advice regarding her family's travel plan, a respondent who was considering travel to the same destination during the same timeframe with his pregnant wife shared factors he had considered in the process of making a final travel decision:

We've looked at many of the factors really carefully, and are comfortable going at this point.... Currently, the following factors are in our favor: 1) We won't be going into a humid area. ...2) This is the low season for mosquitoes. ...3) The number of cases confirmed in [country] is still very low....4) Most importantly, we know Zika exists, and can take preventive measures...5) Our hotel has air conditioned rooms... There is still a slight chance that my wife might contract Zika, but compared to all the other risks associated with international travel, that risk is pretty minimal.

DISCUSSION

In this paper, we reported a qualitative study of how people utilized online forums to seek information when confronted with partial, ambiguous, and even conflicting authoritative information. People used local information gleaned from online interactions to inform their risk assessments about travel within Zika-infected areas and areas at risk of infection and to inform consequential travel decisions.

Extreme Uncertainty in a Public Health Crisis

Extreme uncertainty characterized the Zika-induced public health crisis. Uncertainty existed at the fundamental scientific level, among governmental, non-governmental, national, and international public health agencies and individual healthcare professionals. We have identified several gaps in authoritative knowledge leading to this uncertainty, including scientific knowledge about Zika, Zika symptoms, accuracy and temporality of authoritative information, and authoritative recommendations. These uncertainties were often interrelated and tended to compound one another, leading to an exponentially increased level of uncertainty. Scientific uncertainty in Zika symptoms contributed to organizational level uncertainty about identifying and publicizing geographically infected areas and populations. Doubt and distrust arose among laypeople, who judged authoritative suggestions to be an inadequate basis for travel-related decision making. Further, these circumstances are ripe for the proliferation of rumors and faulty information, which further complicates health related decision making amidst crisis.

Gundel [24] proposed two criteria to examine crisis: predictability and manageability. A crisis is predictable, if place, time, the probability, or the manner of its occurrence are knowable [24]. Human-induced crises like bombings and shootings are unpredictable but manageable. Many natural crises, such as seasonal floods and hurricanes, are predictable but not easily manageable. Disease crises are highly unpredictable and difficult, if not entirely impossible, to manage. In our case, the complexity of information seeking was increased because of multiple information sources and dubious credibility of many sources (both because much is still unknown about Zika and because people perceive that different sources present biased information to serve some other end). Our study is unique in that previous crisis informatics research examined information uncertainty largely associated with rumors created by the public, while official information was relatively reliable and informative [47,61]. However, in the Zika crisis, even official information exhibited high uncertainty. Crises that are the subject of previous research tend to be location-based (i.e. natural disasters). This limits the scope of impact, and presents opportunities for sharing local information and dealing with uncertainty at the community and regional level. However, Zika impacts a wide range of dispersed locations at the same time, and a relatively small portion of the population at each location. Local opportunities for navigating the crisis and

sensemaking are limited. Additionally, in the case of natural disasters and human-induced crises, information is often less ambiguous (at least over time). In the Zika case, it was hard to identify helpful information for individuals to make decisions— as the crisis unfolded, the highly uncertain nature of the disease meant that key information, and information needs, were constantly changing.

Information-Seeking Amidst Uncertainty

The extreme uncertainty shaped forum goers' information seeking. They paid close attention to local information shared by previous travelers or locals. In contrast to previous research findings that local information was important for local people to make sense of the crisis situation and respond [29,37,55,61], in the case of Zika, local information was also important for outsiders to make travel decisions. People attached considerable trust to such local information, even when it came from a single source and a stranger. Such local information was hardly verifiable. Each situation presented different information needs. Few people have access to such knowledge, and even fewer report it online. The specificity of desired information rendered ordinary people a crucial information source, and the forums became a site of connection and access to highly situated and contextual information.

While local information sharing was essential for individuals, individuals also learned about the reasoning processes used by others to analyze local information and reach meaningful conclusions. This was essential for people to make risk assessments about their own travel. For example, inferring the probability of Zika in a particular country based on knowledge about its neighboring countries requires geographic knowledge to make connections. Such reasoning processes were missing in authoritative information. Personal risk assessment took place in a situated, bottom-up manner. People had to assess risk for themselves and their families based on their own conditions, resources, and needs. These included one's own health condition, travel necessity, and complex local and hyper-local (i.e. hotel based) information. There was no clear answer; some decided to alter or cancel trips, while some deemed insect repellent a suitable protective measure.

Implications for Health Risk Communication and System Design

Findings about information seeking, risk assessment, and decision making resonate with Palen and Anderson's call to pay attention to important, creative efforts at the "corners of social media space" [45]. As uses and gratifications theory explains, people are not passive consumers of media, rather, their choices of media are goal-directed and purposive [52]. Our study stresses a need to identify which kinds of information sources to use for certain kinds of information. Previous research has identified the importance of social media for public health agencies to communicate health risk effectively [10,43]. The deep uncertainty characteristic of many disease crises also means that authorities' warnings and guidelines are likely to be fluid, subject to changes

based on the scope of the crisis and evolving scientific knowledge of the disease. Thus, it is important to effectively communicate emerging information to the public, and to communicate the quality of available evidence underlying official guidelines. Lastly, it is also important for various authorities to form consensus regarding disease knowledge and preventative measures.

Since authoritative information about Zika contained several shortcomings identified in our study, we propose a participatory approach where laypeople can engage in information sharing, curation, and analysis. For example, local residents and previous travelers had rich knowledge that only surfaced on online forums. However, such information sharing only occurred in a question-and-answer scenario in a random manner. It is thus important to consider how people can be encouraged to share information that they consider critical for assessing risk and making decisions amidst public health crises. Designers should consider ways to visualize shared local information in terms of scales and timeline, as well as highlight the rationale behind decision making.

Finally, disease crises like Zika have broad geographic reach across different countries. Language barriers pose a challenge to people seeking information about a specific location where another language is spoken. In this study, English speakers gathered on forums where English is the primary language, but they looked for information in Latin America where Spanish and Portuguese are spoken. In our pre-screening phase of data collection, we observed much information sharing in the latter two languages. Effectively supporting social media information exchange during global public health crises may be augmented by finding ways to bridge geographic and language boundaries.

CONCLUSION

We reported a qualitative study of personal risk assessment and travel-related decision making during the Zika crisis. Through analysis of discussions on three forums, we showed how uncertainty characterized the crisis, as well as people's online communication and decision making. Local information was key to individuals' information seeking in the face of Zika, while probabilistic reasoning that draw upon rich local knowledge supported their decision making processes. The study provides insights into public health crises induced by diseases, as well as novel modes of intervention focused around information seeking and sharing on social media.

ACKNOWLEDGMENTS

Many thanks to Kai Zheng, Tera Leigh Reynolds, and Clara Caldeira for their cogent comments, and to our anonymous reviewers for their insightful feedback. This work was partially supported by the National Science Foundation under grant HCC-1219197 and 2015–2016 UC Irvine Academic Senate Council on Research, Computing and Libraries (CORCL) award.

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