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ORIGINAL ARTICLE

Ebola and healthcare worker stigma

MISSE WESTER[1] & JOHAN GIESECKE[2]

[1]*Division of Risk Management and Societal Safety, Lund University, Sweden, and* [2]*Department of Medical Epidemiology and Biostatistics, Karolinska Institute, Stockholm, Sweden*

Abstract

Aims: Exposure to infection is a risk for all healthcare workers. This risk acquires another dimension in an outbreak of highly contagious, lethal disease, such as the Ebola epidemic in West Africa in 2014. Healthcare workers are usually well and correctly informed about the risks from such diseases, but family, neighbours, friends, or colleagues may react strongly to the risk that staff might bring infection home from an epidemic overseas. Research around such stigmatization is scarce. We wanted to investigate how common it is, which expressions it assumes and how it is influenced by dissemination of information. *Methods:* We interviewed a sample of Swedish healthcare workers who had worked in West Africa during the 2014 outbreak of Ebola, as well as one close contact for each of them, about reactions before leaving and after returning, and also about information received. ***Results and conclusions:*** **The majority of contact persons reported no or little concern, neither when the healthcare worker revealed the plan to leave, nor on the healthcare worker's return. The prevailing reason was trust in the judgement of 'their' healthcare worker, mainly using information received from the healthcare worker to assess risks, and relying little on other information channels. This means that the person assessing the risk was at the same time the hazard. There were indications that instructions regarding quarantine and self-isolation were less stringently followed by healthcare workers than by other aid workers in the outbreak, which could give confusing signals to the public. Simple, clear and non-negotiable rules should be preferred – also from an information perspective.**

Keywords: *Outbreak, infectious disease, transmission, healthcare worker, risk assessment, stigma*

Introduction

Exposure to common infections is an occupational risk for many healthcare workers [1, 2]. But even if several of these diseases are non-trivial, the risk acquires yet another dimension in an outbreak of highly contagious, lethal disease. Examples of such outbreaks are the AIDS epidemic in the early 1980s, the SARS outbreak of 2003, the influenza pandemic of 2009 and, most recently, the epidemic of Ebola virus disease in West Africa in 2014 and 2015.

One can assume that healthcare workers are well and correctly informed about the risks of highly contagious disease; that they are aware of precautions to be taken and trained to observe them; and that they can feel reasonably comfortable in their professional role. But family, neighbours, friends, and colleagues may receive their information from completely different sources and may react very strongly to the risk that staff bring infection home from the hospital – or from an epidemic overseas.

There is thus a risk that healthcare workers become socially stigmatized, both at work and at home, and there exist anecdotal accounts of such stigmatization, ranging from a partner's strong dislike and the wary attitudes of colleagues (e.g. avoiding sharing a lift) to discussions about their children's right to attend day care. However, research around how common such stigmatization is, which expressions it assumes and

Correspondence: Misse Wester, Division of Risk Management and Societal Safety, Box 118, Lund, 22100, Sweden. E-mail: misse.wester@risk.lth.se

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how it is influenced by dissemination of information is surprisingly scarce.

We decided to conduct an interview study with healthcare workers who had been deployed to assist with the Ebola virus outbreak in West Africa in 2014, and with one close contact for each of them. We wanted to study incidents of stigmatization and especially how risk perception was influenced by the information received by the different groups.

The international response to the Ebola outbreak in 2014

The international response to the Ebola crisis has been criticised for being slow, as authorities were unprepared [3]. However, as the epidemic unfolded, several international agencies became involved. For example, *Médecins sans Frontières* (MSF) had roughly 4000 national and 325 international staff working at the peak of the outbreak, and over 10,000 patients were seen at the Ebola centres that were set up [4]. Similarly, the International Federation of the Red Cross also deployed volunteers to the affected areas, distributing information and providing medical expertise [5].

The deployment of international healthcare workers during this epidemic was slow at the onset. To better understand the reason, a few studies were conducted to investigate how the Ebola outbreak was perceived by this group [6–9]. The results from these studies show that for the healthcare workers who were uncertain whether to go or not, the three main reasons for hesitancy were: lack of information on the situation and how they could help; fear of contracting Ebola; and their families' reactions or resistance to them going [6]. For those who had decided not to go, their families' reaction was the primary reason for this decision. Another study found that, of a sample of physicians in the EU, only 15% had considered working in Ebola-afflicted areas at all [9]. This study also lists family concern as being a factor that hinders volunteering, followed by the perception of being essential in one's current position.

Stigmatization after returning was not seen as a factor that would deter professionals from going [9]. Interestingly, another study conducted in healthcare settings indicated that co-workers would feel uncomfortable around a colleague who had returned from working in regions with Ebola [7]. This stigmatization of healthcare workers was a real problem for indigenous healthcare workers active in communities struck with Ebola, as returning home was connected with suspicion and avoidance [10].

Information about how Ebola is transmitted and what precautionary measures could be taken to protect oneself from exposure was, of course, very important for potential healthcare workers when making decisions about volunteering or not. However, there are results that suggest that healthcare workers are less knowledgeable about Ebola than those who did not receive special training. According to the study by Chan et al. [7], fellow healthcare workers would feel uncomfortable around a colleague who had worked in Ebola-afflicted areas but had not been directly exposed to the virus. This indicates that even if this group had been trained in how infectious diseases spread, this did not diminish their perception of risk. Contrary to this, the results from Sridhar et al. [8] show that increased training did not affect the level of knowledge about Ebola among professionals, but that it did decrease their perception of risk. This indicates that risk perception is influenced by more than factual information. Indeed, studies in risk perception suggest that it is the consequence of a particular risk, rather than the probability, that affects risk perception [11].

Media reporting of the outbreak of Ebola 2014

Reporting on the outbreak in Europe and the USA concentrated on medical, statistical and public health issues, but some more personal stories about individual suffering could be found. Public health authorities tried to speak with one voice and focus on transmission, symptoms, personal protection and number of affected victims. This 'formal' message was, however, re-framed in the media: for example, personal stories of victims of Ebola were often reported [12]. It has been argued that what was communicated in the media was not the public health policy that should ideally have been reported. Stated another way – what was reported did not necessarily convey the best public health policy [13]. Some reporting also focused on local resistance from the public against measures taken by national authorities and international aid organizations. This reflects the stigma around Ebola, the problem with local practices (such as burials) and public health concerns. In Europe, the outbreak was seen as a mostly African problem and not a large threat to European countries, even if there were examples of xenophobic attitudes linked to reporting on the outbreak [14, 15].

In light of these results, we wanted to investigate what role the healthcare workers' families – partners, friends, parents or siblings – had on their decisions to go and work in an Ebola-affected area, and how these reacted on the healthcare workers' returns. We also wanted to see what type of information they received and whether media reporting affected their perception of risk related to Ebola.

Method

In April 2016, six healthcare workers to be interviewed were identified by contacting the Swedish branch of MSF, by snowballing and by approaching employees at the Infectious Disease Department of the Karolinska Institute University Hospital in Stockholm. All six had worked in Sierra Leone in late summer or autumn of 2014. Each healthcare worker was asked to name a contact person, such as a partner, close friend or relative, who could also be interviewed. The healthcare workers were three doctors, two nurses and one biomedical analyst. The contact persons were two partners, two sisters, one mother and one friend.

The 12 subjects were interviewed in May or June 2016 for about one hour each by both authors jointly in semi-structured formats, one for those who went out and one for those who stayed behind. For logistic reasons, half of our 'couples' were interviewed together and half separately. We cannot say if candour was influenced by the model used, only that we did not register any such differences. The questions centred on information received (for both groups), on experience of stigmatization for the healthcare workers and on issues around transmission risks for their close contacts.

The interviews were recorded and transcribed and textual analysis was performed using NVivo 20 software to discern common themes and views.

Results

We conducted a thematic analysis of our material, based on the categories of the semi-structured information. Interview transcripts were coded separately by the researchers; the fit of the material in the categories was discussed in cases of disagreement. The themes were 'information', 'experiences of stigmatization' and 'risk perception'. One additional category – 'compliance' – emerged during the analysis.

Information

All healthcare workers felt that they had been adequately informed by their deploying organization before they left, and that they had been sufficiently trained in the use of protective clothing. However, most of them also admitted that at that time much was still unknown about transmission risks, and one even said that had she known beforehand what she then knew, she would not have gone. Almost all of them also experienced minor or serious incidents during their stay, such as nearly recapping a needle by hand, riding in a taxi with a driver who fell ill with Ebola virus disease the day after, etc. One of them had clearly unprotected exposure to a severely ill patient and was repatriated the following day.

Regarding the contact persons, it was a constant finding that they almost exclusively relied on direct information from 'their' healthcare workers regarding risks, both concerning the risk of working in the outbreak area and the risk of spread after return.

> 'So I never cared to read up on Ebola and, like I said, she's trained, she knows her job and she knows about the risks better than I know. So I trust her judgement and I didn't look actively [for information] on Ebola afterwards either.' (Informant P, contact person)

The contact persons had not read the printed information issued by the sending organization, and they had not followed reports of the outbreak in detail. A few telephone calls and irregular emails provided them with the information they needed during the deployment.

> '…now I barely remember getting that paper, but…' (Informant M, contact person)

The information distributed was thus mainly aimed for training healthcare workers and was then indirectly, or by association, disseminated to family or friends. This seemed to be the way information travelled, despite ambitious efforts from both the Swedish Civil Contingencies Agency and MSF to provide those who stayed at home with information. Overall, our subjects seemed to trust that organizations involved in this work 'know what they're doing' and that healthcare worker would not be dispatched to areas or put in situations where proper precautions could not be taken.

In our sample of contact persons, we thus found that media played little role in perception of risk.

One of the healthcare workers we interviewed was among the first Swedes to go to Sierra Leone; she was consequently interviewed in the field several times by Swedish television. This was hard on her family:

> 'So it was a lot of media and stuff. And it became difficult for [the family]. It was kind of… Since the situation was like it was. [ ] Yes. So they had to watch their mother on TV, when they sit and I am on the screen saying that this is like hell here and this is the worst I've ever seen.'

Not being able to explain in person to the ones left behind seemed to be a concern for those in the field.

Risk perception

Risk perception among contact persons. The majority of the contact persons felt no or little concern when

'their' healthcare workers revealed plans to leave for Africa – in fact several of them had already expected this. For some, it seems the decision to go on missions is part of the character of the person.

> 'So, I had it presented to me. [ ] And I knew it couldn't be stopped.' (Informant M, contact person)

None of them admitted special concern of becoming infected after the homecoming, but several of their actions showed that this was not completely accurate: at least one couple practised safe sex during the quarantine period of 3 weeks, and a friend contact person postponed a meeting with his healthcare worker until the 3 weeks had passed. The rationale behind this was that it just felt unnecessary to take risks if one did not have to. An interesting observation was that their assessment changed when there were children involved. Two of the contact persons had young children, and even if they themselves felt that they could meet with their healthcare worker shortly after his or her return home, they were much more hesitant when it came to their children.

> '…then, I think it's not right to expose your closest to this and say "It's ok, I'm coming home but I won't work for 2 to 3 weeks," or if it's 4 weeks. "But I will see my friends and in particular [your] sweet children that have an immune system that is developing and would love to cuddle and kiss you." No, really weird. It doesn't add up I think, in my head, really.' (Informant A, contact person)

There were a few concerns about the natural course of an Ebola virus infection. For example, one informant expressed concerns relating to Ebola victims becoming contagious one hour after showing symptoms. The official recommendation to potentially exposed healthcare workers was to remove themselves from public areas as soon as they developed a fever. But for a relative, having spent a whole day with his or her healthcare worker, this information was not enough.

> '…we spend *x* hours with you or so. Is there a risk? We were never told at all, nothing.' (Informant A, contact person)

This indicates that risk perception among contact persons was influenced by the lack of scientific data. Also, the uncertainties in the early days of the Ebola outbreak cast some doubt over how organizations would manage to evacuate potentially exposed healthcare workers.

It should be noted that since we only interviewed healthcare workers who had been deployed, we do not know how often negative reactions from close contacts led to a decision not to go.

Risk perception among healthcare workers. The recommendations from the Swedish health authorities did not prescribe strict self-isolation for 21 days, but rather that the healthcare worker should meet an infectious disease consultant or a medical officer of health directly on return home and agree on restrictions to be observed. However, all healthcare workers measured their temperatures twice daily; in two instances, they cancelled meetings with relatives after having noted a slight temperature rise.

One way to control the risk to which the healthcare workers were exposed seemed to be by using routines or rituals when working with patients infected with Ebola.

> '… What was important, it was to practice the routines "How to dress" or to dress is one thing, but how you undress your suit [ ] how you keep yourself safe.' (Informant Nurse A, healthcare worker)

> 'And every time I went out, then that was the most important, most important. Because I didn't want to leave and then think "Did I really do that last thing? When the suit and everything was off and I had washed my hands? Was it really right?" ' (Informant Doctor A, healthcare worker)

To some extent, is seems that control was important for both the healthcare workers and their contact people.

Healthcare workers' perception of stigma – own and others

None of the healthcare workers reported any major experience of stigmatization after their return, but there were some smaller incidents, such as a colleague taking another elevator at work, or a neighbour staying on his side of the fence when chatting. They felt they could talk about their deployment rather freely, even if one of the sending organizations had warned its volunteers not to.

Again, we found that when children were concerned, the experience changed. That the healthcare workers could be looked upon with some apprehension was understandable, even if it was slightly hurtful. When this spilled over to how the healthcare workers' children were treated, it became worse:

> 'I can tell if people are afraid of me and such. And I can understand it and I can try to avoid. But that my children would be affected or stigmatized in some way, over something I did. That was… that was just awful, I

> got really sad and upset and such.' (Informant A, healthcare worker)

One of our contact persons also avoided doing specific things that could lead to unnecessary talk. For example, when it was his turn to bake for the office afternoon coffee-break, he decided to switch dates with a co-worker to avoid speculation on whether the home-baked goods could contain the virus.

Compliance with restrictions

In our sample, one healthcare worker had been directly exposed to one person infected by Ebola, and another had been in direct contact with another exposed healthcare worker. On both occasions, we found that the healthcare workers were very confident in their own ability to determine if and when they would show signs of infection after their return.

> 'Because we [the exposed healthcare worker and the medical officer of health] discussed if I should work or not. Because I really could have at that point, I think. But that wasn't the opinion of the [medical officer of health], and they could have been right, so if I developed a fever then and – but I've never been infected at work before in my life, so I don't know why I would have been there [working with Ebola] – but it would have been troublesome.'

It is likely that healthcare workers were given greater latitude in deciding which restrictions to observe when returning from the outbreak than non-medical staff.

Discussion

Although there were some minor situations when friends or colleagues avoided close contact with the healthcare workers, none of them stated that they had felt stigmatized for an extended period of time. This is in contrast with one report from the USA [7], where colleagues' attitudes towards a physician who returned from the Ebola outbreak were clearly more cautious. It should be noted, however, that in that study the colleagues were asked to fill out an anonymous questionnaire, which probably made it easier to admit sentiments that they refrained from expressing openly.

The contact persons did not report any particular fear of becoming infected by their returning healthcare worker – with exceptions concerning children in two cases. However, their actions indicate that they underplayed their concern (both in the actual situation and in our interview), and several of the pairs did observe some kind of distancing during the 3-week incubation period. It was obvious that even if all information received pointed to 'no risk', the contact persons still applied a precautionary principle.

The recommendations from the Swedish health authorities divided returning personnel into four categories, depending on level of exposure to patients with Ebola virus disease. However, not even for the healthcare workers in Category 4 was strict self-isolation prescribed. Instead, recommendations were based on a risk assessment arrived at in a discussion between the healthcare workers and an infectious disease consultant or a medical officer of health. This made the rules around isolation slightly fuzzy, and we found that healthcare workers might have been allowed greater latitude in interpreting the recommendations than other staff categories. From an information perspective – taking into account the message that these recommendations would give to the public around the healthcare workers – it would probably have been advantageous to have clearer, simpler and less personalized rules uniformly applied to returning aid workers. This could also be interpreted as a reflection on how much confidence is placed in healthcare workers' knowledge – both of how to avoid getting infected but also to be aware of one's own possible symptoms. Even if information and training certainly increase knowledge [8], it is ethically problematic to allow one professional category to have greater power over their own situation than others.

Linked to this is the finding from this and other studies that control is an important factor when dealing with risk. For our healthcare workers, one example of this is the rituals they engaged in to minimize risk. For our contact persons, however, control over how they wished to interact with their healthcare workers was also clearly expressed. In some cases, this was respected; in other cases it was not. Even if it is important for a person who has been in the field for weeks to be greeted by his or her family, it must also be part of the training to respect and honour the wishes of their family and loved ones, regardless of what the medical scientific information states. Being able to have control over one's own situation is vital to the well-being of individuals facing risks and should be respected.

A UK study [6] also included respondents who had at first contemplated volunteering for the Ebola virus outbreak, but who later decided not to go. One of their main reasons for this change of mind was the negative reactions from their partners. Since we only interviewed healthcare workers who had been to Sierra Leone, we could not study this 'stigmatization that never happened' and we do not know how common it was. Also, a drawback of our sampling method

is that it mostly identified healthcare workers who were already experienced from other outbreaks in less developed countries, and whose contact persons were thus not new to the situation.

The most interesting finding in our study is that all the contact persons almost exclusively relied on the information they received from 'their' healthcare workers and that they collected very little additional information on which to base their perception of the risk posed on return. This creates a rather unique situation when it comes to assessing a risk, since the main information source is at the same time the potential hazard. A person explaining the assessed risk of living close to a nuclear power plant to the public in the surrounding area is not him- or herself radioactive. After having worked under severe pressure – and in sometimes frightening situations – the healthcare workers all expressed a wish to get back to a normal social life as soon as possible. The objectivity of their risk assessments as regards face-to-face contacts before the 3 weeks had passed could thus in some cases be questioned.

One recommendation we would give is that the sending organization, already before the deployment, identifies a named, objective person and arranges for a meeting between this individual and the contact persons. The contact persons could then turn to this objective individual with questions regarding risk of infection after the return.

In conclusion, the issue of stigmatization on return from an outbreak seems less of a problem than could perhaps be expected. One should note, however, that our study includes mostly experienced field workers as well as contact persons who were – or at least felt – well-informed about the risks. Moreover, the actions of the contact persons did not always mirror their expressed feelings about these risks.

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