Taking rumours seriously

Why organ thieves matter to malaria control

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This article documents what happened when a group of researchers tried to gain consent to carry out a survey for a malaria-related research project in the Sabah region of Malaysia at the end of 2015. Within weeks, rumours had begun to spread on social media that the team were fake and using the guise of a research project to steal organs. The refusal to participate is often considered only relevant to researchers in so far as it has implications for the project itself. However, non-participation in research is a valuable area of inquiry in its own right, precisely because of what it reveals about what lies beyond the research project.

Rumours are for real

Rumours that contribute to non-participation are indicative of the murky space of social relationships and connections that surround health. In fact, as is illustrated in this case study, rumours do more than just reveal or represent this interconnected world: they incite affect. It is within this space that bodies are put at risk of a number of health issues ranging from malaria to organ theft and this is thus where researchers should focus more attention.

On 10 November 2015, a group of Malaysian fieldworkers entered *kampung* (village) Tinindoi in the Sabah region of Malaysian Borneo in order to take blood samples to screen for malaria. The researchers were carrying out a survey as part of an international research project called 'Monkeybar', led by the London School of Hygiene and Tropical Medicine, which was investigating risk factors for an emerging strain of human malaria – *Plasmodium knowlesi* (*P. knowlesi*). Shortly after beginning work, the lead researcher received a call telling him that villagers had ordered the research team to leave within the hour.

The researchers immediately convened a community meeting with *kampung* residents to address their concerns. In a tense exchange, villagers reported hearing that the team were 'fake' and were using the guise of the malaria research project to 'steal' villagers' organs. The situation escalated. Community members arrived with machetes and chainsaws, chasing the research team out of the village by throwing stones. Ultimately, the team were refused re-entry to carry out their survey. Similar accusations circulated in other *kampungs* via social media and residents warned each other against taking part in the project. Within weeks, hundreds of villagers were refusing to participate.

Such refusals to take part in health research are not unique to this project. In order to try and untangle some of the factors that led to their emergence here, as well as the implications, I conducted in-depth interviews with members of the field team following the completion of the survey. My findings are presented in this article.

Field staff viewed the claims that they were organ thieves as 'just rumours'. In their opinion, such accusations stemmed from the villagers' lack of 'understanding' of scientific processes, coupled with their cultural 'beliefs' in malevolent entities. Staff dismissed the organ thieves as fictitious and therefore irrelevant subjects of these stories. Instead, they took seriously the emergence of 'false' information in a more general sense. For them, it was an indication that the research team needed to do things 'better'.

Conversely, for the anthropologist, rumour is important precisely because of the kind of 'truth' it implicates – a truth that needs to be engaged with here, if the scientists are serious about controlling malaria. In a context of widening health inequalities, increased migration, (legal and illegal) organ exchange and burgeoning social mediascapes, rumours shed light on an interconnected, multifaceted and opaque web of relations (Bubandt 2017). While these are difficult for anyone (anthropologist, health worker or participant) to untangle and tackle, they are potentially very relevant to how malaria exists.

However, rumours do more than just speak *of* the sociopolitical realities that surround health. Imbued with materiality, rumours also speak *to* these realities – they incite affect. As such, the 'rumoured' organ thief *is* a relevant social actor that travels between individuals, villages and social media spheres invoking emotions such as intrigue and fear, and actions such as text messaging and stone throwing. In doing so, the 'fictitious' thief both occupies and constructs a 'true' web of ambiguous affects and entanglements. Following Bubandt (2017), I argue that it is precisely within this murky space of complexity and uncertain connections that anthropologists and health professionals should be engaging.

Rumours 'go viral'

Monkeybar is a multi--disciplinary research programme that explores the biomedical, environmental and social risk factors for human infections with *P. knowlesi*. *P. knowlesi* is a primate malaria that afflicts long-tailed and pig-tailed macaques but also has the potential to infect humans via bites from the *Anopheles leucosphyrus* group of mosquitoes (McWilson & Wharton 1963). Monkeybar is exploring conditions surrounding the transmission of this zoonotic infection in two sites: northern Sabah in Malaysian Borneo and Palawan Island in the Philippines.

Recent reports from district hospitals in Borneo indicate that *P. knowlesi* is now the most common cause of human malaria in the Kudat region of Sabah (Singh & Daneshvar 2013; William et al. 2013). Consequently, Monkeybar has been running primatological, entomological and social science activities in the area since 2012 as well as conducting a clinical case control study. In 2015, the team began a malaria survey in over 170 *kampungs*, taking blood samples to detect exposure to the *P. knowlesi* parasite and interviewing participants regarding their movement patterns, travel history and land use practices. Together, these activities are vital for understanding the complex relationships between humans, parasites, mosquitoes and macaques that contribute to the transmission of *P. knowlesi*.

As is now compulsory in all research involving human subjects, Monkeybar was approved by various research ethics committees and organizations before any data collection began. Before going into the field, the research team made contact with public health offices at district levels, asking them to inform local public health teams within each *kampung* of their planned survey-related activities. At a *kampung* level, the

team, which was composed of Malaysian fieldworkers, gained approval from the village Development and Security Committee (JKKK) representative and the *ketua kampung* (village leader) of each area. At an individual level, they sought free, prior and informed consent from every participant, providing them with written and verbal information regarding the project as well as contact details of research supervisors should any questions or issues arise. The researchers made themselves easily identifiable as they conducted their work by wearing official uniforms and driving branded vehicles. In total, over 10,000 participants were recruited in 10 weeks from over 170 *kampungs*.

As is often the case in health research, the field team recounted that a minority of people declined to be involved at the consenting stage. Refusals came from young children who were afraid of having their fingers pricked for blood or mothers who didn't want their young babies to undergo the procedure. In some cases, adults agreed to take part but later asked for their samples to be returned to them stating that, on reflection, they didn't want the samples to be stored in the United Kingdom for fear they would later be used for other purposes. However, in *kampungs* where the team had not conducted other aspects of the Monkeybar project and were therefore less known to local people, more significant problems began to emerge. Community members repeatedly questioned who the team were, where they had obtained their permissions from and why they were taking blood samples rather than the local public health staff with whom villagers were more familiar. In particular, potential participants were keen to make sure that the research teams had approval from the local *ketua kampung* and JKKK representative before giving their individual consent. In some cases, villagers were worried they would have to pay foreign researchers to take their blood and called the local hospital to check. In one *kampung*, questions over identity and authority led to numerous refusals as villagers said they were unhappy about the fact that the team were working with *orang putih* (white people/foreigners). They accused the Malaysian field team of being 'servants of Obama'.

As well as questions about identity and authority, individuals also queried the selection criteria. People asked why they had been chosen to participate but not their whole family or neighbours. A member of the research team explained:

> I think they didn't understand … why we had randomly selected them … I think one the villagers even said 'you are lazy because you won't do the whole *kampung*'. It is very different from the public health team's approach [there] which is just convenience sampling, so it is anyone who turns up. So there was a lot of confusion about why we were doing it that way.

Prior to selecting participants to be surveyed, the research team enumerated all the houses in each village. Uncertainty surrounding this process led to anxiety amongst some:

> We put a small sticker to mark the house number so that we could find it again … but the villagers told us that they thought that we were marking their house to do something bad. With the stickers, we try to put it somewhere so that the rain will not ruin it, so we put it somewhere [hidden] and they thought that we were hiding the mark from them …There is one family that stayed up the whole night because they were afraid something bad would happen.

A more consistent and distressing problem for community members was the suspicion and fear that emerged around the project being 'fake' and a guise for more disturbing operations:

> There were not many villagers around in their houses at that moment and some villagers said that in the morning someone went house to house to tell the villagers that fake doctors and nurses were going to come and put drugs inside them during the finger prick [in order] to steal their organs.

In this context, information was spread at pace due to social media. Specifically, many of the villagers told the fieldworkers that they had sent and received information regarding the project via the smartphone messaging service, WhatsApp. In Sabah, it is common for *kampungs* to establish WhatsApp groups for all their inhabitants allowing hundreds, if not thousands, of village members to keep in constant contact with each other and rapidly share information. Villagers told fieldworkers that prior to the Monkeybar project numerous messages and pictures had been exchanged amongst various *kampung* WhatsApp groups warning of gangs in Sabah posing as researchers in order to try to steal organs. In addition, rumours specifically relating to Monkeybar began to appear on social media cautioning against involvement with the project for fear that the team were in fact an illegal gang trying to steal organs, clone people or sell their blood.

Within days, other allegations against the Monkeybar team began to appear on social media. In one area, a resident posted a picture on Facebook of the project staff in their uniforms warning that they had come to his house asking for blood as an excuse for 'robbery, kidnapping and murder operations'. Claims spread to such an extent that they became the main barrier to participation in a number of *kampungs*. Many people accused the Monkeybar team of being part of a much larger foreign (specifically American)-led organ theft conspiracy. As this member of the team explained:

> Near the end, it didn't matter who we brought in with us as they thought we were all part of the conspiracy. They thought all these other people were going to get money from their organs.

As a result, some *ketua kampungs* refused to allow the research team to work in their areas, citing these rumours as one of the main factors influencing their decision:

> Then the *ketua kampung* came and asked us to gather all the people. He said that he didn't agree because he heard rumours about the organ thief and he didn't want to take responsibility if anything happened because he said if there is a problem then the villagers were going to go to him to ask and he didn't want to take any responsibility.

In other areas, residents took action themselves as one fieldworker explained:

> In the morning, I called the public health staff [member] at the nearest clinic and asked if he is going to come with us to the *kampung* as an escort and he told us there is problem with the *kampung*. The night before, the villagers came to him and told him that they didn't want to take part and … the entrance to the *kampung* was blocked by motorcycles . so I contacted the public health inspector and the JKK office and they say that there is a problem in the *kampung* and not to go to the *kampung* for our safety.

In total, out of 170 *kampungs* recruited into the study for the cross-sectional survey, issues relating to consent arose in 12. In total, five *kampungs* were excluded from the recruitment process altogether.

Murky spaces

Refusals such as these highlight important issues regarding participant's rights, factors that influence the decision to consent and the challenges associated with ensuring participant engagement – issues which the Monkeybar team considered and acted upon during the course of their project. Field staff described what happened as 'just rumours', reflecting their own scepticism regarding the 'truth' of these stories. They attributed the emergence of these rumours to villagers' 'confusion' about the project and their lack of 'understanding' of medical/scientific 'knowledge'. This

was coupled with what researchers described as local residents' 'beliefs' in ghosts and headhunters and their conflation of reality with things they 'got that from movies'. Staff interpreted what happened as a result of 'communication' breakdown. One fieldworker described how his efforts to 'explain' were 'no good' as the villagers were like 'frogs under a coconut shell' – a Malay phrase implying they were inward-looking, parochial and ignorant of things outside their immediate surroundings. The organ thieves were dismissed by field staff as fictitious and thus irrelevant subjects of these stories. Instead, what was important to fieldworkers was the fact that the research staff were misunderstood, their intentions questioned and false accusations made against them. In their view, the emergence of such rumours indicated that the team needed to do things 'better'. In their eyes, 'improved communication' and 'more information' would have helped minimize 'confusion', 'explain' the truth and ultimately increase participation and compliance with science.

However, for the anthropologist, rumour is important precisely because of the kind of 'truth' it implicates. As a number of authors (Geissler & Pool 2006; White 2000) have highlighted, rumours do not need to be proven beyond their being talked about. As they are uttered, spoken or sent (via text message), they weave together empirical elements that carry different weights: some that index material aspects of the world, some that are allegorical and some that are completely fictitious (ibid.). However, in combining these elements, the rumours in this case shed light on a 'true', much broader web of social relationships in which malaria is situated. Rather than displaying narrow-mindedness about their world, the villagers were expressing their (albeit uncertain) understanding of its interconnectedness, complexity and breadth.

In Sabah, widening health inequalities, increased migration, (legal and illegal) organ exchange and burgeoning social mediascapes are just some factors that combine to form an interwoven and opaque network of relations that include but also extend beyond this particular project. Following independence from the British in 1957, Malaysia has undergone significant economic and social change which is associated with improvements across many national health indicators (Mariapun et al. 2016). However, the effects of development have not been equally distributed and income disparities remain, with indigenous groups in Sabah and Sarawak faring the poorest (ibid.). Health inequalities and poor access to care are indicated by significantly lower birth rates and doctor-population ratios when compared with Peninsular Malaysia (Cipta 2012). It is under such conditions of structural violence (Farmer 2004) that inequality, insecurity, poverty and ill health persist.

Disparities in health have been exacerbated in recent years due to increased migration. Sabah now hosts one of the highest proportions of foreign workers in the country (Cipta 2012). Migrants come to work in the burgeoning palm oil and rubber plantation sector which, in itself, is likely to be contributing to the transmission of infectious diseases (including *P. knowlesi*) due to changes to land use and environmental degradation (Cox-Singh & Singh 2008). In addition, although documented workers are screened for communicable diseases, including malaria, porous sea and land borders mean that considerable numbers of undocumented migrants from malaria endemic countries such as Indonesia and the Philippines are bringing parasites with them as they cross the border (Sanders et al. 2014).

Scheper-Hughes (1996) has highlighted how the very subjects of rumours (the organ thieves that were dismissed by researchers) may well be indicative of more than just underlying social relationships. Given the global rise in the international exchange of organs (both legal and illegal), these rumours potentially point to something that may be 'true'.

With Malaysia registering one of the lowest rates for organ donation in the world, a number of government-led initiatives have been intensified since the Ministry of Health launched the first Organ Donor Card in 1999. Potential participants explained to fieldworkers that they had had 'doctors from Kuala Lumpur' visit them in the past, asking them to sign cards. Residents reported that they were not told what the cards were, only to discover later that they were in fact organ donation certificates. One resident showed their card to a member of the Monkeybar team who confirmed that 'on the back of the card [signed by the participant] [there were all] the organs that they [were] going to give when they died … like cornea, skin, bone, liver'.

Coupled with numerous media stories claiming that Malaysia is a site for illegal organ trade, the 'rumoured' organ thief is entirely plausible and 'factish' (Latour 2010). If rumours are 'true at that indeterminate level between fact and metaphor' (Scheper-Hughes 1997: 5), then they point to both the metaphorical *and* the real political, state, police and medical collusions that cause bodily harm to marginalized people (ibid.). As such, the organ thief becomes very 'relevant' to how malaria exists.

Finally, this case study indicates how technology is contributing to the web of social relations in which health persists. The Asia-Pacific region is now home to half of the world's social media users (Roux & Webb 2014). Here, the entanglement between mobile phones, cell towers, social conventions and relationships has coalesced, allowing information to be spread quickly between individuals and groups. As such, the murky space of truths, falsehoods and uncertain connections (Bubandt 2017) grows as social media and the internet spreads, allowing technology to facilitate the mobility of rumour.

Conclusion

Engaging participants in health-related research has long been a goal of health practitioners. However, outside the arena of explicitly participatory research, reflection on participation has been limited. In the case of 'non-participatory' research projects such as clinical trials and observational studies, discussion about participation remains largely confined to issues that relate to the enrolment, consent and retention of participants. As is evident in this case, refusals to take part are often considered only relevant to researchers in so far as they have implications for the project itself. Here, staff attributed the rise of rumours to villagers' misconception of and refusal to engage with the world beyond their 'coconut shell'.

However, non-participation in research is a valuable area of enquiry in its own right, precisely because of what it reveals about what lies beyond the research project. Rumours that contribute to non-participation are indicative of the murky space of social relationships and connections that surround health. In fact, as is illustrated in this case study, rumours do more than just reveal or represent: they incite affect. It is within this space that bodies are put at risk of health issues ranging from malaria to organ theft. These seemingly distant afflictions are united by the entanglement of structural, social, political, economic and cultural factors that coalesce to make them unfold in the way they do.

As such, it was the project team who failed to see the bigger picture. It was they who were trapped inside their own 'coconut shells'. By suggesting that rumours should be taken seriously, I am calling for anthropologists to continue to offer a 'more than representational' (Bubandt 2017) analysis of rumours and to unpack the contextual complexity that rumours both speak *of* and *to*. Similarly, health researchers working on understanding and treating disease should directly engage with the web of social connections that lie beyond their projects. It is here that rumours have their effect, malaria persists and efforts should thus be targeted. ●

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Fig. 1. *Monkeybar staff taking a finger prick blood sample for malaria testing in Ranau district (credit: Dellroy Donny).*
Fig. 2. *Monkeybar staff taking a finger prick blood sample for malaria testing in Ranau district (credit: Dellroy Donny)*
Fig. 3. *Monkeybar staff collecting data and blood samples in Kudat (credit: Jamrih bin Mustapha)*
Fig. 4. *Monkeybar staff collecting written informed consent (credit: Tommy Rowel Abidin)*
Fig. 5. *Monkeybar staff measuring haemoglobin levels in Kudat (credit: Tommy Rowel Abidin).*