**Ethical Issues in Contact Tracing of Health Care Workers in Nipah Outbreak In South India**

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**Abstract**

A highly fatal emerging zoonotic virus in the form of Nipah Virus (NiV) with potential threat to global health security and declared as a candidate for bioterrorism (WHO), was reported for the first time in the South Indian district of Kozhikode (Kerala state) on May 20th 2018. Following the declaration of outbreak emergency control measures, isolation, barrier nursing and contact tracing were implemented by the State Health Department. Since there were no prophylactic drugs or vaccines available to prevent further transmission, the health care teams responded by initiating contact tracing which was the only tool available. Thus there were 2642 contacts that included 40% hospital contacts. ( 185 Doctors, 476 Nurses,344 other Hospital staffs).

Quarantine and isolation of healthy persons especially Health Care Workers involve certain ethical issues . In this paper we conducted an ethical analysis and discussion of contact tracing of Nipah out break in Kerala based on seven principles of public health ethics namely Justice, Beneficence , Utility , Autonomy, Liberty /Freedom, Reciprocity and Solidarity.

The contact tracing in Nipah out break involved several knowledge gaps and ethical issues. It should be understood and addressed in future out breaks. Setting up decision‑making systems and procedures in advance is the best way to ensure that ethically appropriate decisions will be made if an outbreak occurs.

**Introduction**

Infectious disease outbreaks are periods of great uncertainty and particular complexities . As events unfold, public health response will need to be quickly to be done in the face of limited resources and capacities as well as scanty evidence to support decision‑making. This can generate or exacerbate social crises weaken health systems and cause institutional disruptions[1,2] .

A highly fatal emerging zoonotic virus in the form of Nipah Virus (NiV) with potential threat to global health security and declared as a candidate for bioterrorism (WHO), was reported for the first time in the South Indian district of Kozhikode (Kerala state) on May 20th 2018[3,4]. The identification followed recognition of a clustering of 3 encephalitis deaths in a family . A total 23 cases were reported including the primary, of which 21 died with case fatality rate of 91%. The un diagnosed primary case died on May 5th and the index case died on May 18. Nipah outbreak was declared in the state Of Kerala. Excluding the primary case the remaining 22 persons contracted infection by person-to-person transmission from hospital set up (Nosocomial). The transmission happened in three hospitals ( H1-9, H2-10, H3-3 total 22 ), one tertiary, and other 2 secondary level where the patients were treated[4,5]. Retrospectively it was proved that the primary case contracted the infection from Pteropus bat which is a natural reservoir of Nipah virus[5,6] .

Following the declaration of outbreak emergency control measures, isolation, barrier nursing and contact tracing were implemented by the State Health Department. The disease was confirmed in the index case 15 days after the death of the primary case who was a sibling of primary case and individuals such as patient’s relatives and other contacts were hospitalized with similar symptoms – some succumbed to deaths, during the following days. In the initial period, details on actual source and route of transmission were not clear resulting in panic. Even though no prophylactic drugs or vaccines were available to prevent further transmission, the health care teams responded by initiating contact tracing which was the only tool available. The process involves identification and assessment of contacts, monitoring them to permit rapid identification of those with concerning symptoms followed by prompt isolation and supportive treatment. Those in the contact were line listed and maintained in voluntary home quarantine and social distancing for a minimum 3 weeks period corresponding to the maximum incubation period of Nipah. During the period they were kept under direct surveillance by health workers. These included family members, care takers ,co-patients and patient by-standers belonging to the community along with doctors, interns, nurses and ancillary staff belonging to the healthcare teams that took care the Nipah patients either alive or dead. Thus there were 2642 contacts that included 40% hospital contacts. ( 185 Doctors, 476 Nurses,344 other Hospital staffs)

Quarantine and isolation of healthy persons especially Health Care Workers involve certain ethical issues . The central ethical dilemma, during out break control is to balance the freedom and liberty of individuals with the responsibility of Government to provide their citizens with some degree of protection in relation to health (Community benefit ). This may impose some infringements on a person’s freedom (Risks ) but bring about significant benefit for a large number of people (Public good)[1,2].This paper will discuss the ethical issues of contact tracing of Health care workers (HCW) in the current out break of Nipah. The analysis and discussion will be in following seven principles of public health ethics namely Justice, Beneficence , Utility , Autonomy, Liberty /Freedom, Reciprocity and Solidarity[1] .

**1.Justice**

The process of ethical analysis involves identifying relevant principles,(7 numbers) applying them to a particular situation, and making judgments about how to weigh competing principles when it is not possible to satisfy them all [1]. Justice, or fairness, encompasses two different concepts; The first is *equity*, which refers to fairness in the distribution of resources, opportunities and outcomes. The second concept is *procedural justice*, which refers to a fair process for making important decisions. Elements of procedural justice include a) process - providing notice to interested persons and an opportunity to be heard, b)transparency - providing clear and accurate information about the basis for decisions and the process by which they are made and requiring the decision‑makers to publicly explain the basis for decisions in language that is linguistically and culturally appropriate, c)inclusiveness- ensuring that all relevant stakeholders are able to participate in decisions, d) accountability- allocating and enforcing responsibility for decisions and e) oversight - ensuring appropriate mechanisms for monitoring and review[1,2] .

Since Nipah has been a new disease out break with high case fatality information regarding routes of transmission and options for prevention were not known to the medical community [6]. There was information asymmetry between different category as well as levels of HCWs. There was the concern that the do’s and don’ts were not properly communicated while dealing with patients . Most of the health care workers had physical contact with the patients or exposure to their body secretions during the care . Though all of them were aware of the practice of barrier nursing and used personnel protective equipments (PPE), the adherence was not optimum. Since a National guideline for Nipah management was not available, some of the facilities suffered inadequate supply of equipments . Applying “steward ship model” in justice, the authorities should support facilities to practice barrier nursing through supply of personnel protective equipments where ever necessary[1] . The higher authorities should arrange appropriate risk communication methods to protect the HCWs from acquiring infection while caring patients. It was observed that no authentic printed materials were circulated among them and only a few had received any form of risk communication and training in barrier nursing even after the episode. Instead most HCWs had to find information for protecting themselves .

Internationally, quarantine of contacts for 21 days involving early detection of symptoms and isolation is the only tool available to prevent secondary transmission of Nipah.[3,4].‘Intervention ladder “ is a tool used for ranking public health measures according to their coerciveness or intrusiveness [2]. A mea­ sure at the top of the ladder in managing Nipah is the compulsory quarantine or isolation in the event of an outbreak ,both of which involve a signifi­cant infringement of liberty. These measures may be ethically justified where the harm to others can be significantly reduced. In the case of Nipah where there is no available treatment , there is high case fatality associated with significant knowledge gap, this measure has received a high rank. But it appears that procedural justice was not satisfactory and could be improved.

Another area of debate under justice is the equity and fairness which implies that during an out break restrictions on freedom of movement should be applied in the same manner to all persons posing public health risk[1]. While the public were ( home , community contacts )advised to follow strict home quarantine along with social distancing for three weeks, the health care workers had no such restrictions . For meeting the opportunistic costs, the local self governments (LSG) had supplied food materials to the house of detainers during quarantine period. However, the non-allocation of sickness leave during quarantine may be criticized as unfair as these restrictions cause economic loss and loss of livelihood to the community members.

The ethical principle of equity may sometimes justify providing greater resources to persons who have greater needs, so the government could declare sick leaves for them including those working in private sector. The principle of equity also requires attention to the fair distribution of benefits and burdens[1]. Since the HCW were not given sick leave they had to resume duties during the contact tracing period, thereby exposing them to potential new cases and transmitting to other patients. This may be one reason why some hospitals were boycotted by public during the period.

**2.Beneficence**

Contrary to traditional bioethics that concerns with the benefit of individuals, beneficence in the realm of public health ethics concerns with the acts executed for the benefit of others [1]. In this context underlies society’s obligation to meet the basic needs of individuals and communities particularly humanitarian needs such as nourishment, shelter, good health and security. The contact tracing was not aimed at early treatment but for early identification of symptoms and isolation to prevent transmission and harm to others, that is for public good. The others in this case include general public as well as those patients seek treatment from them. Thus by adopting quarantine the number of prospective contacts who needs to be monitored can be reduced. By contact tracing, the HCWs were under surveillance so any symptoms develop during that period can identify early and can be isolated treated early by supportive measures. Thus a young nursing trainee from a secondary care center contracted Nipah infection was saved during this out break. Though it was understood only after the out break was over that a person that acquired infection, during the incubation period does not transmit Nipah to others[6].

***3.Utility***

The principle of utility states that actions are right insofar as they promote the well‑being of individuals or communities. Efforts to maximize utility require consideration of proportionality (balancing the potential benefits of an activity against the risks of harm) and efficiency (achieving the greatest benefits at the lowest possible cost). Utility requires allocating resources to maximize benefits and minimize cost burdens.[1,2] . Infectious disease outbreaks also compete with other important public health issues for attention and resources. Naturally, a question that would arise is “whether human resources be devoted to contact tracing at the possible expense of patient management?”[ 1] Contact tracing is resource intensive as those in contact tracing have to be monitored daily by HCWs directly. Since there were more than 2000 contacts, the task demanded heavy tolls in terms of human resources and logistics from the department of health and represent huge opportunistic cost. Implementation of non-institutional quarantine helped compensate for this without compromising efficiency.

Since health care services need to be available round the clock and hospitals can not be closed in the light of human resource scarcity, the authorities could not allow sick leave for those in the list . Finding substitutions were considered to be non-feasible as well as cost prohibitive. Also, their absence could lead to denial of services to poor patients seeking health care. Thus, using the criteria of “intervention ladder “and the “proportionality of benefits and harm” contact tracing without sick leave among HCW could be considered justifiable but remains contentious. [2]

**4. Autonomy**

Respect for autonomy is respect for persons themselves and requires letting individuals make their own choices based on their values and preferences. This includes paying attention to values such as privacy and confidentiality; social, religious and cultural beliefs; and important relationships including family bonds. Autonomy also refers to treating individuals in ways that are fitting to and informed by a recognition of our common humanity, dignity and inherent rights.[1]

In the case of Nipah which is an infectious and fatal disease the frontline workers in hospitals are highly vulnerable. In the first out break reported from Siliguri in West Bengal, India thirty three of the forty five that succumbed to death were HCWs [7]. Since the disease was diagnosed too late, there were no proper platform for communication and HCW s were neither informed or aware of the risks. “Individuals should not be expected to take on risky work assignments during an infectious disease outbreak unless they are provided appropriate training and tools for PPE. The authorities should also provide resources necessary to minimize the risks of infection ”[1]. In the current outbreak, appropriate barrier nursing and use of personel protective equipments were not adequate. In some facilities, the equipments were either unavailable or insufficient. This contributed two nurses getting infected by Nipah , one of whom died and another unconfirmed case of death of a radiology assistant. It appears that all secondary cases acquired infection from three hospitals. If there was freedom or knowledge to make choices the magnitude of these nosocomial cases could have been decreased. One of the most important steps in dealing with public anxiety during an epidemic like Nipah is ”risk communication”. Inadequate information regarding the illness can be identified as the major reason for the “exaggerated risk perception” and associated behavioral responses during this outbreak among HCWs and Public. In the absence of official communication, the misinformation that spread through social media made the situation more complex. [6,8]

During quarantine or isolation, it is important to ensure that individuals have adequate physical space, opportunities to engage in activities and means to communicate with their loved ones and the outside world. Fulfilling these needs is essential to respect individual dignity. Though the HCWs are not isolated or kept in home quarantine their movements and activities out side the hospitals were restricted. They were under stress and anxiety. Due to fear of death, some had even written their will. Their appetite and sleep were also affected both of which impact the quality of life. Since they were restricted contact from other family members and the members of the family or society limited their interaction with them , their social life could also be perceived to be affected.

During out breaks the privacy and confidentiality should be protected. Even without authorized disclosure their personal information were leaked by the media either directly or indirectly by revealing the names of the hospitals. Thus they were identified by the public/community members during the out break thereby exposing them to stigma and prejudice by the community. If the authorities had taken extra vigilance about the possibility, this issue may have been potentially averted . Unfortunately, failure to protect the confidentiality and personal information of the HCWs during isolation period led to stigma, avoidance and discrimination. Some reported experiencing discrimination and distancing from family members while everyone reported it from friends and community. There were reports were staff in public transport system were reluctant to allow them to travel with other passengers. But the superiors and co-workers in the hospitals continued to provide support.

Those responsible for outbreak response should ensure that all individuals are treated fairly and equitably regardless of their social status or perceived “worth” to society. They should also take measures to prevent stigmatization and social violence. During out breaks a communication strategy should be designed to avoid the stigmatization of individuals whose liberty has been restricted[1] .

The main source of information to the public about Nipah disease was media .The media will always play an important role in any outbreak response efforts as well as in influencing community behaviors . The media ethics should be uplifted to protect their privacy and confidentiality. Their roles are significant in educating the community properly and reducing panic and spread of incorrect rumours. To ensure this, media was provided access to accurate and timely information about the course of the outbreak through the director of Health service Kerala ( DHS) who was appointed as single spoke person. Notworthy efforts were made towards timely and structured dissemination of information, media management and balanced reporting[5,6].

Nipah created panic and confusion among the health workers and the general public. This could lead to more stigma and discrimination of HCWs**.** One of the ethical principle in communication is transparency which requires that decision‑makers publicly explain the basis for decisions in language that is linguistically and culturally appropriate. With this in mind, Aarogya Jaagratha : *“ Don’t Panic ,stay vigilant*”-a social media platform was started by Department of health . Cyber cell of the Government of Kerala was also active in their surveillance and charged 6 cases of attempts at spreading false information [5,6].

Rapid Data sharingdoes remain critical as health emergencies like Nipah unfold[9,10] . In the present outbreak, the rate of sharing of information about transmission, risks, prevention remained inadequate. In appropriate communication from officials such as anticipation of a second wave of cases or expectation of multi cluster of out breaks created panic but may have reflected insufficient knowledge about the disease in general. Published data on infection rate of Nipah is now available[11] . According to the mathematical modeling developed by this group, the basic reproduction number – the number of secondary cases generated from a primary case (R0) ranges from 0.5 to 0.6. This means that Nipah will not propagate widely. The transmission from human to human occurs through body fluids like respiratory secretions during close contact. Epidemiologically Nipah out breaks will be sporadic and self-limiting to a small geographic area[7,11].

***5.Liberty and freedom***

During an outbreak management, some measures might constitute minor infringements of a person’s free­dom but bring about significant benefit to the community and hence the analysis need to balance freedoms of individual with com­munity benefits[2]. Liberty includes a broad range of social, religious and political freedoms, such as freedom of movement, freedom of peaceful assembly and freedom of speech. Usually an out break like Nipah where there is minimal prior experience and where knowledge gaps exist, the authorities are forced to take response measures that may be disproportionate to burdens of outbreak but designed with best intentions . This however may inadvertently place a disproportionate burden to the public.

Restrictions on freedom of movement include isolation, quarantine, travel advisories or restrictions and community-based measures to reduce contact between people (for example, closing schools or prohibiting large gatherings). These measures can often play an important role in controlling infectious disease outbreaks, and in these circumstances, their use is justified by the ethical value of protecting community well-being. All such measures impose a significant burden on individuals and communities, including direct limitations of fundamental human rights; Particularly the rights to freedom of movement and peaceful assembly. Even short-term restrictions on freedom of movement can have significant — and possibly devastating —financial and social consequences for individuals, their families, and their communities. The directorate of health service and district civil authorities declared Public health Emergency . As a result, “*public meetings, gatherings and marriages were cancelled or postponed. Panic caused people to remain at home. Bus services to the affected areas were cancelled, markets and cinema halls were closed . Hospitals remained empty”.*  The Siracusa Principles provide that any restrictions on human rights must be carried out in accordance with the law and in pursuit of a legitimate objective of general interest and must be based on scientific evidence and not imposed in an arbitrary, unreasonable, or discriminatory manner[12].

***6.Reciprocity*** *—*Reciprocity consists of making a “fitting and proportional return” for contributions that people have made.[1,13] An effective infectious disease outbreak response depends on the contribution of a diverse range of frontline workers, which includes professionals with direct patient care responsibilities (a specialist in the tertiary centre, ancilliary staff) to field level community workers like ASHAs . They often assume considerable personal risk to carry out their jobs. Once a worker has taken on these risks to protect society , society has a reciprocal obligation to provide necessary support. If the reciprocal obligations are not met, frontline workers cannot legitimately be expected to assume a significant risk of harm to themselves and their families [1,13].

At a minimum, fulfillment of reciprocal obligations to frontline workers required the following actions :

a)To minimizing the risk of infection they should be provided complete and accurate information known about the nature of the pathogen and infection control measures, updated information on the epidemiological situation at the local level, and the provision of personal protective equipment. Immediately after the declaration of the out break a central team from Indian Council of Medical Research (ICMR) and All India Institute Of Medical Science (AIIMS) were deployed to the tertiary centre – Medical College Calicut where patients were admitted and conducted training to the engaged staff. This was not extended to the peripheral hospitals. Minimizing risk of infection was not properly addressed due to resource constraints and lack of prior experiences.

***b)Priority access to health care*** — In such situations the frontline workers who become sick, or any immediate family members that become ill through contact with the worker, should be ensured access to the highest level of care available . This was assured through contact tracing by close monitoring of symptoms and by equipping a designated isolation centre at Calicut Medical college. The vulnerability and the felt need of psychological counseling were not properly addressed[8].

***c) Appropriate remuneration*** — Government should ensure that frontline workers should be given fair remuneration for their work paid in a timely manner . These has been done as reported[6]. Many workers involved in Nipah activity were given increments or promotions but there were complaints that few were excluded .

***d)Support for reintegrating into the community*** — Frontline workers may experience stigma and discrimination, particularly those involved in unpopular measures such as infection control or burials not conducted according to the traditional customs[1]. In this case, the burials were done by a special team in a public grave yard without religious customs[5,6]. Government did take efforts to reduce the risk of stigmatization and discrimination and help such workers who were involved in Nipah control to reintegrate into the community. The authorities also sought corporation from religious leaders and were assured of the same[6].

***e) Assistance to family members*** — Assistance should be provided to families of frontline workers who need to remain away from home in order to carry out their responsibilities or to recuperate from illness[1]. Death benefits should be provided to family members of frontline workers who die in the line of duty, including volunteers or “casual workers.” In the present out break, out of the 2 nurses who were infected, one died and the other recovered. The deceased nurse’s family was compensated and husband was offered a Government job . But In the case of a contract worker, the compensation was rejected due to non confirmation of diagnosis. Since her death happened before declaration of Nipah her samples were not tested.

In an ideal situation, it is essential that frontline workers’ rights and obligations be clearly established during the pre-outbreak planning period. But in the case of Nipah, there was no preplanning period and it was an un expected event.

***7.Solidarity*** — Solidarity is a social relation in which a group, community, Nation or, potentially, the global community stands together[1,7] The principle of solidarity justifies collective action in the face of common threats. The Kerala Community of Doctors, administrative personnel, Political and religious leaders ,Local Self governments, Police personnel all demonstrated commendable solidarity in controlling Nipah. Because of the solidarity, the out break was controlled in a timely fashion - the last case was reported on May24 and the area was declared free of Nipah on July 24. The collaborative efforts of all the stakeholders including the state and central government teams in the form of timely diagnosis, data sharing and sample transport, and contact tracing were key to successfully containing the outbreak and potentially reducing costs in terms of loss of life and commerce (given the role of international fruit and vegetable trade in Kerala farmers’ livelihoods)[5]. It may also have potentially helped limit Nipah’s spread beyond the geographic area initially affected.

**Conclusion**

We conducted an ethical analysis and discussion of contact tracing of Nipah out break in Kerala based on seven principles of public health(1). The contact tracing in Nipah out break involve several knowledge gaps and ethical issues. It should be understood and addressed in future out breaks. Setting up decision‑making systems and procedures in advance is the best way to ensure that ethically appropriate decisions will be made if an outbreak occurs. Governments have an ethical obligation to ensure the long‑term capacity of the systems necessary to carry out effective epidemic prevention and response efforts. This should be carried out taking Nipah out break as a lesson.

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