

# Ethics of Infection Control

*[Announcer] This program is presented by the Centers for Disease Control and Prevention.*

[Sarah Gregory] Hi, I'm Sarah Gregory, and today I'm talking to Dr. Babette Rump, an infectious disease MD and doctoral candidate at the RIVM National Institute of Public Health and the Environment. She's calling me from the Netherlands. Dr. Rump, we'll be discussing the ethics of precautions taken to reduce the spread of antimicrobial resistance. So, welcome.

[Babette Rump] Thank you, Sarah, and thank you so much for having us, also, on behalf of my coauthors, Professor Timen, Professor Hulscher, and Professor Verweij.

[Sarah Gregory] Okay, let's start with talking a little bit about ethics in public health. This is a very interesting topic. Public health traditionally looks at the good of the whole population. So, tell me about how ethics concerning the individual comes into it.

[Babette Rump] Well, in its essence, public health indeed is about promoting the good for the whole population, but there is another side to the coin. Specifically, when dealing with infectious diseases, more often than not, working towards collective health, in practice, means that we have to trade off some interests or some freedoms of a particular individual. I think we've all seen the television images of Ebola patients. When we look at that and look at how they were placed in isolation and how their caregivers wore...were wearing all sorts of protective clothing when taking care of them, I think it's not hard to imagine how these precaution measures may influence the quality of care and the timeliness of care these people are receiving. Here we were thus trading off, to some extent, the health of the individual Ebola patient for the sake of the health of the public at large. So, when talking about infectious disease control, I think we need to talk about both sides of the coin, the public at large on the one hand and the individual on the other.

[Sarah Gregory] Okay. And what is antimicrobial resistance and why is it important for us to be concerned about it? What has contributed most to its evolution?

[Babette Rump] In short, antimicrobial resistance relates to the phenomenon that microorganisms, or bacteria, become resistant to the antibiotics, the medications that we are used to treat them with. This may mean that infections that today are relatively harmless or mild, or maybe not so harmless, but at least easy to treat, will become very hard to treat in the future. And, well, this will pose a severe threat to the patient and the public. It's important to realize that antibiotics are not only used for treatment, but we use them also in surgery or in other common medical procedures as a preventive measure. Some even say that when antimicrobial resistance...that it threatens most of what we consider the success of modern medicine. Well, I'm not quite sure if that is all true, but it is clear that it comes with high costs, high morbidity, and high mortality rates.

[Sarah Gregory] In your study, or your article, you talk about carriership. That's not a term we're real familiar with. What is carriership?

[Babette Rump] Well, carriership or carrier or carriage or carrier state relates to being a carrier of a microorganism. And I can imagine you might wonder why I don't talk about patients instead of carriers, but when it comes to infectious diseases, being a carrier does not necessarily mean that you are ill yourself. Perhaps the most famous, or infamous, example is that of Typhoid Mary.

She worked as a cook in New York area in the beginning of this century and caused some devastating family outbreaks of typhoid fever. It took the public health authorities quite a while to identify her as the cause of all these outbreaks because she was carrying the typhoid bacteria without falling ill to it. But carriership comes with many infectious diseases. Think about hepatitis B or staphylococcus aureus. So, when it comes to antimicrobial resistance, most of the people carry it without ever falling ill. Therefore we talk about carriership.

[Sarah Gregory] Okay. So, studying the ethics of carriership is groundbreaking, I believe anyway. Would you explain what this means and why it's important to start having dialogue about it?

[Babette Rump] Yeah, well, I think it's really important to have dialogue about it. AMR is one of the top scientific priorities today. Much research is done about the effect of the control measures, but these studies all aim at bringing down morbidity, mortality, and cost related to the introduction and circulation of antimicrobial resistance. This is important, clearly, but as I stated before, we still need to look at both sides of the coin. We should also look at the individual carrier and what is at stake here, because control measures can have a serious impact on people's wellbeing. The question is how to diminish this impact.

[Sarah Gregory] Healthcare workers have started taking control measures to prevent their infected patients from spreading antimicrobial resistant diseases, as you sort of already talked about. What are some of these examples of these precautions and are they helpful in any way in reducing disease?

[Babette Rump] Well, the type of control measures vary for microorganisms. It depends on resistance pattern, virulence, and mode of transmission. They can include isolating a patient in a single room, with limiting visitors. But it can also include protective clothing during patient care, such as the use of aprons and masks. Sometimes it means that carriers are treated for their carriership so they can get rid of the microorganisms. And it can even mean, sometimes, exclusion from work or joint facilities. But it's also important to note that the actual control measures recommended by health authorities are known to vary largely between countries. In my country, for instance, we are very strict.

[Sarah Gregory] Before we get into more details, let's talk a little bit about stigmatization. I remember during the SARS outbreak, stigma was a very big issue.

[Babette Rump] Oh yes, that's true with SARS, but I think with all infectious diseases stigma is a large issue. The thing about infectious diseases is that they are always prone to stigma. The line between reasonable precaution measures and actual stigma is always very thin. But still, the line is distinct and we should be very careful not to cross it.

[Sarah Gregory] What impact do these precautionary measures on...have on carriers? Tell us about some of the negative implications in various settings.

[Babette Rump] Well, control measures may have an impact on the quality of care or the timings of care. We know of cases in which surgical interventions were postponed or rehabilitation was postponed because of carriership. But it's also problematic when you live in a nursing home. So we know of elderly people who were not allowed to share their meal with fellow residents or other people who are banned from their social activities. It may thus have a significant impact on people's wellbeing.

[Sarah Gregory] So, can you tell me a little bit about how it affects people in their daily life?

[Babette Rump] Yes, we also noticed that it can affect people's daily lives. We know of children who face problems when they return back to school after a...after a hospitalization period. And we have, for instance, also an example that may really well show what the problem may...what the problem consists. We know of a family who happens to adopt children with special health needs. They had already adopted a first child, who happened to be a carrier of MRSA. Now they were offered to adopt a second child, but they were really hesitant because they knew that, once the child would join their family, the child would get colonized or would become a carrier, as well. This could threaten, of course, the health of the second child, but this could also become very problematic because of the strict control measures you find in the Netherlands. So, here you can see how the measures can really touch upon people's autonomy.

[Sarah Gregory] And what about healthcare workers?

[Babette Rump] Yeah, healthcare workers, they can also face lots of...lots of problems because of the control measures. Often, people are assigned administrative tasks because they are not allowed to perform any healthcare-related tasks, and herewith they are missing out on the substantial financial benefits that's come along with performing patient care during night and weekend shifts. Sometimes it's also very complicated to care for their own parents or their own children. We also know of healthcare workers who were not carriers, but they care for other people who are carriers. They, for instance, care for a child who happens to be a carrier, or, in their spare time, they take care of their parents, and then also they are banned from activities that are health related. And the measures not only start to involve the healthcare workers themselves, but they may include also their family or their close surroundings. And we see that healthcare workers, as well as their close family, are pressured to undergo all sorts of intense eradication treatments that you may assume people would prefer not to have. So, the measures touch upon issues of privacy and autonomy and wellbeing. So, yes, the control measures come with negative implications for carriers.

[Sarah Gregory] So, what is surprising? Did you find things that were surprising?

[Babette Rump] Yeah, what was really surprising for us, though, is that, although challenging, the impacts and the moral dilemmas at hand and the values at stake that I just showed, they are not fundamentally different from the dilemmas that arise in infectious disease control, in general. Now, as you may know, measures like quarantine or isolation or social distancing are at the heart of outbreak management. And these clearly involve sanctions with respect to autonomy and otherwise undermine the quality of people's lives.

[Sarah Gregory] So, tell me what makes a person who carries an antimicrobial-resistant organism different from someone carrying a different infectious disease.

[Babette Rump] Ah yes, well the difference is not that much in the control measures they take, as I said...told you before, these are quite similar to other infectious diseases. But, what we did notice is that there are some ethical features that seem to influence the way we think about what is fair and reasonable in terms of control measures.

First, we see that patients in this study were asymptomatic carriers for whom the carriership, as such, did not really affect their health. This is really different for most communicable diseases, in which the health of the person who are carrying the microorganism is threatened or affected by

the infection. And clearly, other infectious diseases can also involve asymptomatic carriership and, moreover, being a carrier can certainly also cause infection. But what remains really ethically noteworthy is that carriership primarily threatens a specific subgroup of vulnerable patients in hospitalized settings. From a broader public health perspective, the health threat of being a carrier is actually pretty limited.

Then a second feature is that the relevance is almost exclusively limited to healthcare-related settings. In case of AMR, whether a carrier is subjected to control measures, does not depend on the severity of the pathogen, but only on the likelihood that the resistant pathogen will be transmitted to a healthcare-related setting where these vulnerable patients are cared for.

What also is different from AMR that is not seen in other infectious diseases, that it resembles more a state of being. Carriership could last for a very long time. In some cases, people were colonized for such a long period, some children even starting at birth, that it can be reasonably argued that the resistant microorganism is now part of their regular flora. From an ethical perspective, this persistence is particularly relevant given that, inevitably, within the older population, but also in a care or cure setting, there will be a significant group of unidentified asymptomatic carriers. Therefore, if known carriership faces work restrictions and unknown carriership doesn't, this could also be considered rather unfair.

Finally, or maybe most importantly, being a carrier is a nondefining factor in the whole problem of antimicrobial resistance. In all the cases we analyzed for this study, individual carrier was a possible link in the chain of transmission, but certainly not a defining factor in the epidemic. So, it's not that much the control measures that made the difference, these four specific ethical features that influenced what we think is fair and reasonable when it comes to control measures.

[Sarah Gregory] So, how did you go about conducting this study?

[Babette Rump] Ah well, we analyzed a set of cases and I think it's fair to say that we looked at the tip of the iceberg. As you may know, the Netherlands has very strict control measures, and regional public health services and local hospitals can turn to the National Institute of Public Health and the Environment for consultation and advice when things become complicated. We were given the opportunity to analyze these extraordinary cases documented there. A total number of 227 cases were analyzed, representing a period of 2008 to 2016.

[Sarah Gregory] And your study ended up showing what?

[Babette Rump] Well, I think what we specifically found is that it's not that much the control measures that influence the compromises people are willing to make on their wellbeing, but it is these specific ethical features that I talked about earlier that make antimicrobial resistance a problem different from all the other infectious diseases that we know.

[Sarah Gregory] And did anything you found surprise you?

[Babette Rump] Well, to be honest, it did surprise me. When I first started to conduct this study, I thought it was going to be about the control measures and whether they were fair or reasonable. And it did surprise me to find out that it's not that much these control measures, but it's these specific features, these specific ethical difference of antimicrobial resistance that has not been getting that much scientific attention so far, but that really seems to influence the way we think about the problem.

[Sarah Gregory] Okay, so for the hard question now. Are there any solutions to these conflicting needs?

[Babette Rump] Well, that's different. I think control measures need to be taken and when you look at the Northern European countries, they are successful. But I think we need to shift our focus. I think we need to take a far more person-centered approach rather than asking whether it is justified to impose strict control measures, as we actually do now in infectious disease control. We could better ask how we can best care for this person's wellbeing in ways that do not imply unacceptable risks of transmission for other patients. You see, some patients for instance, may enjoy the privacy that comes along with isolation measures and many will probably dislike the solitude. But yet there may also be another group of people that is most concerned about the quality of care they receive and are relatively indifferent about the isolation, as such. So, when you look at the personal values and the personal needs of people, you might may come...you may come to a better solution.

[Sarah Gregory] Finally, do you have any next steps, based on your findings?

[Babette Rump] Yes. I think we have to look at what truly is at stake for carriers and be more concerned with protecting the imposed control measures on people. In the end, when it comes to antimicrobial resistance, which is a super-complex and highly interrelated problem, scientific knowledge is only going to get us to a certain point. From there on, we need to talk to each other and ask the relevant questions. What can we reasonably ask from carriers and what can be expected in return? And in the end, it all comes down to the question: What kind of risk is acceptable?

[Sarah Gregory] Dr. Rump, why...why did you do this study? As we've discussed, ethics in health care is not something that gets a lot of press. How did you become interested in this?

[Babette Rump] Oh, yeah, well, indeed, ethics in health care, in itself, does not get enough attention, but when it comes to public health ethics or ethics of infectious disease control, it is even less. But on the other hand, when you work in infectious disease control and you impose people to all these control measures, and you see how this influences their freedom, their autonomy, their wellbeing, you immediately become interested in ethics.

So, I have been conducting ethical projects over the last years, mostly focusing on the relation with other people. When people are carrier of a microorganism, they only spread it because they socialize, they interact, they have contact with other people. When we impose people to control measures, we inevitably also limit their opportunity for social activities or for doing what they really like. So, when it comes to infectious disease control, what is at stake is not only their autonomy, in the more limited, negative sense of the word, but it's actually their opportunity to socially interact and to be of worth for others and to live a life that is worth living.

Now, when it comes to Ebola or SARS or really life-threatening infections, people are maybe more willing to accept severe imposition on their wellbeing, but when it comes to these really complex, interrelated problems like antimicrobial resistance, people may well think or hesitate about what we ask them. Therefore, I think ethics, specifically in antimicrobial resistance, is a topic that needs a discussion of its own.

[Sarah Gregory] What happens to people if they don't adhere to these strict guidelines in the Netherlands?

[Babette Rump] I've been working as a medical doctor for over 10 years now and I haven't found any person who didn't really want to adhere to this. The whole thing is that I think that people are really willing to help out and to work out. And maybe this is exactly the reason that we really need to be careful what we are asking, because people are really willing to help us out here.

[Sarah Gregory] Thank you, Dr. Rump, for a most interesting conversation. Listeners can read the September 2018 article, Ethics of Infection Control Measures for Carriers of Antimicrobial Drug-Resistant Organisms, online at [cdc.gov/eid](http://cdc.gov/eid).

I'm Sarah Gregory for *Emerging Infectious Diseases*.

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