## Episode 13 Transcript

## Moral Experiences of Healthcare Providers in Covid-19 Research

Hosted By: Eliza Yadav

Guest: Professor Matthew Hunt, Ani Chenier

Transcripts may have been edited for clarity.

**Rebecca:** Hello and welcome to another episode of the Just Emergencies Podcast.

In today's episode, McGill University student and Research Assistant Eliza Yadav, sits down with two other members of her research team – Research Co-ordinator Ani Chenier and previous Just Emergencies Guest and Project Collaborator Professor Matthew Hunt - to discuss the preliminary findings of their study entitled 'Ethics of Implementing Research in a Crisis: Understanding moral experiences of healthcare providers and clinician researchers at the intersection of COVID research and clinical practice'.

Now, as you can imagine, this is very timely and important research, so it's very exciting that Eliza, Ani, and Matthew took the time to share their insights with us.

[Intro Music]

This is 'Just Emergencies', the podcast where we show that global health emergencies are anything but just. In each episode we explore an issue, question, or event that makes us think about global health emergencies, humanitarian crises, and how to best respond to them.

Without further ado, let's get into the episode!

**Eliza:** Hello. I'm Eliza, a final-year B.A. candidate at McGill. I study International Development and Global Health. I'm currently a Research Assistant on a COVID-19 research study led by academics and researchers at

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McGill University and McMaster University. Our study is called "Ethics of

Implementing Research in a Crisis: Understanding moral experiences of

healthcare providers and clinician researchers at the intersection of COVID

research and clinical practice." Our study aim is to understand the moral

experiences and support needs of healthcare providers (HCPs) and clinician-

researchers involved in caring for patients who are enrolled in or excluded

from COVID-19 clinical research. Thus far, we have conducted 26 interviews

with clinicians, healthcare providers, and researchers from countries such as

France, Canada, and the US, among many others.

There are 5 other members of the research team including Co-PI Prof Lisa

Schwartz from McMaster University, Research Assistant Takhliq Amir, and

one of two Research Coordinators Rachel Yantzi. Today, I'll be interviewing

the study's Co-PI, Dr. Matthew Hunt, and our Researcher Coordinator Ani

Chenier. Matthew is an Associate Professor at McGill's School of Physical and

Occupational Therapy. You might have heard him speak during episode 5 of

the Just Emergencies podcast. Ani has a Masters in Anthropology from

McMaster University.

Welcome, Ani and Matthew.

Prof. Hunt: Thank you, Eliza.

**Ani**: Thank you.

Eliza: Let's get started with the questions. Matthew, this first question is

directed towards yourself, but Ani please feel free to pitch in. What were some

of the motivations which informed the creation of this study?

**Prof. Hunt**: Well, it's great to be able to come back to Just Emergencies and

talk about this new research project. You asked about the origins of this

project. We can put that into context of previous research we have conducted

as a team. We have been looking at various situations in which a natural

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disaster has occurred and through that work we were led to a set of questions around the interface between clinical research and clinical practice in a crisis situation that may arise. With that as background we were thinking about this applied to a clinical setting. It was a spark of reflection and opened a series of questions for us. And then with Lisa Schwartz and Rachel Yantzi who is an ICU nurse we asked questions about how this would play out. What would be the moral experience to go to the framing of the study? By moral experience, what we are really thinking about are the situations in which people's values are in some being threated or thwarted in the context of everyday life, or in this case clinical practice, research practice, and its interface. That is some of the background that led us to pursuing this project and developing it. We started back in April and May and now we are continuing till today.

**Eliza:** Thank you. That was very comprehensive. This question is directed towards yourself, Ani. What are the key themes or issues from the interviews you have transcribed or summarized thus far?

**Ani**: Thank you very much. There are some clear common threads that are already coming through. First, we are learning a lot about COVID research landscapes outside of very specific emergency contexts. Some key elements we have learned are intense or unrelenting news coverage; disruptions in people's personal lives due to public health or other unrelated measures; fear for their own, their loved ones, their colleagues' health. One particular set of findings relate to participants' motivation behind becoming involved with research. Almost universally, participants described pressure to do something in the face of COVID. Many saw research as either a tool or in some cases an added challenge that made it more difficult for what they thought they should be doing. Research in some ways was the best way for them to gain access to possible therapies that could be effective for their patients. It is important to keep in mind that high level of uncertainty around what treatments may or may not be effective and what diagnostics may or not be effective. For others research was the best way to fill important knowledge gaps and therefore

contribute to improving treatment guidelines. With that group there is a need to quickly share results and the desire to produce results that will be usable quickly. All that said, analysis is ongoing. We are looking forward to sharing more in coming months.

**Eliza:** So, this question is directed to the both of you. How do you see this study connecting to concepts of justice?

Prof. Hunt: I can start and build on what Ani has been saying. I am going to emphasize two aspects in particular. This is in a broader sense where there are all sorts of questions on justice. In this current moment, we are talking about vaccine distribution which is the result of research. We are thinking about who is going to be prioritized and how we are going to distribute the vaccine. And if we back up and we're thinking about the nature of research in the context of the pandemic, then there are questions about justice. The two that I would emphasize that come forward in the interviews are questions of what is being prioritized. One of the things we think of in the context of crisis research is that the justificatory bar, that is the threshold that justifies the initiation of a particular research project is raised. We need a stronger argument, the rationale tends to be more robust, especially in a clinical environment. So that requires some level of assessment and prioritization. And so, what are the questions and research topics that should garner those resources and be prioritized in these settings? One of the things participants spoke about was a concern about missed opportunities. This is because research wasn't pulled together in a robust or formal enough way. We have participants saying strongly that we need research and research that is going to lead to knowledge that is going to have a clear impact on care providers and people who are affected by COVID. What questions are going to be important and how do we get those questions answered in an effective way. Those are the two elements that I think connect up with concepts of justice.

**Eliza:** Okay. Makes sense. This leads me to the final question we have for today. It is directed to the both of you. What are some of the implications for policy and practice that you see emerging from the study so far?

**Ani**: So, I think in terms of policy and practice, there is definitely a need for resources to support and kind of educate about their roles. The front-line workers who are drawn into taking expanded roles in research. So, kind of anything about explanations of that role and kind of information tools to support them. Opportunities for them to discuss some of the troubling things that they experience because of their engagement with research. So, there is a need for a diverse and easily accessible set of tools aimed at front-line healthcare workers who get invited to be taking on roles in research.

**Prof. Hunt**: Maybe I can build on that for a second too. That seems to be interesting set of implications from the study. There is a tension sometimes too where people are feeling like "oh, more information!" Or just broader inservices and it is not clear that patients will actually be enrolled. So, there is a worry that even information can be a form of burden. So then how do you tailor it for effective communication that is really on point for the areas of concern. I do really appreciate Ani's second point too on offering support and opportunity to share. What we might say is making moral spaces for sharing the sorts of tensions that people have. The essence there too about what sort of support, like what are the areas where people are expressing the need for support? One of them that comes across for front-line providers giving consent. This is especially so where family members aren't present, there is more PPE and the challenges around communication. That sort of process around not just the initial moment of informed consent being a deliberate process but on an ongoing basis especially with further blood draws or other activities. And specifically, there were two with patients expressing deliria and dementia and the challenges involving the families. And so that enters into the communication spaces of families. People are feeling the need for support around those questions. So that is an example of a particular domain in which support may be especially beneficial. I don't know, Ani, if you want to layer in

more about communication, but I think that is theme that comes across very

strongly.

**Ani**: Sure. I will say that the flip side of communication is the frustration with

not knowing what happens next. It has been expressed by many participants

including people with a long history of engagement with research. So, it is a

long-standing and serious issue for COVID research. And then unrelated but

there is a lot of higher-level coordination either between trials, between

institutions hosting multiple trials, and what we are seeing is that pre-existing

programs like ones that were set up in Canada in response to SARS. But

setting up a response to prior emergencies have been drawn on and

empowered people to mobilize resources and to move things through the

ethics review board but not less rigorously. So, this is one area of policy where

prior calls have been taken up by practitioners and where improvements have

had a manifest impact on COVID. That is something I'm sure we will be able

to identify opportunities for refining some of those policies. But where we have

seen positive impacts from past calls for action.

Eliza: That was super insightful. I would like to thank the both of you for your

time.

Ani: Thank you very much for having us.

**Prof. Hunt**: Yeah, it was great to talk to you today.

**Eliza:** I will now close this and pass it back to Rebecca.

[Outro music]

That's it for today – we hope you enjoyed the today's episode.

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in this episodes, but also give you some further resources if you're interested in learning more about today's topic.

If you have any questions, comments, or ideas for topics you'd like to hear about in future episodes, please emails us at ghe@ed.ac.uk. We're also on twitter as @GanguliMitra and @reb\_richards.

Be sure to check out and explore our website "Justice in Global Health Emergencies and Humanitarian Crises" for more great content, just go to https://www.ghe.law.ed.ac.uk/.

Thanks for listening and see you again for the next episode.

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