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## Thinking About Health

### Dr Havi Carel Podcast Transcript

**Duration:** 0:13:10

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*Welcome. This is a podcast from the Arts and Humanities Research Council.*

Interviewer: I'm talking to Dr. Havi Carel, senior lecturer in philosophy at the University of the West of England. Havi, thanks very much for joining us this morning. Your project is using certain philosophical tools to help us understand what illness is from the point of view of the sick person - trying to uncover as you say the lived experience of the sick person. What does that lived experience mean and how exactly do we uncover that lived experience?

Havi Carel: Well, the lived experience of illness is all the aspects of the illness that the patient or the ill person undergoes and we can think about these in sort of three general terms.

The first is the changes to the physical body and these are obviously the changes that are, you know, the most interesting for health care and health professionals. The changes to bodily experiences so limitations in mobility, something like pain, incontinence, discomfort – all of these things come under the umbrella of the lived experience of illness and the physical dimension.

There's further changes that come about as a result of these physical changes. There's changes to the social world of the ill person, the ways in which she interacts with society at large, changes to personal relationships, effects her illness might have on her family and friends and so on.

And the third change can be thought of as a maybe temporal change or a change in the ways in which people think about their life plans, the way they think about time, the way they conceive of their life span and might modify their plans and expectations in light of the illness or in light of the prognosis that isn't so good.

Now all of these things I think have to be described through a particular methodology which is phenomenology which is a particular approach within philosophy that helps us mime the first person experience of anything at all. But in this case what I'm trying to do is apply phenomenology to the experience of illness in order to uncover some of these changes and transformations. And the methodology is roughly speaking one that goes beyond what the social sciences call autoethnography. It means going beyond just verbal reports so it's not just talking about your symptoms with a doctor. And really describing in great detail the changes that come about and the three dimensions I mentioned and that there might possibly be others.

So the main thrust of the project is, of my contribution to the project which is a joined project with Dr. Rachel Cooper from Lancaster University, is to try and develop tools to understand the lived experience of illness but also to provide health professionals with the opportunity to study these tools and hopefully apply them in their work.

Interviewer: To many people the lived experience that what you've been describing to us would be a given for most health professionals. They would expect that a health professional or doctor or a nurse would understand that where the patient is coming from if you like. I

suppose the underlying contention in your work is that they don't. Is that the case would you say?

Havi Carel: Well, I don't think you could be a health professional and not pay some sort of attention to the lived experience of your patients. But what we want to do in the project is to provide impact in terms of improving health care provision by giving health professionals the opportunity to reflect on the meaning and the impact of illness on the patient. Another thing we want to try and do is to help health professionals who work within an incredibly constrained and stressful environment to take the time to see the whole phenomenon which you can call illness rather than just the physical disease.

Interviewer: I'm interested in this exchange between the sick person and the health professional. For example, if I'm sick I have certain symptoms and I express these somehow to a health professional. Is there something that we as sometimes sick people can do better to express our lived experience as sick people? Is there a problem with the language that we use in that exchange? Would we as sick people also benefit from phenomenology?

Havi Carel: Yes, absolutely. I mean phenomenology would give the ill person or any person at all who is interested in this approach, an opportunity and a vocabulary and a set of principles with which to explore their first person experience of anything at all. So, if somebody wanted to enrich their own self understanding of their condition or wanted to increase their vocabulary with which they're talking about it, then phenomenology would certainly be a useful methodology there.

Now there's also as you say a very big potential problem in the interaction with the health professional in that the health professional and the patient sit in the same room and seem to be talking about the

same object as it were, but in fact they might be two very different objects that they're discussing. So the health professional might be thinking about a list of symptoms that they studied in a text book or they've seen a lot of cases of in their clinical experience, while the ill person might think of their illness as a set of limitations, as a shadow cast over their lives and might give it a very different significance and a very different meaning.

So one thing we want to do is to use this opportunity to use this AHRC project to come up with ways with which we can narrow or even close the gap in the interaction. And that would obviously make consultations more efficient and also help the two parties understand each other better so there's less friction and less frustration. One comment patients often make is they feel that they weren't appreciated as a person in the interaction with the health care, medical world. And I think again one of the reasons why we want to stop and sort of pause and consider this lived experience, is because there does seem to be quite a lot of pressure on health professionals to understand illness in the narrow sense of the physical disease for various reasons. And moving away from that narrow understanding I think would be helpful for patient physician interaction.

Interviewer: How has your project and your work been received by health professionals because there are obviously certain questions for them. Presumably there's a spectrum of reactions from real curiosity and willingness to learn on the one hand but also possible scepticism, fear maybe worse on the other.

Havi Carel: Well, I think what we try to do is try to interest health professionals both personally in thinking about their own practice in light of these ideas but also intellectually. So the project is called The Concepts of Health, Illness and Disease and I think there is a real intellectual thirst amongst health professionals, the ones I've encountered at least in

wanting to really reflect on the concepts themselves and to do some sort of conceptual philosophical work, as a form of reflecting on their practice. The two groups I would say showed the most interest in the project so far were psychiatrists and nurses, physiotherapists and occupational therapists. But we've certainly have been trying to reach out to GPs, to consultants, to registrars, to other groups in the health professions and we'd be absolutely delighted to have further interaction with more medical professionals.

Interviewer: Just give us a couple of examples if you would of the particular areas that you've been working on and had some, the insights that you've provided have really helped in specific health related areas.

Havi Carel: So one workshop we've run a couple of times is called The Concepts of Health, Illness and Disease. And in this workshop we present the health professionals who, you know, come in after work and are obviously sacrificing their own free time for this. We talk to them about what would be good way of describing or capturing these notions of health, illness and disease so we present them with a few concepts, with a few approaches. For example, we talk about naturalism so they adhere that disease is simply a biological dysfunction, and we compare that with the more sort of social model of illness that understands it as a social impairment or disadvantage. And we just discuss these concepts and then we talk a bit about phenomenology.

And I think that was incredibly fruitful for us as well because these people come and have all this clinical experience and all of a sudden they can couch this experience in a sort of broader, philosophical framework. So I think this engagement between the disciplines is very fruitful.

Interviewer: As we all know there is a demographic time bomb in the population at large. People are living longer and so on so it's, these kinds of issues are important to policy makers. What kind of reception have you had, has your project had with policy makers in the field?

Havi Carel: Because the project was only started in January and it's meant to run over two years and three months we've got lots of future planned activities. And one of the things we want to do, we obviously want to have the academic outputs we've committed to, but we also want to try and maybe interest policy makers in the NHS in some ways in which these ideas could possibly be incorporated into health care teaching and training. So both Dr. Cooper and myself teach medical students and that's another way of introducing these issues to future medical professionals.

Interviewer: So your project began in January. It's running for two years, what stage are you at now and what are your next plans?

Havi Carel: We've held three of the four workshops already. There was a workshop on disability and chronic illness, a workshop on philosophy of psychiatry on the notion of mental disorder and a workshop on culture bound syndromes. And we've got another workshop on phenomenology that will take place at the University of Hull in 2010. And then we've got a series of public debates that will take place in various parts of the country as well as more of these workshops for health professionals that again will take place in various places throughout the country.

And the final activity would be a big multi disciplinary conference that will be held in September 2010 at UWE, which will be just called The Concepts of Health, Illness and Disease. And we hope to draw people from philosophy, from the health professions, from psychiatry,

sociology, law, economics, health economics and so on to discuss the concepts and we're very excited about that.

Additionally we've got a website that archives all of the material of the workshops and additional material and that's accessible via my UWE homepage.

Interviewer: Great. It sounds like a very busy time. Havi Carel, thank you very much.

Havi Carel: Thank you.

*That was a podcast from the Arts and Humanities Research Council. For further information please go to [www.ahrc.ac.uk](http://www.ahrc.ac.uk) Thank you for listening.*

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