FAB Gab Ep 3 Dirk Lafaut

Emma Tumilty: [00:00:00] Hello, and welcome to FabGab. This is the podcast for the International Journal of Feminist Approaches to Bioethics brought to you by the Fab Network. My name is Emma Tumilty, and I'm from the Department of Bioethics and Health Humanities at the University of Texas Medical Branch in Galveston in the US.

My co-host is Dani Davis from the Bioethics Center at the University of Otago in Dunedin, New Zealand. Today, we're joined by Dirk Lafaut from the Vrije University, in Brussels, in Belgium. He's in the Interdisciplinary Research Centre on Migration and Minorities, as well as the Centre for Ethics and Humanism, and the Centre for Expertise on Gender, Diversity and Intersectionality.

He's here to discuss his paper with co-author Gily Coene, entitled, "Autonomy Without Border, Understanding the Impact of Undocumented Resident Status on Healthcare Relationships in Belgium" and this appears in Volume 16, Number 2 of the journal. [00:01:00]

Hi, Dirk. How are you?

Dirk Lafaut: I'm good, thanks. How are you?

Danica Davis: So, do you want to begin by telling us a little bit about how the paper came about?

Dirk Lafaut: Yes, it's, uh, the paper was written as one of the articles for my PhD thesis. So that's, I mean, the academic context that it came about and I think the idea for the paper was informed by one of the observations that I made during my research that many undocumented migrants decided to withdraw from healthcare seeking, and that this was caused by, by structural problems in the healthcare system.

But that many healthcare systems said this is an autonomous decision of the patient, so we leave it at that. So that was what kind of drew my attention. The theoretical framework was partially inspired by a colleague, Michiel de Proost, who's also working at Vrije, and he does research on social egg freezing.

He used [00:02:00] this concept of relational autonomy in the context of reproductive autonomy. And I was curious, can we use that concept outside of the area where it's usually used?

Emma Tumilty: Well, and maybe this is a good point where you could give us an overview of the paper and how you're talking about your interest.

Dirk Lafaut: Well, the paper is about the impact of residence status on health, on care relationships. And I started by pointing out the structural context in Belgium of how healthcare is provided to undocumented migrants and then I looked into how this impacts on the position of the healthcare worker. So the framework, how that changes the position of the healthcare worker and then of the patient who's undocumented, and then how that relationship changes just because of the undocumented resident status.

And I, from those elements, then I come to a more theoretical reflection on, on relational autonomy.

Danica Davis: You use an integrated [00:03:00] empirical ethics approach. I wonder if you can tell us a little bit more about that approach and how the data collection went. And that's both in terms of the interviews and the observations.

Dirk Lafaut: All right, so that's, that's two questions. So the integrated empirical ethics approach, let me start there. That's a concept from Bert Molewijk and colleagues, um, who developed it. And, um, he developed it, or he theorized it because he thought there's, within social science, there's often like a, kind of, clear gap between the social sciences and the ethicists, where the social sciences, they, they deliver the data and the ethicists do the, do the normative analysis, and he thought there's a large space between those two X between in this role division, there's a, the roles are too clearly defined and often in the way data are collected, there's already normative assumptions.

So he thought that ethicists actually also should participate in the actual data collection. He actually advocated for a larger role for [00:04:00] ethicists throughout the research process, but the goal of integrated empirical ethics is still to try to come to some kind of normative conclusion. But, um, yeah, moving away from that tricked role division between ethicists and social scientists.

And then the second part of the question was, I think, about the data collection.

Danica Davis: Yeah, I was just really interested in how the data collection went in terms of your experience with the interviews and the observations made from your research.

Dirk Lafaut: Before starting, I had a clear plan, but that's often the case.

But it's actually… as I was about to start the, that was in, in September, 2015, that was the moment where the, uh, the European refugee crisis happens. So where the, the image of Island Kurdi being washed up at the beaches in Bodrum made global headlines, I think. And then also, this was also quite, um, a big political and also humanitarian [00:05:00] topic in Belgium as I started my research.

So I think as I was starting the. There was also a lot of initiatives to provide care to refugees in Belgium and that got very politicized. So I kind of shifted my focus and focused on what was there because there was suddenly a lot of medical humanitarian organizations providing care to refugees. And after a while it become and became unclear who, who are the, is it necessary to make the distinction between the asylum seekers and undocumented migrants that are already there?

So that became very interesting for my research and I started focusing there and that actually shaped the rest of my data collection. I gathered a big network there by starting to data collection there, and that facilitated the rapport with possible respondents and it gave me a network. So that's, um, it shaped my, the rest of my, my research really that, yeah.

Emma Tumilty: And if I can just follow up on that, because you were telling us before that you were a GP and I wondered how you found sort of the interaction [00:06:00] between you because I'm going a little off our sort of initially discussed questions. But I wondered how you found the interaction with what are still patients, but as a researcher rather than a clinician and how you felt switching between those, those kinds of identities.

Dirk Lafaut: Yeah, a good question and one that I, something that I found difficult. I've actually just finished a paper that I've submitted in another journal in medical anthropology. It's the last phase of the revisions where I elaborate on the complexity of this position of, of, uh, being a researcher who is trained in the field that he's researching, but who is also looking at things that go wrong in that field where he is trained in.

It gave a lot of ethical dilemmas on how open I could be about, about why I was there. Also it gave dilemmas in terms of where does my GP function stops and where does my researcher function start because sometimes you get [00:07:00] confronted with somebody who has a clinical problem and, and, and yeah, for participants, it's not always that obvious or that easy to make that distinction.

Uh, you say I'm a researcher, uh, but they, then they hear your, you have, or then somewhere along the line they get to know that you're also clinically active and they start asking clinical questions. So yeah, it's, it became, sometimes it became a bit messy. I've written a paper on this recently.

Emma Tumilty: Well, hopefully we can link to that one too, uh, when we send out the podcast.

Dirk Lafaut: Well, uh, yeah, I will let you know if it's, uh, completely published.

Emma Tumilty: We can tell people to look out for it either way. The other question I had, and what I found really fascinating about this paper was what you were saying about relational autonomy and how understanding it, how understanding it allows you to recognize that certain relationships open up more choices than necessarily close them.

And I think often our conversations with relational autonomy are always just to contrast it with informed [00:08:00] consent rather than necessarily start expanding out in new ways about what it can offer. So, uh, I wonder if you could explain that a little bit more to the listeners, this idea that relational autonomy allows us to see certain kinds of relationships differently and that they might be doing something else.

Dirk Lafaut: I think a lot has to do with, well, the research context in which I did my research or did my data collection, it's a context where there's a lot of structural barriers in access to healthcare. And I, I heard from, from respondents and, and then I'm specifically talking about undocumented migrants, that a lot of them had connected to one specific trusted healthcare worker that they consult wherever they want to go.

And they ask advice, they ask, often ask permission, can I go there? And I also noticed they just, they told me, but I also, during my observations, I noticed they are very grateful, but sometimes even submissive towards that [00:09:00] specific healthcare worker, acting overly grateful, um, like almost, yeah, overly performative way.

And yeah, of course, from an ethical perspective, there's a lot of problems with that. It's very paternalistic. If you have to ask one specific healthcare worker, if you can go to, to others, but in interviews or in conversations, my respondents actually value these, these relations very much. They were very positive about them.

They didn't see them as, as patronizing and, well what I try to do with this concept of relational autonomy is showing that in this particular context of structural barriers, um, actually this one specific relationship, uh, opened up new options for the, for the patients because healthcare workers that they had that connection with because of the history of that relationship, they would connect patients in their network to other healthcare workers, to social workers that they know. So they would open up the healthcare system [00:10:00] through their informal networks. And that's what I'm trying to, that's what I'm referring to in my paper.

Danica Davis: Wonderful. Thank you for walking us through that. It's incredibly interesting.

You touched upon earlier those tensions between the different roles or different hats that you were wearing throughout the research process. Are there any other challenges that, um, or obstacles that you encountered conducting your research?

Dirk Lafaut: Yes, there were, there were quite a lot, obviously research never goes, uh, goes that smooth.

Uh, this paper took a bit before the first version and, um, the final accepted version. I think this paper took four and a half years. I looked it up before the, the, the, uh, the interview. So my very first draft, I made it in 2018 and it took me quite a while to apply that concept in, in a context where it hasn't been used a lot.

So it's usually used in a context of, of reproductive issues. So in the context of migration. [00:11:00] Um, I also initially had used it in a more normative way. So I had in, in initial versions of the paper, I had described different health trajectories that, that undocumented migrants can, can make, uh, or can follow in the healthcare system where some have like a history of chronically unstable relations and others attach very strongly to what one, um, healthcare workers, others are completely embedded in a kind of healthcare network. And I would use this concept in that earlier version, I used the concept in a normative way to see is this decision or are the decisions taken by these patients, can we say these are autonomous decisions or not?

If somebody decides to stop looking for, for health whilst having, for instance, epilepsy. Can we say that's an autonomous decision? So it took me quite a long time to find a balance between the empirical and the normative aspect of the paper. To balance it [00:12:00] out, it took me long.

Emma Tumilty: I think that's really helpful to hear though.

For many of us who have that mix of sort of empirical and normative work together, I think that is often the tricky part of things. And like I say, I mean, I really love what you're doing here with relational autonomy because as someone who teaches it often to med students, med schools, it's really often used only to think about the patient differently, not as to trouble that idea of like the rational decision maker capable of making independent decisions.

Um, and I think what really nicely comes out in this paper is the role of the clinician in that relationship, um, which is, you know, add it to mid-curricular around the world.

Dirk Lafaut: Okay!

Emma Tumilty: that's apart from what I'm taking away, what would you like people to take away from your paper?

Dirk Lafaut: It depends, of course, to whom I'm talking. I think in the paper I specifically make a recommendation to healthcare workers. As you say in the paper, I point to [00:13:00] the importance of the relational network of the healthcare worker. And I think in a context of structural barriers, there's particular responsibilities for healthcare workers. Um, often, what I saw in my observations, there's a lots of initiatives to make people aware of their rights to give them information: 'This, these are your rights. This is how the procedure works to get access to healthcare.' So, giving people information, but I think in the context of structural barriers, there's additional responsibilities to, uh, to giving information and it's a recommendation. So what I would want healthcare workers to take away from this paper is that creates extra responsibilities.

You have to walk that extra mile in, in such context. Of course, we cannot put all the responsibility on these. It needs to go with this, this awareness of extra responsibilities with, with politicization of the, the structural barriers. So yeah, it's, it's an, it's a complicated takeaway message. [00:14:00]

Danica Davis: You've mentioned that you may have an upcoming paper, which is very exciting. I would love to read it. What else is next for you?

Dirk Lafaut: Well, in the paper, I, the lens that I use is, is undocumented migration. So what's in my more recent work, I, I focus more on, on structural racism, on race as a, uh, instead of migration as a, as a lens. I know in the U S there's a long tradition of, of, uh, research on, on race and health inequalities.

In Europe, there's, there's historically, much more resistance to using race as a, as a lens. But I think there's, yeah, uh, I see you're frowning, uh, Dani, but there are indeed, uh, there's, there's more resistance to use that as a lens. And I think, uh, we should get over that. I think it's, it's time to not use migration as a lens to talk about race, which is often happening.

So in my next work, I'm actually, uh, I want to look to structural discrimination, uh, structural racism in [00:15:00] healthcare, uh, settings. And I'm particularly interested in the concept of implicit bias, how, how that is, how we can research that and then how we can, if it's possible to change to conceptualize racial implicit bias in a healthcare system.

Emma Tumilty: Fascinating. And the point about sort of race in relation to migration is I think a really important one. Especially if we look at sort of the differences that occurred between Ukrainian refugees versus refugee from the Middle East. We look forward to your future work, which I'm sure will be as interesting as this has been.

Is there anything else you'd like us to add to the audience about your paper or the work that you've done?

Dirk Lafaut: No, I want to thank you for having me over for, uh, for showing interest in my paper for, for this interview. So, so thanks. Thanks a lot.

Emma Tumilty: It's been a real pleasure. Thank you, Dirk.

Danica Davis: Thank you so much.

It's been incredibly interesting. It's been really cool to have a look at a paper that has more of a, um, offers more insight in terms of the actual, the research process and the data collection. That was [00:16:00] so incredibly interesting. So, thank you so much, Dirk.

Dirk Lafaut: You're welcome.

Danica Davis: Thanks so much for listening to this episode of Fab Gab.

You can find the paper we discussed linked in this episode's notes, along with the transcript. You can find out other episodes on Spotify. This has been your hosts, Emma Tumilty and Dani Davis. Once again, thanks for listening. Bye.