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Ethics in Qualitative Research: Nishita Nair on marginalised researchers' ethical processes

Speaker information

- Sohail Jannesari (Interviewer) (Sohail)
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- 00:00:10 Sohail Hi. I am Sohail, a migration researcher. I'm very happy to be able to introduce you and invite you into the *Qualitative Open Mic* podcast. Today we are having the last episode in our series on ethics. We are looking at how we can do ethical qualitative health research. And with us today we have Nishita. Nishita has done some really pioneering research looking at the cultural relevance, or not, of ethical codes and the ethical codes we use to conduct our research. So I would like to invite you, Nishita, to introduce yourself and your work.
- 00:00:49 Nishita Hi Sohail. This is Nishita Nair, and I am—I work at the Institute of Education at the UCL's Faculty of Education and Society as the research ethics officer where I help applicants process ethics applications. I work really closely with the chair of the ethics committee and the ethics committee themselves to develop guidance and, yeah, help applicants, you know, navigate ethical issues in their research. And it's good to be here.
- 00:01:22 Sohail Brilliant. It's lovely to have you. So, how does one get into doing ethics as a job? Is that something you set out to do when you started your sort of academic career or how did you get into it?
- 00:01:35 Nishita So, I—my most previous job was at the NIHR. So I worked as a manager for one of their research programs there. And I think I was always interested in health research particularly, but then, I don't know, it was sort of a mid-career sort of change and, you know, I got interested in ethics. We are all interested, isn't it? And what's right for you may not be right for me. What's the correct way? You know, so it's those kind of thoughts that motivated me to take up a masters in bioethics at King's College London, and I simultaneously began working at the Institute of Education as the ethics officer.
- 00:02:14 Sohail I was going to say, this might sound like a bit of an obvious and sort of stupid question, but I want to know why does it matter so much if things are right in the realm of qualitative research ethics? Why does it matter?
- 00:02:26 Nishita Well, I think we live in a really complicated world and, you know, things are changing all the time. You know, ethics has become so important. I think these conversations about what is right, what makes something ethical, and how to live ethically, plague people. We talk about it, you know, in so many different realms from science to technology to health. It's just a fascinating question. I think it's an intriguing and fascinating question, and it's an amazing journey to go on because I think that's what it is. It's really the discovery rather than arriving at that destination of what's right. But it's really enjoyable and I love doing what I do.
- 00:03:03 Sohail Brilliant. And can you tell me a bit more about what you do in terms of the research that you've just done?
- 00:03:08 Nishita Yeah. So we all know that ethnic minority communities tend to suffer worse health and social outcomes compared to the majority population, but yet there seems to be a lack of good quality research data on minority communities. So we can understand the reasons behind these inequalities and develop services to alleviate the inequalities. And I think it boils down to this lack of participation in research. And there's lots of literature available on the several barriers to the participation of ethnic minority communities in research in the UK. So you've got like the more obvious barriers like language, maybe financial barriers, certain cultural and religious barriers, which we—seem maybe easier to overcome with translation or with certain appropriate incentives so that they participate in research. And then there are the more complex barriers like the fear, mistrust, and suspicion which has been caused by historical and contemporary injustices, which are a lot harder to navigate. And I mentioned, I worked at the NIHR previously, that's the National Institute for Health Research, where I was also the chair of the EDI committee. And we all had these conversations about how to improve the participation of minority communities in research. And I thought there was a lot of

literature available, there's lots of conversations, but there were no real solutions or no concrete solutions as to how to address this gap. And I found that really quite surprising and frustrating at the same time, because we kept having these same conversations and seemed to be going around in circles. So moving on, like I said, I became interested in ethics, started doing this masters in bioethics at Kings, working at the IOE as the research ethics officer. And for my dissertation, I decided to revisit this question, "Think about what guidance are we giving researchers when they go into the field and do this work with ethnic minority communities. How are we helping them address these barriers to participation?" But also, I just think there is a moral reason. I mean, are we treating ethnic minority communities ethically? And so I, you know, embarked in this research. My research question was 'Do social research ethics codes and institutional ethics practices aid researchers in their work with ethnic minority communities in the UK?' What aspects were beneficial? Where are the barriers or the gaps? But moreover, do these codes and the processes that we've developed around these codes actually guide ethical thinking? So I did some semi-structured qualitative interviews with eight social science researchers across Kings and the Institute of Education. And just for the sake of, you know, the listeners who may not be aware, so these ethics codes that I'm talking about are research ethics guidelines that are developed by professional learned societies such as Social Research Association, the British Educational Research Association, the British Psychological Society, et cetera. And these codes, really, they have shaped the institutional ethics review processes. So it's like the codification of these codes in practice, if you like. So my question is essentially, are those codes and the processes culturally competent? And I must say Sohail, I mean, the literature that's there is very, very limited. We were having this conversation, you know, earlier on and what literature is out there is really written from the biomedical context. So very little on the social sciences.

00:06:45 Sohail

So why do you think the literature is limited in this area? It seems like it's such an important thing to know about so why is there a gap in the first place?

00:06:55 Nishita

So the reason is that ethics codes originated from the biomedical space. If you think about, you know, the Declaration of Helsinki, I mean, that was the beginning of ethics codes which began in the biomedical space. And then it kind of infiltrated into the social sciences, and social sciences was largely unregulated before. And it's only now that, you know, this whole kind of ethics review of social sciences. It's quite a recent thing.

00:07:22 Sohail

Great. Well, I think it's about time we hear about your research and the findings that came out of it. So please hit me.

00:07:30 Nishita

Alright. So, in terms of the social research ethics code now, like I've said, they originated with the Belmont Report in 1979. So this was after, you know, the United Nations' the Charter for Human Rights, Declaration of Helsinki. And this was the first document that actually governed the ethics of social science research. And because it was—again, it was all kind of rooted from the codes within the biomedical space, there are the influences of principlism within the codes. So principlism is an ethical theory that was proposed by Beauchamp and Childress. You've got the four foundational ethical principles, the respect for autonomy, nonmaleficence, so intent not to cause harm, beneficence, you know, you want to promote benefits, and justice. But it does state that, should the principles come into conflict with each other, respect for autonomy must always prevail. And so it really betrays its', you know, individualistic Western leaning, you know, which is really difficult when you try to translate these concepts into, you know, research within collectivist societies that prioritise the benefits to the community over individual gains. You know, the researchers in my study spoke about issues seeking informed consent, securing confidentiality arrangements. Again, very, very individualistic concepts which are really difficult to translate. The importance to nonmaleficence, so you really need the focus on not causing harm, but not enough focus on really realising benefits which are very important to these communities. And if you think about justice Sohail, I mean, you know, the codes understand it as the equitable distribution of burdens and benefits. But what about, you know, addressing inequality? So [chuckles] you know, one may choose not to

participate because of some, you know, issues with mistrust or some longstanding fear and, you know, those kind of issues. And the codes would say, “Well, that is just if somebody declines participation. You know, you have to respect their autonomous choice.” But is it really? I mean, you know, it doesn’t have this holistic idea about how to sort of deal with justice in this space. Another thing about principlism is it professes sort of a universality to ethical norms, with the white majority norms taken as the norm and any deviance from that is considered improper. But like we said before, again, morality is fluid. What is right in one culture may not be right in another. There’s so many difficulties translating these codes, which has actually led to certain indigenous communities in New Zealand, Australia, and Canada developing their own ethical guidance on how they wish to be treated when they are being—you know, engaging with researchers in those countries.

00:10:22 Sohail So what are those principles then from these communities? How do they differ?

00:10:27 Nishita So they bring in a little bit more of their sort of cultural understanding of these, you know, ethical principles and they feed it into the codes. So they don’t change it entirely, but they sort of build on the codes. So for example, I was talking about, you know, the importance of benefits and not just harm. So I think it is the Māori community that has really, you know, designed codes where they have brought in their own people to actively participate in the research. So for example, to feed into the research design, take on active roles within the research process, work in the dissemination of the results. So those kind of things. So it’s really about an adaptation and feeding into what we have already to make it sort of better suited to those cultures. And [chuckles] I think the one thing that I thought was really interesting about principlism that came up in the research is, there’s a very intellectual kind of way of ethical decision making. So, really, if you think about the principles, it’s about balancing those principles to see which one should really prevail. And it’s a very kind of like calculative, very more—a very kind of intellectual way of thinking about ethics, which does detract people from the emotional side of things and how that feeds into the ethical process. So if you think about research with ethnic minority communities, they hinge upon building trusting relationships with these communities. So if you tell a researcher to remove that emotional kind of engagement, then it’s really not an effective way to engage them in a dialogue that would be meaningful. I must say that the research is—the one thing that the researchers said about the codes were that they were quite broad and open to interpretation and really offered them the flexibility of ethical conduct in the field. And, you know, I had some researchers say that they had used the codes to really sort of justify certain ethical processes, whether it was verbal consent or the use of subterfuge. So they used those kind of processes to defend, you know, their research, to sort of defend that to the committee, and they stood by that. And they were really pleased to find these within the ethics code. So that’s the kind of, yeah, bits that I found around the ethics codes. Really, the influence of principlism being a problem.

00:12:52 Sohail Okay. And so you are suggesting that maybe the principles for biomedical—bioethical principles that a lot of research ethics is currently based on, could be reformed and built upon, I guess. But is that enough? Is that—because it still feels to me like you are anchoring the codes in these principles, why not start from scratch?

00:13:14 Nishita No, that’s—I think that’s a good point, Sohail. So there are the codes and then how they’re interpreted and how they are practiced. So how does this actually become part of the process? So that’s, again, a place where there is a breakdown in terms of how we digest the ethics behind these codes. So whether there is a problem with the codes or whether there’s a problem with the way they are kind of taken up is the question. And I think—I mean, from my research anyway, the codes seem to really—you know, there is an agreement of what is the right thing to do. Researchers have found that very useful, but what they did want was for it to be flexible. And that’s, I think, where the adaptation element comes in. There’s probably no need to reinvent the wheel, but it’s about thinking of using what we have to best suit our needs.

00:14:04 Sohail Thank you for that. Please, let’s hear about the other findings.

- 00:14:09 Nishita Now, I must say, like with my work at the IOE, I'm really familiar with the ethics review processes and it's always we think about how to make them better for the researchers. We don't want to make them burdensome, we want to make them useful and we want to help researchers where we can. Okay? So from my research, the researchers found the actual ethics application process quite useful in the planning stages of the project. So when it came to thinking about ethical issues and how to mitigate the risks around those ethical issues, so they really went into the field prepared and they were quite, like, happy to have gone through the ethics application. But [chuckles] there were quite a few barriers to ethical thinking. So they said, well, it helped them, but it didn't really instigate ethical thinking. So if you think about an ethics application form, it's a really static, non-continuous sort of document that makes you think about your research at the beginning, but it really doesn't make you consider, you know, those other elements that may arise as your research evolves. Because research is unexpected and you kind of—you know you may face things you wouldn't have known when you began your work. Also, like, I think the form. I mean, it's really hard to get away from the bureaucracy of a form. Filling a form. And I wonder if this sort of kind of has added to all the other research administration that we have encountered in the past many years when it comes to bidding for research or initiating research processes. And I wonder if ethics kind of slots in there, you know, for researchers anyway. But here's something that's also—it was quite interesting. [chuckles] So reviewers, really, in—you know, when they are reviewing an ethics form, they really have no—they don't have any understanding of the research setting. And this is because I think the form in itself is really hard for applicants to kind of talk about all these things within the limited space available within an ethics form. And this is where things like situational ethics are gaining prominence in educational and social research, where they state that ethical thinking is really incomplete without attention to research context and when based on ethical principles alone. So, again, another drawback with using the form. [chuckles] And I think—another thing I think that's really important, which was really sad to sort of note, was there is a relationship breakdown between applicants and the REC members and the reviewers. And again, several reasons for this, which came up in my research but has also been documented in the literature, things that came up, like one of the things—the top things were the perceptions by researchers that the ethics review process was geared towards institutional protection and not participant protection, serving more of an audit sort of function. Another thing was also there were like paternalistic attitudes of reviewers sometimes that led to the overprotection of research participants and caused barriers to research and caused that friction. And also there were—there are, like, trust issues. So there is evidence of the lack of trust some reviewers have on researchers to do their job ethically. And this is something that was perceived by researchers themselves. So all of this doesn't really help. These issues of mistrust doesn't help engage with the application process.
- 00:17:35 Sohail And is there a structural legacy? Why—how did we get here? So you said that—so, again, is it the biomedical route that got us here? Are there any other things along the way that enforce this kind of rigid structure?
- 00:17:50 Nishita No. I think it's the biomedical route. So it started off in the biomedical space and unfortunately there was a standardisation of ethics review processes without appreciating the differences of social sciences. And this is what's caused us to get here. And if you think about, like, social sciences, they were, like, largely unregulated before. And, I don't know. I mean, again, this is something I'm not really sure of, but it could be actually pressures from funders that have actually, you know, led us along this path of standardisation where we need to protect participants and protect institutions. I don't know. It's hard to say but I definitely think the biomedical, kind of there's this importation from the biomedical context which is to blame. [chuckles] That's my opinion.
- 00:18:39 Sohail Well, thank you. Are there any—is there anything else from your research findings that you want to highlight that really stood out and was...?
- 00:18:47 Nishita Yeah. So in terms of the—again, the ethics review processes, so, yeah, we were talking about the biomedical influences and I can like elucidate a little bit further. So this focus

on nonmaleficence, minimising harm, very important from the biomedical sort of space. But in social sciences, I'm not saying that there isn't the risk of harm, but the risk of harm may be smaller or we may need to actually think about some other ethical considerations. You know, this focus of minimising harm can sometimes be— [sighs] I don't know. Just, are we focusing on the right things? I think that's the question. So that focus unfortunately has led to ethics processes that are not proportionate to the risk you see within social sciences, and that's something that was highlighted by one of the researchers within this study. And again, I think particularly interesting for your listeners, positivist orientation of reviewers. So if REC committees tend to be staffed by, you know, reviewers that are more closer to methodologies used within the medical spaces, it's present in the literature and it's also been highlighted by researchers in this study. That there are difficulties approving qualitative projects, particularly participatory action research, ethnography. You know, so you've got long review timelines, you have harsher criticism and sometimes, you know, applicants receiving comments that are actually incongruous to the aims or the purpose of the research, which is really off-putting and quite alienating. So we've also been speaking—so apart from the biomedical space, we've also spoken about that Western thinking and the Western philosophical kind of influences on the ethics codes, on the ethics processes. And while the codes, like I said, was quite broad, the institutional ethics processes, you know, the influences of that Western thinking or the—what is acceptable to the norm, the majority, like that's what came up in the research. It is quite heavily ingrained within institutional processes and researchers found that part much harder to navigate. So I can give you some examples: Cumbersome participant information sheets and consent forms. Now we have information sheets that are lumbered with GDPR, ethical and regulatory compliance, et cetera, which frankly are really hard to translate into other languages. It's really hard to communicate to people with lower levels of education. Very, very difficult, again, to communicate to all those speakers who have different ways of knowledge acquisition. The signing of consent forms, you know, for asylum seekers or refugees, reluctance to—you know, the reluctance for them to sign written documentation is very well evidenced. And yet we have these processes that has somehow stuck, which really complicate the lives of the researchers that go into these spaces. Our research—my research has also spoke a lot about, you know, issues with co-production and collaborative research. So again, things that came up were the conflict of ethical principles that were used at the institutional level and those that were on the ground, you know, that were experienced by the communities themselves. So there seems to be differences in the way people prioritise the ethical principles. So, you know, going to your question about: Should we revamp it completely? I don't know. I mean, I think the principles are quite sound. The principles are useful and valuable, but it's about how do we focus on them? What do we focus on and what do we prioritise? I think those are the questions that would really be important to ask. And again, in relation to co-production and collaborative work, when publishing lots of issues came up. So universities generally want you to keep your participants anonymous, but then when they're enrolled in collaborative research they may want to be known. But then what do you do when, you know, revealing their identities could cause them harm, particularly if they're vulnerable. So these are questions that really are not covered by the ethics processes and, you know, because they come from this very Western thinking, individualistic sort of background, which is very suitable to the majority population, but they've really missed the mark on [chuckles] dealing with the issues when working with ethnic minority communities.

00:23:05 Sohail So can I ask, did you interview people from ethics committees as part of your research, or have you had a chance to put some of these points to people on ethics committees? I just want to get the sort of other perspective. Because for me—from my side, and I was one of your interview participants, it feels like things aren't going the way they should be, especially around things like participatory research. But do people who sit on ethics committees feel like that? Do they feel like there's a need for change as well?

00:23:37 Nishita I think they do. I think especially—and this is the thing. I mean, within the IOE we have a special—sorry, a separate ethics committee for social sciences. Again, a great start, you know, not to have social science research reviewed by committees that are more used to reviewing medical sciences. And there is appetite for change. And again, I'll

come to that perhaps a bit later, but we are having these discussions but it's really important for all of us to get involved and have these conversations. So I would be definitely presenting this work to my committee and seeing where we can make the changes and how, but it's also important for social scientists, people involved in participatory action research and ethnography to come forward and engage with their ethics committees. So there is, like, a burden of responsibility, I think, that we all share so that we can drive this change. We are not there yet. I agree, Sohail. [chuckles] But we have an appetite to sort of instigate that change and we should welcome the opportunity.

00:24:41 Sohail Great. Thank you. So I think there's a couple more points around your research findings around positionality, also the popularity of virtue ethics. If you could explain these, I'll be very grateful.

00:24:54 Nishita Yeah. So I was really—You know, I think one of the gaps I found in both the codes and the processes were really considerations to positionality and reflexivity. And both of these, you know, almost all the researchers I interviewed said how important it was to steer ethical thinking in this space. So if you think about positionality, you know, researchers would think about what they brought to the research, how it influenced the research process, and, you know, the way it helped them with their research with the minority communities. It ensured that, you know, the relevant team members were included, so it really helped them build cultural competence of the research team. It helped them navigate power imbalances. So not just cultural, but also educational, social, health imbalances. And it helped them deal with any potential negative sentiments of their research being extractive. And they did this by having open and honest conversations with their participants and being very clear about what the expected achievements were at the end of the research process. So you really had to think about your positionality before you went into the research field and before you engaged with your participants. Same goes with reflexivity. Again, understanding your own biases and assumptions, it helped—it can help you sort of challenge any negative or unhelpful prejudices you may have, which is essential for you to progress your work. And given the space is so complex [chuckles] and very unpredictable, unless you engage in that continuous ethical thinking, you know, the reflexive thinking about whether what you're doing is sound, is ethical, is, really, checking in with yourself is really key. So reflexivity, again, missing from the ethics review process particularly. But, again, that may be down to the structure as we discussed before. But I was really pleased—like I will betray my love for virtue ethics but I'll go ahead anyway. [chuckles] So researchers, you know, they were really driven by personal values and belief systems and an intrinsic understanding of what was right. And a lot of this came up, you know, by, for example, their desire to achieve social good by all the activities they were involved in, even beyond their research. They really stressed on the justification for the need for the research. You know, how over researching these communities had not just led to fatigue but also like harm due to stigmatisation, you know, through the association of certain negative conditions with these communities. And they all seem to have this amazing genuine appreciation and curiosity about cultural diversity, and all of these values, I think, really fed into the ethical thinking. And this is why, I think, there is—you know, virtue ethics is gaining prominence in terms of how to develop ethical thoughts. But unlike principlism, it does not impose principles but it states that these—you know, the virtues or good qualities are deeply entrenched within an individual, so deeply entrenched within the researchers themselves. And it's only, you know, with the practice of these virtues, of these qualities, that we learn to be ethical. The last thing I just want to say in terms of my findings was, researchers really learned from the practice of ethics in the field. So whether it was by their, you know, conversations with their peers, so they learned from the experiences of their colleagues who had worked in similar spaces, or even the student supervisory relationships. So students were really influenced by their supervisor's ethical conduct, and supervisors were really interested and went on this ethical journey with their students, you know, and engaged with the ethical process through the experiences their students had. So again, it's really practice in the field that was relied upon to develop ethical thoughts.

00:28:57 Sohail And there seems to be a mutual sort of learning process going on as well.

- 00:29:01 Nishita Yeah, absolutely. Absolutely. I mean, we are all learning from each other and so that's the kind of—you know, and that's where, you know, in terms of my recommendations I'm happy to sort of go on to next.
- 00:29:14 Sohail Please talk about the recommendations. I think you've mentioned some around sort of having specialised ethics thoughts and the importance of positionality and reflexivity, but is there anything else that we really need to get on with basically? [chuckles]
- 00:29:29 Nishita Yeah. So I think in terms of—you know, in terms of the codes, so like I first spoke about the ethics codes, and I think they're not useless, they're very valuable. But I think we really should increase the visibility of these codes. You know, either through the application process or through certain training initiatives. You know, research ethics training initiatives really talk about these codes. But if there were any improvements, I think we need to increase the input from social scientists. And this is something the academy of social sciences is working on. I think processes—the ethics processes are important. As much as— [sighs] we have to admit that malpractices do happen, Sohail, and they'll always happen, and we need certain processes to keep certain, I think, behaviours in check. But, you know, one of the things that we are considering at the IOE is an approval in principle sort of process where researchers can come up with their basic research before they have done the collaboration, present it to the ethics committee, get the approval, sort of initial approval if you like, and then revisit, you know, the committee after they have done their work with the participants. So after the collaboration has taken place. So that kind of thing. But it's, you know, there are innovations and adaptations, but it's really unlikely to happen if you don't have social scientists working within these spaces. You could also increase the diversity of the committee. I think that's an obvious one. Really important to diversify the methodological expertise, particularly in qualitative research, participatory action research, ethnography. But I must say, Sohail, I think, you know, these codes and processes do not sit in isolation, and they need to be layered with opportunities for researchers to engage in effective ethical dialogue. [chuckles] And by that I mean bringing in those conversations and positionality and reflexivity, inviting considerations to the practice of ethics in the field, shedding light on those intrinsic qualities and personal attributes that researchers relied on to guide ethical conduct. But how do we do this? I frankly think we've become, like, much too ambitious with what the ethics processes can do. So we've really kind of—you know, we make them shoulder the burden of this responsibility of guiding ethical thinking. So my proposal would be to really strip back any bureaucracy associated with the expectation of ethics processes guiding ethical thinking. To keep it really light touch and really basic so that, you know, the basic sort of standards, regulatory, ethical, the basic things are met. But to supplement the process with formal spaces for researchers and the REC committee members to come together and discuss and share ethics best practice. And again, it's important to say that there needs to be proper time allocation, you know, for such activities and appreciation of the efforts that go into these activities. So there is some kind of investment involved there, but I really think that the reward will be some true ethical capacity building that will extend beyond research with ethnic minority communities that really, really get to the heart of ethical thinking.
- 00:32:43 Sohail Brilliant. Thank you so much. And what a lovely way to end things. I just want to say thank you so much. This is the last episode in the series and it's a really beautiful message to leave off with. And it's so interesting you ended with saying spaces—there needs to be formal spaces for researchers and ethics committee members to come together and discuss. Well, I can suggest an informal space where ethics committee members are more than welcome, and that's with the Inspiring Ethics group, which is a QUAHRC collaboration. So please look on the QUAHRC collaborations in the website if you want to come along and have some of these discussions and build on some of the amazing work that Nishita has been doing. So thanks very much for your time and thanks everyone for listening to the series.[downtempo electronic music fades in] The next series is going to be on interpreting qualitative data. It promises to be a banger and I will see you there. Thank you. [music fades out]

[End of recording]