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Consent through art: a critique of a visual method developed with peer-researchers in southern Nepal

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ABSTRACT

Obtaining informed consent can be challenging during peer research when the boundaries between researcher and participant are blurred. We developed a novel visual consent method with illiterate artists in Nepal who conducted peer interviews in their communities. Artists discussed and sketched images related to ethical principles to create a visual consent form. This improved comprehension about research ethics and developed the confidence of artists to conduct peer-interviews, but we found that artists memorised the form; they did not engage participants in looking at the pictures with them; and they did not use the pictures that they disagreed with. In future research, the visuals should be developed in consultation with participants and be used to explain the study to participants. The tool development process can be used to establish a joint understanding about the research, its harms, and benefits, and to develop relational and iterative consent processes in participatory action research.

Introduction

Participatory action research (PAR) is a process of collaborative, self-reflective inquiry that researchers and participants take part in to stimulate action (Baum, 2006). Participants and researchers use, analyse and reflect on their experiential knowledge to plan and implement action to improve their situation (Cargo & Mercer, 2008; Jagosh et al., 2012). The extent to which participants can and do get involved can be constrained by a lack of trust (Cooke, 2001). Using peer-research methods in PAR can help with these challenges.

In peer research, participant-researchers with lived experience of the phenomena under study collect data from their peers (Carlisle & Cropper, 2009; O'Reilly de Brún et al., 2016). This can facilitate research participation and enable access to the lived experience of marginalised and hard-to-reach groups who may not fully trust an 'outsider' who lacks experience, knowledge or status within their community (Elliott et al., 2002; Ryan et al., 2011). 'Insider' peer researchers with connections and empathy with study participants can make them feel more comfortable taking part (Minkler, 2004). Additionally, this method may benefit peer-researchers themselves, as they develop self-confidence and skills (Devotta et al., 2016; O'Reilly de Brún et al., 2016).

Consent processes can be challenging in PAR because unanticipated ethical issues can arise during the research which require negotiation (Shore, 2006). Additionally, the blurred boundaries between researchers and participants can make it unclear how and from whom consent should be obtained (Balakrishnan & Cornforth, 2013; DePalma, 2010). These challenges are amplified in peer

research (Carlisle & Cropper, 2009; O'Reilly de Brún et al., 2016) and PAR researchers have argued for a flexible, dynamic approach to research ethics, instead of a procedural approach (Cargo & Mercer, 2008; Dawson & Kass, 2005). We discuss a novel visual consent method which we developed with artists in the southern plains of Nepal who conducted peer-research about type 2 diabetes. We critically reflect on the method noting that while it enabled discussion and comprehension of research ethics among artists and researchers, it did not ensure that established ethical procedures were followed. Our experience shows the need to adapt the method before future use in two ways. Firstly, the method should be used to discuss and design locally appropriate ethics guidance and secondly research participants, as well as peer-researchers, should be involved in the design of the visuals to broaden its' utility.

Type 2 diabetes in Nepal

In Nepal, diabetes is often diagnosed late and opportunistically (Khanal et al., 2017). There is a lack of awareness about signs and symptoms among those with diabetes and among the general population (Gautam et al., 2015; Gyawali et al., 2018; Yadav et al., 2016). Nepal's health system is struggling to manage the increasing burden of non-communicable diseases (Mishra et al., 2015; Sharma et al., 2018; Shrestha et al., 2017), and there is a need to engage communities in prevention. We collaborated with artists at the Janakpur Women's Development Centre (JWDC) to co-create a public engagement process (Morrison & Arjyal, 2021) informed by peer research.

Research context

This research was conducted in August 2018 in a rural area outside the Provincial headquarters of Janakpur in Province 2 in the central southern plains of Nepal, bordering Bihar in India. Most of the population are Hindu (90%) and 88% speak Maithili. Province 2 has the second lowest Human Development Index scores in Nepal, 0.463 (UNDP & Government of Nepal, 2014), the lowest literacy rate (49.5%) (National Planning Commission, 2011) and lowest median age at first marriage (16.5 years old) (Ministry of Health et al., 2017).

The JWDC seeks to promote and preserve Mithila art which has traditionally been painted by women on the walls of their homes (Figure 1). The centre sells Mithila handicrafts and aims to improve women's agency through workplace engagement and economic empowerment. Artists are Maithili-speaking women and only a few are literate. Most of the artists have experienced social and

Figure 1. JWDC artists doing Mithila wall painting.

economic marginalisation through unstable home environments, chronic illness, disability, widow-hood, and economic hardship.

Peer-research method development

Artists and researchers were both interested in addressing the problem of type 2 diabetes. To decide the focus of our community engagement, we wanted to understand diabetes from perspectives that were missing from our reference group. Only two artists had diabetes, several artists were caring for those with diabetes, and some had no first-hand experience of diabetes. Our group were almost all women and we wanted representation from men. To start discussions, researchers with experience of researching diabetes in Nepal, interviewed two artists with lived experience of diabetes, and developed a true/false quiz about risk factors and symptoms of diabetes. Artists answered true of false by 'voting with their feet', moving to a cross or a tick drawn on the ground. We discussed what we were interested in learning more about and where there were differences of opinion. Researchers encouraged everyone to reflect on their different and similar identities (as artists, researchers, artists with diabetes, caregivers for family members with diabetes, older women, younger women, and women of a particular ethnic identity). This helped introduce the concept of reflexivity to artists. We suggested that artists could discuss with peers to see where differences of opinion lay. We brainstormed who artists could interview, what they could ask and how they could approach peers. We used participatory methods and games to introduce concepts of rapport and communication skills. Artists were keen to record interviews to help them remember the discussions.

Informed consent and research ethics

We discussed three main ethical principles (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979), using examples as they applied to our research: (1) Respect for persons – participants should be free to decide if they want to participate and no harm should result from participation or non-participation. (2) Beneficence – we should consider the disadvantages of participating in interviews and take steps to prevent people getting upset during discussions. (3) Justice – interviewing should not disadvantage anyone disproportio-nately and we should take steps to include different types of people.

We condensed a template consent form into 13 statements and a 'do you understand?' question to be used after every statement. As a group we then discussed a suitable image for each statement. Two artists sketched ideas on flipcharts as discussions occurred. The resultant sketches were painted, discussed and refined. For example, the confidentiality statement image evolved from a picture of a locked mouth to a covered mouth as artists felt uncomfortable depicting women as unable to speak (Figure 2). The full form can be found in the supplementary material (Figure 3) (Morrison et al., 2018). Artists then role-played consent and interviews using the visual consent forms and they learned how to use a digital recorder. Five pairs of artists conducted eight interviews with men and eight with women. Of these, four women and three men had diabetes. One man had type 1 diabetes. Fifteen were Hindu and one was Muslim. Caste was reported for 12 participants, and three were of low caste. We observed two pairs of artists doing peer interviews and we had a group debriefing session each day.

Visual consent in practice

Adaptation

Artists used the visual consent form, but they omitted pictures whose meaning they had forgotten or that they felt were unnecessary. Its benefit as a reminder of the common components of consent was limited to the first few interviews. Thereafter artists had memorised the components that they felt were important to discuss.

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Figure 2. Visual prompt for discussion of confidentiality.

The invitation, project purpose, stopping the interview at any time, time for the interview, recording of the interview, confidentiality, benefits and information that would be public were discussed consistently. Voluntary consent and explanation of why the participant was being invited for an interview had been discussed when researchers had approached participants, and artists felt that it was unnecessary to ask again. The harms statement was routinely omitted, and one artist said: 'This interview will do you no harm.' In one observed interview a participant cried while discussing her diabetes. The artist handled this situation sensitively and supportively. We discussed this with artists as an example of how the interview could cause psychological distress which people should be warned about. Artists felt that this was a demonstration of the therapeutic benefits of the interview: "The most important thing was that the people we interviewed didn't share their problems before, they kept it to themselves. But when we interviewed them, they said we are already suffering from this problem and now we are sharing our views so that it doesn't affect others'". This has been described as a therapeutic misconception in other research (Logie et al., 2012; Marsh et al., 2011). It may not be a misconception in our context and may be driven by artists experience of cultural norms and fatalistic beliefs which emphasise that women should bear hardships without complaint (Cameron, 1998). Artists were pleased to give the opportunity for others to talk about their experience with diabetes and presumed a shared desire to prevent others from suffering ill health.

Confidence

The development of the visual consent form was helpful in providing a participatory way of discussing research ethics, which may have improved comprehension and confidence. The visual consent form was not explained clearly to those who were interviewed and artists were occasionally asked to 'hurry up' while taking consent. One man with diabetes asked, 'Why are you only turning pages instead of discussing with me?'. The booklet had been based on artists' ideas, and the artist and participant did not look at the pictures together. The consent form may have impeded rapport building between peer researcher and participant (see also (Dawson & Kass, 2005)). This could be addressed by developing a form

based on participant feedback during piloting phases. Participants and artists could go through the form together in a discursive way to enhance understanding. Future research could evaluate the effect of the form on increased understanding about the research objectives, benefits and potential harms.

Vulnerability and knowledge

Some artists were afraid that they would not know the answer to a question if a participant asked, and only one artist asked if the participant had any questions. Peer interviews with men and women who didn't have diabetes were shorter than with men and women who had diabetes, and artists tended to ask participants about a family member with diabetes or interview someone they perceived would know about diabetes. In de-briefing, artists said that they were unsure what to ask people who didn't have diabetes, as they were like them, and therefore these interviews wouldn't provide any new information. Artists felt able to educate researchers about the barriers to reducing diabetes risk in their community, because researchers were from outside the community, but found it difficult to ask about what (they presumed) they already knew from community members who were similar to themselves.

Conclusion

The visual consent process enabled in-depth discussion about research ethics in our PAR, and enabled artists to feel comfortable recording interviews. This enabled important access to the lived experiences of those not part of the critical reference group leading the PAR. After a few interviews, artists had memorized the consent process, making the form less useful for them. In future research, we recommend that the visuals are designed by artist-peer-researchers and piloted with eligible participants so that the form can be used to build rapport and improve comprehension of participants during the peer-interviews.

   When artists did not agree or feel comfortable with parts of the consent process, they did not discuss them, despite the picture prompt. Although ethical review boards provide strict guidance on consent form content and procedures, a locally negotiated informed consent process which is relational and iterative is more appropriate in PAR (Khanlou & Peter, 2005). We suggest that the visual consent tool development process is used in PAR to discuss and establish a joint understanding about the research, its harms, and benefits, and to develop locally appropriate ethical guidance.

Notes on contributors

Joanna Morrison is a Senior Research Associate at the University College London Institute for Global Health. She has lived and worked in Nepal since 2002, conducting health systems research and supporting the implementation of large cluster randomised controlled trials of participatory, community-based interventions to improve maternal & newborn health, nutrition and prevent and control type 2 diabetes in low-and middle-income countries. She specialises in qualitative methodologies, participatory action research, formative research for the design of interventions, and process evaluation. She has led collaborations conducting qualitative and process evaluation research in Nepal, India, Bangladesh, Malawi, Niger, Somalia and Thailand. Her current research interests include adolescent health and non-communicable diseases in low-and -middle income countries.

Abriti Arjyal is an experienced mixed methods researcher based at HERD International, a leading research organisation in Nepal. She is experienced in developing qualitative tools and techniques, participatory action research, health policy and systems research, and community engagement. Her areas of work include maternal and child health, reproductive health, nutrition, health systems, diabetes, violence against women, gender and intersectionality. She is currently conducting participatory action research to address antibiotic resistance in peri-urban Nepal.

Awantika Priyadarshani is an experienced mixed methods researcher who completed her master's in public health from BRAC University, Bangladesh in 2018. She has been part of a large research team conducting health systems research in southern Nepal to support in evidence-based planning and went on to work as Technical Advisor-Public health for USAID Clean Air.

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Ethical approval

This study received ethical approval from the Nepal Health Research Council 235/2018 and from the UCL Ethics Committee 4199/005.

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