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On the Edge of Ethics: Emotional Precarity, Knowledge Seeking and Health Research Ethics Committees

Marshall, T. (2021). On the Edge of Ethics: Emotional Precarity, Knowledge Seeking and Health Research Ethics Committees. *BMJ Open*, 11(Suppl 1), A17. <https://doi.org/10.1136/bmjopen-2021-QHRN.47>

Published in:
BMJ Open

Document Version:
Publisher's PDF, also known as Version of record

Queen's University Belfast - Research Portal:
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In my own fieldwork, I predicted that trust and mistrust would be key themes that would benefit from investigation, particularly between activists, NHS managers and politicians. Although I also predicted that I would have to negotiate mistrust in my own relationships with people, I was surprised by how mistrust manifested itself. Activists expressed mistrust for me in various ways, and yet continued to engage with me.

Reflecting on that mistrust for me was uncomfortable. It brought to the surface the common emotional theme of the fledgling ethnographer: betrayal. But reflecting on their mistrust for me, and the different kinds of engagements and relationships that followed from that mistrust, led me to focus on mistrust itself as a particular form of engaging with uncertainty. Thinking about their relationships with me helped me to understand their relationships with other actors in health-care and policy.

8 PARTICIPATORY RESEARCH – CHALLENGING THE KNOWLEDGE SYSTEM OF DEMENTIA?

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10.1136/bmjopen-2021-QHRN.46

The knowledge system of dementia reflects the hierarchical medical system. Traditionally, scientists have been regarded as the ones who produce knowledge, have knowledge and decide which knowledge is relevant in health care and nursing for people living with dementia (PlwD). As ‘patients’, PlwD were objects of research or recipients of care. The lay perspective had in general little authority in the knowledge system of dementia. Particularly, PlwD’s perspectives were systematically devalued against the background of a biomedical-cognitivist, deficit-oriented understanding – information provided by PlwD was considered less trustworthy. This systematic exclusion of PlwD’s knowledge also applies to qualitative dementia research. However, a change in thinking has set in and PlwD are increasingly included in research as research participants.

Parallel to this, a more far reaching development is now gaining momentum: PlwD demand equal shares in research. ‘Participatory research’ is no longer just about being a participant, but about a share in the power to decide on the research process – from the formulation of research questions and data collection to interpretation and dissemination of results. Many qualitative dementia researchers are open to this type of research and some funding bodies are beginning to call for it.

The aim of this contribution is to theoretically discuss the following questions: How can participatory involvement of PlwD in dementia research influence trust in dementia-related health care research? Can participatory research increase trust because the plurality of perspectives is recognized as a value? Or could it reduce trust because the perspectives of PlwD appear untrustworthy?

This contribution offers a knowledge-sociological reflection and places the current turn towards participatory research with PlwD within the topic of trust in different forms of knowledge. It is argued that participatory research can change the knowledge system of dementia when local and experience-based forms of knowledge gain authority.

Day 2: Friday 19th March – 14.50-15.50

9 ON THE EDGE OF ETHICS: EMOTIONAL PRECARITY, KNOWLEDGE SEEKING AND HEALTH RESEARCH ETHICS COMMITTEES

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10.1136/bmjopen-2021-QHRN.47

Preparing for anthropological fieldwork is an emotional and physical endeavour. However, seeking ethical approval to conduct research within the NHS places (qualitative) researchers in an increased emotionally tenuous position. Firstly, researchers spend months navigating and producing copious documents to prove they are capable, and their knowledge-seeking methodology is ethical. Secondly, scrutiny of their research by a distanced bureaucratic structure has the ‘power’ to alter and constrain the production of knowledge. The researcher’s academic and personal well-being is vulnerable amidst the tensions of proving the merits of their research methodology and adapting it to a national, biomedical biased, Research Ethics Committee (REC).

Anthropological fieldwork, in part, can be conceived as truth, or knowledge-seeking. However, can knowledge-seeking be constrained even before we enter the site of knowledge, the field? Through autoethnography, together with the writings of other authors, I will argue that the process of seeking NHS ethical approval impacts not only on empirical knowledge-seeking; it also has undesirable consequences for the researcher. Does the anonymous structure, distanced from anthropological knowledge-seeking hold the monopoly on ethics and subsequently knowledge-seeking? How then does the interplay between Kafkaesque bureaucratic regimens impact on a researcher’s emotional (un)well-being? What are the emotional consequences of knowledge-seeking, particularly when research authority, control and oversight is wrenched from the autonomous researcher?

I will draw on Kirsten Hastrup’s conceptualisation of anthropological knowledge and Hochschild’s perspective on emotions management when faced with research precarity. In this paper, I discuss how personal experiences with health-related RECs can hinder the search for knowledge. I will also discuss the actual consequences on personal health and the potential impact on general, public health outcomes.

10 COVID-19 & COMMUNITY LIFE: A CREATIVE PARTICIPATORY APPROACH TO UNDERSTANDING COMMUNITIES AND TRUST DURING A GLOBAL PANDEMIC

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10.1136/bmjopen-2021-QHRN.48

The Young Foundation, supported by The Wellcome Trust, is conducting a real-time inquiry into how Covid-19 is affecting interactions between individuals, experiences of community, and how trust in both science and health research are shaped. Between August and December 2020, we are capturing a cumulative long-term perspective, with particular focus on the ways in which trust and understanding are shaped among different groups, and the role and influence of digital.