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Towards more inclusive research: Repositioning the “hard to reach”

The terms ‘difficult to access’ or ‘hard to reach’ are widely used within research communities. Indeed, we have ourselves used these terms. However, recent research that we have conducted with so called ‘hard to reach groups’ such as people living in areas of significant deprivation, Black and ethnic minority communities, vulnerable young people, and fathers, has prompted us to question both the validity and the helpfulness of such labels. Here we examine whether it is, in fact, the researcher who is ‘difficult to access’ or ‘hard to reach’ and we highlight the need to debate the position of nurse researchers in this context.

The spaces in which we live, by the nature of geography, are likely to be similar to those of our neighbours. Our lifestyles may also be comparable, and it is probable that we will broadly understand the everyday lives of the people around us. For the purposes of international health and social policy, and research, this is expressed through classifications of broad features of economic and social conditions, which can be helpful but can also divide populations into distinct groups and, as a result, reinforce societal hierarchies. Bourdieu (1984) discusses this in his concept of habitus, in which internal structures and perceptions are common to all people of the same category. In the United Kingdom this is reinforced in the class structure, but internationally the concept of habitus is also evident in the distinctive features that characterise the spread of wealth, and in which Bourdieu distinguishes those with the advantages of education from those without (Bourdieu 1984).

This distinction is seen between those from the lowest income countries and those in the wealthiest, and there now exists a challenge to address this inequity and improve health outcomes amongst the most deprived, within the structure offered by United Nations Sustainable Development Goals (2019). In relation to research led by nurses, this challenge sometimes falls to those who are perceived as the most educated, accessing those people most deprived of education. However, as Bourdieu theorises, the differences of internal structures within distinct groups can be the vehicle to sustainable change in certain health outcomes. Unless those studying health outcomes dedicate time to understanding the everyday lives of people and seek ways to locate a window into a particular group’s lived experiences, we will miss this opportunity.

A central aim of nursing research is to improve health outcomes, but if research participants who differ socially and economically to nurse researchers are considered ‘other’ and difficult to reach, structural barriers emerge that can prevent research engagement with the very individuals and communities that are most in need of impactful health interventions. In our experience, such barriers are sometimes played out within the protective discourses of research ethics committees and other gatekeepers who are reluctant to support research that addresses what may be considered ‘illicit’ issues, populations with limited cognitive ability, those who are very ill or dying, and those who are deemed marginalised or vulnerable, including children and young people. Whilst we are aware of the challenges involved in conducting research with such groups in a sensitive manner, everyone has the right to be heard and to contribute to healthcare research. In the UK’s NHS, shared decision-making is presented as integral to holistic care, with the phrase ‘No decision about me, without me’ having been coined. However, if certain voices are not being heard in planning and conducting research, clinical decision-making processes, which are themselves underpinned by an evidence base, risk overlooking the needs of many who will have been excluded during the creation of this evidence.

Examples of under researched, or 'seldom heard' groups are numerous and perpetuate many health inequalities. People over 85, sex workers, people with learning difficulties, children who have been abused, travellers, asylum seekers, minority ethnic communities, and a plethora of others are all potential health service users but research about their particular needs often fails to focus on social influences on health. Phrases like 'hard to reach' can suggest a degree of culpability on the part of individuals and populations for being 'different' to the cultural norms of most healthcare researchers. Such language can also legitimise the choices of researchers in crafting research proposals, such as employing proxies or considering designs that avoid the inclusion of participants who are considered risky due to being considered vulnerable or 'other'. However, if nurse researchers are to fulfil the goal of improving health outcomes for all, an examination of the assumptions that underpin research conducted with less commonly researched groups is vital since it is well recognised, on an international level, that health outcomes are affected by social gradients. This is relevant to the extent that a difference in life expectancy can be as much as 20 years between those living in the most and the least deprived areas of the same country or region (Marmot, 2015). Marmot (2015) argues that in order to close this gap we need to understand the cause of such variations, rather than rushing to solutions, and take the time to do so by working with people in such areas of deprivation to understand their health beliefs and cultures. In other words, as researchers we need to make ourselves accessible.

In our experience, individuals are rarely difficult to access if gatekeepers (who can act to grant or limit access to certain participants) are given the opportunity to understand the value of a particular research study, and if researchers access relevant spaces and demonstrate flexibility and respect as integral values when planning research, during the data collection process, and dissemination of findings. Examples from colleagues who have successfully conducted research with young people and ethnic minority communities include settings such as boxing clubs, Capoeira venues, youth settings and schools, whilst being flexible in respecting individual's preferences for individual versus group data collection techniques and the availability of appropriate spoken language alternatives to help with recruitment and data gathering. Recently, Fry et al. (2022) studied social understandings of prostate cancer risk in men living in areas of deprivation. This work involved extensive community engagement to obtain the trust of the men in deprived and ethnically diverse neighbourhoods and developed theories of community health talk and community-generated knowledge of health risks. In this case, the researcher made herself accessible by spending time in, and contributing to, local community events, so becoming an approachable and reliable contact.

This style of research involves working alongside communities to plan and present research proposals and studies using Patient and Public Involvement principles (PPI) at each stage of the research process (Pii et al., 2019). By its very nature, PPI helps to bring the researcher closer to populations of interest, thus making the researcher, the research and the findings easier to access. For example, PPI representatives are often service users or carers themselves, or those living in the environment of interest. This approach can help facilitate better quality and meaningful research by working with the people who will directly benefit most from the findings by improving health outcomes, if the findings can have impact. Integral to the work of Fry et al. (2022), was the establishment of PPI groups with Somali and African Caribbean men in an urban suburb in South Wales, with the aim of exploring together how awareness of prostate cancer risk can be made accessible to the men in these communities. The initial meetings of these groups informed ideas for developing culturally sensitive health promotion materials, using succinct and accessible messages. The men themselves came up with ideas for delivering these messages for maximum impact and expressed enthusiasm at being involved in designing research to test this material, and to be part of the study's recruitment process. Throughout the study, the researcher placed these communities central to all stages of the research process, which made it easier to access their needs and document them in the study.

This approach also guards against a paternalistic attitude where the researcher already ‘knows’ what is needed and sets out to collect data that reinforce this expectation, meaning that benefit is mainly directed towards the researcher (and their career) but actually achieves little for the group or community involved.

Recently, there has been a significant challenge to all community health systems with the COVID-19 global pandemic, which has brought health inequality into sharp focus and tested the ability of health researchers to learn about the effect of this virus on the most vulnerable. The pandemic also tested the ability of public health departments to produce health information that was relevant and accessible. As we recover and rebuild, to meet the United Nations Sustainable Development Goal 3, ‘Ensure healthy lives and promoting wellbeing for all ages’ (United Nations 2019), which has been set back by the devastating effects of the COVID-19 pandemic, care must be taken to re-engage with populations and invite communities to develop sustainable ways to improve their health and to live fulfilling lives. By excluding certain populations from health research, the external validity and generalisability of studies risk being compromised. In addition, excluded groups are denied the benefits of being involved in research (including clinical trials) meaning that the applicability or safety of health innovations for sub-groups of the population cannot be assessed accurately. Subsequently, a lack of understanding concerning health inequalities will only persist.

This comment piece highlights and challenges the responsibility that should be placed on health researchers to take the time to make themselves approachable when working with individuals and communities that may be considered vulnerable or ‘difficult to reach’. Drawing on the philosophical approach of Bourdieu (1984), we propose that researchers will not be able to fully understand what motivates people to engage in healthier behaviours if we do not take the time to understand how internalised health beliefs are affected by the community around them. We suggest that health researchers working with vulnerable and marginalised groups should involve people in developing the focus of the research and continue to work together in the planning, design ,and dissemination phases. This will help to produce sustainable changes to people’s lives which, after all, is the ultimate goal of nursing practice and research. We have suggested that this can best be achieved by giving greater attention to patient and public involvement in our research. This approach must become, and remain, integral to the planning, execution and dissemination of any research that focuses on people’s experiences of health and illness in what are currently considered marginalised and vulnerable groups. Additionally, organisations funding research should promote the expectation that patient and public involvement are integral to the research process and should allow additional resources, including time, for researchers to work with people who may not have previously been involved in this type of research activity.

We must also be cautious of becoming complacent about definitions as exclusion can take many forms. The role of the researcher is to question accepted norms and to challenge our own stance in perpetuating systematic inequities within research. By remaining alert to this challenge there will undoubtedly emerge benefits, such as multiple new opportunities for research that asks novel questions and reaches into populations and social spaces where light has not always been shone. This challenge is one for us all to address.

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