

No voice, no choice

Romana Farooq and Imran Abbas look at the challenges and benefits of doing research with ethnic minorities

Giving 'voice' and 'choice' to clients who access psychological services is fundamental to the work of psychologists. But what happens when the 'voices' of some groups are not heard and the 'choices' offered not for them? Doing research is one way to unmute these voices and as a result develop culturally appropriate psychological interventions. Yet doing research with minority groups has brought forth many challenges for researchers.

This article, therefore, begins to deconstruct some of the commonly cited barriers associated with researching the lives of ethnic minorities and provides some useful strategies that could be easily applied in everyday practice.

Becoming human is one matter. Becoming French, Mongolian or African-American is another. Becoming Georges Sand, Ghengis Khan, or Martin Luther King Jr, is still another. (Scarr, 1993)

Historically, one of the most commonly shared assumptions in psychology has been that there are universal features of development: psychological phenomena, processes and structures on which culture has no effect (Miller, 1999). More recently, however, there have been calls for professionals to become culturally competent in their practice and research, therefore making cultural competency a critical and core facet of healthcare education and provision (Harvard Catalyst, 2010). Predictably there is a scarcity of psychological research with ethnic minorities making it difficult to provide the right treatment and interventions as well as understand their experiences of psychological therapy. (Our expertise is in healthcare and clinical research, but much of what we say applies to psychology research in general).

So we have to ask, why is research with ethnic minorities important, why are they underrepresented in psychological research and what strategies can be employed to enhance their uptake?

Why is research with ethnic minorities important?

Undeniably we are living in a multicultural, multiracial and

multilingual society. This brings forth many challenges in terms of addressing the healthcare needs of this diverse population, especially since recent evidence suggests that the mental health of ethnic minorities in the UK is deteriorating (Dein & Bhui, 2005; El-Khorazaty et al., 2007). Therefore it is highly unlikely that a mental health practitioner will not encounter clients who differ from them in terms of race, religion, ethnicity and culture.

Despite this there is little evidence to suggest that any significant progress has been made, both in terms of improving mental health services and in the experiences of black and minority ethnic (BME) service users and carers (Mason et al., 2003). Their mental health needs continue to be unmet and they frequently access services at crisis point and then prematurely terminate (Rugkása & Canvin, 2011). Furthermore, current treatments and interventions offered are seen as antagonistic and are often in conflict with their cultural values, mainly because the system of care is Eurocentric (Nadirshaw, 2009).

Doesn't this highlight the need to further understand the experiences of BME groups and to investigate possible interventions and treatments that are best suited for their specific needs? In addition, if psychology as a profession is based on the scientist-practitioner model, then isn't it logical to move towards developing and implementing evidence-based interventions for diverse populations? The best way to do this is by conducting innovative and culturally informed research projects and clinical trials in order to develop an evidence base that can then inform clinical practice. Without this useful information practitioners are at risk of failing to provide adequate and appropriate services and treatments for ethnic minorities. Excluding patients from a BME group in research is unethical and introduces substantial bias; the results are no longer representative of the population (Mason et al., 2003).

So what are the barriers to recruiting

question

How can we begin to 'hear' the voices of ethnic minorities?

resources

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and retaining ethnic minorities in research and what can we do to maintain their involvement?

The barriers – fact and fiction

A number of barriers to ethnic minority participation and inclusion in research have been highlighted in the literature (Hussain-Gambles et al., 2004). But which of these are actually real and which are based on misconceptions or cultural stereotypes?

Often mentioned as a key barrier to the recruitment of ethnic minorities is general distrust of researchers and the purposes of the research. Participants report seeing informed consent as relinquishing rather than protecting their rights: they fear mistreatment or exploitation; for example, 'I will be treated as a guinea pig'. There are concerns that the data would be used to show their community in an unfavourable light (Hussain-Gambles et al., 2004; Meinert, 1999; Shavers et al., 2005).



Written consent can be complicated by differing cultural norms, concerns and expectations around signing documents

Therefore BME groups may require a different approach whereby the emphasis is on building trust over a longer period of time, rather than the expectation that the person will be willing to participate after a single appointment. This can be difficult to manage, considering the short amount of time allocated to the pre-data-collection phase and issues around additional costs.

Some see the additional costs associated with recruiting ethnic minority participants as a major hindrance. For instance, one study showed that by including women and ethnic minorities in a clinical trial the costs almost doubled (Meinert, 1999). These costs are normally associated with the provision of interpreters and translated information sheets. In addition the study would also need to employ researchers who were bilingual and had some cultural knowledge. It is true that there is a huge shortage of ethnic minority trial coordinators and researchers (Ross et al., 1999; Shavers et al., 2005).

Gaining informed consent from ethnic minorities has also been reported to be very challenging and one of the most difficult barriers to overcome (Dein & Bhui, 2005). Written consent can be complicated by differing cultural norms, concerns and expectations around signing documents. In addition, when working with high-risk minority groups such as refugees and immigrants, written informed consent can be viewed with scepticism, resulting in an unwillingness to sign the form. In some cases informed consent has only been given after the participants have experienced the research (Ross et al., 1999).

All of the aforementioned barriers have often led to a failure to invite or offer individuals from an ethnic background the opportunity to participate in research, citing the main reason as language differences. However, there is

Cultural competency tips

- | Understand and acknowledge how individual, group and universal features of being human affect the client.
- | Be willing to discuss and integrate religion and spirituality.
- | Have an awareness of values and customs of the client's culture
- | Manage self-disclosure appropriately.
- | Adapt assessment, intervention and research methods in line with the client's cultural background.
- | Have knowledge of the language and pragmatics of its use.
- | Identify and challenge own assumptions and stereotypes.
- | Understand your own cultural background and how it influences your work.

strong evidence to suggest that once people are invited to participate in a language they understand, the rate of uptake is unrelated to the ethnic background of the participants (Ramcharan & Cutcliffe, 2001; Umaña-Taylor & Bámaca, 2004).

Useful strategies

Developing sensitive research methodologies is an important part of research design, but when working with ethnic minorities the method of recruitment becomes the single most important component of the project. One of the most successful strategies in recruiting and retaining ethnic minorities in health research has been the inclusion of members of the participating cultural group in the research team, and the formation of flexible and innovative community partnerships. Establishing an interdisciplinary team with experts in the area under investigation as well as bilingual researchers can be the first, and

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most important, step towards recruiting ethnic minority participants. Ethno-linguistic researchers can bring valuable cultural knowledge to the study and can be a useful asset to the team. This would then need to be followed up with collaborations with community-based organisations. So, for example, if the research was investigating the experiences of intimate partner violence in South Asian women, then it would be beneficial to work in collaboration with local domestic violence helplines and support groups as a source of expertise, and as an avenue to recruit potential participants. Working collaboratively with community organisations and lay outreach workers (Andrews et al., 2004) can also aid in reducing the uncertainty that can be associated with research.

Sampling will also affect the likelihood of uptake. Inclusion criteria need to be carefully considered so that it is culturally appropriate; for instance a study investigating sexually transmitted infections would be met with disapproval and deemed offensive if it were to recruit unmarried Asian women, resulting most likely in a lack of uptake and minimum support from the community. Therefore it may be useful to adapt the inclusion criteria to better suit the community under investigation, especially when the 'word-of-mouth' sampling technique is extremely useful in research with ethnic minorities (Umaña-Taylor & Bámaca, 2004). It is well documented that gatekeepers' attitudes and reciprocal arrangements with local communities mediate recruitment to research (Rugkása & Canvin, 2011).

Overcoming the challenges associated with gaining informed consent could be easily rectified by avoiding the traditional 'hit and run' approach, whereby the researcher expects to gain consent in one appointment and then fails to revisit the principles of consent at other intervals. To increase the likelihood of consent

it would be more practical to employ a more trust-building and rapport-generating 'ethics as process' model right from the beginning (Ramcharan & Cutcliffe, 2001). This would allow the researcher to make clear to the participant their rights at every stage of the research process, giving the participant the opportunity to withdraw and also to trust the researcher. Providing patient information sheets and consent forms in the language most suited to the participants can be a useful way to convey the information.

Once consent and participation is guaranteed it is also imperative to have sensitive and innovative data collection approaches. Ethnic minorities will be more willing to participate if the method of data collection is appropriate. For example, when conducting research on a sensitive topic such as self-harm, life-threatening illnesses or domestic violence, a focus group may be a better method of eliciting the views of the group as it removes the power dynamics that may be apparent in a 1:1 interview and also provides participants with peer group support. However, you would need to go further than this by having single-sex focus groups and also holding them at venues that would be most suitable.

The type of data gathered should also be carefully considered. For example, due to the negative experiences of ethnic minorities they can be quite distrustful of researchers: collecting income data or revealing photographs of research participants may not be appropriate when



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working with families who have had problems with welfare or immigration authorities (Andrews et al., 2004).

One of the most important things to bear in mind when doing research with BME groups is to make realistic decisions regarding the allocation of time to the pre-data-collection phase. It would be common practice to meet with the potential participant on numerous occasions prior to receiving consent. In addition forming strong and effective partnerships with local community groups would also require time commitments, something which can often be overlooked when designing a research project. Consistent contact will reap rewards in terms of retention: in projects where researchers have maintained frequent telephone contact with participants to remind them of sessions and of missed sessions, this has led to fewer drop-outs (El-Khorazaty et al., 2007).

Is the Gold Standard possible?
So is it possible to overcome all these

"BME groups face immense barriers when accessing mental health services"

psychosis for ethnic minority patients by exploration and incorporation of service users' and health professionals' views and opinions. *Behavioural and Cognitive Psychotherapy*, 38, 511.

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challenges? Has anyone successfully recruited ethnic minorities? Yes! There is a multitude of evidence out there, slightly disjointed but it can still be valuable. Some of the most significant projects recently have been on developing culturally sensitive cognitive behavioural therapy for ethnic minorities suffering from psychosis (Rathod et al., 2010), the prevention of self-harm through culturally adapted manual-assisted problem-solving training (Husain et al., 2011) and the development of a social intervention for South Asian women suffering from depression (Gater et al., 2010). These projects utilised culturally sensitive research methods, including multilingual female facilitators, greeting participants in a traditional manner and selection of culturally appropriate venues.

Many other projects have used feminist research methods to break down the power dynamics and have successfully recruited (Bhopal, 2001; Chew-Graham et al., 2002; Farooq, 2010). These projects utilised interviewers/facilitators with similar backgrounds to the participants; self-disclosure would be a common way to break the ice; and active participation was sought, for example participants would be

given an opportunity to read the interview/focus group transcripts prior to publication of their voices.

Our responsibility

Bringing about change can be a formidable task, especially when resources and funding is scarce, competing priorities numerous, expertise in the area sparse and interest in the issue at a senior level lacking. But those practitioners who have often encountered clients from a BME background and have experienced failed therapy, therapeutic resistance or just diagnostic confusion will fully understand and appreciate the need for more evidence-based research to inform and aid assessment and treatment.

There is international interest in enhancing recruitment and retention of BME groups into research, particularly in disease areas with substantial ethnic inequalities. Clearly the evidence suggests that BME groups face immense barriers when accessing mental health services and then prematurely terminate when they do access them. Doesn't this suggest a need to understand the processes behind unequal access to mental health services as well as

develop interventions that could assist this client group?

In the end many would ask whose responsibility this is? The simple answer would be; isn't it ours? If medical practitioners are now realising the importance of conducting clinical trials with ethnic minorities so that they can provide the best treatment options to their patients, then isn't it time that psychologists realised the importance of providing the right psychological interventions to their clients?



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