Disability and cultural issues in research – lessons learned

Mili Doshi BDS MFDS RCS (Eng) MSc¹, Mary Burke BDS FDS RCS (Eng)² and Janice Fiske MBE BDS MPhil FDSRCS (Eng)³

¹Senior Dental Officer Tower Hamlets Community Dental Service, ²Consultant in Special Care Dentistry, Guy’s and St Thomas’ NHS Foundation Trust, ³Senior Lecturer/Consultant in Special Care Dentistry, King’s College London

Abstract

Aim: To discuss the disability and cultural issues, which need to be considered during the planning and implementation of a study to investigate the oral health of young adults with a learning disability and from a minority ethnic group.

Design: A study of the oral health of Bangladeshi young adults with a learning disability is used as an example, to highlight the barriers identified in the research process for this group. These barriers included: access, culture, language and literacy, consent, communication and co-operation. The paper highlights the approach required to gain co-operation for access to the study population via day centres; the development of an oral health questionnaire relevant to the particular ethnic community; and translation requirements. It also describes how support was given during a structured, informed consent process and the use of props, photographs and scales used to support and aid understanding.

Results: A participation rate of 98% was obtained in the study and 80% of individuals appeared to enjoy participating. The results showed participants were very aware of oral health and their social implications indicating that the approach used facilitated understanding and communication.

Conclusion: By considering and adapting the research process to meet the needs of people with a disability and from an ethnic minority background, the study was acceptable to their needs and participation levels were high.

Key words: Bangladeshi, learning disability, research adaptations

Introduction

Studies have consistently recognised that the oral health of people with learning disabilities (PWLD) is poor compared with that of the general population (Ouellette-Kuntz, 2005). Generally, PWLD have similar dental disease levels to the general population, but have higher levels of unmet dental need and less contact with dental services (Tiller et al., 2001; Gray, 2005). In the British Bangladeshi community, oral health inequalities have been demonstrated in the level of dental disease, dental attendance patterns and oral health related behaviour (Pearson et al., 2001). Although it has been suggested that the oral health of PWLD may be exacerbated by factors relating to their ethnicity, and vice versa, little research has focussed on the oral health of PWLD from minority ethnic groups (British Society for Disability and Oral Health & Royal College of Surgeons of England, 2001).

The Bangladeshi community is among the most socially and economically deprived ethnic group in the UK (Merrell et al., 2006). The prevalence of severe learning disability in the UK South Asian population, aged between 5 and 32 years, is up to three times higher than that in all other UK communities (Emerson et al., 1997; Kerr, 2001; Emerson et al., 2002). The Bangladeshi population has a young, demographic profile and is growing fast. It is estimated that by 2021, 7% of all PWLD will be of South Asian origin with the greatest increases in school–aged children and young adults (Hatton et al., 2003).

To help reduce oral health inequalities of PWLD from different ethnic backgrounds and improve access to dental services, research is needed to ascertain oral health levels and to help plan the provision of oral health care services that meet the needs and demands of this population.
Preliminary work by Doshi et al., (2009) investigated aspects of oral health status, oral health behaviour, attitudes and awareness to oral health of Bangladeshi young adults with a learning disability. Results showed that this group had complex and unmet oral health needs. The results also revealed that awareness of, and sensitivity towards, different oral health conditions and their social implications were high, with aesthetics being especially important. The group had high levels of treatment need, especially for periodontal treatment, and, although caries levels were lower than in a similar age-groups of the general population (Kelly et al., 2000), a large proportion of the participants had untreated caries. Oral health behaviours of this group were unmanageable with generally poor oral hygiene practice; high betel nut use; and dental attendance patterns that tended to be symptom-based rather than regular, routine and preventive care. Additionally, female subjects demonstrated a high level of dental anxiety and had an overwhelming preference to see a female dentist from their own background.

During the planning and implementation of this study, many considerations and adaptations were necessary for the research process to engage and be sensitive to the needs of PWLD from the Bangladeshi community, bringing together disability and ethnicity/cultural issues. Barriers that can prevent vulnerable groups, including PWLD and minority ethnic groups, from participating in research studies include: access, culture, language and literacy, consent, communication and co-operation (Rodgers, 1999; Kalsbeek, 2003; Cameron et al., 2007).

**Aim**
The aim of this paper is to describe:

- The disability and cultural issues which needed to be addressed to facilitate the study carried out by Doshi et al. (2009)
- The adaptations made to the research process to meet the needs of Bangladeshi young adults with learning disability, in order to engage them in the research study, in such a way that this could be adopted for other minority ethnic groups.

**Access**
Problems of recruiting and sampling individuals from minority ethnic communities have been documented in the literature (Hughes et al., 1995; Kalsbeek, 2003). They include:

- High levels of illiteracy and lack of fluency in English
- The relatively small size of ethnic groups among the general population which can make it difficult to find representative or adequate sample numbers
- Cultural values which may mean research is viewed as intrusive, strange (because of unfamiliarity with research procedures) and anxiety provoking, because of fears over how the collected information may be used (Bernal, 2002).

Previous studies of Bangladeshi communities have used door to door random sampling (Brown, 1985) and recruitment from organisations, community services, religious centres, and medical practices that provide links to the Bangladeshi community (Williams et al., 1996; Pearson et al., 2001).

Bangladeshi communities in the UK are geographically clustered in inner city areas (Butt et al., 1996). Although people of Bangladeshi origin account for 0.5% of the total UK population, this figure rises to 33% (65,553 people) in the London Borough of Tower Hamlets making this one of the largest ethnic groups in this area after the indigenous Caucasian population (Census of Great Britain, 2001). Because of this population concentration, Tower Hamlets provides day centre facilities for Bangladeshi young adults with a learning disability. This forum provided a ‘gateway’ and relatively easy access to a reasonably large number of the study population.

**Minority ethnic health research training**
To help ensure that the research process and research tools were agreeable to the cultural needs of the Bangladeshi community, the lead researcher underwent training with the Support Unit for Minority Ethnic Health Research (SUMEHR) in North Central London. SUMEHR provides a practical facilitative role for researchers and ethnic minority populations involved in ethnic and cultural health research. From this training, and by engaging with the local Bangladeshi community, the researcher learned skills that helped with the design of, recruitment to, and conduct of, the study. For example the researcher was made aware of the importance of:

- Using researchers from a similar background to the study group as this may increase compliance
- Using female researchers for female respondents
- Avoiding sampling during religious periods such as Ramadam (Muslim daylight fasting month).

Cultural issues were also highlighted. For example, some of the Bangladeshi community practice alternative oral hygiene methods such as the use of a wooden chewing stick called a miswak stick (Figure 1) instead of a toothbrush and the use of tooth powders instead of toothpaste (Figure 2). This information was incorporated into the questionnaire regarding oral health behaviour. Additionally, information related to cultural habits led to the inclusion of questions related to betel nut use.
Language and literacy

Language and literacy levels and trends affect the research process in terms of recruiting individuals, obtaining informed consent and identifying the most suitable method(s) for collecting data (for example focus groups versus questionnaires or structured interviews).

Bangladeshi men and women have the lowest levels of English language fluency of all South Asian groups in the UK (Aitkens, 2002), although English language skills are better in the younger generations (Dale, 2002). According to the Fourth National Survey of Ethnic Minorities (NSEM), English was spoken among 75% of Bangladeshi men and only 4% of women aged 45-64 years. Thirty per cent of Bangladeshi women in the 25-44 year old age group were fluent in English compared with nearly 80% of women between the ages of 16-24 years (Modood et al., 1997).

Sylheti is the main spoken dialect of the UK Bangladeshi community, which gives them a strong cultural identity; although literacy may be compromised as there is no written form of Sylheti. Bengali is the language of literacy, yet literacy levels as low as 16% have been reported (MORI, 1993) with little improvement in the last decade (Dustmann et al., 2003). The improvement seen in fluency in spoken English is not reflected in literacy level.

Difficulties related to language and literacy involved with research related to minority ethnic groups have also been identified (Kalsbeek, 2003). Recruiting Bangladeshi individuals using written information, such as sending letters to carers, can be unproductive due to the high levels of illiteracy in both English and Bengali amongst this population, particularly in the first generation population. Ali and Begum (1991) obtained response rates of less than 40% in Bangladeshi community studies using bilingual questionnaires, and cited illiteracy as a major factor in the low response rate. In Doshi’s study (2009) a structured interview was chosen to collect oral health related information, rather than using a questionnaire, partly due to the expected low levels of literacy. A translator who was fluent in Sylheti and Bengali was present during the study and the interview schedule was translated into Bengali. A process of translation and back translation was used to ensure there were no discrepancies in the delivery of questions. Back translation is important as when questions intended for English speakers are translated into another language the meaning may be lost or misinterpreted (Hanna et al., 2006). Interviewees were offered the choice of the structured interview being carried out in their preferred language.

Both the recruiting information sheet and the consent form were translated into Bengali so that it was available both in English and Bengali, and a translator was available to speak in Sylheti as necessary.

In this study, 88.5% of subjects spoke English and 59% were literate (mainly in English) and the majority opted to conduct the interview in English. Their English literacy level was significantly higher than findings of other studies involving the Bangladeshi community as a whole (Summers et al., 1994; Williams et al., 1996). Their younger age and the fact that English language is taught in day centres explains the language and literacy results found in the study. Although not directly measured, it became apparent from comments made by the participants that many of the people with learning disability had greater English language skills than their parents/carers. For example, one individual commented that he could not go to the dentist as his parents did not speak English and thus could not make an appointment.

Familiarisation with the day centres

Both distrust of the research process by the Bangladeshi community (Hussain-Gambles et al., 2004) and high levels of anxiety amongst PWLD (Stalker, 1998) have been cited as barriers to participation in research. To help engage with the community the researcher (MD) spent time getting to know the study population, day centre staff and carers by attending a social event for Bangladeshi PWLD and their carers and by visiting the day centres several times prior to the study.

Additionally, the researcher (MD) met the managers of all the day centres involved in the study to discuss the proposed research and the possible involvement of users of their centres. This was followed by a written request for permission to conduct the study at the centre. Once this agreement was obtained, letters were sent in English and Bengali to the main carers (parents, siblings and spouses) of the day
centre users, to inform them about the proposed study and to allow time for any issues or concerns to be discussed prior to the commencement of the study. One week before the visit, information sheets about the project in English and Bengali were sent to the day centres to remind the staff to make their clients aware of the upcoming dental visit. The researcher’s perception was that building this ‘rapport’ significantly improved co-operation for the study. This was especially the case for the clinical examination, where the anxiety levels of people who use dental services irregularly, if at all, were likely to be high for this unfamiliar process.

**Informed consent**

Informed consent was required from all individuals who were to participate in the study. This has been reinforced by the Mental Capacity Act 2005, introduced in 2007, which states that research cannot involve anyone who does not have the capacity to consent.

There are well documented ethical challenges in obtaining valid, informed consent from PWLD for research participation, including communication impairment, level of understanding and decision making ability (Iacono et al., 2001; Cameron and Murphy, 2007; Dye et al., 2007). Recommended adaptations to obtaining consent include:

- Involving people who know the participants well in the initial approach
- Using pictorial explanations
- Giving participants more time
- Repeating explanations (using different words or methods as necessary) when describing the nature of their involvement in the study (Cameron and Murphy, 2007).

The use of pictures, signs, scales and photographs has been shown to enhance understanding, in PWLD (Baxter, 2005). These methods can be used to gain informed consent and to obtain opinions from PWLD who might not be able to participate using written and verbal information only (Young et al., 2006).

Although research participants are usually provided with written information and consent forms, the low literacy levels of English and Bengali anticipated amongst this client group meant relying solely on written information for recruitment may be insufficient. The following process was adopted to overcome some of the difficulties of gaining informed consent:

1. The initial contact with the researcher for each individual at the day centre was facilitated through their ‘key worker’ who had previously completed a ‘pre-assessment’ form for each service user which included information on the client’s:
   - Preferred language, method of communication and literacy, enabling information to be provided in the most appropriate form
   - Level of learning disability
   - Additional disabilities, if any, such as visual or hearing impairments
   - Main carer
   - Capacity to give informed consent.

2. Having identified an individual’s likely capacity to give informed consent, the researcher (MD), with the aid of the translator if necessary, explained the purpose of the study and outlined what it would involve. Efforts were made to achieve a relaxed, unhurried non-threatening process. In many cases a rapport built from previous visits and the presence of a ‘trusted’ key worker helped. Reassurances were given that participants were not obliged to take part and could withdraw from the study, or ‘stop’, at any point.

3. Participants were given an information sheet, in English or Bengali as preferred, which used pictures and simple language. For people who were illiterate or experienced visual problems, the information sheet was read to them. Guidance for the information sheet was taken from the DoH document Seeking Consent: Working with People with Learning Disabilities (2001) which encourages the use of simple language and pictures.

4. If the service user agreed to participate, (s)he was asked to complete a consent form, again based on DoH guidance. For service users who were not literate, verbal consent was obtained in the key worker’s presence and recorded.

5. The key worker was present throughout the consent process to provide support for the service user and to ensure that consent had been freely given.

**Communication**

The structured interview was designed to meet the needs of Bangladeshi PWLD. The interviewer adhered to instructions on a schedule that consisted, primarily, of closed ‘yes’/‘no’ type questions to facilitate ease of use. Prompts from the schedule were introduced when necessary. Photographs, visual scales and props were used wherever possible to help with clarity and understanding. Gestures such as thumbs up and thumbs down (commonly used in the day centres to indicate approval and lack of approval) were used to indicate that a good or not good response was required. Initial results indicated that a smiley face scale (SFS) with five faces (Figure 3) was too complex and this was modified to a three face SFS (Figure 4), which worked well.

A series of six photographs was used to gain opinions on differing oral health conditions (Figure 5.1-5.6). Additional comments made by the service user indicated a good understanding of the oral health conditions and its impact on appearance and social acceptability. For example regarding the missing tooth one person commented “The tooth has come out, it looks very bad, and my husband would leave me if I looked like that”.

*Note:* The figures and tables mentioned in the text are not included in this transcription.
Figure 3 The five face ‘Smiley Face Scale’ proved too complex

Figure 4 The three face ‘Smiley Face Scale’ worked well

Figure 5a - 5f Digitally modified photographs used to illustrate six different oral health conditions

Figure 5a Healthy mouth
Figure 5b Anterior Caries
Figure 5c Gingivitis
Figure 5d Fractured tooth
Figure 5e Missing tooth
Figure 5f Betel nut staining
Immediately before the interview rapport was built with participants by asking about their general likes and dislikes. They were then asked to relate their positive and negative responses to these likes/dislikes using the SFS and thumbs up/down gestures to demonstrate understanding of this research tool. All questions were directed to the service user (and not the key worker), at their own pace, and allowing adequate time for responses.

Co-operation
The time and effort invested in communication and building rapport paid dividends in terms of co-operation for the research study. Using the Frankl Scale to assess co-operation (Frankl, 1962), 42 subjects (80.8%) were interested and appeared to enjoy the clinical examination and 10 (19.2%) were cooperative but reserved. After giving consent one individual became reluctant to participate. Their wish to withdraw was respected and the examination was stopped immediately.

Incorporation of the issues discussed above into the research design resulted in good participation and co-operation on the part of the study group and, as a result, the quality of the results was enhanced. Whilst this study relates to a specific ethnic minority group, the principles used can be related to any other ethnic group (Table 1).

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Conclusion
The methods used in investigating aspects of oral health of Bangladeshi young adults with a learning disability demonstrate there are many adaptations that can be made to make the research process more acceptable to the study population. Adoption of these and similar methods by other researchers may facilitate research participation of other vulnerable groups, thus allowing health services to be adapted to meet their needs.
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Address for correspondence:
Mili Doshi
Senior Dental Officer
St Leonard’s Family Dental Practice
1st Floor, ‘B’ Block
St Leonard’s Primary Care Centre
Nuttall Street, London N1 5LZ
Email: mili.doshi@thpc1.nhs.uk