Snails in bottles and language cuckoos: an evaluation of patient information resources for South Asians with osteomalacia

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Objective. To assess the acceptability for use of information on osteomalacia for South Asian patients.

Methods. Ten focus groups of South Asian persons speaking Bengali, Gujarati, Hindi, Punjabi and Urdu (one male and one female group for each language) were used to evaluate the written (leaflets) and spoken information (CD) on osteomalacia for South Asian patients produced by the Arthritis Research Campaign (ARC). Focus group discussion was facilitated by community-based workers using the Social Action Research Method. A subsidiary evaluation of the information was conducted by a questionnaire-based survey sent to British Society of Rheumatology/British Health Professionals in Rheumatology (BSR/BHPR) members and others who had requested such materials from ARC in the past.

Results. Evaluation by focus groups revealed that there were potential difficulties relating to the understanding of the information leaflets and CDs and problematic issues regarding the quality of translation and pronunciation. Evaluation by BSR/BHPR members and others who had requested such material was that although the information was culturally appropriate, there were some weak areas such as mispronunciation, the quality of translation and specific customs.

Conclusion. Healthcare information resources for minority ethnic groups has traditionally been developed depending upon the needs of the community, the language spoken and cultural norms. Such information is regarded as ‘culturally sensitive’. However, an additional dimension is required. Information should be evaluated by the community and also specific users in order to determine its acceptability. This test of ‘cultural competence’ can ensure that such information has real practical value. An iterative evaluation process with feedback and refinement of information resources for minority ethnic groups is essential.

Key words: Minority ethnic groups, Patient information, Cultural sensitivity, Cultural competence.

Introduction

The UK Census 2001 showed that nearly 10% of the population is made up of black and minority ethnic groups. South Asians comprised 4.4% of the population, accounting for nearly half the minority ethnic groups [1]. It is expected that the minority ethnic population will increase further in the future, not only due to an increase in numbers in existing groups, but also due to an increase in migration, for example from Africa and Eastern Europe [2]. The demographic shift has implications for health care provisions through the duty imposed on NHS organizations to provide health care facilities that are sensitive to diversity among users. This is underpinned by the principle of promoting equality of opportunity for minority ethnic groups, and legally required by the Race Relations (Amendment) Act 2000 [3].

It is well known that the production, provision and distribution of information is a fundamental component of healthcare care [4]. A. Samanta, Department of Rheumatology, Leicester Infirmary, Infirmary Square, Leicester LE1 5WW, UK.
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the accessibility and insight from communities and users. It incorporates grey literature into literature review, involves community members in design of data collection, trains community-based facilitators to conduct interviews and helps with data collection and validation.

The community facilitators in this research were given a brief of the issues and helped by the research team to refine the topic guide to lead discussion. This involved a day’s training by clinicians and social scientists. Participants for the focus group were recruited from community centres in Leicester, Coventry, Leamington Spa, Birmingham and Manchester. Interviews were held using the participants’ ‘mother tongue’ language. The focus group interviews lasted between 60 and 90 min.

Focus groups were based on the five Asian languages and on gender (as focus group discussions in minority ethnic communities are most successful when organized in ‘single sex’ settings). There were 10 single-gender focus groups, each from a distinctive language community. There were five male groups (n = 62) and five female groups (n = 52). The range of participants’ ages was from 16 to 83 yrs and the majority had been living in the United Kingdom for more than 10 yrs. A standard procedure was followed. After a short introduction by the community facilitator, participants were asked to read the written material and then listen to the ARC CD in the language of the group. At section breaks, short probes were used to ask about the comprehension and quality of translation. Following this, there was a short ‘quiz’ about the key messages of the leaflet and CD, and this was used to stimulate discussion and as a means of testing comprehension. This is a novel approach that was developed following discussion with community facilitators about the best way to ensure that all participants contributed, and to overcome a fear of giving a wrong answer or treating the discussion as a potential test of knowledge.

Each community facilitator led one or more focus groups. Content analysis was conducted using the established framework approach by two separate and independent assessors (G.F., N. Hudson) who drew out the main emergent themes. Notes were compared and collated leading to a preparation of a final report.

Evaluation by questionnaires

Questionnaire to BSR/BHPR members. A simple questionnaire was developed, piloted and refined. The purpose of the questionnaire was to ascertain the views of all members of the British Society for Rheumatology (BSR) and British Health Professionals in Rheumatology (BHPR) resident in the United Kingdom with regard to the patient information on osteomalacia. This was sent to all members with the agreement of the BSR and allied BHPR.

Questionnaire to those requesting ARC materials. A similar instrument to the above was developed and mailed to all persons who had requested ARC material from the ARC warehouse.

Ethical issues

Ethical approval was obtained from Human Research Ethics Committee of De Montfort University. Participants were only interviewed or required to fill in a questionnaire. There was no invasive procedure involved in this study. Confidentiality was ensured and informed consent was obtained. Due to the use of community-based groups, the nature of this study which was aimed to improve service development and the fact that no patients were recruited, NHS ethical approval was not required. The research process was approved and overseen by ARC steering groups.

Results

Focus group evaluation

Understanding of CD and leaflets. Generally the participants felt ‘reasonably happy’ about the contents of the leaflet and the CD. The use of a multilingual CD appeared to be good practice, as some participants spoke more than one South Asian language. There was also a lot of support for the idea of an audio CD in addition to a simple leaflet, and for the inclusion of a parallel-track English version (both in print and on the CD).

Some participants felt that the speech on the CD was too fast to be followed and some indicated that it was rather boring, primarily because of the way in which the speaker read the text as though ‘he is reading without understanding, as if he is a school child’. Some of the older participants indicated that it was difficult to listen to, and as a result they would be not very inclined to re-play the CD.

Quality of translation. The general opinion was that the quality of translation needed to be improved. The Punjabi-speaking focus group commented that a number of words used were difficult to follow and were not words that were used in common parlance. A number of words were also translated wrongly (for example, the words used for ‘skin’ and ‘liver’). One member of the Punjabi-speaking group commented ‘When we go from here to India … the Punjabi spoken there in official circles is very difficult to follow. In the UK, when we listen to English or Punjabi, we can understand most of the points but in India we cannot decipher whether those people are speaking Punjabi, Hindi or English … I do not know if the language has changed but it is certainly not the Punjabi that we were used to when we were there.’ This quotation reveals the immense complications and difficulties in translating from one language to another.

In the Urdu-speaking group, it was felt that the translation of osteomalacia was incorrect and rather than trying to translate this as one word, it would have been better to explain it in a sentence. The Hindi-speaking group also commented that a number of the words were too technical and that in some instances a more colloquial form of language or words could have been used.

In the Bengali-speaking group, a particular comment that emerged related to the types of fish described that were recommended to be eaten. The Bengali women in particular were more familiar with fish available from Bangladesh (much of which is now available in the United Kingdom) and were puzzled by the types of fish mentioned in the CD.

There were also general comments about the appropriateness of information in some languages. For example, speakers of Punjabi are predominantly Sikh or Hindu, but could be Muslim as well. This raised the question of appropriateness in terms of information regarding dress (the burkha would not be relevant to Sikh Punjabis) and diet (the relevance of different types of meats in relation to Muslims or vegetarians). A theme that emerged from the Gujarati-speaking group was that the majority of them were vegetarian, and advice about vegan and vegetarian diets would have been more relevant than advice on fish.

Pronunciation. There were a number of problems identified with the pronunciation of speakers. The pronunciation in Punjabi was thought to be ‘not consistent with written Punjabi’. The Urdu-speaking group identified that the speaker on the CD was not a native Urdu speaker and the Bengali-speaking group commented that the dialect that should have been used was Sylheti, as the majority of Bangladeshis in the United Kingdom are from the Sylhet region.

Other issues. A number of groups suggested that more information was required, in particular as to how osteomalacia...
differed from RA or osteoporosis. They also suggested that more health and dietary information was needed.

There was lack of clarity in terms of what was meant by oily fish and white fish, confusion over the mode of cooking and unfamiliarity with margarine: most South Asians in the United Kingdom cook with ghee (clarified butter) or oil.

There was some criticism about the guidance offered in terms of exposure to sun and the general view was that this could have been done in a more culturally sensitive manner by recognizing that many South Asians practice yoga and the early morning ‘surya namaskar’ is traditionally done in the early morning facing the sun, and that this could have been a useful way to gain the required exposure to generate vitamin D. There was also a concern about avoiding sunlight because of cancer risks.

### Evaluation using questionnaires

**Questionnaire to BSR/BHPR.** All members of the British Society of Rheumatology (BSR) and the allied British Health Professionals in Rheumatology (BHPR) were sent a questionnaire. Out of 1769 responses, 706 were returned, representing a response rate of 39.3%. A total of 86% of the respondents gave their origin as white and 66% as Christian. There was a small representation from other faiths: Jewish (n = 22), Hindu/Muslim (n = 29), Buddhists (n = 3) and Sikhs (n = 4). The minority ethnic distribution of the respondents was as follows: Asian Indians (n = 42), Chinese (n = 14), other Asian (n = 10), Pakistani (n = 9), Black African (n = 5), Black Caribbean (n = 3) and Bangladeshis (n = 2).

Of the respondents, 97% thought that there was need for information in languages used by minority ethnic groups, but only 32% had been previously aware of ARC materials. Thirty-four percent suggested that materials should be available in other languages, including Tamil, Somali, Turkish, Chinese, Vietnamese, Welsh and Eastern European languages.

In addition, a number of qualitative themes emerged from this questionnaire survey through free text comments. These were as follows:

- ‘I thought the CD was excellent and passed copies to GP colleagues.’
- ‘I will be ordering some now that we know they are available.’
- ‘I feel that all the agencies delivering information about this condition should unite to give good, concise, non-conflicting information.’
- ‘I think the audio CD is a good idea, as from previous experience the target audience are often unable to read.’
- ‘More dietary advice would be helpful with culturally applicable food recipes.’

It is also worth noting another perspective that emerged:

- ‘Immigrants to the UK should be English speaking, and if not the material can be translated to the person by a member of the family or other persons.’

**Questionnaire to those previously requesting materials.** A total of 407 individuals had been sent ARC materials and a questionnaire was sent to them and 102 replies (25% response rate) were received. The majority were from doctors (n = 46), nurses (n = 29), and community workers (n = 6). The ethnic origins of the respondents were as follows: Asian Indian (n = 7), Pakistani (n = 2), Chinese (n = 3), the remainder were ‘White British’ or did not state. The majority who had requested the materials had found them ‘useful’ but a small number felt that the materials ‘did not look attractive’ and were ‘not easy to understand’.

Some of the themes that emerged from free text comments were as follows:

- ‘I cannot read Punjabi but a friend has said the written Punjabi is not too good.’
- ‘The speaker was clear but mispronounced … She sounded stilted.’
- ‘The burka is not worn for religious reasons. It is a traditional uniform used by people from certain countries.’
- ‘They were very informative, however I feel a booklet-style plus being more eye-catching would have been better.’

### Discussion

We believe that the present study is the first evaluation of its kind. It has focused on ARC information on osteomalacia for South Asians. A number of factors were identified which impact on cultural competence of this information. Whilst there is generally a reasonable acceptance about the contents of the CD, and offering six versions of languages in a single CD appeared to be good practice, as several participants spoke South Asian languages. Criticisms were made of the oral presentation as well as the quality of the translation. There were some comments about the appropriateness of information in certain languages, thereby flagging the fact that some cultural features were singular to specific communities that speak that particular language. Furthermore, it was also felt that information regarding diet, as well as information about osteomalacia in general and its difference from other rheumatic conditions was limited and further development of these themes would have been advantageous. Alternative media formats, such as podcasts may be options for the future but remain costly and are not sufficiently widely available at the present time. Similarly, although access to the internet is increasing, it remains a relatively expensive and limited means of disseminating health information of this type, particularly as it disadvantages those people of low socioeconomic status.

The results from the questionnaire study are of interest in as much as health care professionals were more accepting of the written and audio information, although there were some comments raised about the quality of translation and pronunciation. The numbers of responses received were not sufficient in order to draw any distinction between South Asian health care workers and others. However, there may be differences in perception between the ‘raw users’ in the community and the more ‘sophisticated’ health care workers in their perceptions and evaluation of health information resources. Health care workers are used to handing out health information in leaflet forms and are consequently likely to be positive about disseminating information in this format. Similarly, medical charities like ARC are used to providing health information in leaflet and audio form. ARC has however undertaken to modify future revisions of the CD and the provision of these information resources in general, to incorporate this feedback.

The role of minority ethnic health care workers in developing information is two-fold. First, input is required in the initial information-developing process. Second, they may play a role in the refinement process following community or user evaluation. The key tenet underlying the development of information resources that would be of real value to minority ethnic group users is a combination of cultural sensitivity and cultural competence. Cultural sensitivity is the principle that underpins the primary governance framework for developing information for minority ethnic groups. Such information must be evidence-based, geared to the specific health care needs, and appropriate to the target community. This would necessarily involve developing such information in partnership with professionals, patients and community representation. Cultural competence is the principle that underpins the governance at the next level. It evaluates the
acceptability of the information and provides the necessary feedback for refinement and redevelopment so that the fitness for purpose of information is enhanced. In the absence of such an iterative process, parlous ‘snails in bottles’ (issues that diminish understanding and appropriateness of content) or ‘language cuckoos’ (issues of translation and misrepresentation of words and ideas) may decry the fundamental purpose of information resources, which is to improve patient care.

There is currently only limited information about rheumatic diseases available for patients from minority ethnic groups [13]. The ARC has been at the forefront of developing such information and following expert discussions, literature review and consultation, it recommended that patient information should include a mind map, an audio tape and a basic leaflet in specific languages to address a range of musculoskeletal conditions [14]. Mind maps are an information resource that provides pictorial representation of the subject matter [15]. Another source of information is the community-based information centre BARC (Birmingham Arthritis Resource Centre), which stocks a large range of materials and has multilingual competent volunteer staff [16]. Other possible sources of information include the NHS Specialist Library for Ethnicity and Health [17] and the Leicester Centre for Ethnic Health Research [18].

General beliefs play an important part in compliance with disease management [19]. For example, in a study of patients with cardiac problems, those of South Asian origin were more likely to believe that their health was very much in the hands of God and fate [20]. Information for minority ethnic groups needs to incorporate such beliefs and needs to address these in a manner that ensures compliance. This is particularly relevant in chronic disease where some form of long-term pharmacological intervention may be necessary. A recent study addressed at determining whether patients with RA and SLE who are of South Asian origin had different beliefs about medicines in general, and about disease-modifying agents in particular, showed that they had very high levels of concerns, particularly about disease-modifying agents when compared with their white British counterparts [21]. The present study was not addressed at exploring this particular aspect, but some of the comments received (in particular, those suggesting the requirement for more dietary advice and general information about osteomalacia) may indirectly reflect some of the concerns and beliefs regarding drug therapy. Acculturation, which refers to the process by which immigrant (or minority) groups adapt to the behaviour and cultural traits of the host country (or majority group) in various degrees [22], may also affect attitudes to disease [23], although the present study was not designed to determine this effect on information evaluation.

The present study has focused on information in South Asian languages. This is because the bulk of information for minority ethnic groups has been directed towards the South Asian community, as this has historically been the largest minority grouping in the United Kingdom. Population demographics indicate that there will be a wider variation of minority groups in the future, mainly due to immigration. Our study has also highlighted the need for information to be developed in a range of different languages. Various research methods can be used in evaluations, for example, documental analysis, questionnaire surveys, individual interviews, focus group interviews, case study and observations. This study has predominantly used a focus group approach to the evaluation process. A focus group is a method using group interviews to generate data by group interactions, and to collect information on a designated topic [24]. It has several advantages as a data collection technique in the area of minority ethnic participants. They do not discriminate against people who cannot read or write and they can encourage participation from people reluctant to be interviewed on their own. They are particularly useful for reflecting beliefs about health and the social realities of a cultural group, through direct access to the language and concepts which structure participants’ experiences [25]. However, its limitation of ‘group thinking’ cannot be excluded, and like other qualitative methods, the ‘representativeness’ of the studied population is hard to achieve. It is arguable that the participants of the focus groups may be more familiar with some of the processes used, as they may have taken part in previous studies, and that their views therefore may not be necessarily representative of the community as a whole. The Social Action Research Method that we have used is an accepted and validated method for qualitative social sciences research and is regarded as a method that produces a rich texture of thoughts, ideas and opinions that are relevant and representative of the social and ethnic group of the participants. We accept that an evaluation by patients with osteomalacia would have added value to this study. However, this was not feasible due to difficulties in identifying adequate numbers of such subjects, as well as stringent ethical committee requirements.

There has been forward movement in the development of patient information for minority ethnic groups in the United Kingdom. It is generally agreed that this information must be culturally sensitive. We propose that this needs to be taken further forward by using an evaluation, and a cultural competence approach that determines fitness for purpose of such information. We would propose a five-stage model for cultural competence in minority ethnicspecific information. First, information needs to be developed on the basis of the existing evidence-base and targeted to the specific health care needs of the community in question. Information should be developed in partnership with professionals, patients and community members so that it is appropriate for the community that is being addressed (cultural sensitivity). Second, an independent evaluation should take place using an appropriate methodology, by submission of materials to the relevant community. Third, information should be refined by the developers using feedback received from stage two. Quality assurance could be enhanced by input from bilingual clinicians, monolingual potential users and persons of educational levels similar to target users. Fourth, information should be disseminated and publicized to all relevant constituencies. Fifth, there should be periodic re-evaluation (stages two, three and four) in order to ensure cultural competence and maintain high-quality fitness for purpose. It is acknowledged that this exhaustive five-stage approach may not be easily undertaken by the average researcher. However, such an approach is essential for quality control of educational health care resources for minority ethnic groups and an ongoing evaluation could perhaps be undertaken under the aegis of national organizations that have a responsibility to ensure and maintain higher standards in health care delivery.

### Rheumatology key messages

- Information for patients is key to disease management.
- Information developed for minority ethnic groups has focused only on cultural sensitivity.
- Further evaluation by community users for cultural competence provides added value.

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