Self reports in research with non-English speakers

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association with head trauma, although this is yet to be validated in other studies.15

For football players the avoidance of exposure to brain injury is important, although currently there are few means by which this may be achieved. Most head to head contact is inadvertent, and coaching techniques and visual perception training may help in a few cases but are unlikely to eliminate this problem entirely. Soft shell helmets or head protectors currently do not have the biomechanical capability to prevent concussive trauma and hence cannot be recommended.

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1 Shaw P. Heading the ball killed England striker Jeff Astle. Independent 2002 Nov 12.

Self reports in research with non-English speakers

The challenge of language and culture is yet to be met

Assessment of the health and healthcare needs of ethnic minority populations, often relying on self reported data, is important in health and social services.1 Major problems exist with the reliability of such information, particularly among recent and older immigrants and refugees who may have little or no competency in English and may be at high risk of health problems. Approximately 25% of immigrants to Britain born in China, Bangladesh, India, and Pakistan have no functional skill in English, and 70% cannot function fully in an English speaking social environment.2

When a measure is probing differences within a group it must be appropriate, valid, and reliable for the group concerned. However, if the data are to be used to make comparisons between groups as in clinical trials and most epidemiological studies, then the questions must be conceptually and functionally equivalent and appropriate for all the groups compared. Non-English speakers are often excluded from clinical trials and epidemiological studies, for reasons including the lack of valid and reliable cross cultural measurements.3

In clinical and epidemiological studies questions developed for native English speakers are usually translated into other languages. It is assumed that the modes of inquiry appropriate for native English speakers are applicable to other linguistic groups. These assumptions may reflect pragmatic issues relating to time and finance or lack of understanding of the complexities of language and culture. Translations, even by experts, may fail to achieve questions that are comparable to the original English in terms of appropriate-ness and meaning.4 It is therefore important to consider conceptual matters, cultural relevance, and the subtle connotations of words and phrases.

In multilingual studies, if each language is translated and compared to the English, each may resemble the English version, but the different non-English languages may differ in important ways, sometimes because it is impossible to find equivalent translations. For example the term “feeling blue,” used in the original American version of the short form Rose angina questionnaire into Punjabi and Cantonese, has different connotations in different languages whereas the terms “check up” and “Pap smear” have no conceptual equivalent in any Chinese language.5

Research in our department, analysing the translation of local and national health surveys, has uncovered numerous potential problems—for example, asking Muslims whether they drink more at Christmas, and the use of terms such as weekend and hangover with questionable relevance to some ethnic groups.6 Detailed examination of translations of the Rose angina questionnaire into Punjabi and Cantonese has highlighted subtle issues potentially explaining the recently shown lesser validity of this instrument in South Asian populations.7

In face to face interviews complications arise where different forms of the same language are used—for example, Bengali and the Sylheti variant of Bengali, the latter having no written form. For some languages the written and spoken forms are not the same—for example, Arabic or Cantonese. At interview the questions asked will not be the same as the questions written on the questionnaire or interview schedule, with unknown effects on data quality.

An alternative to seeking cross cultural equivalence is to define issues as, firstly, salient and meaningful within a culture, for example, chewing paan, and, secondly, concerns of salience between cultures, for example, smoking tobacco. This strategy requires a participatory approach whereby monolingual and bilingual representatives of the target group(s) are involved in developing culturally relevant questions.8

1 Shaw P. Heading the ball killed England striker Jeff Astle. Independent 2002 Nov 12.
involved, to generate items for inclusion in a mode of enquiry relevant to that group. The result would be a combination of some common to all study groups and some group specific. Such a procedure would allow for comparisons within groups over time and between groups for the shared items.

Translators should be trained to advise both on the target language and the cultural acceptability of the questions to be asked. Unless requested to do so translators may not regard it as part of their task to comment on the salience or sensitive nature of the questions asked.

Researchers doing research with ethnic minorities should be cognisant of the customs, values, and beliefs of a challenge and not as an obstacle, a stimulus to innovative thought and the development of new techniques of investigation. This is no small task. In a recent randomised controlled trial that showed no optimistic conclusion must be set against the results of nine observational studies that have addressed the disease, particularly when taken long term. But this evidence that gave rise to it was far from secure. More data have now accumulated, but the matter remains unsettled. Surveys in France and Australia, for example, failed to find any protective effect from non-steroidal anti-inflammatory drugs. On the other hand, the Rotterdam study, a longitudinal, population based investigation of nearly 7000 middle aged and elderly people, reported a considerable reduction in risk of Alzheimer’s disease in those who had taken these drugs for two years or longer, although the reduction in risk was less and did not reach statistical significance for people who had used them for shorter periods.

A systematic review, published recently, identified a prime suspect in the pathogenesis of Alzheimer’s disease is the 42 residue β amyloid peptide. This peptide is a fragment of a much larger molecule, the amyloid precursor protein—a membrane protein whose function is as yet unknown. The proteolytic processing pathways of amyloid precursor protein are complex, but it seems fairly clear that in Alzheimer’s disease overproduction of the 42 residue β amyloid fragment occurs relative to other cleavage products.

This β amyloid peptide is the principal component of extracellular amyloid plaques, which are a characteristic histological feature of Alzheimer’s disease. Activated microglia and reactive astrocytes surround these plaques, and evidence of a local increase in pro-inflammatory mediators exists. Whether this inflammatory response contributes to the progressive neurodegeneration of Alzheimer’s disease is not known, but it is generally assumed to do more harm than good.

The anti-inflammatory activity of non-steroidal anti-inflammatory drugs resides in their ability to inhibit isoforms of the enzyme cyclo-oxygenase, which

London alone over 300 languages are represented, and the research implications of this are enormous, not least in the decision about which languages to address initially.

Cultural and linguistic differences have yet to be incorporated as fundamental to sound public health, primary and secondary care, and health promotion. Health and social services would achieve their goal of equitable services for Britain’s diverse populations faster were the cultural dimensions of self report given more attention than hitherto.

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Anti-inflammatory drugs and Alzheimer’s disease

Evidence implying a protective effect is as yet tentative

The first inkling that anti-inflammatory drugs might lessen the risk of Alzheimer’s disease came from an observation that people with rheumatoid arthritis had an unexpectedly low prevalence of dementia. It was an imaginative idea, but the evidence that gave rise to it was far from secure. More data have now accumulated, but the matter remains unsettled. Surveys in France and Australia, for example, failed to find any protective effect from non-steroidal anti-inflammatory drugs. On the other hand, the Rotterdam study, a longitudinal, population based investigation of nearly 7000 middle aged and elderly people, reported a considerable reduction in risk of Alzheimer’s disease in those who had taken these drugs for two years or longer, although the reduction in risk was less and did not reach statistical significance for people who had used them for shorter periods.

A systematic review, published recently, identified nine observational studies that have addressed the question. The pooled estimates of risk from these studies suggested that non-steroidal anti-inflammatory drugs do offer some protection against Alzheimer’s disease, particularly when taken long term. But this optimistic conclusion must be set against the results of a recent randomised controlled trial that showed no

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