

Health literacy: Why it matters to South Asian men with diabetes

Emee Vida Estacio¹, Robert K. McKinley², Sirandou Saidy-Khan³, Toni Karic³, Linda Clark⁴ and Judy Kurth⁵

¹Lecturer in Psychology, School of Psychology, Keele University, UK

²Professor of Academic General Practice, School of Medicine, Keele University, UK

³Research Assistant, School of Psychology, Keele University, UK

⁴Senior Health Improvement Specialist, Public Health, Stoke-on-Trent City Council, UK

⁵Healthy Cities Project Coordinator, Stoke-on-Trent City Council, UK

This study aims to explore the health literacy needs of South Asian men with diabetes to generate scoping data to inform culturally appropriate interventions with this group. Health literacy levels were measured using the TOFHLA-UK ($n = 45$) and supplemented by semi-structured interviews with healthcare providers ($n = 12$). Data suggest that the majority of participants from this cohort tend to have marginal to inadequate health literacy levels. A generational gap was also found. Although language is a common barrier, low literacy confounds this issue since some patients are unable to read even in their own language. Thus health communication and care plans need to be simplified to match current health literacy levels of South Asian men with diabetes. Interventions need to work around cultural norms and collaborate with community members. Research and interventions that consider the needs of older generations of South Asian people with diabetes are also needed.

Key words: diabetes management; health literacy; South Asian men

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Introduction

Although information on diabetes prevention and management are readily available, its prevalence continues to rise, with ~366 million people affected worldwide (IDF, 2013). In the UK alone, over 3 million people have been diagnosed (Diabetes UK, 2013), costing the NHS around £10 billion annually (Diabetes UK, 2012). For people from South Asian backgrounds, the risk of developing diabetes is even higher. In the UK, Type 2 diabetes is up to six times more common in people of South Asian descent (Diabetes UK, 2009).

Health literacy plays an important role in diabetes management. Health literacy involves the knowledge and competencies which help people to meet the health-related demands in modern society

(Sorensen *et al.*, 2012). People with diabetes need adequate health literacy skills to effectively manage their condition. Diabetes management involves complex tasks that require people to demonstrate, at the very least, functional reading and numeracy skills. Examples of these tasks include, among others, monitoring and normalising blood glucose levels, taking medications and counting carbohydrates (Ahola and Groop, 2013). Listening and communication skills are also important in consultations with healthcare professionals, as well as cognitive skills to enable people to understand and apply the information and advice provided. Previous studies suggest that health literacy influences diabetes knowledge (Gazmararian *et al.*, 2003; Bains and Egede, 2011; Al Sayah, *et al.*, 2013), self-efficacy (Bohanny *et al.*, 2013) and access to adequate healthcare among people with diabetes (Coffman *et al.*, 2012). Health literacy also explains some of the racial disparities in diabetes medication adherence (Osborn *et al.*, 2011). For South Asian people with diabetes in the UK,

Correspondence to: Dr Emee Vida Estacio, School of Psychology, Keele University ST5 5BG, UK. Email: e.v.g.estacio@keele.ac.uk

knowledge about diabetes is generally low (Choudhury *et al.*, 2009; Alam *et al.*, 2012) and language and literacy problems are not uncommon (Alam *et al.*, 2012). Thus, social networks are frequently used among South Asian communities in the UK as sources of information or as informal interpreters (Stone *et al.*, 2005; Singh *et al.*, 2012).

Attitudes towards diabetes among South Asian people are largely influenced by cultural norms (Osman and Curzio, 2012). Religious practices (Holt, 2012), cooking traditions (Lawton *et al.*, 2008), and the social stigma surrounding diabetes (Singh *et al.*, 2012) are other factors that need consideration. While an important determinant of health-related attitudes and behaviour, culture does not influence diabetes management in a rigid way; rather, individuals negotiate their way through the system depending on contextual and personal circumstances (Fleming and Gillibrand, 2009). In a similar fashion, health literacy alone cannot account for differences in diabetes self-care (Bains and Egede, 2011; Fransen *et al.*, 2012). Although diabetes self-management is influenced by the patient's knowledge and capabilities, difficulties could also arise from the lack of cultural sensitivity among healthcare providers (Wilson *et al.*, 2012). Thus there is a need to take into account the role of culture-specific norms and practices, as well as individual competencies, so that culturally and individually tailored interventions can be developed to promote more effective self-management of diabetes among South Asian people (Hill, 2007; Holdich *et al.*, 2012; Zeh *et al.*, 2012).

The study presented in this paper is part of a wider action research project on health literacy and diabetes management in Stoke-on-Trent as part of its Healthy Cities Programme. It aims to generate scoping data concerning the current health literacy needs of South Asian men with diabetes to inform future interventions that are locally sensitive, culturally appropriate and empowering for this group.

Method

Research recruitment of South Asian people can be challenging (Bartlett *et al.*, 2003; Mason *et al.*, 2003). Thus, we adopted a variety of recruitment procedures for this study. South Asian men with diabetes aged 18 years and over ($n = 45$) were recruited in the Stoke-on-Trent area through

invitation letters sent via GP practices, snowballing (Rankin and Bhopal, 2001), walkabouts and engagement with local organisations and events. We aimed to assess the current baseline health literacy level of this priority group and used the British version of the Test of Functional Health Literacy in Adults (TOFHLA-UK) (von Wagner *et al.*, 2009).

To supplement the quantitative data, semi-structured interviews were also carried out with healthcare professionals ($n = 12$) (eg, diabetes nurses, lifestyle coaches, practice manager) to gain their insights into diabetes care and management. The interviews focused primarily on the health literacy needs of South Asian men with diabetes with the aim of determining the areas of system change needed to support behaviour change and to enable patients to better navigate the healthcare system.

Quantitative data were coded and analysed using SPSS v. 19. The interviews were audio recorded and transcribed verbatim. Interview transcripts were analysed and coded by two researchers using thematic analysis (Braun and Clarke, 2006). Ethical approval was obtained from the Keele University Research Ethics Committee.

Results

Patients' ages ranged from 26 to 85 years old ($M = 52.02$; $SD = 14.8$). Participants identified themselves according to the following categories: Pakistani ($n = 19$), Indian ($n = 8$), Bangladeshi ($n = 5$), Kashmiri ($n = 2$), Sri Lankan ($n = 2$) and Other (eg, 'South Asian' or 'British Asian') ($n = 9$). The mean reading comprehension score was 21 ($SD = 12.30$) with a range from 2 to 36; 44.4% had inadequate reading comprehension levels; 6.7% marginal; and 48.9% adequate. This means that more than half of the participants from this cohort may have difficulties reading and understanding written text. A Pearson r test of correlation was carried out to test whether these scores were related with age. The results indicate a significant negative correlation between age and reading comprehension scores, $r(41) = -.402$, $p = 0.007$.

Qualitative findings

It is already well-established that language is a common barrier for South Asian men with diabetes. Qualitative findings from this study suggest

that inadequate health literacy confounds this issue. Since healthcare professionals (HCPs) often have limited time with their patients, they may be unable to sufficiently assess whether people understand the health information provided or not. Thus, HCPs sometimes provide leaflets to expand upon important points. Although some materials are translated into different languages (eg, Punjabi, Urdu, Bengali), simply providing leaflets could still be problematic since some people are unable to read even in their own language. In such cases, family and friends who have adequate literacy skills are usually called upon for support.

HCPs also observed variations in knowledge and attitudes on diabetes among people from South Asian backgrounds. While some are knowledgeable about diabetes and its management, there are those who are unaware of its health risks and that these can be prevented or managed through lifestyle changes. In addition, since some South Asian men are often not involved in cooking the meals they eat, any education they receive on healthy diet may not be transferred into practice. Some HCPs have also experienced some resistance to their suggestions. HCPs recognise that this is particularly evident among older generations,

'some of the older patients, if they were born in other countries, they sometimes have different health beliefs to our health beliefs in the UK so they sometimes have perhaps might not want to consult a doctor, they'd perhaps go to a religious leader or that kind of thing or leave symptoms for longer before they access healthcare.'

(HCP)

Discussion

Health literacy matters to South Asian men with diabetes. As reflected in this study, South Asian men with diabetes tend to have poor levels of health literacy. Our findings suggest that some people will have difficulties in reading and understanding written text. This could have detrimental consequences to their ability to manage their condition since diabetes management involves routines that require literacy skills. Furthermore, poor health literacy could also compromise their ability to access adequate healthcare and could reduce their ability to understand and apply health information.

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Our findings also support previous studies which highlight language and culture-specific issues among South Asian people with diabetes (Alam *et al.*, 2012). Although language is a main barrier for this group, this current study demonstrates how literacy confounds this issue. Simply translating written health information will be inadequate since some people are not able to read even in their own language. As reflected in this study and in previous work with South Asian communities (Stone *et al.*, 2005; Osman and Curzio, 2012), family and social networks who have adequate language and literacy skills are used to bridge the gap between patients and healthcare providers, and are therefore valuable assets within this community.

This study is also consistent with previous literature which suggests that although cultural norms (Osman and Curzio, 2012), religious practices (Holt, 2012) and cooking traditions (Lawton *et al.*, 2008) may influence attitudes towards diabetes; South Asian communities do not represent a homogenous group (Holdich *et al.*, 2012). There are variations on knowledge, attitudes and how cultural norms influence the way diabetes is managed. Our findings suggest that the generational gap could explain some of these variations. The quantitative findings suggest that older people tend to have poorer health literacy levels; while the qualitative findings suggest that they may be more rigid with their attitudes towards diabetes and may be less open to adjust dietary and other traditional practices accordingly.

We were aware that recruitment of South Asian people to research can be challenging (Bartlett *et al.*, 2003; Mason *et al.*, 2003). While our sample was small we did succeed in recruiting participants from this hard to access population. We acknowledge that our participants may not represent all South Asian men in the UK but the data suggest that majority of these men had marginal to inadequate levels of health literacy using a standardised instrument and that this is validated by the accounts of the healthcare professionals from the same health economy. Low health literacy among South Asian men is a challenge in our health economy and we contend that it is likely to be a problem in others.

Implications

For future interventions, it would be useful to consider simplifying health communication and

care plans to ensure that the level of information and the complexity of the activities suggested match the current health literacy levels of people. Individualised plans may be required considering the variations in skills, attitudes and knowledge reflected in this study. Considering the role of cultural norms and traditions, we agree with Holdich *et al.* (2012) that it is important that interventions work with these norms, rather than against it. For South Asian men with diabetes, it would be useful to involve the whole family in health promotion and education, particularly those individuals who are responsible for family meals. It would also be useful to collaborate with religious leaders and respected community elders in developing culturally appropriate health improvement programmes. Peer mentoring might also be worth considering wherein community members with adequate literacy skills could mentor those who might need more support. Finally, research and interventions that prioritise and consider the needs of older generations of South Asian people with diabetes are also needed to address the generational gap found in this study.

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