

Model of diabetes management: Have we got it right for South Asian people in the UK?

Leah Macaden, Charlotte Clarke

Empowerment of people with diabetes through education that is inclusive of initiating and sustaining lifestyle changes has been identified as the cornerstone of effective diabetes management. There is an increasing emphasis on concordance, which enables goal setting, and a negotiated agreement between practitioners and people with long-term conditions. Variations in health beliefs, socio-cultural values, religious preferences, locus of control, family and their social networks influence South Asians' diabetes management and engagement with diabetes-related risks. This brings into question whether the empowerment model, which emphasises self-management, is the right model of diabetes management for minority ethnic groups. This paper explores alternative models of diabetes management around service provision and education, with implications for policies on diabetes management for minority ethnic groups.

The largest ethnic minority group in the UK includes people from Bangladesh, Pakistan and India, commonly known as South Asians. South Asian people have a four-fold higher risk of developing diabetes (Kramer et al, 2004) and are diagnosed on average 6.4 years younger than people from other ethnic groups (Khan et al, 2011). It is a well-documented fact that the prevalence of diabetes and diabetes-related risks (cardiovascular risk, in particular) is also significantly higher among South Asian people (Forouhi et al, 2006).

Educational initiatives towards promoting self-management must be cognizant of the needs of minority ethnic groups, such as South Asians, who are inherently vulnerable to developing diabetes. This could be a very challenging task, however, given the influence of perceptions on ageing, gender, choice and control, sociocultural factors, religious beliefs and family dynamics on diabetes-related risk perception among South Asian people (Macaden and Clarke, 2006). This paper discusses some of the alternative approaches to diabetes care for older South Asian

people living in the UK with type 2 diabetes.

Background

Access to primary care and regular contact with care providers for monitoring is critical to preventing diabetes-related complications. The Indian Diabetes Prevention Programme in 2006 demonstrated that the progression of diabetes could be influenced by lifestyle interventions (Ramachandran et al, 2006).

There has been a major paradigm shift towards empowering people through advocating self-management, particularly within the NHS in the UK (Henshaw, 2006). There is an increasing emphasis on concordance, which enables goal setting and a negotiated agreement between practitioners and patients, leading to a “therapeutic alliance” (Adiseshiah, 2005), which empowers people to make informed lifestyle choices in diabetes management.

A significant element of empowerment is “self-efficacy” (Bandura, 1997), which, in this study, relates to the locus of control based on the Health Belief Model (Rosenstock et al, 1988). Empowering

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Article points

1. Variations in health beliefs, socio-cultural values, religious preferences, locus of control, family and their social networks influence South Asians' diabetes management and their engagement with diabetes-related risks.
2. The aim of this study was to develop a conceptual model on risk perception among older South Asian people with type 2 diabetes in the UK.
3. As risk perception is predominantly driven by affect and the external locus of control in the South Asian people in this study, practitioners will need to be supported with the challenge of promoting the concept of empowerment and “collaborative care” to immigrant groups.

Key words

- Empowerment model
- Risk perception
- South Asian people

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Page points

1. Empowering older South Asian people to take control of their diabetes management can be very challenging for practitioners given the predominant role of “affect” and “external locus of control” influencing risk perception.
2. The study used Grounded Theory within qualitative research. As part of the data collection, all participants in both the focus group and individual interviews were asked what they thought should be the model of diabetes management and support for South Asian people living in the UK.

older South Asian people to take control of their diabetes management can be very challenging for practitioners given the predominant role of “affect” and “external locus of control” influencing risk perception and subsequent behaviour towards diabetes risk prevention (Macaden and Clarke, 2010).

A lack of balanced and critical understanding on the whole discourse of empowerment can pose the risk of a “myth of empowerment” among practitioners (Paterson, 2001). Interventions to effectively empower individuals with diabetes are known to be effective only when based upon individual focused goal setting, coping skills and problem-solving strategies (Henshaw, 2006). Practitioners, therefore, need to be adequately knowledgeable about South Asian people’s personal, socio-cultural and religious beliefs, and the role of locus of control that influences their risk perception, while using the empowerment or concordance model of diabetes support. They also need to be mindful that attitudes, subjective norms, perceived behavioural control and behavioural intention are key determinants of self-management in diabetes (Gatt and Sammut, 2008).

Aim

The aim of this study was to develop a conceptual model on risk perception among older South Asian people with type 2 diabetes in the UK. This paper reports on the model of diabetes care and support

that South Asian people believe would be more relevant to them.

Methods

The study used Grounded Theory within qualitative research. Ethics approval was obtained from the School Research Ethics Committee where this doctoral study was undertaken and the Local Research Ethics Committee. Data were collected through a focus group interview with six health development workers, and individual interviews with 20 older South Asian people with type 2 diabetes (11 women and nine men) and seven practitioners (three GPs, three DSNs and one dietitian). The study took place in north-east England. Participation was sought from both non-English-speaking and English-speaking South Asian people, in addition to ensuring representation from the three major South Asian communities in the UK (Bangladesh, India and Pakistan). The Cross Language Interpretation process (Larson, 1998) was used to address the methodological challenges with the language barriers using bilingual health development workers for data collection with non-English speaking participants (nine out of 20). All the interviews were digitally recorded and transcribed. Respondent validation was used by returning the transcripts to the participant or the interpreter as required to enhance data credibility. Data and interdisciplinary triangulation, reflexivity (Ahern, 1999), peer debriefing and maintaining an

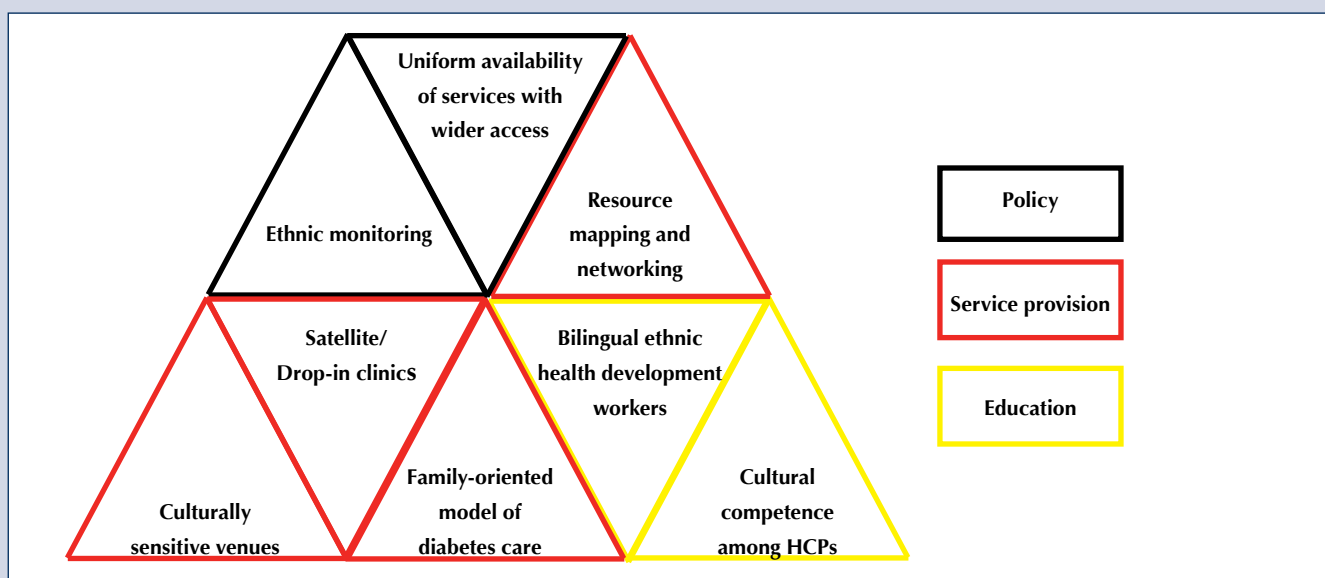


Figure 1. Model of diabetes support for South Asian people in the UK.

audit trail (Cutcliffe and McKenna, 2004) were used to ensure, validity and rigor (Robson, 2002).

As part of the data collection, all participants in both the focus group and individual interviews were asked what they thought should be the model of diabetes management and support for South Asian people living in the UK. Themes generated from the data collected primarily focused on alternative models of diabetes support around service provision, education and policy, as shown in the *Figure 1*.

Results

Family-centred model of diabetes care

With regard to service provision, both practitioners and the South Asian people had many suggestions for the future. With type 2 diabetes being commonly seen among family members in the South Asian community, a family-oriented approach was suggested as a way of preventing and managing diabetes. One healthcare professional, Lyn, reported:

“They prefer to have a family member. But in some ways that is quite good...I find that I can educate the son and the daughter as well as educating the parent for, if their time ever comes because as you know their risk is very high.”

With the dynamics of managing type 2 diabetes being family oriented and the lifestyle changes required, it was expressed that it would be helpful to educate the family unit instead, as expressed in the following quote from Madhur, from Bangladesh:

“They can form a group and they can run various educational sessions with the people who have got the diabetes, or even like not with the patient, with the carers because sometimes if it is men [with diabetes], he is not the one who does the cooking, organising the food. In fact, from the Bangladeshi community, it is the woman nowadays, who does the shopping, cooking everything.”

Culturally sensitive services with more uniform and wider access

Services need to be more uniformly available, with wider access and increased cultural sensitivity. Services, such as an annual review for early detection of complications, are not available in all the GP surgeries. Some people reported being seen by the GP,

while others were referred to the Regional Diabetes Centre and this led to misconceptions about the severity of one's diabetes.

There is also a lack of standardisation in the way these services were run, especially in terms of follow up. This was articulated clearly in the quote from Dhiren (focus group) below.

“One of the other things is hopefully within ten years, access to services will be the same across the board because it varies so much from one practice to another. One doctor is quite willing to refer you to the diabetes centre and the other one says, ‘No, come to my surgery.’ And for somebody who has been given that message, ‘Oh, he is going to the diabetes centre. So, he must be more serious than I am because I am just going to see my doctor.”

The need for ethnic monitoring by healthcare professionals was emphasised by Purva in the focus group:

“And then, I would like all health professionals to be doing ethnic monitoring so that we can measure. So often we can't measure things because people don't do it. Everybody should have more training, so that they are more aware of, like, racial equality issues and deliver better services and like the empowering people is about, about working with people.”

The model of involving ethnic health development workers in GP surgeries to provide services and education with subsequent follow up was suggested during the interviews with practitioners. The commonality of their background, language and a shared understanding of socio-cultural and religious values, family dynamics and lifestyle issues were proposed to be the strengths of involving the ethnic health development workers in the service delivery and health promotion for South Asian people with type 2 diabetes. This is explained by a GP, Malcolm:

“I have to say that the support workers have been a major step forward because ten years ago, this was a difficult-to-reach group and it was, you had no idea how your advice was getting home. To have that given by specialist trained workers here in that sub group is excellent. I support that very strongly.”

Page points

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2. Services need to be more uniformly available, with wider access and increased cultural sensitivity.
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1. Involving the ethnic health development workers in education had multiple benefits, such as bilingual language skills, a shared cultural background and it also released qualified professionals to look at other details, rather than be involved in giving health education messages.
2. Inclusion of cultural practices by different ethnic groups in the curriculum for training diabetes professionals was strongly recommended.
3. Networking with religious leaders using existing social and religious networks as effective avenues for health education was also suggested as a way to improve the educational programmes for minority ethnic groups with diabetes.

Resource mapping and joint working of health authorities, local authorities and third sector organisations to use resources more efficiently and make the services more streamlined was another suggestion in relation to service provision. Practitioners expressed from their past experience that trying to create new services each time was “reinventing the wheel” rather than achieving its purposes. Purva from the focus group suggested:

“And coordination as well, I think there needs to be much better coordination of lifestyle things because there’s heart disease, diabetes, cancer, stroke. We’re all working on lifestyle issues.”

Education

Suggestions for support with education ranged from involving ethnic health development workers to implementing changes in the curriculum towards promoting cultural competence among practitioners involved in diabetes care. Involving the ethnic health development workers in education had multiple benefits, such as bilingual language skills, a shared cultural background and it also released qualified professionals to look at other details, rather than concentrating on giving health education messages during a consultation due to time constraints. Hita, from the focus group said:

“Actually in this surgery, the GP sometimes, they’ve got many patients and haven’t got time to explain to them. Because GPs they, when they see they can’t explain everything. Then, there should be one setting... of our healthcare team worker should be there to explain and the patient from GP should pass on to the care team.”

Madhur from Bangladesh suggested that having professionals from the same ethnic background with cultural competence would help improve services, especially in terms of providing education on diet and lifestyle issues, since they would be more familiar with their cultural practices, values and belief systems as in the quote below:

“Even the dietitian sometimes, when I went to see the last time, this dietitian perhaps, she is not aware about Asian food habits. They need to keep one Asian dietitian who can help these people because I was

asking her a question about the rice and she couldn’t [answer].”

Malcolm, a practitioner also shared that it would be appropriate to have workers who are familiar with the culture to provide services since health promotion is the bedrock of diabetes care.

Inclusion of cultural practices by different ethnic groups in the curriculum for training diabetes professionals was strongly recommended. Provision of services for diabetes involved education on lifestyle changes and practitioners quite often felt inadequate to educate people since their knowledge on the socio-cultural beliefs and values influencing health behaviour was often very limited. This imposed barriers to their understanding of health practices among different ethnic groups. Practitioners expressed that their current training did not equip them sufficiently to address these challenges in their practice, as explained by a DSN, Cheryl:

“I think, really, from a health professional point of view, we truly don’t know enough about their customs and we’re not aware enough of you know... I’m sure if all of us as health professionals knew a bit more about the different cultures, the different dialects, even cultures within cultures, we can then look and think this is possibly why they’re not complying with their treatment or why this is the barriers.”

Networking with religious leaders using existing social and religious networks as effective avenues for health education was also suggested as a way to improve the educational programmes for minority ethnic groups with diabetes. The use of drop-in centres and satellite clinics was also suggested.

Discussion Service Provision

Most South Asian people who participated in this study were very satisfied with the services that they received for their diabetes care. They were able to compare the services with their country of origin and expressed satisfaction with the services being high quality and free of charge, in contrast to most healthcare services in their home countries. With regard to practice and service provision, both practitioners and the South Asian people had many suggestions for improving services further. As the

management of type 2 diabetes usually involves the whole family (for example, in terms of the lifestyle changes required), it would not suffice to just deal with the patient on a one-to-one basis. A family-oriented approach may be more appropriate considering the significance of both the family and socio-cultural dynamics involved in diabetes management in this population.

An ethnically diverse healthcare workforce is positively correlated with the quality of care provided to diverse patient groups (Joseph et al, 2003). Issues, such as lack of language-specific information on services available and access to those services need to be addressed. In terms of service provision, services need to be more uniformly available with wider access and increased cultural sensitivity. Information not only needs to be made available but also made accessible given the language and literacy barriers within the South Asian community. The role of using the media in different languages and employing additional ethnic health development workers who share the same cultural background for interventions on health promotion within the health service are some of the options that could be explored.

Resource mapping, coordination of the available resources and joint working of health authorities, local authorities and third-sector organisations would enable optimisation and efficient utilisation in addition to making the services more streamlined. Attempting to create new services each time is “re-inventing the wheel” rather than achieving its purposes.

The model of involving ethnic health development workers in GP surgeries as link workers to provide services and education featured significantly from interviews with practitioners. Shared ethnicity, language and understanding of socio-cultural and religious values, family dynamics and lifestyle issues are valuable assets for service delivery and health promotion for South Asian people with type 2 diabetes. Evidence from the UK Asian Diabetes Study suggests that diabetes support that is tailored to the needs of South Asian people, delivered by Asian link workers, with additional sessions from a community DSN had the potential to improve risk factors for diabetes-related complications, and, therefore morbidity and mortality (O’Hare et al, 2004). Involving the ethnic health development workers in education had multiple benefits, such as bilingual

language skills, a shared cultural background and familiarity with cultural practices, values and belief systems. This would enable practitioners to focus on the more complex aspects of diabetes care rather than be involved in primary care aspects of diabetes management during a consultation. This is of great benefit, considering with the resource constraints that currently exist for diabetes care.

Education

Implications for education ranged from involving ethnic health development workers to implementing changes in the curriculum to promote cultural competence among practitioners involved in diabetes care. A recent mixed methods study on the effectiveness of a Community Health Worker (CHW)-led Diabetes Self-Management Education programme in the US revealed that people ($n=497$) who participated in the programme experienced a statistically significant decrease both in mean HbA_{1c} levels and systolic blood pressure readings in the first year of follow up (Collinsworth et al, 2013). Bilingual CHWs have been engaged especially in chronic disease management of immigrant minority ethnic groups to address health inequalities. There are a range of benefits (American Association of Diabetes Educators, 2003) in engaging these workers who share the same ethnicity as South Asians with diabetes. They act as an effective bridge between practitioners and people with diabetes to facilitate communication (Thompson et al, 2007; McElmurry et al, 2008) and work on health promotion to help prevent unwarranted hospital admissions (Brownstein et al, 2011) thus enabling cost effective health care delivery (Volkman and Castanars, 2011).

Networking with religious leaders and using the existing informal groups as effective avenues for health education could also improve the educational programmes for minority ethnic groups with diabetes. Establishing drop-in centres and satellite clinics for diabetes support are the other avenues that need to be explored further.

Inclusion of cultural practices by different ethnic groups in the curriculum for training professionals caring for diabetes will be a significant breakthrough in promoting cultural competence among practitioners. Provision of services for diabetes involves education on lifestyle changes and practitioners interviewed felt inadequately prepared to educate

Page points

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2. The model of involving ethnic health development workers in GP surgeries as link workers to provide services and education featured significantly from interviews with practitioners. Shared ethnicity, language and understanding of socio-cultural and religious values, family dynamics and lifestyle issues are valuable assets for service delivery and health promotion for South Asian people with type 2 diabetes.
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1. Management of most chronic disease involves significant lifestyle choices and changes. It is, therefore, essential to focus on familial and other inter-personal relationships while managing chronic disease in order to understand how illness is “lived” and negotiated in people’s everyday lives.
2. The current study, as well as other research, has shown that the self-care behaviour that South Asian people are inclined to adopt was to take their prescribed medications. They were less likely to adhere to physical activity and dietary advice.

people since their knowledge on the socio-cultural beliefs and values influencing health behaviour among immigrant minority ethnic groups was very limited.

Policy

Despite the recognition in the National Service Framework for diabetes in the UK that there is a disproportionate increase in the incidence of diabetes among minority ethnic groups, the specific strategies to address this issue among these groups are not clearly outlined. Good risk communication will facilitate the current trend of improving an individual’s choice and self-management in health care, and there is a need for practitioners to be sensitive to issues around diabetes management that are unique to South Asian people (Macaden and Clarke, 2006).

Risk perception is multidimensional (Park et al, 2001). Both the cognitive and affective domains significantly impact upon the individual’s perception of risks and risk engagement. It therefore becomes necessary for practitioners to understand that they need to also factor in the influence of affect in an individual while planning services to promote diabetes care and prevent long-term complications. Currently, the service provision predominantly focuses on the cognitive domain and provides factual knowledge expecting patients to understand diabetes-related risks solely from a medical perspective.

Arguably, this poses major challenges with risk prevention for older South Asian people, as demonstrated by the findings from this study. Concepts, such as concordance and empowerment, require participation from both practitioners and patients in the process of decision making. With issues around understanding diabetes as a disease, perception of its severity and the risks involved, barriers with language and literacy and the predominance of affect over cognition in risk perception, one needs to seriously examine if the empowerment model would be successful in improving the diabetes services for this population.

Healthcare sciences such as medicine are inclined towards “professional dominance” and the “monopoly of medical knowledge” (Lawton, 2003). This leads to patients not being part of the decision-making process, contrary to the contemporary emphasis on participatory healthcare. Management of most chronic disease involves significant lifestyle choices and changes. It is, therefore, essential to focus on

familial and other inter-personal relationships while managing chronic disease in order to understand how illness is “lived” and negotiated in people’s everyday lives (Lawton, 2003). The strength of an individual’s social network and the support systems available are critical elements that need to be understood in diabetes management for South Asian people, for whom family and their social networks are significant. For instance, in the South Asian community, a woman with diabetes may be highly motivated to comply with the treatment and lifestyle changes but may not be able to make it a reality due to the intricacies within the family dynamics, such as having to cook and also eat what is preferred by the men in the family, unable to exercise due to her role and associated responsibilities as a wife and mother and the cultural expectations of a woman not going out on her own.

In this study, both cognitive and affective domains interact with diabetes-related risk perception among older South Asian people. Risk engagement that resulted from risk awareness was either proactive or reactive and was dependent on whether the locus of control was internal or external. In the light of this study’s findings, the relevance of the concordance/empowerment model of diabetes management, which advocates self-management and aims towards risk prevention, needs further exploration.

The current study, as well as other research, has shown that the self-care behaviour that South Asian people are inclined to adopt was to take their prescribed medications. They were less likely to adhere to physical activity and dietary advice (Gatt and Sammut, 2008). The performance of any behaviour is resource and outcome dependent (Ajzen, 2002). This is clearly apparent from the findings of the current study, as participants in the study attributed their lack of exercise to shortage of culturally sensitive venues, language barriers and the controversies with using family members for interpretation during a medical consultation, and the family dynamics that interfered with dietary adherence and risk prevention.

Empowering older South Asian people to prevent and manage their diabetes-related risks has multiple challenges. The empowerment model advocates a joint decision-making process, with patients taking responsibility for self-management and positive behaviour change that would ultimately promote

good diabetes control (Meetoo, 2004). The role of cognition is vital in the empowerment model, which emphasises the importance of self-management and educational interventions for long-term risk prevention. This study has also demonstrated, however, that the role of affect is significant with the way South Asian people understand and engage with diabetes-related risks. It is being increasingly evidenced that affect plays a more significant role than cognition in the prediction of behavioural intentions (Lawton et al, 2009). Some people in this study chose to engage with risky behaviours, such as indulging in sweets, and missing medications and hospital appointments, despite risk awareness when driven by affect. It is within these trajectories that an understanding of the various factors influencing risk perception in this population becomes crucial for practitioners to consider an alternative model of diabetes support.

Conclusion

Concordance reinforces mutual goal setting, with practitioners facilitating people with diabetes to make informed choices about diabetes management. The relevance of an empowerment model of diabetes care for older South Asian people with type 2 diabetes, rather than a traditional hierarchical model, needs to be carefully scrutinised to ensure optimal utilisation and achievement of its primary goal, which is long-term risk prevention. Recommendations towards service provision and education that have emerged from the data in this study also have significant implications for policy review. In light of these findings and considering the economic burden that long-term complications impose, it would be worthwhile to invest in planning strategies to address issues in relation to risk perception and risk communication. As risk perception is predominantly driven by affect and the external locus of control in the South Asian people in this study, practitioners will need to be supported with the challenge of promoting the concept of empowerment and “collaborative care” to immigrant groups. ■

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