A conceptual model on risk perception among older South Asian people with type 2 diabetes

Leah Macaden, Charlotte Clarke

Research has shown that an underestimation of personal health risk can reduce the motivation to change behaviour and reduce risk factors. This paper describes a conceptual model on risk perception among older South Asian people (representing Bangladesh, India and Pakistan) with type 2 diabetes living in the UK; this model was developed using qualitative research. Risk perception in this study is interpreted in terms of risk awareness and risk engagement. This research indicated that the concordance/empowerment model of diabetes management, which advocates self-management towards long-term risk prevention, needs further exploration in older people from minority ethnic groups with type 2 diabetes.

An underestimation of personal health risk has been shown to reduce the motivation for a change in risky behaviours and can decrease compliance with medical prevention strategies (Kraywinkel et al, 2007).

This fourth paper from a doctoral study describes the development of a conceptual model on risk perception in older South Asian people with type 2 diabetes in the UK. Using qualitative methodology, risk perception in the older South Asian people with type 2 diabetes was examined within the theoretical framework of the theory of planned behaviour (TPB; Ahern 1999; Ajzen, 2002a; Ajzen and Manstead, 2007). TPB has been widely used in understanding diverse health-related behaviours such as exercising, diet and other lifestyle-related issues. According to the TPB, human action is influenced by behavioural beliefs, normative beliefs and control beliefs (Ajzen and Manstead 2007).

The strength of an individual's social network and the support systems available are very critical in the management of diabetes. This is particularly important among older South Asian people with diabetes for whom family and social networks are significant. There are several factors that influence the way in which diabetes is experienced at the macro-contextual level, such as knowledge of the disease, access to services, health beliefs and cost of treatment. At the micro-contextual level, there should be a focus on familial and other interpersonal relationships while managing diabetes in order to understand how illness is negotiated in people's everyday lives (Lawton, 2003). Research into risk has been dominated by the psychometric paradigm that is rooted in psychology and decision theory (Rippl, 2002) and the landmark "Cultural theory of risk" (Douglas and Wildavsky, 1982). It is increasingly believed, however, that risk perception is a social phenomenon that needs to be studied within a social context since cultural adherence and social learning influence perception of risk (Oltedal et al, 2004).

Aim of the study

To develop a conceptual model on risk perception among older South Asian people with type 2 diabetes in the UK.

Method

An evolved form of grounded theory methodology (McCann and Clark, 2003) was used, and ethical

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Article points

1. Risk is a social phenomenon that needs to be studied within a social context since cultural values and beliefs influence risk perception.
2. Engagement with diabetes-related risk depends on how visible, imminent or tangible the risk is, and the perceived severity.
3. Models of diabetes care need to integrate socio-cultural and religious beliefs for minority ethnic groups living in the UK.

Key words

- Diabetes
- Older people
- Risk awareness
- Risk engagement
- Risk perception
- South Asian people

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1. In this study, attitude towards diabetes and its related risks were based on the South Asian people's understanding of diabetes, immediacy of the risk, visibility of the proposed risk and perceived severity of the illness.
2. Perception of diabetes severity was dependent on the number of tablets that one was taking, presence or absence of insulin therapy, frequency of hospital appointments and the type of services accessed.
3. Normative beliefs refer to the perceived behavioural expectations of significant referent individuals or groups, such as the individual's family or religious groups. The normative beliefs, along with motivation to comply with the expected behaviour, determine the behaviour.

and governance approval was secured from the School Ethics at the Northumbria University and the Local Research Ethics Committee.

Data were collected from March, 2004 to February, 2005 through a focus group interview with ethnic health development workers, as well as seven individual interviews with healthcare professionals (physicians, DSNs and a dietitian) and individual interviews with 20 older South Asian men and women with type 2 diabetes in North-East England. The average age of the participants was 63 years, although one woman of 44 years was included in the study as it was particularly difficult to recruit from the Bangladeshi community. Participants were recruited through ethnic health development workers, DSNs and links made with South Asian social networks.

Maximum variation sampling and theoretical sampling (Robson, 2002) within the qualitative research paradigm were used. This was best achieved by choosing the subsequent samples only after the previous set of data were analysed. The first interview functioned as the "gate keeper" and set the stage for further data collection. This approach posed the risk of limiting the scope of a complete understanding of the phenomenon being studied if the first participant had a limited understanding or inability to articulate the related experiences (Cutcliffe, 2000). This was overcome by conducting the focus group interview with health development workers as the first interview; this provided insight into several issues (socio-cultural and religious practices, priorities, understanding of diabetes) around risk perception of diabetes in this population.

Interviews with those who were non-English speaking (9 out of the 20 participants) were carried out using the ethnic health development workers as interpreters using the Cross Language interpretation process (Larson, 1998). All the interviews were digitally recorded and transcribed. Credibility of data was ensured using respondent validation by returning the transcripts to the participant or the interpreter as required. Issues related to validity and rigour were addressed using triangulation at two levels (data and interdisciplinary; Robson, 2002), reflexivity (Ahern, 1999), peer debriefing, and maintaining an audit trail (Cutcliffe and McKenna, 2004). Data management was carried out using NVIVO 2 (QSR International Pty Ltd, 2002).

To answer the research aim of this study, the evolved form of grounded theory was adopted and data were analysed using theoretical sampling, constant comparative method, coding and categorising, memo writing, theoretical sensitivity, measure of rigour and identifying the core category (McCann and Clark, 2003).

Results

Perception of diabetes risk

According to the TPB, attitude towards behaviour is believed to be determined by beliefs about the consequences of adopting that behaviour. In this study, attitude towards diabetes and its related risks were based on the South Asian peoples' understanding of diabetes, immediacy of the risk, visibility of the proposed risk and perceived severity of the illness. For instance, one respondent described how their individual belief was that diabetes was caused due to the cold weather and lack of sunshine in the UK, so they chose to travel to their home country for extended periods of time and also discontinued medication since the perception was that the diabetes had disappeared while they were back in their home country.

Perception of diabetes severity was dependent on the number of tablets that one was taking, presence or absence of insulin therapy, frequency of hospital appointments and the type of services accessed. This was also largely attributed to the lack of visibility and immediacy of the proposed risks.

Normative beliefs

Normative beliefs refer to the perceived behavioural expectations of significant referent individuals or groups, such as the individual's family or religious groups. The normative beliefs, along with motivation to comply with the expected behaviour, determine the behaviour. Data from the study revealed that religious requirements, such as fasting during Ramadan, were strictly adhered to even without consulting health professionals for fear of being advised not to comply with the religious requirements.

The socio-cultural and religious factors explicitly describe the influence of perceptions about ageing, gender and family dynamics on risk perception. There was identification of priorities and ranking of risks that people exercised internally. Participants reported a preference to prioritise social etiquette over diabetes control when offered sweets at social occasions.

The risks were weighed or ranked and people were generally inclined towards taking risks that were not visible, or non-imminent (health risks) and were averse to those that were visible and imminent (social risks).

Control beliefs

Control beliefs deal with the perceived presence of factors that can facilitate or impede performance of behaviour. This was associated with the locus of control influencing risk awareness and risk engagement in this study. An individual's perceived locus of control and their ability to be in control of the situation seemed to guide risk behaviour. Individuals with an internal locus of control viewed themselves as being responsible for the consequences of their actions as in the case of Danaa:

> *"Long time ago, we stopped, in the eighties I think, we stopped using butter, pure ghee. We moved to using vegetable oil and then we changed to corn oil. Now, we use olive or sunflower oil. I told my wife that we needed to change and the whole family changed. They were all happy to change."*

On the contrary, individuals with an external locus of control, viewed things like fate, luck and their creator as being responsible for the consequences, despite their actions, as described by Haala's husband:

> *"Her husband affirmed very strongly that everything was in God's hands and that there was nothing much they could do as human beings."*

Risk taking that results from vulnerability in individuals could be the consequence of their loss of control over the situation, or the inability to make choices within the context that they are in. It could often be due to lack of alternatives. In this situation, they are not left with much choice but to contend with the predetermined conditions that already exist. Examples of this from this study identified gender issues in relation to choosing healthier cooking options for a woman with diabetes as in the case of Baqueer's wife. The healthier cooking options were considered only after Baqueer was diagnosed with diabetes, even though his wife had the same diagnosis a year earlier.

Positive expectations

Individuals take risks from having hope or positive expectations of a possible, but uncertain, beneficial outcome. Individuals tend to choose the option that offers hope, however insignificant it may seem. In case of diabetes and risk engagement with the Muslim participants in particular, they were often found to be acting from the hope that was based on their religious values and beliefs. The hope that they held strongly was that God was in control of whatever happened in their lives and therefore it was considered to be very important to please Him by following all the religious requirements (for example, fasting during Ramadan and visiting Hajj). This resulted in individuals taking risks, such as fasting without seeking medical advice while taking insulin and changing medications around their meal times during Ramadan. This was done in the hope that God would look after the consequences. Understanding the interaction between these elements helps us to see risk taking as "clinging to hope" rather than being irrational and irresponsible. The hope that was adhered to was that their lives were preordained and that God was in control.

South Asian people in this study ranked risks and this resulted in a "risk averse" attitude to risks that were imminent and visible, such as a social risk. In contrast, there was a "risk-o-phillic" (Clarke, 2006) attitude towards risks that were invisible and non-imminent, such as diabetes-related health risks. Risk perception was mostly influenced by socio-cultural and religious beliefs and were driven by emotions rather than cognition; this resulted in risk engagement that was reactive. This was also compounded by a strong external locus of control.

The current study demonstrated that the locus of control among South Asian older people was largely external and the response to risks varied from "depathologising" the illness to resilience (Macaden and Clarke, 2006). Individuals who were educated, bilingual and who had a family member as a healthcare professional had a strong internal locus of control. This influenced their risk awareness and proactive engagement with diabetes-related risks (Macaden and Clarke, 2010).

Conceptual model

Factors, such as the understanding of diabetes, perceived severity of diabetes, personal experience

Page points

1. An individual's perceived locus of control and their ability to be in control of the situation seemed to guide risk behaviour. Individuals with an internal locus of control viewed themselves as being responsible, whereas those with an external locus of control believe that fate, luck or God would be in control of the situation.
2. Individuals take risks from having hope or positive expectations of a possible, but uncertain, beneficial outcome. Individuals tend to choose the option that offers hope, however insignificant it may seem.

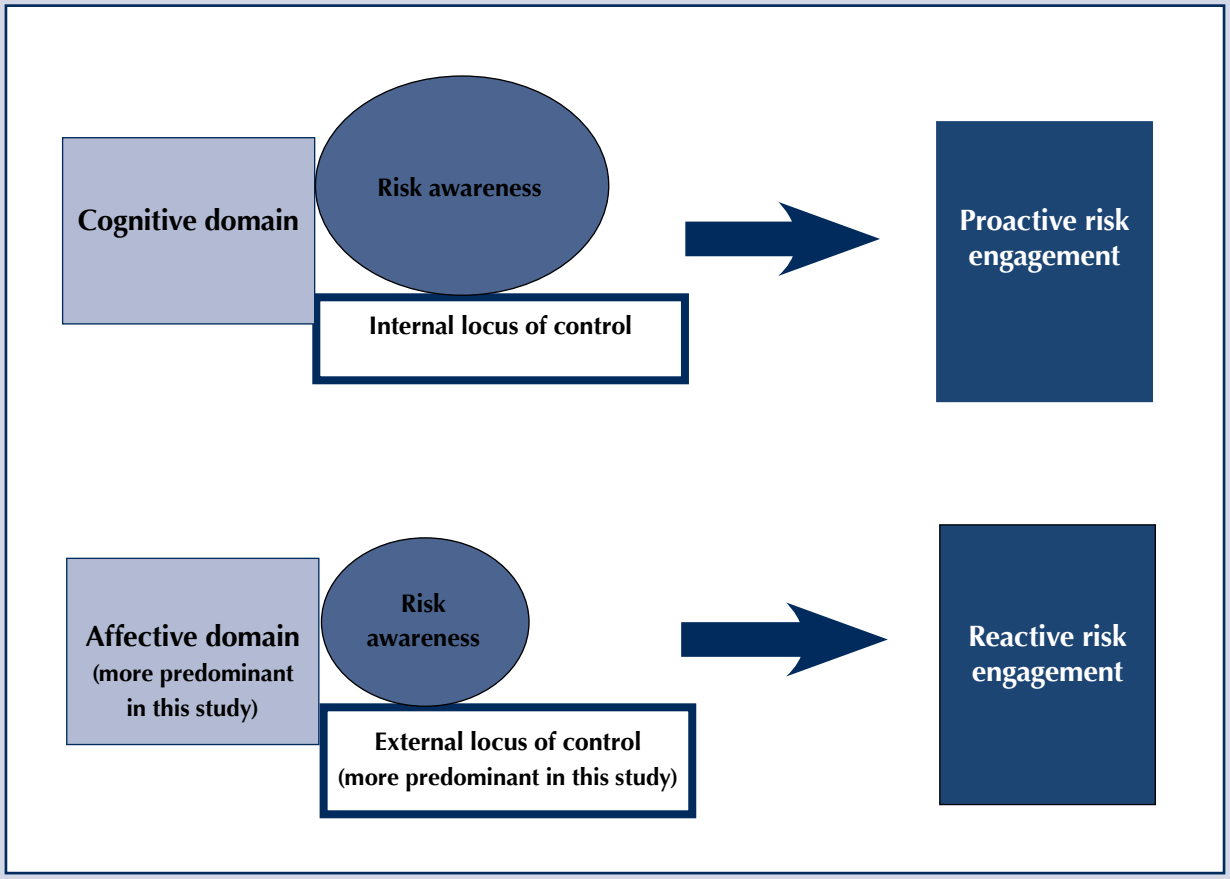

Figure 1. Older South Asian people in the UK with type 2 diabetes: A model on risk perception.

with risk, and immediacy and visibility of risks operated in the cognitive domain. The socio-cultural and religious factors, such as spirituality, adherence to cultural norms, social expectations and priorities in an individual's life, operated from the affective domain.

Risk awareness involving the cognitive domain, when influenced by internal locus of control, resulted in proactive risk engagement among the South Asian people with diabetes. Individuals with an internal locus of control viewed themselves as being responsible for the consequences of their actions and consequently sought to proactively engage with risks and worked towards risk prevention. This is demonstrated in Madhur's case:

> *"Last time when I went to see the doctor, they said they found a little bit of retinopathy. That is why I'm saying you know, over these so many years if I had known it was not controlled properly, I would have taken precautions. Perhaps, it could have been prevented."*

The specific variables that influenced internal locus of control leading to proactive risk engagement were literacy, bilingual language skills, personal experience with risk, motivation and having a healthcare worker within their immediate family.

Discussion

Risk conceptualisation can be influenced by prior knowledge and access to information of a specific risk (McGregor, 2006). Participants in the study made decisions about a particular risk (for example, requesting anti-hypertensive medication even when their blood pressure was normal) depending on their past experience with the risk (family member dying because of renal failure), rather than depending on a complete understanding of the risk in its entirety (how diabetes affects renal function) and engage proactively in the preventive behaviour (optimal control of blood glucose with lifestyle changes).

Risk perception

A risk framework that analyses individual risk-taking behaviour in terms of poor outset conditions, lack of reasonable options, hope and liability to dis-information, rather than focusing on perceived benefits that outweigh the risks has been made available (Hayenhjelm, 2006). The author also argues that explanations, such as individual risk-taking behaviour alone do not sufficiently explain individual risk taking in a meaningful way.

Our current knowledge on risk perception in clinical settings is diverse and complex. It is evident from the findings of this study that both South Asian people and their practitioners have varied perceptions of the same risk, and this is influenced by the magnitude and consequences of the risk and also individual characteristics, such as a desire for control, past experiences and the personal belief system (Macaden, 2007).

Framing of risk information is yet another significant factor that influences risk-related decision making (Walter and Britten, 2002). The lay person's risk perception is often much "richer" (for example, including knowledge of the individual and the family life courses) when compared to (diagnostically dominated) risk assessments done by the healthcare professional (Slovic, 1987). The paradigms of illnesses between lay people and practitioners have been proven to be different. Such variations and incongruence can adversely influence patient compliance, satisfaction, utilisation of healthcare services and response to treatment, since they are unable to understand and interpret each other's "language" regarding the illness (Cohen et al, 1994). Perspectives of risk in South Asian people and practitioners are varied (Macaden, 2007), as demonstrated by the current study.

Model of diabetes care

The dominant model of disease is the "biomedical model", which suggests diseases are due to deviance from the norm of somatic variables (Cavan, 2001). It exclusively deals with the somatic dimension and is not inclusive of the psychological, social and behavioural dimensions of a disease. With chronic illnesses such as diabetes, the concept of health risk is no longer external to the self as a result of interactions between the individual and their environment alone (Ogden, 1995). It is, instead, very inclusive of the self, within the individual who is faced with the need to take control and make choices in managing health-related risks, since they largely involve lifestyle changes that could be challenging.

As the number of people with diabetes increases, the International Diabetes Federation and the World Health Organization have made a declaration to optimise the management of care for people with diabetes (International Diabetes Federation. 2010; World Health Organization, 2010). Self-care behaviour has been identified as the cornerstone of effective diabetes management, including dietary changes, physical activities and medications.

Traditional models of diabetes care relied on individual compliance. This often led to poor control of diabetes. With changes in healthcare policies and the modernisation of the NHS, there is a paradigm shift towards the development of the patient empowerment approach (Henshaw, 2006).

Empowerment approach and concordance

The empowerment approach recommends concordance rather than compliance. While compliance embodies a traditional model of prescriptive care, concordance emphasises the importance of respect for mutual goals between the healthcare professional and the individual. Development of such a "therapeutic alliance" (Adiseshiah, 2005) where healthcare professionals share their knowledge and expertise enables people to make informed choices about diabetes care.

On the contrary, people with diabetes often feel misunderstood and blamed for not following the advice given by their healthcare professionals. This often fosters conflict and tension between patients and practitioners (Anderson and Funnell, 2005). Terms such as "patient-centred approach", "collaborative care" and "self-management education" (Henshaw, 2006) all relate to a process that gives people with diabetes more control of their own lives. A significant element of empowerment is "self-efficacy", which, in the current study, relates to the locus of control based on the Health Belief Model (Rosenstock et al, 1988). It has been widely documented that empowerment and self-efficacy are directly proportionate to each other (Bandura, 1997). This study shows that risk perception is predominantly driven by affect (emotions) and the external locus of control and, as a result, practitioners should promote the concept

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2. The paradigms of illnesses between lay people and practitioners have been proven to be different. Such variations and incongruence can adversely influence patient compliance, satisfaction, utilisation of healthcare services and response to treatment.
3. The empowerment approach recommends concordance rather than compliance. While compliance embodies a traditional model of prescriptive care, concordance emphasises the importance of respect for mutual goals between the healthcare professional and the individual.

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1. The concept of concordance that advocates the empowerment model, which would facilitate informed decision making and self-management of diabetes, needs to be critically reviewed especially for people from minority ethnic groups with a chronic disease such as diabetes.
2. As with the current study, other research has found that the self-management that people were most inclined towards was taking medications that were prescribed and they were least inclined towards physical activity and dietary adherence.
3. Challenging as it may seem, the empowerment model of diabetes care is undoubtedly vital in diabetes care. Practitioners need to blend information giving, psychological support and education with cultural sensitivity for the model to be effective.

of empowerment and "collaborative care" when considering risk management among South Asian people with diabetes.

The concept of concordance that advocates the empowerment model, which would facilitate informed decision-making and self-management of diabetes, needs to be critically reviewed, especially for people from minority ethnic groups with a chronic disease such as diabetes. Caution is required, however, as healthcare professionals adopting the discourse of empowerment without critical review and a balance may lead to a false sense of security that everyone with a chronic disease will be completely empowered and result in a "myth of empowerment" (Paterson, 2001).

A systematic review on empowerment, diabetes and the National Service Framework (Henshaw, 2006) has clearly shown that interventions effectively empower individuals only when based upon individually focused goal setting, coping skills and problem solving strategies. For practitioners to be able to achieve this with South Asian people, they would need to be adequately knowledgeable regarding the South Asian person's personal, socio-cultural and religious beliefs, and the role of locus of control in relation to risk perception in diabetes. The current study, therefore, has made significant contribution in terms of providing information on all these variables in relation to risk awareness and risk engagement in this population.

An exploratory study that aimed to explore the relationship between attitudes towards self-care behaviour, subjective norms, behavioural control, behavioural intentions and actual self-care behaviour in people with type 2 diabetes in Malta (Gatt and Sammut, 2008) reports that attitudes, subjective norms and perceived behavioural intention were important predictors of intent to carry out self-care behaviour in individuals with type 2 diabetes. The study also demonstrated that perceived behavioural control was one of the key determinants of self-care in people with type 2 diabetes. The authors strongly recommend that healthcare professionals must factor this in while recommending strategies for self-management. To extend this further, in relation to this study on risk perception, it would be similarly valuable for practitioners to assess the perceived behavioural control while caring for South Asian people with type 2 diabetes.

As with the current study, other research has found that the self-management that people were most inclined towards was taking medications that were prescribed and they were least inclined towards physical activity and dietary adherence (Gatt and Sammut, 2008). The performance of behaviour is dependent upon the extent to which resources are believed to be present and are perceived to facilitate or impede the performance of the behaviour (Ajzen, 2002b). This is apparent from the findings of the current study, with people attributing their lack of exercise to lack of culturally sensitive venues, language barriers and the difficulties of using family members for interpretation during a medical consultation, and the family dynamics that interfered with dietary adherence and risk prevention.

It is, therefore, certainly evident from this study that empowering older people with diabetes to manage their condition and work towards risk prevention has multiple challenges. The successful learning of any health behaviour is an on-going process that requires a sustained relationship between practitioner and the person with diabetes. The empowerment model is geared towards facilitating a joint decision-making process, educational interventions, positive psychological wellbeing and positive behaviour change that would ultimately promote good diabetes control and prevent long-term risks (Meetoo, 2004).

Conclusions

Challenging as it may seem, the empowerment model of diabetes care is undoubtedly vital in diabetes care. Practitioners need to blend information giving, psychological support and education with cultural sensitivity for the model to be effective. The conceptual model on risk perception from the findings of this study gives significant clarity on an ambiguous concept, such as risk perception among South Asian people with diabetes.

The role of cognition is vital in the empowerment model, which emphasises the importance of self-management and educational interventions in achieving long-term risk prevention. The current study has also demonstrated, however, that the role of affect (emotion) is significant in the way South Asian people understand and engage with diabetes-related risks. When there is incongruence between cognition and behaviour, where individuals are aware of the risks yet still engage in the risky

behaviour, research indicates that affect may be an influencing factor (Loewenstein et al, 2001). This is very similar to findings from this study where people with diabetes chose to engage with risky behaviours, such as indulging in sweets and missing medications, when driven by affect.

There is growing evidence to support the belief that, for many behaviours, affect is more predominant than cognition in the prediction of behavioural intentions (Lawton et al, 2009). As a result, there is an increasing emphasis that research involving attitude needs to measure both the cognitive and affective components (Ajzen and Manstead, 2007).

Relevance to clinical practice

Understandably, the whole concept of empowerment may be challenging for both practitioners and older South Asians with type 2 diabetes given the predominant role of affect and external locus of control influencing risk perception and subsequent behaviour. Since the management of diabetes and prevention of long-term risks involve lifestyle changes that are heavily dependent upon the socio-cultural and religious factors in South Asian people, it is imperative for practitioners to become aware of these issues. Healthcare professionals should provide services that are culturally sensitive and relevant, while still keeping pace with the recommended national standards of care for diabetes. ■

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