

## **A Conceptual Model on Risk Perception among older South Asians with Type 2 Diabetes**

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## Article points

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

**Key words** – *South Asian, Diabetes, Risk awareness, Risk engagement, Risk perception.*

## ABSTRACT

This paper describes a conceptual model on risk perception among older South Asians (representing Bangladesh, India & Pakistan) with Type 2 Diabetes living in the United Kingdom that was developed using qualitative research. Risk perception in this study is interpreted in terms of risk awareness and risk engagement. Risk awareness was influenced by factors from both the cognitive and affective domains that resulted in risk engagement. Risk engagement was proactive if risk awareness was present with an internal locus of control. Risk awareness involving the affective domain when influenced by external locus of control resulted in reactive risk engagement through ranking of risks and risk repair. The relevance of the concordance / empowerment model of diabetes management that advocates self-management aiming at long term risk prevention in diabetes in the United Kingdom needs further exploration in minority ethnic groups such as South Asians with Type 2 diabetes.

## **Introduction**

This paper describes the development of a conceptual model on risk perception in Type 2 Diabetes among older South Asians in the United Kingdom with the concept of risk being central to the study. An underestimation of personal health risk could reduce the motivation for a change in behaviour- dependent risk factors and could decrease compliance with medical prevention strategies (Kraywinkel, Heidrich et al. 2007). In this study, 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 (Ahern 1999, Ajzen 2002 a, Ajzen, Manstead 2007).

## **Background**

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 South Asians with diabetes for whom family and their 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, it is worthwhile to focus on familial and other interpersonal relationships while managing diabetes in order to understand how illness is 'lived' and negotiated in peoples' everyday lives (Lawton 2003).

Research around issues related to risk has been dominated by the psychometric paradigm which is rooted in psychology and decision theory (Rippl 2002) and the landmark cultural theory of (Douglas, Wildavsky 1982). However, it is increasingly believed 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 and the amount of risk one chooses to take (Oltedal, Moen et al. 2004). The Theory of Planned Behaviour (TPB) has been widely used in understanding diverse health related behaviours such as exercising, adhering to a low fat diet and other life style related issues. According to the Theory of

Planned Behaviour, human action is influenced by behavioural beliefs, normative beliefs and control beliefs (Ajzen, Manstead 2007).

### **Aim of the study**

To develop a conceptual model on risk perception among older South Asians with Type 2 Diabetes in the United Kingdom.

### **Method**

An evolved form of grounded theory methodology (McCann, Clark 2003b) was used and ethical and governance approval was secured from the School Ethics and Local Research Ethics Committees. Data was collected between March 2004 - February 2005 through a focus group interview with ethnic health development workers; seven individual interviews were conducted with healthcare professionals (Physicians, Diabetes Nurse Specialists and a dietitian) and 20 older South Asian men and women with Type 2 diabetes in NE England. Participants were recruited through the ethnic health development workers, Diabetes nurse specialists and links made with South Asian social networks.

The participants were chosen purposively (Health care professionals working among South Asians with diabetes and older South Asians with Type 2 diabetes). 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 also 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)(Cutcliffe 2000). This was overcome by doing the focus group interview with health development workers as the first interview which provided insight into several issues (socio cultural and religious practices, priorities, understanding of diabetes etc) that needed exploration around risk perception in Diabetes among the South Asian population.

Interviews with those who were non-English speaking were done 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 rigor were addressed using triangulation at two levels (data and interdisciplinary) (Robson 2002), reflexivity (Ahern 1999), peer debriefing and maintaining an audit trail (Cutcliffe, McKenna 2004). Data management was done using NVIVO 2, a Qualitative data management software. To answer the research aim of this study (develop a conceptual model on risk perception in older South Asians with Type 2 Diabetes in the United Kingdom), the evolved form of grounded theory was adopted and data were analysed using theoretical sampling, constant comparative method, coding and categorizing, memo writing, theoretical sensitivity, measure of rigor and identifying the core category (McCann, Clark 2003b).

## **Results**

According to the Theory of Planned Behaviour, 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 Asians' 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 severity with their diabetes 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 due to the lack of visibility and immediacy of the proposed risks.

Normative beliefs refer to the perceived behavioural expectations of significant referent individuals or groups such as the individual's family or religion as in the case of South Asians with diabetes. The normative beliefs along with motivation to comply with the expected behaviour determine the behaviour. Data from the study clearly 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 those requirements because of the health risks involved.

The socio cultural and religious factors explicitly describe the influence of perceptions on ageing, gender and family dynamics on risk perception. There was identification of priorities and ranking of risks that people exercised internally. For example, when faced with having to make choices between the risks involved such as suboptimal diabetic control versus causing a social offence, the risk preference was to comply with hospitality gestures of eating sweets that were offered during social occasions at the risk of poor diabetic control. The risks at hand were weighed or ranked and people were generally inclined towards taking those risks that were not visible or non-imminent (Health risks) and were averse to those which were visible and imminent (Social risks).

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.” (Danaa from Pakistan whose daughter was training to be a dentist)*

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.'* (Field notes of Haala from Bangladesh)

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 which they have no control over. 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 to have diabetes in spite of his wife having been diagnosed to have diabetes a year or so before his diagnosis was made) or societal values such as hospitality that expect the individual not to turn down sweets that are offered while visiting someone as in the case of Galina from India.

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 South Asian Muslims 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 very 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 (eg. Fasting during Ramadan, going on 'Hajj' etc). This resulted in individuals taking risks such as fasting without seeking medical advice while on insulin, changing medications around their meal times during Ramadan in the hope that God will look after the consequences that came along. Understanding the interaction between the above elements helps us to see risk taking as clinging to hope rather than being irrational and irresponsible. The hope that was adhered

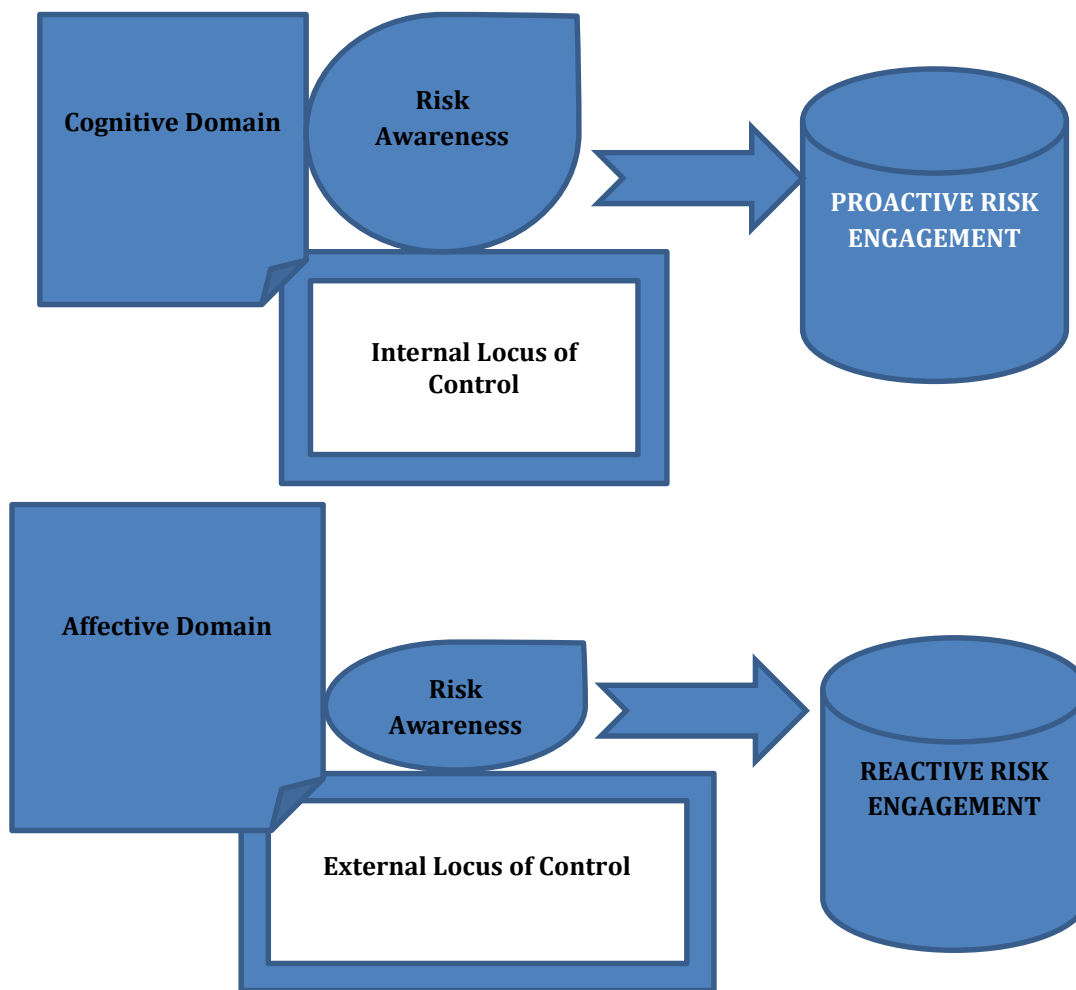
to was that their lives were preordained and that God was in control of whatever happened to them and that was very central to the way risks were perceived.

South Asians in this study engaged with risks by ranking them that resulted in a “risk averse” attitude towards risks that were imminent and visible such as a social risk as against a “risk phillic” (Clarke 2006) attitude towards risks that were invisible and non-imminent (diabetes related health risk) and were driven by socio cultural expectations and religious beliefs. Risk perception was mostly influenced by socio cultural and religious beliefs that were driven by affect rather than cognition and resulted in risk engagement which was reactive. This was also compounded by a strong external locus of control.

The study demonstrated that the locus of control among South Asians was largely external and the response to risks varied from depathologising (Macaden, Clarke 2006) (Macaden & Clarke 2006) the illness to resilience. Individuals who were educated and bilingual with the presence of a health care worker as their family member had a strong internal locus of control that influenced their risk awareness proactive engagement with risks related to diabetes. (Macaden, Clarke 2010).

Findings from the study led to an innovative conceptual model on risk perception among older South Asians with Type 2 Diabetes as outlined below.





**Fig. 1 – Older South Asians in the UK with Type 2 Diabetes: A Model on Risk Perception**

Factors such as understanding of diabetes, perceived severity of diabetes, personal experience with risk, 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 led to either proactive or reactive engagement with risks and was influenced by either internal or external locus of control as discussed below. Individuals with an

external locus of control, viewed fate, luck etc as being responsible for the consequences despite their actions. This led to consequences such as denial, depathologising of diabetes and an attitude of resilience and powerlessness. Socio cultural and religious factors beliefs along with external locus of control resulted in reactive risk engagement through ranking of risks and risk repair.

Risk awareness involving the cognitive domain, when influenced by internal locus of control resulted in proactive risk engagement among the South Asians 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 as in the case of Madhur.

“I’ve got... 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.” (Madhur whose daughter was training to be a doctor)

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 the presence of a health care worker within their immediate family.

## **Discussion**

Individuals made decisions about a particular risk depending on their past experience with a particular risk rather than depend on a complete understanding of the risk in its entirety and engage proactively in the preventive behaviour that is recommended. This is similar to the description of factors such as prior knowledge of specific risk, locus of control, degree of perceived risk and access to information that individuals normally use in conceptualizing ‘risk’ for themselves among consumers in the marketing industry (McGregor 2006).

A risk framework which analyses individual risk taking behaviour in terms of poor outset conditions, lack of reasonable options, hope and liability to disinformation 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 Asians and their practitioners have varied perceptions of the same risk which is influenced by the magnitude and consequences of the risk, and 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 decision making in relation to taking risks (Walter, Britten 2002). The lay person's risk perception is much 'richer' (and includes knowledge of the individual and the family life courses) when compared to (diagnostically dominated) risk assessments done by the professional experts (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, utilization of health care services and response to treatment since they are unable to understand and interpret each other's "language" regarding the illness (Cohen, Tripp-Reimer et al. 1994). Perspectives on risk between South Asians and practitioners were quite varied (Macaden 2007) as significantly demonstrated by the data from this study.

The dominant model of disease even today is the biomedical model that proposes diseases to be 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 his 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 life style changes that could be challenging.

With the exponential increase of diabetes worldwide, all European countries, the International Diabetes Federation Europe and the World Health Organisation have made a declaration to optimise the management of care for patients with diabetes that is aimed at

decreasing the risk of long term complications (World Health Organization. 2010) (International Diabetes Federation. 2010) (International Diabetes Federation. 2010, International Diabetes Federation. 2010) . Self-care behaviour has been identified as the cornerstone of effective diabetes management by integrating dietary changes, physical activities and medications inclusive of insulin into one's daily routine.

Traditional models of diabetes care relied on individual compliance. This often led to poor diabetic control. With changes in health care policies and the modernisation of the NHS, there is a paradigm shift towards the development of the patient empowerment approach (Henshaw 2006). The empowerment approach recommended concordance as against compliance. While compliance embodies a traditional model of prescriptive care, concordance emphasises the importance of respect for mutual goals between the health care professional and the patient. Development of such a "therapeutic alliance" (Adiseshiah 2005) where health care professionals share their knowledge and expertise that enable patients to make informed choices about diabetes care is being increasingly seen as the way forward.

On the contrary, patients often feel misunderstood and blamed for not following the advice given by their health care professionals in managing their diabetes. This often fosters conflict and tension between patients and practitioners (Anderson, Funnell 2005). Variables such as 'patient centered approach', 'collaborative care' and 'Self-Management Education' (Henshaw 2006) within the concept of empowerment 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 this study relates to the locus of control based on the Health Belief Model (Rosenstock, Strecher et al. 1988). It has been widely documented that empowerment and 'self-efficacy' are directly proportionate to each other (Bandura 1997). Risk perception being predominantly driven by affect and the external locus of control in this study, practitioners will be faced with the challenge of promoting the concept of empowerment and 'collaborative care' in providing services towards risk prevention and risk management among South Asians 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 minority ethnic groups with a chronic disease such as diabetes. Health care 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 individual focussed goal setting, coping skills and problem solving strategies. For practitioners to be able to achieve this with South Asians, they would need to be adequately knowledgeable regarding the South Asians' personal, socio cultural and religious beliefs and the role of locus of control in relation to risk perception in diabetes. The 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 patients with Type 2 Diabetes at Malta (Gatt, Sammut 2008) using the Theory of Planned Behaviour 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 health care professionals must factor this in while recommending self-care activities to these patients. 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 in relation to prevention of long term risks related to diabetes while caring for South Asians with Type 2 diabetes.

Similar to the findings from this study, other studies have also reported that the self-care behaviour which the participants in their study were highly inclined towards was taking medications that were prescribed and were least inclined towards physical activity and dietary adherence (Gatt, 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 2002 b). This is clearly apparent from the findings of this study as in people attributing their lack of exercise being due to lack 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.

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

## **Conclusion**

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 Asians with diabetes. It is within these trajectories that an understanding of the various factors influencing risk perception in this population becomes crucial for practitioners. The role of cognition is vital in the empowerment model that emphasises self-management and educational interventions towards long term risk prevention. However, this study has also demonstrated that the role of affect is significant with the way South Asians understand and engage with diabetes related risks. When there is incongruence between cognition and behaviour where individuals are aware of the risks, know the risks are not favourable and yet engage in the risky behaviour (e.g. Smoking) the role of affect leading to engaging with the risky behaviour

is being increasingly evidenced (Loewenstein, Weber 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, missing medications and hospital appointments despite risk awareness when driven by affect. There is growing evidence to support that for many behaviours, affect is more predominant than cognition in the prediction of behavioural intentions. As a result, there is an increasing emphasis that research involving attitude needs to measure both the cognitive and affective components contributing towards attitudes (Ajzen, Manstead 2007).

### **Relevance to Clinical Practice**

Understandably, the whole concept of empowerment will be very 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 towards risk prevention. Since the management of diabetes and prevention of long term risks involve life style changes that are heavily dependent upon the socio cultural and religious factors along with family dynamics within the South Asian context, it becomes imperative for practitioners to become aware of these issues and their impact upon risk perception in South Asians with diabetes in order to provide services that are culturally sensitive and relevant in addition to keeping pace with the recommended national standards of care for diabetes.

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