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Feeling misidentified: Understanding migrant's readiness to engage in health care screening

## **ABSTRACT**

*Rationale:* For developed countries there has been a significant, fast-paced rise in migrant populations. Society has a vested interest in these members of the population being aware of their risk of a communicable disease, and seeking health screening. Currently, screening interventions rely heavily upon socio-cognitive, majority-orientated theories that may not account for cultural factors differentially affecting migrant groups.

*Objective:* To develop an inductive theory to explain processes underlying the readiness of migrants to engage in health screening. In understanding why some groups engage in screening more than others we examined the U.K. South Asian population, and screening for hepatitis B and C.

*Method:* We conducted eight focus groups with first-generation South Asian migrants. Results were analysed using a three stage, process-orientated methodology based on the principles of grounded theory, with the explicit aim of developing new theory.

*Results:* A theory of 'readiness to engage' is presented; embedded within participants' testimonies. The results highlight personal identity, family identity and the collective identity of the South Asian community; with family and community conceptualised as a singular force, acting to either silence or support. Identity issues and screening readiness were also strongly related to interactions with the healthcare-system, with participants often feeling misidentified, misunderstood, or under personal threat.

*Conclusions:* Our theoretical model takes account of the complex, interlocking relationship between the individual, the community, and healthcare system, and provides practical implications for healthcare providers of screening interventions.

## **Introduction**

The rapid increase in population movement over the past decade has led to health challenges, with health care systems in host countries or receiving countries struggling to adapt (Tognetti, 2015). One challenge such countries face, remains their need ensure that the population, no matter how transient or well-settled, is appropriately screened for disease. However, health screening is mostly focused on communicable diseases that are a threat to public health such as TB, HIV and hepatitis B and C, which can lead to issues of migrant stigma and low levels of uptake (Seedat, Hargreaves & Friedland 2014; Hargreaves et al 2014). Screening is defined as ‘any intervention that involves providing information about the chances that an asymptomatic individual will develop a particular disease’ (Shaw, Abrams & Marteau, 1999, p.1572). Screening and prevention are effective in terms of both outcome and cost. A diagnosis may cause distress and anxiety, as an individual who previously considered themselves healthy must come to terms with a diseased identity (Asif et. al., 2014), but distress is often short-term, owing to the positive effect of early detection and intervention (Shaw et. al., 1999).

In Europe up to 2 million cases of hepatitis B and 900,000 cases of hepatitis C are prevalent amongst migrants from intermediate and high endemicity areas (European Centre for Disease Prevention and Control, 2016). Migrants from the Indian subcontinent, who make up the largest ethnic minority group in England and Wales (ONS, 2015), are disproportionately affected by viral hepatitis (European Centre for Disease Prevention and Control, 2016). This

group are 7-10 times more likely to present with end stage liver disease, and 16-35 times more likely present with liver cancer than the general population, as a result of chronic hepatitis B or C (Mann et al 2008). Amongst migrants from Pakistan, for example, the prevalence of chronic viral hepatitis is 5%, compared to 1% in the general population (Lewis, et al 2012). With recent developments both forms of hepatitis are treatable, and hepatitis C can be completely cured (National Liver Plan, 2009).

A London pilot study screening for infectious diseases found that in areas with large migrant populations the number of patients presenting at primary care was disproportionately low (Hargreaves et. al., 2014), suggesting migrant groups are less likely than the general population to be diagnosed at an asymptomatic stage (Mann et. al., 2008). Research from Australia and the United States suggests migrant groups report general awareness of viral hepatitis but this does not translate into a perceived need for screening (Rashrash et al 2016; Ma et al 2007; Owiti et al 2015). This lack of risk awareness may be attributed to culturally informed ideas about disease transmission and prevention, as well as the association of communicable diseases with their country of origin, rather than their new home (Jones et. al., 2010; Shtarkshall, Baynesan & Feldman, 2009).

Addressing increased prevalence by encouraging migrants to access screening is complex (Owiti et al 2015; Kelly et 2018;). Hepatitis B and C is a disease that fulfils WHO classic screening criteria, with the condition being important and treatment post-screening being clinically effective and largely curable (see Anderman et al 2008). Despite this, other pragmatic issues such as language proficiency, transportation and limited knowledge of the healthcare system are common barriers (Dressler & Pils, 2009; Holmes, 2012; Kalengayi et al 2012; Lee et al 2017).

The use of theory to explain health behaviour and inform interventions has been found to

have benefits when applied to screening (Glanz & Bishop, 2010). The most commonly cited theories in this context are the Health Belief Model (HBM) (Rosenstock, 1966) and the Theory of Planned Behaviour (TPB) (Ajzen, 1991). HBM constructs have been effective in predicting the uptake of screening, and the model has been used to inform interventions for non-communicable diseases; primarily cancer (Edwards et. al., 2013). Of all elements, perceived barriers have been shown to be the most predictive of actual uptake, whilst research suggests that external cues to action can be manipulated to reduce barriers (Ogden, 2007). However, this evidence cannot easily be extrapolated to infectious diseases, which involve additionally, the potential of becoming a disease carrier – so not only being a threat to others but carrying the potential stigma of this (Brämberg & Nyström, 2010; Seedat, Hargreaves & Friedland 2014).

The Theory of Planned Behaviour (TPB) applies general social cognitive constructs of attitude, perceived behavioural control and subjective norms to health contexts to explain behavioural *intention* (Ajzen, 1991). Its main divergence from the HBM is its grounding in social behavioural theory with the addition of subjective norms. These norms account for the context in which health behaviours take place, as well as the symbiotic relationship between behaviour and the environment (Cooke & French, 2006). Unlike the HBM, the TPB has been used to inform screening interventions targeting communicable and, or stigmatising diseases (Booth, et al 2014; Shepherd & Smith, 2017). TPB constructs have been found to have roughly comparable predictive value to HBM, although perceived behavioural control is most significant (Ogden, 2007), nevertheless, in the context of screening, intention has a relatively small impact on actual uptake (Cooke & French, 2006).

Within both models the common denominator and most predictive construct of *actual* not *intended* health behaviour is a form of control called self-efficacy (Bandura 1977). Self-

efficacy is an individual's belief in their own ability to exercise influence over their life and accomplish desired tasks. In the context of health, self-efficacy refers to the individual's belief in their ability to enact health behaviours, as well as their belief about the effectiveness of that behaviour (Holden, 1992; Evangeli, Pady & Wroe, 2016; Garcia, 2016). Despite its strong ability to predict behaviour, self-efficacy is problematic, in potentially having a far greater predictive effect on screening uptake for diseases with perceived curability (see Shepherd & Smith, 2017). The experience of self-efficacy can also differ between majority and minority populations (see Reynolds et al 2016). For example, women of conservative cultures, like those of the Indian subcontinent, are less likely to feel efficacious when visiting a healthcare professional (Dressler & Pils, 2009; Marlow et. al., 2015).

The bulk of research validating the HMB and TPB has focused on majority populations, so it does not specifically account for the differing experience of minority groups (Garcia, 2016; Hajian et, al., 2011). The conceptualisation of health behaviour, as being the result of an individual decision-making process does not fully account for sociocultural and socio-structural factors, and the importance of social connectedness and integration, (Garcia, 2016; Yarbrough & Braden, 2001). The TPB construct of group-based elements, 'subjective norms' does not adequately explain broader issues such as gender difference and acculturation; highly salient issues within many migrant groups (Ebrahim, Davis & Tomaka, 2016). Recently, there have been calls to test extended models of TPB, and/or abandon the model to make way for theories with greater utility (Sniehotta, Pesseau, & Araujo-Soares, 2014).

For many migrants re-establishing oneself in a new environment requires strong community support (Malmusi, Borrell, C. and Benach, J. 2010). with social networks an important influence on health behaviour. The additional issue of being 'infectious' can invoke wider community consequences. In addressing some of these barriers, the PEN 3 model developed

by Airhihenbuwa (1990) is a response to the apparent omission of culture in explaining health outcomes. It utilizes cultural identity and culture linked constructs of ‘relationships and expectations’ as well as ‘cultural empowerment’ to analyse health behaviours. The model has been used to inform prevention strategies for hepatitis interventions (see Owiti et al 2015) as well as a number of health conditions; ranging from HIV, high blood pressure, diabetes and domestic violence (Iwelunmor, Newsome, & Airhihenbuwa, 2014). Despite this new focus, the specific cultural aspects of health behaviour in one setting may not be applicable to another, with culture treated broadly. This makes the transferability of this model to different migrant populations problematic (Iwelunmor et al., 2014), particularly in regard to complex issues such as social identity (Timotijevic & Breakwell 2000).

In terms of identity evidence from migrants and healthcare professionals suggests cultural beliefs about illness and healthcare held by many non-Western migrants can clash with Western medical models (Suurmond et al 2010; Van Wieringen, Harmsen & Bruijnzeels, 2002). On a dyadic level, cultural incompatibilities can lead to misunderstandings between the patient and healthcare provider (Akhavan & Karlsen, 2013; Holmes, 2012; Suurmond et al., 2010; Lee et al 2017). At a broader level, these incompatibilities can result in a decreased willingness amongst migrants to access healthcare (Jones et. al., 2010; Kalengayi et. al., 2012). Work from socio-ecological models (Kalengayi et al, 2012; Shtarkshall, 2009) has been used to investigate disparities in migrants' access to health services, by focusing on the intertwined relationship between individuals and their social environment, across different levels of the system. Issues associated with identity can be a substantial barrier in the healthcare encounter, in terms of feeling alienated and invisible but the impact on identity is not specifically, theoretically explored (see Kalengayi et. al., 2012; Arsenijević et al 2018).

Work on migrant identity (Jaspal & Breakwell, 2014) highlights the increased associated

threats to identity when relocating (Timotijevic & Breakwell 2000; Albert, Schneeweis, & Knobbe, 2005; Arsenijević et al 2018). The extent to which the migrant wants to participate and acculturate or retain their old culture can be area of tension (Timotijevic & Breakwell 2000; Albert, Schneeweis & Knobbe 2005). When people migrate to a new environment, they need to adjust how society sees them, and although they have some agency in this creation there are constraints and threats imposed by the new environment, particularly in terms of self-efficacy and self-esteem (Timotijevic & Breakwell 2000; Arsenijević et al 2018). Equally, the threat to identity may simply be a question of things being different and whether host society is perceived as opposing or welcoming. Qualitative research suggests migrants consider themselves less valued ‘outsiders’ within the healthcare system, owing to its inadequacy in addressing their needs (Akhavan & Karlsen, 2013; Arsenijević et al 2018). In this context, collective identity (i.e. the sense of how we define ourselves as members of groups in distinction from other groups ('we' vs 'they')), may more salient than personal identity (i.e. how we define ourselves as unique individuals in contrast to others ('I' vs 'you')).

The aim of the study is to develop an inductive theory to explain processes underlying the readiness of South Asian migrants to engage in hepatitis B or C screening. In-depth research into the experiences and attitudes of migrants engaging in health screening in the UK is sparse, and at the time of writing there has been no work specifically targeting South Asians (see Jones et. al., 2010; Owiti et al 2015 and Kelly et al 2018 et al for systematic reviews). This study seeks to address this gap, building knowledge grounded in participant’s own words and experiences.

## **Methods**

### *Study design*



The study is qualitative, underpinned by a constructivist perspective, in which participants are viewed as creators of their social world, which the researchers subjectively interpret (Payne, 2007).

### *Recruitment and participants*

Initial contact was made with key individuals within community hubs across the south of England, such as mosques, women's centres and GP surgeries - with high levels of attendance by South Asians. Recruitment was facilitated by these key individuals. The aim of this method was to attract 'naturally occurring' groups and facilitate a supportive atmosphere (Morgan, 1997). Advertisements were transmitted to participants by community contacts and via email, in English and Urdu. The researcher who ran the groups carried out translation work in discussion with other multilingual members of the research team; and was integrally involved in each stage, afforded by her parity of experience. In this way, the methodological pitfall of relegating the translator to a 'silent partner' was avoided, and adherence to the meaning of participants' words facilitated (Larkin et al 2007).

Eligibility criteria were: being 18 years of age or older, being born in India, Pakistan or Bangladesh and having fluency in English, Urdu (or Hindi – which when spoken is similar to Urdu). Second-generation migrants were excluded as they were likely to have a different level of acculturation (Van Der Veen et. al., 2009). First-generation migrants are also at greater risk of contracting viral hepatitis, having lived a portion of their lives in areas of high endemicity (ECDC, 2016). See table 1.

[Insert table 1 here]

### *Data collection*

Focus groups are the method of data generation as, unlike interviews, they go beyond the scope of question and answer, allowing for free-flowing interaction (Millward, 2012). Eight focus groups were conducted, in no particular order (lasting from 1 hour to 1.5 hours) with 53 participants, 7 by a researcher of South Asian ethnicity who was culturally and linguistically equipped to understand the target community. The exception was our last group, which was conducted at later date when we realised a certain demographic was not well represented (highly educated South Asian young men).

A focus group discussion guide was developed by the research team and iteratively moderated as the study progressed (see Payne, 2007). Questions concerned personal knowledge and attitudes towards viral hepatitis, and knowledge and attitudes of the community. After eight focus groups the research team agreed that data saturation had been achieved. The recordings were transcribed verbatim and translated into English. Further methodological details on how the research team engaged with the community while conducting this research are available.

### *Analytic framework and analysis*

The data analysis was conducted by 4 people to agree themes, and was conducted in first-order and second-order phases (see Gioia, Corley and Hamilton, 2012). The first phase involved gaining a familiarity and understanding of the literature and context. Following an initial review of the literature, we conducted an in-depth reading of five transcripts by writing 372 memos and reflections of the various processes and structures that emerged (collective, systemic and individual). Memos were informally written observations about the participants experiences, offering reflections on potential relationships between events and between

emotional and attitudinal responses. For example, we discussed how the community interacted with the individual and what this revealed about agency (taken from the viewpoint of different social and individual lenses). We then systematically collated our notes by exploring individual interpretations through an analysis of key themes (a basic framework we have named ‘The Testing Triangle’ below).

[Insert Figure 1 here]

At the top of the triangle are external, socio-structural factors many health theories do not account for, below shows the interlocking relationship between the individual and their collective group and the wider community. At this stage we theorised that alignment between the identity of the individual and the community can impact on health behaviours, in terms of an individual engaging in screening; likewise, the expression of self-efficacy is entwined with the external environment. This triangle acted as a guide to later data collection (the remaining three focus groups), and an anchor for subsequent analysis.

For the second stage we drew on a complex, collective, and process-orientated methodology, explicitly based on the aim of developing new theory (see Gioia, Corley & Hamilton, 2012). We wanted to gain theoretical insight into why some participants seemed unable or unwilling to seek screening, and what issues contributed to this. We discussed second order themes in relation to our initial framework and how different rationales fitted with current theory. Drawing on literature and theory that explains these processes wider theoretical categories were formed (Gioia et al, 2012), see figure 2 below.

[Insert Figure 2 here]

In our final stage of analysis, earlier static codes identified in figures 1 and 2 were developed to add ‘three-dimensional’ relational dynamics and intertwined movements, showing how the themes related to each other to create outcomes (to test or not to test). Figure 3 below represents the final stage of this analysis: a four-stage process model.

[Insert Figure 3 here]

## **Results**

The following results section unpacks in more detail the model presented in Figure 3 above. The aim of this model is to theorise (see Gioia et al 2012) South Asian migrants’ readiness to engage in screening for hepatitis B and C.

### **1. Disease identity and my identity**

Participants’ conceptualisation of disease (viral hepatitis) played a significant role in their attitude towards screening. The majority described the wider South Asian community’s knowledge of hepatitis as low, despite the disease having devastating consequences. Across all groups hepatitis was described as “silent” and ‘*life threatening*’, with many participants reporting the death of a family member or friend. This disease identity intensified perceived severity:

*“...everything seems to be fine. And it’s only later on, it’s a very silent thing. Later on somebody, you go, and say, you do a blood test and your doctor looks at your liver function and says, ‘hey there’s something really odd here, this guy looks normal.’ And it’s then when they check your liver they see your liver’s completely gone, yeah? The virus has invaded your liver and just turned it into mush, yeah?” (Group 8)*

Being tested positive for viral hepatitis was associated with myriad anxieties about the loss of one's self. Illness in general was described as a threat; intrusive and destructive to familial roles and the ideal of family life. The potential impact of illness on one's role within the community was recurrent throughout. Participants identified the detrimental effect of illness on their resources and ability to provide.

Individuals were highly aware of the role they played within social networks. These roles and responsibilities fell into gendered categories, and both men and women expressed anxiety about being unable to fulfil these roles.

*"I think men don't want to tell anything about sickness. Most of the men at least... They won't come out with it...because there's much more big stigma against men being sick. That means they're weak."*

*[another person in the group replies] "So I think the stigma for a man being at home and unwell would be more. Much more than a woman."* (Group 4)

For a woman, the main source of anxiety appeared becoming unable to manage the household and fulfil caring responsibilities.

*"Cut off from everyone and she has so many wishes, getting her children married, issues around the house, but she couldn't give time to anything because her own condition kept getting from bad to worse. And all she thought was the next moment I might die and my eyes will close and all these issues will be left as they are."* (Group 1)

Concern was expressed for young people, with illness viewed as a barrier to marriage.

*"Then there are family, who thinks well a lady is ill, we don't know, whether it's going to be fit for our boys or not, you know, and then she, she is already suffering before she gets married, the boy's life will be hell, in the later life, after the marriage"* (Group 5)

Here, disease identity relates closely to the life burden it represents – however this burden could be dissipated if participants felt that they could engage in behaviours to prevent the disease. One of the most interesting and surprising results we uncovered was the varied response to feeling efficacious (Bandura 1977). Amongst many Muslim participants, a strong link was made between self-efficacy and the will of God:

*“I have seen, when you talk to people, they don't want to disclose themselves... They don't want to go [for the testing] and see or get the treatment or even tell someone. All they say is, "As Allah wills." They leave everything to Allah.”* (Group 3)

This expressed sense of fatalism appeared to be informed by their perceptions about the incurability of hepatitis and its silent nature.

*“I think it's more to do with the luck really, if you have got, life, it, it goes on, but if you haven't that's the end of the story, see, uh, I don't think...”*

*[another person in the group replies] “Before they find out, before they find out they got Hepatitis, you are too late, they are gone. You see? Well, that's what I think sometimes, you know.”* (Group 5)

For female participants in particular, we observed some reaction against fatalism, with the need to be proactive – in terms of protecting the family. The potential risk to other family members was a motivator in accessing screening,

*“But in our religion there's is this thing foremost that, of course we have the strongest belief in fate, but we have this in our religion also that treatment is also equally important...Fate is linked to the treatment of illness...We need to believe that Allah will save us from the disease when we receive treatment for it”* (Group 6)

*“No. I mean, for me, it's better to know, than to just live in a false- [...]. Why would you live under the false illusion that everything is good with you? [...] [another*

*person in the group replies] Yes! So you should find out! And, and then deal with it.”*

(Group 8)

A strong theme was the perceived saliency of hepatitis. Despite all eight focus groups containing at least one participant who knew someone with hepatitis, it was not seen as personally significant. For most of our migrants their personal experience of hepatitis was associated with pre-migration lives, with perceived risk not translating to the UK.

*“you are less exposed to contact with blood and saliva. So you feel safe here. But this is not the case with Pakistan, God forbid.”* (Group 6)

In several groups the idea was raised that if a person felt healthy, it was difficult to prioritize preventative medicine. However, this reluctance to access preventative care was not the case for all illnesses; for more well-publicised diseases like cancer, diabetes and even HIV/AIDS participants did express feelings of vulnerability.

## **2. The role of social networks and support**

The perceived reaction of the family and community to a diagnosis was an important consideration. The importance of family was expressed as typical of South Asian culture, and female groups were vocal about the difference a supportive family could make.

*“The patients tend to worry too much about the future of their children and under these circumstances, I think only family members can reassure the patients and tell them that the doctors would provide them with the best treatment and they would be fine Allah willing. When patients get the emotional support, their will power increases and they believe that they can fight it out and become well again.”* (Group 6)

As well as the immediate family, the wider community was viewed as a source of strength. Overall, any differentiation between the family and community was uncommon, both were

enmeshed together and considered as a single group influence. Male participants spoke about passing on awareness and empowering others as part of their familial and community responsibilities. Group identification here was seen as playing an important role in protecting the community against negative consequences.

*“The point is, if it will help my community this way, I don't have a problem with it... I am just sitting here because I thought it is useful for me and for my community as well. So, everyone would think in the same way and if I think that half an hour of my time can help any other member of the community, I think I have done my part.”*

(Group 3)

In contrast to this issue of community support, some participants raised the issue of ‘*cultural silence*’ and ‘*stigma*’, which had the potential to discourage people from screening. In this case, belonging to a social group and the stigmatisation of illness, could lead to failure to screen. This silencing effect was attributed to fear or uncertainty about the reaction of the community, and traditional superstitions.

*“We have this culturally... we are being raised with many things, like, oh, don't tell others, you know... [tutting sound] It's, like if you spread to me, something bad will happen or something like that. So...those beliefs and stuff...Superstitions.”*

Although the reaction of the family was an issue, the most pressing concern for some female participants was the fear of gossip and being made vulnerable to the ‘*judgements*’ of others.

*“The person who is suffering from hepatitis, he or she also really has to be really strong in himself or herself, because generally there are people who get, like... they pull themselves away from the group, basically. They feel like, I have a disease. They start feeling uncomfortable, basically. They're like, what will they think? Might... Will people be uncomfortable with my presence?”* (Group 4)



For some, the stigma attached with sexual transmission was damaging within their largely conservative community.

*“When you said that about the, needles and syringes and, like, you know, sexual, uh...interaction... So those kind of things can be really, um...Because we are not a very open...”*

*-“Conservative. We are conservative, yes”.*

*“Very conservative. So it's like, you know, if someone's husband or, [laughs] like, you know, someone's wife is diagnosed, then it... it is a possibility that people might think that, okay, what's going on, kind of thing.” (Group 4)*

There was a prevailing association between illness and secrecy; with families choosing to hide illness from the community. This practice appeared to stem from a sense of concern for the social standing of the family, as well as the idea that a seriously ill family member could be a source of shame and isolation. Social judgments were of particular concern amongst female groups.

*“Yes, there is also the fear of being ‘achoot’”*

*“They are worried about being made into an untouchable...People shun the person...Because people fear that they may contract the illness from them.” (Group 6)*

### **3. Identity Misalignment**

The theme of identity strongly lay at the heart of our participants’ discussion of screening. This encompassed their personal identity, their family identity and perception of the collective identity of the South Asian community in the UK. Misalignment in these sources of identity was strong, for example, the individual might be ousted from the community or feel not ‘worthy’ of visit to the physician. Across all groups, participants expressed a lack of entitlement when it came to healthcare; visiting a doctor was perceived as an imposition.

One participant described a routine blood pressure check as “*wasting the GP’s time*”. The idea that accessing healthcare was being burdensome appeared to increase participants’ reluctance to make use of primary healthcare services,

*“recently I went to the surgery because I’m feeling a lump here, so... First time I saw that there is written, the prices are written there. [...] Every visit is costing this much to the NHS. [...] Everything is costing this much- [...] So what, are they trying to tell us that don’t come to the surgery?”* (Group 8)

The theme of misalignment applied to individual-level encounters between participants and healthcare professionals, as well as a general lack of trust in primary care:

*“Firstly I add to this, like, the normal symptoms of hepatitis like tiredness, fever and all- [...] You will not go, and even if you go, you, you, you don’t feel they will do anything.”* (Group 8)

For some, misalignment resulted from unmet expectations:

*“The doctors must tell the patients that they need to be screened because they have the risk factor due to their age or other circumstance. This brother here has experienced this and that’s why he knows about screening while others don’t seem to know anything about the screening of Hepatitis... I am shocked because I have lived in this country for a long time now but until today, I have not got any information about the screening...”*

All participants spoke English as a second language and for the elderly and women particularly, the prospect of having to express themselves in a time-pressured environment was daunting. The gender of the healthcare professional was an additional concern.

*“More often it is better if females carry it out.”*

*“One feels more comfortable”*

*“Yes feel comfortable”*

*“Like if you are going and you need roll up your sleeves, and if it’s tight then you might need to take it off, so if it’s a male staff then you will feel reluctant to do that. So if a female does it for a female then women will feel comfortable and vice versa men will feel comfortable too.” (Group 2)*

Participants appeared to feel diminished by the healthcare encounter, and almost unanimously portrayed it as a source of tension. Many, especially those with limited English, reported difficulties in making themselves and their needs understood. As first-generation South Asian migrants, many participants felt that their cultural identity was a hindrance.

*“I cannot talk much with the doctor. I don’t have [knowledge of] English. Otherwise I have a strong wish to get myself checked for illness [disease/pain], but I don’t have the language. That’s why I don’t go to the hospital... I have a wish to get checked but I don’t go. I don’t have English, and I am alone here, it is difficult for me.”(Group 1)*

## **Discussion**

This work sought to develop an inductive theory to explain the process underlying the readiness of first-generation South Asians to engage in hepatitis B or C screening. Rather than adapting more commonly used socio-cognitive models, such as the HBM or TPB we developed a new theoretical model. By widening the theoretical lens beyond individual cognitive determinants, the proposed model places emphasis on inter-group and system cultural factors (see Figure 3) of particular relevance to migrant groups, such as the wider community, support networks and individual and collective identity.

It is proposed that, for screening to become viable, it is necessary for an individual to progress through all these potential barriers or facilitators. The most noteworthy contribution, and a strength of this study is in highlighting that these multi-level factors account for how

migrant groups have higher-order health properties i.e. the whole “us” often takes president over the individual “I”. Much traditional theoretical framing of behavioural change fails to appropriately focus on the power of the collective community and the system, and fails to fully appreciate the influence of the collective community (whether positive or negative) (Bramberg et. al., 2010). Work from socio-ecological models (Kalengayi et al, 2012; Shtarkshall, 2009) may address these contextual factors but they do not pay specific attention to psycho-social issues of identity (Timotijevic & Breakwell 2000). We additionally highlight complex, interlacing issues of disease and identity and its alignment (or lack thereof) across our three levels (individual, community and system). In our model (see figure 3) each level represents a personal or social reality that allows for the removal of potential barriers and the constructive use of positive influences within the existing socio-ecological structure of migrants’ lives.

At the individual level, our model is consistent with prevailing conceptualisations of theories of behavioural change. Our model suggests that awareness of the disease itself is a prerequisite for screening, and the individual’s perception of disease salience and controllability are ubiquitous factors. Hepatitis can remain asymptomatic until its advanced stages and its perceived leap to end-stage exacerbates a perceived lack of control. This creates a deep unease around screening, the disease frequently attributed to external forces, a doctor, fate or God. However, unlike many Western communities, migrants from the Indian subcontinent come from collective societies in which familial and gendered roles often play a large part in everyday life (Dwairy, 2002).

Our migrants were concerned about the potential impact of illness on their ability to socialise and remain connected to others (Jaspal & Breakwell, 2014; Bramberg et. al., 2010).

Emphasis is placed upon the enmeshed familial and community role, with their responsibilities toward others within a social network highly salient. Participants conceptualised the family and community as a singular force, acting upon an individual, that could either silence or support, and which had a profound effect upon their readiness to screen. In the current study, our construct ‘social networks’ encompasses the experience of both genders; maintaining identity and purpose within the wider community is a priority for both men and women, although identity-roles fall into gendered categories. Thus, social role and identity are inextricably linked, creating further unease about the potential social, as well as physical, impact of a positive diagnosis.

In the context of family and community life, hepatitis and illness in general, was conceptualised as a disruptive force, associated with secrecy and shame. Community networks therefore have the potential to create buffers of silence, particularly in the case of stigmatised illness. For some migrant groups the fear of stigma may supersede the fear of disease progression. Conversely, having a stable relational network can bolster health, and a sense of responsibility towards family and community members has been shown to encourage preventative health measures, such as screening (Tognetti, 2015).

At a system level our findings draw attention to areas of cultural misalignment between first generation migrants and the identity of the general population. Identity (mis)alignment, between doctor and patient, and between South Asian migrants and the healthcare system as a whole, was identified as a key socio-structural determinant of screening. One participant articulated this as ‘*thinking back home*’. Individuals of minority groups are often heuristically defined by the collective identity of that group (Tajfel, 1982), and this is of significance to first-generation migrants. Our findings suggest that this sense of difference and misalignment

was further grounded in healthcare services with South Asian migrants feeling culturally and socially distinct from the general population. Our findings corroborate previous findings that suggest that this collective identity can have a negative impact on migrants' experiences within the healthcare system if not adequately addressed by health professionals (Akhavan & Karlsen, 2013). The healthcare encounter itself was widely conceptualised by participants, as a source of conflict between doctor and patient, and the wider health system perceived as inhospitable.

### *Limitations*

Moving forward, future research is needed to test the transferability of our results. A potential limitation of the work is our focus on participants from south east England. It is possible that the experiences of differential South Asian groups in the UK varies, depending upon the population dynamics of the geographical regions in which they live. Experiences may also vary across other populations and diseases. For example, it would be useful to test the compatibility of our findings to migrants from other hepatitis-endemic areas, such as sub-Saharan Africa and Eastern Europe. Another key limitation is trustworthiness when discussing a communicable disease, with participants perhaps not wanting to disclose their experiences or the experiences of close family. We were acutely aware of this issue, and sought to conduct ourselves with appropriate sensitivity throughout. Further research could examine the extent to which infectious diseases of particular risk to migrant populations, such as HIV or tuberculosis, can be incorporated into our current model.

### **Conclusions**

This study contributes to existing literature on migrants' screening behaviour by providing a dynamic, grounded theory model of the process underlying migrants readiness for health

screening. By widening the theoretical lens to incorporate sociocultural and socio-structural factors, our model takes account of the interlocking relationship between individual and community, and between community and healthcare system and provides practical implications for healthcare providers of screening interventions.

Identity issues can present a major collective barrier to engaging with health services, especially for more vulnerable individuals within the community. Findings suggest cultural insensitivity to identity issues, from public-sector representatives, was a common experience. Feelings of identity misalignment at the healthcare-system level represent a significant barrier to screening; highlighting the need for healthcare providers to have greater cultural awareness and for the provision of culturally tailored and theoretically informed screening interventions (Kalengayi et. al., 2012). For example, by framing screening and the passing on of health information in terms of its benefit to both the immediate family and wider community, it is possible to design interventions that fit within the existing cultural framework of many migrant and stigmatised groups, and address system level misalignments (Johnson et al., 2009).

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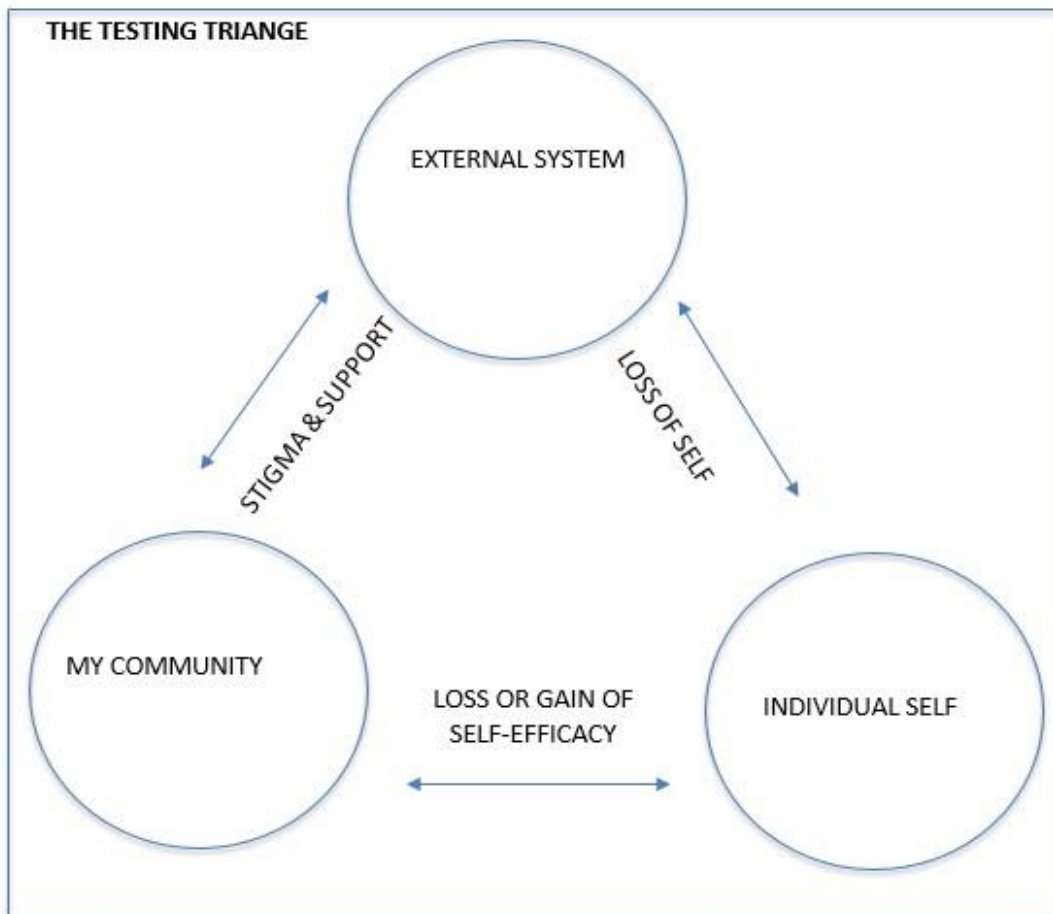
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**Table 1:** Demographic characteristics of the participants

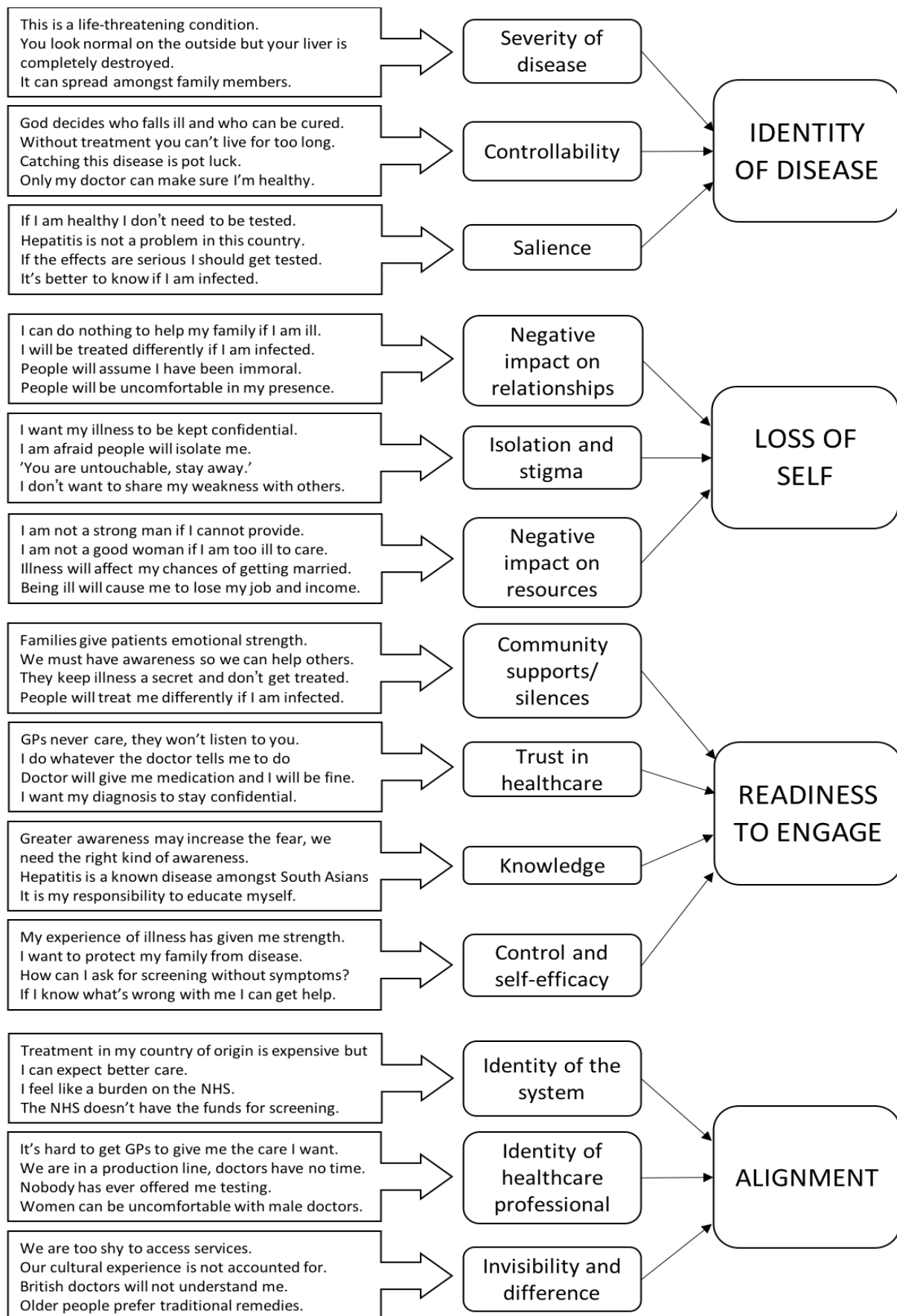
		FG1	FG2	FG3	FG4	FG5	FG6	FG7	FG8
		N=3	N=4	N=9	N=8	N=4	N=11	N=7	N=7
Gender	Male	-	-	9	-	4	-	6	7
	Female	3	4	-	8	-	11	1	-
Age	25-40	2			7	-	3	-	5
	41-50	1	1		1	-	1	1	2
	51-60	-	1	5	-	-	-	1	-
	61 +	-	2	4	-	4	7	5	-
Marital Status	Single	-	-	-	1	-	-	-	-
	Married	1	3	7	7	4	9	6	7
	Separated	2	-	-	-	-	-	1	-
	Widowed	-	1	2	-	-	2	-	-
Education	School	1	2	3	-	1	2	3	-
	College	-	-	2	-	3	2	2	-
	University	1	-	1	5	-	6	-	4
	Other	1	2	3	3	-	1	2	1
Employed	Yes	2	2	4	3	-	1	1	7
	No	1	2	5	5	4	10	6	-
Religion	Islam	2	4	8	1	4	11	1	-
	Hindu	-	-	-	6	-	-	1	5
	Sikh	-	-	-	-	-	-	5	-
	Others	1	-	1	1	-	-	-	2
Born	Pakistan	2	2	9	-	3	8	1	-
	India	-	2	-	8	-	2	3	7
	Others	1	-	-	-	1	1	3	-
Stay in UK	5-10 yrs	3	-	-	4	-	1	-	1
	11-20 yrs	-	-	1	4	3	-	1	6
	21-30 yrs	-	1	1	-	-	-	1	-

English Speaking		-	3	7	-	4	7	5	-
	Yes	1	3	8	8	4	10	4	7
	No	2	1	1	-	-	1	3	-



**Fig. 1:** The testing triangle: theoretical framework of issues affecting the decision of South Asian and other minority groups to access screening services.

Figure 2: Data structure, First-order concepts, second-order concepts, aggregate dimensions



**Fig 3:** Process of engaging in testing amongst migrant communities

