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Views & Attitudes towards Blood donation: A Qualitative Investigation of Indian non-donors living in England

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ABSTRACT

OBJECTIVE:

To explore the views and attitudes of Indians living in England on blood donation.

BACKGROUND:

In light of the predicted shortages in blood supply, it is vital to consider ways in which to maximise donation rates. This includes addressing the issue of lower donation rates amongst ethnic minorities, including Indians. However research specifically amongst minority ethnicities in UK is sparse.

SETTING:

General Practice in North London

PARTICIPANTS:

A convenience sample of 12 non-donor Indians living in England.

METHOD:

A qualitative investigation involving semi-structured interviews. Themes derived were analysed using thematic framework analysis.

RESULTS:

Five key themes emerged from the data, and these concerned participants' perspectives regarding: Attitudes towards blood; Blood donation as a 'good thing'; Donation disincentives; the Recipient matters; the Donor matters.

CONCLUSION:

A variety of attitudes presented, but were generally positive and blood was conceptualised in a manner previously found to be consistent with donation. However, lack of awareness and accessibility were prominent barriers, indicating the need for improvement in these capacities. In contrast to this, blood was also greatly associated with family and acted a symbol of kinship: such degrees of 'emotional charge' often act to dissuade one from separating with their blood through donation. Possibly due to this, there was also a strong preference for donated blood to be distributed within the family, as opposed to strangers: This presents a potential barrier to blood donation for some Indians within the current system in which donations are given to unknown recipients.

ARTICLE SUMMARY

Strengths and Limitations of the study:

- This research provided an in-depth exploration of the views and attitudes of Indian non-donors towards blood donation.
- Both authors independently analysed the data and the themes identified by DJ and RM were compared and agreed upon.
- The convenience sampling techniques and small sample size mean that views of groups not included in the sample may not have been identified.
- Participants were recruited when they came into the practice, and so this sampling technique will not have included the beliefs of people who do not consult their GP.
- Lack of translation facilities may have resulted in the study not capturing the beliefs of non-English speaking Indians who may have different beliefs.
- The interviewer (DJ) was also Indian. In some ways this proved to be advantageous for this study: the researcher had a working understanding of the culture so this aided interpretation; some participants mentioned that they felt more comfortable to express culture-bound views freely; participants occasionally unintentionally conversed in their native language which DJ understood. On the other hand, this could have also had negative implications: the participants may have felt it necessary to give answers that they thought were 'culturally correct'.

INTRODUCTION

With the ageing population, the demand for blood products has been predicted to increase dramatically (1) with a 29% increase in demand for blood products within the NHS between 2004 and 2029, principally because the elderly have a 9-fold higher demand for blood transfusions than those younger (2). The ageing population also means that the proportion of the population eligible to donate blood will decrease, due to the national age limit placed on first-time donors (3). This increasing disparity between the supply and demand of blood products indicates imminent shortfalls in provision.

Current donation rates are sufficient to meet the existing demand (4) but ethnic minorities are greatly underrepresented amongst those donating: Indians account for 2.5% of the population of England and Wales, yet only contribute 0.74% of all donated blood (5, 6). To the best of our knowledge, no studies have been carried out to investigate the reasons behind the disparity in donation rates amongst different ethnicities in the UK.

Lower donation rates amongst ethnic minorities are common outside the UK also, and there have been studies investigating to that effect. These revealed beliefs of perceived social exclusion and distrust in the governing systems to be amongst some of the factors contributing to the lower donation rates (7, 8). Although useful in highlighting potential beliefs of ethnic minorities in the UK, the results cannot be extrapolated to account for neither the situation in the UK, nor the beliefs of its population.

A study in North India found nearly 23% of non-donors reported false-beliefs about blood donation, including views that blood donation could lead to: accelerated ageing; infertility and loss of vitality; permanent weakness and anaemia (9). It is necessary to investigate whether these views also exist within the UK population of Indians because, if so, these false beliefs could be addressed through education programmes aimed at this population, which may lead to increases in donation rates.

A study carried out in South India investigated the factors influencing voluntary blood donation, and reported the vast majority had been prompted to donate by religious leaders (92.5%) or family members (57.1%) (11). This contrasted with results from a study carried out in USA, which had the same investigative focus, but found only 20.7% of blood donors who self-identified as 'Asian' were encouraged to donate by a family member - although admittedly the term 'Asian' encompasses many more ethnicities than 'Indian' alone. This gives some indication as to the differences which exist amongst Indians living in different countries, supporting the case for an investigation into the beliefs of Indians within the UK.

In this study, we aimed to investigate the views of non-donor Indians living in the UK towards blood and donation, to shed some light as to why the blood donation rates are lower amongst Indians than the national average. In turn, this may provide useful information which could be used to encourage donations among Indians living in the UK in the future, and help alter the unfavourable trajectory of predicted blood supply in the UK, narrowing the gap between supply and demand.

MATERIALS AND METHODS

The study design was a qualitative investigation involving semi-structured, private, face-to-face interviews examining the beliefs of non-donor Indians living in the UK concerning blood transfusion. The principal researcher (DJ) was at the time a third year female medical student of Indian descent who carried out the research as part of an intercalated bachelor of science. RM supervised the research.

Before the recruitment process was commenced, Ethical approval was sought from East of Scotland Research Ethics Service and granted in February 2015.

Participant Recruitment

Patients were recruited through a General Practice in Northwest London, as a large proportion of registered patients had already self-identified as 'Indian'. Convenience sampling was carried out and all potential participants were previously unknown to the researchers, and were approached about participating in the study when they came for an appointment with the GP or nurse. Participants were included if they were over 18 years of age and self identified as 'Indian' or 'British Indian' (in order to mimic the ethnicity identification process employed by donation services). Patients were excluded if: they had donated blood before; had previously tried to donate blood and been rejected due to medical reasons; or already knew they could not donate blood due a medical reason. The purpose for this was that the study aimed to investigate the views of the 'untapped resource' of potential donors. Unfortunately, patients also had to be excluded if they could not speak English – this was due to lack of funding for interpreters. The aims of the research were explained to the participants prior to the interviews.

In total, 12 participants were recruited between February – April 2015. Recruitment was carried out alongside data collection, and ended when DJ felt that data saturation had been achieved. 8 patients were approached who met the participant criteria, but refused to participate (see Table 2).

Data collection

Interviews were carried out by DJ in a room at a North London GP practice and recorded for transcription later on. An interview schedule was used which included prompts for conversation topics based on existing literature and two pilot interviews. The audio recordings of the interviews were transcribed verbatim, and then checked twice to ensure accuracy by the researcher, but were not returned to participants for checking. Interviews lasted 20-30 minutes.

Data analysis

The 'Thematic Framework' method of analysis (12) was used and therefore, in accordance with this, analysis occurred in five steps:

- 1. *Familiarisation with the raw data,* achieved by re-reading the transcripts and field notes to create a list of recurrent concepts.
- 2. *Identification* of the thematic framework, which entailed identifying recurring subthemes.
- 3. *Indexing* the transcripts according to the subthemes identified.

- 4. *Charting* and rearranging the data into the area of the thematic framework to which they related.
- 5. *Mapping and interpreting* the data. This involved the interpretation and categorisation of the charts of data collected, in order to create broader themes from the subthemes.

Analysis began soon after the first interview. By carrying out data collection and analysis concurrently, it was possible to employ an iterative approach to the investigation, such that findings were used to shape the discussion in subsequent interviews. As the interviews progressed, data was analysed in comparison to the initial findings, and new themes added where necessary, in line with the 'constant comparison' method (12). The second author (RM) independently analysed the data. The themes identified by DJ and RM were compared and found to be similar. After minimal discussion a final list of themes and subthemes was agreed (see Figure 1 for coding tree)



RESULTS

Sample characteristics

As four participants expressed a wish to be interviewed as pairs, there were 10 interviews in total. The demographic characteristics of the sample are given in Table 1. Five participants identified themselves as Gujarati, two as Marathi and one as Punjabi. The ethnicity was not available for 4 participants. Eight participants identified themselves as Hindu, one as Moslem and one as Jain. The religious identity was not available for 2 participants.

Themes

Five core themes were identified, each with their own subthemes (Table 3).

Theme 1: ATTITUDES TOWARDS BLOOD

This theme addresses how participants conceptualized blood; what they understood to be the functions and properties of blood; the significance and meaning they attributed to it.

<u>'Universal' Physiological Purpose</u>: All participants stated that blood had a functional purpose to deliver nutrients around the body, and did not carry any characteristics specific to the person.

"I think the fact that my blood can work in another person's body – for me that just proves that there isn't much to it. It's just there to do a job. It's quite a universal substance" – P10: male, 40

<u>Ownership of blood</u>: Generally, participants believed that they had ownership over the blood in their body, and that ownership was transferable i.e. through transfusion:

"It belongs to the person ...the house essentially that is carrying it" – P5: male, 27

However, there was a contrasting belief that blood was a universal substance that everyone had a right to, hence could not be subject to claims of ownership:

"There is no point going into it whether it is yours or mine... it's just universal like water" – P4f: female, 29.

<u>Blood as renewable</u>: Blood was widely viewed as temporary and renewable, which led to a sense of indifference about blood loss:

"...something like my heart, my brain, I carry a bit more emotional attachment to it. But your blood, your body is constantly reproducing it. Like to an extent it's almost disposable." – P10: male, 40.

<u>Cultural symbols</u>: Although blood was viewed in a functional and pragmatic way, it was also considered a symbol of 'family' and 'heritage', and in that sense it acted as a common thread connecting people:

"blood symbolizes your heritage...it binds people...I do think blood does in some ways define you, beyond it's functional value" – P9: male, 23.

This participant also mentioned the phrase 'blood brothers', and in this sense, blood represents a bond of loyalty between two people not limited to family.

An idiom in Gujarati was also identified in the discussion when a participant (P3m: male, 37) made a passing comment to his mother. Literally translated, the son asked, "I'm drinking your blood too much, aren't I?". The phrase "lohi pivu" was used, and this can be literally translated into "to drink blood", and the closest English idiom to this would be 'to get on one's nerves': it is a metaphor where by the person 'drinking the blood' is annoying or irritating the other person who is figuratively losing blood. In this instance, the phrase was used light-heartedly by a son teasing his mother. However, the phrase also alludes to the possibility that lack of blood signifies lack of calmness and self-composure, and therefore indicates the negative connotations attached to blood loss.

Theme 2: BLOOD DONATION AS 'A GOOD THING'

This theme describes the positive attitudes towards blood donation and explores the reasons behind this.

Benefit to others: There was a unanimous understanding that blood donation could save the life of the recipient. Donation was considered a selfless act of charity, for which repayment to the donor was not necessary:

"If someone needs blood, then it's a matter of life and death, not a matter of 'is it worth 20 quid?' so it should be given without money" – P9: male, 23

Benefit to self: There was the belief that, in carrying out this charity work, the donor would then feel good about themselves. For one participant, this 'feel good factor' was seen as a personal benefit and believed to override the selflessness of the act:

"I think it's a big feel good factor...yeh you're helping the world... but I think the bigger factor is that you feel nice about yourself for doing something which you think is right and charitable" – P9: male, 23.

Another aspect of personal benefit of blood donation arose from the belief that after giving blood, the body could then create new blood, which would have health benefits for the donor:

"blood donation is useful for us also in creating more for later... it helps us make more blood, fresh blood" "your body feels good because you get new blood" – P6: male, 37

<u>Effortless</u>: The donation process was perceived as easy, which acted as an incentive to donate blood:

"It's something that requires very little effort because it's not like you're pulling out the blood from your veins by yourself ... you just sit there. There's no strain on the person giving blood" – P10: male, 40

<u>Religion</u>: Among participants who identified themselves as Hindu or Moslem, religion did not provide any specific advice on blood donation, but it was widely believed that blood donation, as an act of charity, would be encouraged. There was also the belief their good deed would be rewarded later by God:

"there's probably nothing to say that you should do it [give blood] but I think as an act of goodwill, it is something that religion would promote" – P9: male, 23

 However, for one participant who identified themselves as Jain, religion also provided him instruction to refrain from donating blood where his own health was at risk:

"Non-violence is another key principle of ours, and I guess if you were harming yourself in the process of giving blood, well then that would go against the non-violence rule" – P7: male, 26

Theme 3: DONATION DISCINCENTIVES

This theme describes the various factors that acted as obstacles or deterrents, preventing participants from donating blood. It explores the views of those who did not want to donate, as well as those who expressed a desire to donate but had not done so yet.

<u>Fears and concerns</u>: The donation process was viewed as frightening by some: The fear of needles and low standards of hygiene were some of the worries expressed:

"they are irresponsible towards using hygienic syringes... so that fear is always there in the back of the mind" - P4f: female, 29.

There was a lack of knowledge and uncertainty about what the process entailed which made the procedure daunting:

"It's always quite intimidating...you don't know how the process goes" - P7: male, 26

There was a concern amongst participants over the potential negative effects that donation would have on their own health:

"...there is fear that if that blood goes from our body, then what will happen to us, if that blood goes down?... then the fear is here and real... makes me think 'no I don't want to give blood'" – P1: female, 58.

Some participants felt they would be discouraged to donate by their family members who were concerned about the impact that the loss of blood would have on their health. In one case, the participant's parents were willing to donate themselves but felt that it would be too much of a risk for their children. The reasons for this were ascribed to paternal instinct and the desire to protect their children who they regarded as more vulnerable:

"I think my mum would be worried... probably because she doesn't understand that you can regenerate blood... I think any parents are always a bit worried... like you want your child to stay healthy and have the best in life... I don't think they themselves would mind giving, but they just want to protect their children from everything" – P9: male, 23

Discussion also revealed that some participants felt that their own blood would be inadequate for donation, due to the concern of passing on their own medical conditions to the recipients:

"And another thing that I'm scared of about giving blood, is that in giving blood we don't know what illness we have in our body that we would end up giving to other people" – P1: female, 58

<u>Lack of awareness</u>: There was a general awareness of the high demand of blood, however the majority of participants believe that transfusions were only required in emergency situations and surgery: Participants were unaware of the need for transfusions for people with chronic conditions.

"I only know about blood transfusions for people who have lost blood... in surgery or gun wounds... those kind of emergency situations" – P9: male, 23 Furthermore, there was a lack of awareness of the need for human donors: one participant explained the view of a family member who believed that human donors were unnecessary as blood used in transfusions was made artificially in a laboratory:

"I know some family who think that... yeh, they just have a misperception that blood can be made in a pharmacy lab" - P10: male, 40

<u>Lack of accessibility</u>: Participants who expressed a desire to donate identified a lack of accessibility as an insurmountable obstacle in donating. This included: lack of knowledge where to donate and the steps to initiate the donation process; inconvenient times available for donation (which meant missing time at work). Overall, it was regarded as a long and inconvenient process, which deterred them from donating.

"It just always seems like an inconvenience to doing it [donating blood]...I don't really know how to make that step to actually give blood. It doesn't seem like it's very clearly explained" – P10: male, 40

<u>Lack of impetus</u>: Participants expressing a desire to donate found that it often just 'slipped their mind' and they forgot about it, mainly due to their busy lifestyles. Public media and advertisements were identified as effective reminders, however they were too infrequent and their message was soon forgotten:

"...it's not so much that I'm anti-donation, it's more that I haven't had the chance to. So like 'out of sigh out of mind' type of thing, you know" – P9: male, 23

"I think the advertisements like on the TV, television, there should be more. That is what makes me want to go, but I don't see them anymore and I forget. Too many things in my life" – P6: male, 37

For one participant, the desire to donate blood was diminished by the preference for other acts of selflessness considered more challenging, such as feeding the homeless. This stemmed from the belief that selflessness could only be achieved through performing demanding tasks, and blood donation was considered too effortless:

"I wouldn't feel good if I gave blood because I've not put that effort in...In my opinion there's no quick way to do a good deed. If it's quick, then it's not good enough. You're sort of cheating by doing that... selflessness can't come so easily" – P7: male, 26

<u>Social norms</u>: Participants acknowledged that donation was uncommon amongst Indians and attributed this to the culture: blood donation was not considered the 'normal' thing to do. Although this did not prevent participants from donating, it also did not act to promote donation:

"I guess you learn things from your family and those around you... you end up doing as they do. It's inevitable. I don't think my family would stop me from donating blood, but you know, it's just not something they've ever done themselves" – P5: male, 27

Theme 4: RECIPIENT MATTERS

This theme explores the participants' views on what would be important to them should they donate blood in the future.

<u>'Seeing the fruits of your goodwill'</u>: There was a widespread preference to know about how their blood had helped someone else, and knowing how one's blood had helped was considered an incentive. There current system, whereby the recipient would be unknown to the donor was seen as a disincentive:

"...your blood goes off and you never find out about it, well that's just a bit... disheartening I guess. Maybe lose the importance and actual relevance of it" – P10: male, 40.

<u>'Family comes first'</u>: For some participants, the needs of their family came before the needs of others – an attitude that was attributed to Indian culture by the participants. It meant that participants were willing to donate blood for their family where they otherwise would not have donated (e.g. due to the fear of needles):

"Well I guess the main thing is the family, close-knit tradition of Indian people – your family would come first before the general population ... if it's the case that your family would require something, then yes, you'd give it up for them" - P7: male, 26

<u>Help for all</u>: Some participants held a view which contrasted those aforementioned: they believed that blood should be given regardless of who the recipient is, because anyone who is in need of help should receive it:

"...not just friends and family. Anyone who's come into trouble needs help" – P1: female, 58

Theme 5: DONOR MATTERS

This theme explores how participants anticipated they would feel about receiving a blood transfusion should they need one in the future.

<u>Preference for family donors</u>: Participants expressed a preference to receive blood that was donated by a family member over blood donated by a stranger, mainly because it felt more natural and safer.

"with family I'd feel like it'd be more safe and natural" – P9: male, 23. "stranger's blood seems more dangerous" – P1: female, 58.

<u>Donor's health matters</u>: There was concern about the health of the donor, in part due to the fear of acquiring a blood-borne disease. Moreover, there was the desire to know that the donor's health had not been adversely affected by the donation; that the recipient had not benefitted at the cost of the donor's health.

"If someone I knew wanted to give it [blood], I'd just feel more accepting from them than from someone I didn't know... More just because I know them, I know that they're ok with it, and that they're still healthy and ok after the donation" – P9: male, 23

<u>Donor's character matters</u>: Participants expressed a preference for 'a good person' as the donor of the blood they were receiving: They did not want to

associate themselves with someone of 'bad' character, even through the means of a blood transfusion.

"it just wouldn't sit right with me to have their parts in me... I wouldn't want to associate my life with that type of badness" – P5: male, 27.

This participant regarded donor anonymity positively, as the recipient would not know if the donor was 'bad', and therefore could feel comfortable with the blood they received, following the 'ignorance is bliss' proverb.

<u>Feelings towards the donor</u>: Participants expressed that they would feel grateful towards the donor, and disliked that donor anonymity prevented them from expressing their gratitude to the donor.

"... I actually think I'd feel more indebted to them because they're a stranger who owes me nothing, and get's nothing out of it apart from the knowledge that they're helped save a stranger. In a way that's [donor anonymity] a bit annoying because you'd want to know who they are so you could do something for them, even if it was just to say thank you and tell them you appreciated it." – P9: male, 23

DISCUSSION

Discussion of results

Participants had a pragmatic view regarding the function of blood: it was seen to serve a functional purpose, carrying nutrients around the body, but not individual character or personality. In previous studies, it was found that those who viewed blood in a functional manner ('body as machine') were more inclined to donate organs (13), which raises the question as to why this view was so common amongst Indian non-donors, (albeit that in this case the donation was of blood not organs). This could be explained by the phenomenon of cathexis, which Belk (1990) describes as "the charging of an object...with emotional energy": those who placed greater cathexis on their body parts felt a greater attachment to these parts and so were less willing to donate. It could be that Indian non-donors, despite seeing blood as having a mainly mechanical function, place greater cathexis on blood, thus rendering them less inclined to donate. This greater cathexis could be accredited to the large role of culture in influencing the attitudes of participants in this study toward blood: it was a symbol of familial connections and extra-familial kinship. This would explain the emotional attachment and value placed on blood, and therefore the lack of willingness to donate.

The findings within the second and third themes, blood as a 'good thing' and 'donation disincentives', correspond with many of the positive and negative motivators for donation identified in previous studies (9, 10, 14, 15). Interestingly, this study discovered an additional incentive not reported in other studies: the belief that the loss of blood in the donation process allows for the production of new fresh blood, which will improve health in the donor.

It is important to highlight that this study did not uncover the same false beliefs which were reported in the study carried out in India (accelerated ageing; infertility and loss of vitality; permanent weakness and anaemia) (9). Although one participant in this study identified lack of blood after donation as a disincentive due to the negative health effects, it was acknowledged that this was only temporary. This could be the result of a difference in cultures, as Indians living in England will have a different culture to those in India as a result of 'enculturation' (16). Another possibility is that the small sample size of this study did not reveal these false beliefs held by a very small minority.

Overall, blood donation was regarded in a very positive manner, which raises the question of why participants had not donated. Although all participants agreed that blood donations were necessary, there was a lack of knowledge as to *why* they were necessary, *who* could donate, *where* to donate and *what* the process entailed: This, combined with lack of accessibility to donation services, and social norms favouring not donating, explains in part why these participants were non-donors. Amongst the participants who were keen to donate, advertisements were identified as positive influences and helpful reminders. However it was noted that these were too infrequent and so participants' desire to donate blood would 'slip from their mind' as their busy lifestyles and other commitments took over. This suggests that there is a need for more advertisements about blood donations in order to: raise awareness about why donations are necessary; inform the population about how to donate; and also to serve as a reminder.

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Interestingly, two opposing views emerged in discussion: a preference for donations to be given to family members, and the belief that blood should be given equally to all without discrimination. For those holding to the former stance, the current system, whereby blood is donated into an anonymous 'pool' and then redistributed amongst the population, would be undesirable as they would not be able to influence whom the recipient would be. This ties in with the desire amongst participants to see or know about the results of their donation, i.e. how their donation has helped save a life, as the current system would be undesirable to them in this respect also, as no such information is available about individual donations.

The role and influence of the family with regards to blood was a recurrent concept throughout the core themes: blood symbolised family; family created the behavioural norm; family members' concerns acted as disincentives to donate; there was a preference to donate blood to family, and receive blood from family too. Previous studies had also found a connection between family influence and blood donation (11, 17), but tended to focus on the family's positive impact on encouraging a person's decision to donate. This study identified that family could have a negative impact too, dissuading the participant from donating by expressing their concerns about the participant's wellbeing. According to previous research, donors tend to have low self-esteem and so are more vulnerable to the persuasion of others (15): if so, it may be the case that family members' concerns will have a greater impact on those who wish to donate blood, thus dissuading them from donating.

Limitations

The convenience sampling techniques and small sample size mean that views of groups not included in the sample may not have been identified. It is also important to mention that all participants were recruited when they came into the practice, and so this sampling technique will not have included the beliefs of people who do not consult their GP. It is possible that these members will have had different characteristics, such as differences in their perceived vulnerability to illness, health seeking behaviours and their "locus of control" (18), which could have led to a different beliefs . Furthermore the lack of translation facilities may have resulted in the study not capturing the beliefs of non-English speaking Indians who may have different beliefs.

It is also important to mention that the DJ was also Indian. In some ways this proved to be advantageous for this study: the researcher had a working understanding of the culture so this aided interpretation; some participants mentioned that they felt more comfortable to express culture-bound views freely; participants occasionally unintentionally conversed in their native language which DJ understood. On the other hand, this could have also had negative implications: the participants may have felt it necessary to give answers that they thought were 'culturally correct'.

Conclusion

This research suggests that there is a positive attitude towards blood donation in this sample of the population of Indian origin living in the UK. However, it uncovered a variety of factors (including lack of awareness and accessibility, a high degree of 'emotional charge' on blood, the preference to donate blood to known recipients) previously unidentified in the literature which may been important in helping to understand why donation rates are lower in this population. This suggests a need for further quantitative research to be undertaken to explore their generalizability among Indians living in the UK.



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TABLES

Table 1. Sample characteristics

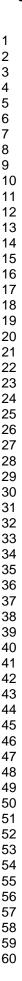
Participant	Gender	Age	Occupation	
identification		(years)		
1	F	58	Housewife	
2	F	80	Housewife	
3f	F	61	Retired factory worker	
3m	M	37	Accountant	
4f	F	29	Retail assistant	
4m	M	33	Retail assistant	
5	M	27	Investment banker	
6	M	37	Grocer shopkeeper	
7	M	26	Office worker	
8	F	18	Student (gap year)	
9	M	23	Student (post-graduate	
			medicine)	
10	M	40	Hairdresser	
		L		
			Hairdresser	

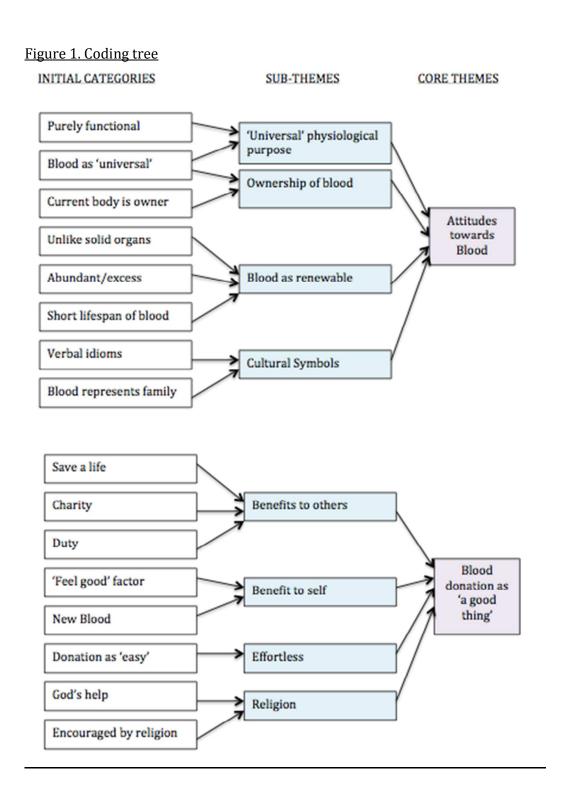
Table 2. Patients who declined participation in the study

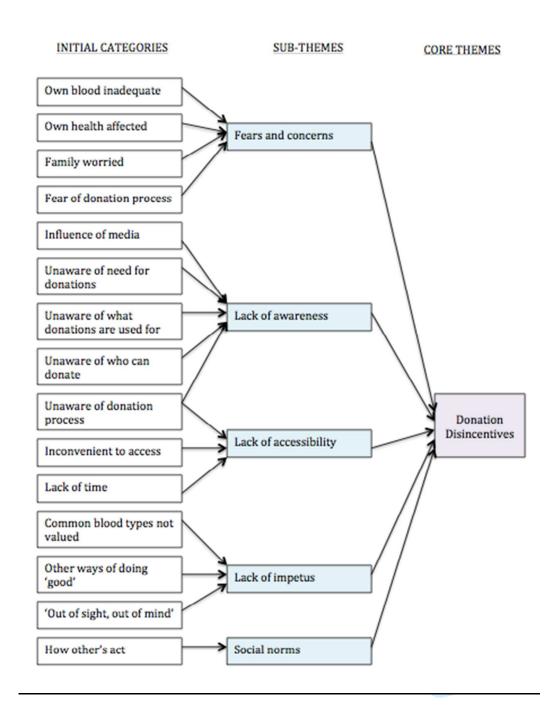
Rejection	Sex	Age	Occupation	Reason for
no.	'			declining
1	M	unknown	unknown	unknown
2	M	43	unknown	Did not have time
3	F	49	Teacher	Did not have time
4	М	unknown	unknown	unknown
5	F	23	Supermarket cashier	Did not have time
6	F	37	Housewife	Did not have time
7	F	unknown	unknown	unknown
8	F	unknown	unknown	unknown

Table 3. Results: 5 Core themes and their respective subthemes

Core Theme	Subtheme
ТНЕМЕ 1:	'Universal' Physiological purpose
Attitudes towards Blood	Ownership of blood
	Blood as renewable
	Cultural symbols
ТНЕМЕ 2:	Benefit to others
Blood donations as 'a good thing'	Benefit to self
	Effortless
	Religion
ТНЕМЕ 3:	Fears and Concerns
Donation Disincentives	Lack of awareness
	Lack of accessibility
	Lack of impetus
	Social norms
THEME 4:	'Seeing the fruits of your goodwill'
Recipient Matters	'Family first'
	Help for all
ТНЕМЕ 5:	Preference for family donors
Donor Matters	Donor's health matters
	Donor's character matters
	Feelings towards the donor







Footnotes

Contributors: DJ and RM were both involved in all of the following stages: design of the study; analysis and interpretation of the data; writing up the report; final approval of the version to be published. DJ carried out the interviews.

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Competing interests: None declared.

Ethics approval: Ethical approval was granted by East of Scotland Research Ethics Service. Written and verbal informed consent was obtained from participants. The interviews were conducted privately and the participants' transcripts were anonymised.

Data sharing statement: No additional data are available.

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team			
and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	5
Gender	4	Was the researcher male or female?	5
Experience and training	5	What experience or training did the researcher have?	5
Relationship with	I		1
participants			
Relationship established	6	Was a relationship established prior to study commencement?	5
Participant knowledge of	7	What did the participants know about the researcher? e.g. personal	
the interviewer		goals, reasons for doing the research	5
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator?	_
		e.g. Bias, assumptions, reasons and interests in the research topic	5
Domain 2: Study design	JI.		•
Theoretical framework			
Methodological orientation	9	What methodological orientation was stated to underpin the study? e.g.	
and Theory		grounded theory, discourse analysis, ethnography, phenomenology,	5
		content analysis	
Participant selection	•		•
Sampling	10	How were participants selected? e.g. purposive, convenience,	
		consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	5
Sample size	12	How many participants were in the study?	5
Non-participation	13	How many people refused to participate or dropped out? Reasons?	5, 19
Setting	JI.		<u> </u>
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-	15	Was anyone else present besides the participants and researchers?	
participants			5
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	7/18
Data collection	ı	I ·	<u> </u>
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the inter view or focus group?	N/A
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed? 5	
Data Jataration		Were transcripts returned to participants for comment and/or	9

Торіс	Item No.	Guide Questions/Description	Reported on Page No.	
		correction?		
Domain 3: analysis and				
findings				
Data analysis				
Number of data coders	24	How many data coders coded the data?	6	
Description of the coding	25	Did authors provide a description of the coding tree?		
tree			20, 21	
Derivation of themes	26	Were themes identified in advance or derived from the data?	6	
Software	27	What software, if applicable, was used to manage the data?	N/A	
Participant checking	28	Did participants provide feedback on the findings?	N/A	
Reporting				
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?	7.10	
		Was each quotation identified? e.g. participant number	7-12	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-12	
Clarity of major themes	31	Were major themes clearly presented in the findings? 20		
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?		

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

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Views & Attitudes towards Blood donation: A Qualitative Investigation of Indian non-donors living in England

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Views & Attitudes towards Blood donation: A Qualitative Investigation of Indian non-donors living in England

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The authors declare that they have no conflicts of interest relevant to the manuscript submitted to BMJ Open

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Abstract: 246

Main text Not including participant quotations, tables, references: 3689 Main text Including quotations, but not tables or references: 4712

ABSTRACT

OBJECTIVE:

To explore the views and attitudes of Indians living in England on blood donation.

BACKGROUND:

In light of the predicted shortages in blood supply, it is vital to consider ways in which to maximise donation rates. This includes addressing the issue of lower donation rates amongst ethnic minorities, including Indians. However research specifically amongst minority ethnicities in UK is sparse.

SETTING:

General Practice in North London

PARTICIPANTS:

A convenience sample of 12 non-donor Indians living in England.

METHOD:

A qualitative investigation involving semi-structured interviews. Themes derived were analysed using thematic framework analysis.

RESULTS:

Five key themes emerged from the data, and these concerned participants' perspectives regarding: Attitudes towards blood; Blood donation as a 'good thing'; Donation disincentives; the Recipient matters; the Donor matters.

CONCLUSION:

A variety of attitudes presented, but were generally positive and blood was conceptualised in a manner previously found to be consistent with donation. However, lack of awareness and accessibility were prominent barriers, indicating the need for improvement in these capacities. In contrast to this, blood was also greatly associated with family and acted a symbol of kinship: such degrees of 'emotional charge' often act to dissuade one from separating with their blood through donation. Possibly due to this, there was also a strong preference for donated blood to be distributed within the family, as opposed to strangers: This presents a potential barrier to blood donation for some Indians within the current system in which donations are given to unknown recipients.

ARTICLE SUMMARY

Strengths and Limitations of the study:

- Both authors independently analysed the data and the themes identified by DJ and RM were compared and agreed upon.
- The convenience sampling techniques and small sample size mean that views of groups not included in the sample may not have been identified.
- Although there were only 12 participants, there was a diverse range, from 18-80 years old, at least 3 ethnic groups and 3 religions.
- Lack of translation facilities may have resulted in the study not capturing the beliefs of non-English speaking Indians who may have different beliefs.
- The interviewer (DJ) was also Indian which may have had some negative implications, however in practice was found to be advantageous as participants commented that they felt more able to express culture-bound views.

INTRODUCTION

With the ageing population, the demand for blood products has been predicted to increase dramatically (1) with a 29% increase in demand for blood products within the NHS between 2004 and 2029, principally because the elderly have a 9-fold higher demand for blood transfusions than those younger (2). The ageing population also means that the proportion of the population eligible to donate blood will decrease, due to the national age limit placed on first-time donors (3). This increasing disparity between the supply and demand of blood products indicates imminent shortfalls in provision.

Current donation rates are sufficient to meet the existing demand (4) but ethnic minorities are greatly underrepresented amongst those donating: Indians account for 2.5% of the population of England and Wales, yet only contribute 0.74% of all donated blood (5, 6). To the best of our knowledge, no studies have been carried out to investigate the reasons behind the disparity in donation rates amongst different ethnicities in the UK.

Lower donation rates amongst ethnic minorities are common outside the UK also, and there have been studies investigating to that effect. These revealed beliefs of perceived social exclusion and distrust in the governing systems to be amongst some of the factors contributing to the lower donation rates (7, 8). Although useful in highlighting potential beliefs of ethnic minorities in the UK, the results cannot be extrapolated to account for neither the situation in the UK, nor the beliefs of its population.

A study in North India found nearly 23% of non-donors reported false-beliefs about blood donation, including views that blood donation could lead to: accelerated ageing; infertility and loss of vitality; permanent weakness and anaemia (9). It is necessary to investigate whether these views also exist within the UK population of Indians because, if so, these false beliefs could be addressed through education programmes aimed at this population, which may lead to increases in donation rates.

A study carried out in South India investigated the factors influencing voluntary blood donation, and reported the vast majority had been prompted to donate by religious leaders (92.5%) or family members (57.1%) (10). This contrasted with results from a study carried out in USA, which had the same investigative focus, but found only 20.7% of blood donors who self-identified as 'Asian' were encouraged to donate by a family member (11) - although admittedly the term 'Asian' encompasses many more ethnicities than 'Indian' alone. This gives some indication as to the differences which exist amongst Indians living in different countries, supporting the case for an investigation into the beliefs of Indians within the UK.

In this study, we aimed to investigate the views of non-donor Indians living in the UK towards blood and donation, to shed some light as to why the blood donation rates are lower amongst Indians than the national average. In turn, this may provide useful information which could be used to encourage donations among Indians living in the UK in the future, and help alter the unfavourable trajectory of predicted blood supply in the UK, narrowing the gap between supply and demand.

MATERIALS AND METHODS

The study design was a qualitative investigation involving semi-structured, private, face-to-face interviews examining the beliefs of non-donor Indians living in the UK concerning blood transfusion. The principal researcher (DJ) was at the time a third year female medical student of Indian descent who carried out the research as part of an intercalated bachelor of science. RM supervised the research.

Before the recruitment process was commenced, Ethical approval was sought from East of Scotland Research Ethics Service and granted in February 2015.

Participant Recruitment

Patients were recruited through a General Practice in Northwest London, as a large proportion of registered patients had already self-identified as 'Indian'. Convenience sampling was carried out and all potential participants were previously unknown to the researchers, and were approached about participating in the study when they came for an appointment with the GP or nurse. Participants were included if they were over 18 years of age and self identified as 'Indian' or 'British Indian' (in order to mimic the ethnicity identification process employed by donation services). Patients were excluded if: they had donated blood before; had previously tried to donate blood and been rejected due to medical reasons; or already knew they could not donate blood due a medical reason. The purpose for this was that the study aimed to investigate the views of the 'untapped resource' of potential donors. Unfortunately, patients also had to be excluded if they could not speak English – this was due to lack of funding for interpreters. The aims of the research were explained to the participants prior to the interviews.

In total, 12 participants were recruited between February – April 2015. Recruitment was carried out alongside data collection, and ended when DJ felt that data saturation had been achieved. 8 patients were approached who met the participant criteria, but refused to participate (see Table 1).

Rejection	Sex	Age	Occupation	Reason for
no.				declining
1	M	unknown	unknown	unknown
2	M	43	unknown	Did not have time
3	F	49	Teacher	Did not have time
4	M	unknown	unknown	unknown
5	F	23	Supermarket cashier	Did not have time
6	F	37	Housewife	Did not have time
7	F	unknown	unknown	unknown
8	F	unknown	unknown	unknown

Table 1. *Patients who declined participation in the study*

Data collection

Interviews were carried out by DJ in a room at a North London GP practice and recorded for transcription later on. An interview schedule was used which included prompts for conversation topics based on existing literature and two pilot interviews. The audio recordings of the interviews were transcribed verbatim, and then checked twice to ensure accuracy by the researcher, but were not returned to participants for checking. Interviews lasted 20-30 minutes.

Data analysis

The 'Thematic Framework' method of analysis (12) was used and therefore, in accordance with this, analysis occurred in five steps:

- 1. *Familiarisation with the raw data,* achieved by re-reading the transcripts and field notes to create a list of recurrent concepts.
- 2. *Identification* of the thematic framework, which entailed identifying recurring subthemes.
- 3. *Indexing* the transcripts according to the subthemes identified.
- 4. *Charting* and rearranging the data into the area of the thematic framework to which they related.
- 5. *Mapping and interpreting* the data. This involved the interpretation and categorisation of the charts of data collected, in order to create broader themes from the subthemes.

Analysis began soon after the first interview. By carrying out data collection and analysis concurrently, it was possible to employ an iterative approach to the investigation, such that findings were used to shape the discussion in subsequent interviews. As the interviews progressed, data was analysed in comparison to the initial findings, and new themes added where necessary, in line with the 'constant comparison' method (12). The second author (RM) independently analysed the data. The themes identified by DJ and RM were compared and found to be similar. After minimal discussion a final list of themes and subthemes was agreed (see Figure 1 for coding tree)

RESULTS

Sample characteristics As four participants expressed a wish to be interviewed as pairs, there were 10 interviews in total. The demographic characteristics of the sample are given in Table 2.

Interview	Participant	Gender	Age		
no.	identification		(years)		
1	1	F	58		
2	2	F	80		
3	3f	F	61		
	3m	M	37		
4	4f	F	29		
	4m	M	33		
5	5	M	27		
6	6	M	37		
7	7	M	26		
8	8	F	18		
9	9	M	23		
10	10	M	40		

Five participants identified themselves as Gujarati, two as Marathi and one as Punjabi. The ethnicity was not available for 4 participants. Eight participants identified themselves as Hindu, one as Moslem and one as Jain. The religious identity was not available for 2 participants.

Table 2. Sample characteristics

Themes

Five core themes were identified, each with their own subthemes (Table 3).

Core Theme	Subtheme
THEME 1:	'Universal' Physiological purpose
Attitudes towards Blood	Ownership of blood
	Blood as renewable
	Cultural symbols

ТНЕМЕ 2:	Benefit to others
Blood donations as 'a good thing'	Benefit to self
	Effortless
	Religion
ТНЕМЕ 3:	Fears and Concerns
Donation Disincentives	Lack of awareness
	Lack of accessibility
	Lack of impetus
	Social norms
THEME 4:	'Seeing the fruits of your goodwill'
Recipient Matters	'Family first'
	Help for all
ТНЕМЕ 5:	Preference for family donors
Donor Matters	Donor's health matters
	Donor's character matters
	Feelings towards the donor

Table 3. *Results: 5 Core themes and their respective subthemes*

Theme 1: ATTITUDES TOWARDS BLOOD

This theme addresses how participants conceptualized blood; what they understood to be the functions and properties of blood; the significance and meaning they attributed to it.

<u>'Universal' Physiological Purpose</u>: All participants stated that blood had a functional purpose to deliver nutrients around the body, and did not carry any characteristics specific to the person.

"I think the fact that my blood can work in another person's body – for me that just proves that there isn't much to it. It's just there to do a job. It's quite a universal substance" – P10: male, 40

<u>Ownership of blood</u>: Generally, participants believed that they had ownership over the blood in their body, and that ownership was transferable i.e. through transfusion:

"It belongs to the person ...the house essentially that is carrying it" – P5: male, 27

However, there was a contrasting belief that blood was a universal substance that everyone had a right to, hence could not be subject to claims of ownership:

"There is no point going into it whether it is yours or mine—it's just

"There is no point going into it whether it is yours or mine... it's just universal like water" – P4f: female, 29.

<u>Blood as renewable</u>: Blood was widely viewed as temporary and renewable, which led to a sense of indifference about blood loss:

"...something like my heart, my brain, I carry a bit more emotional attachment to it. But your blood, your body is constantly reproducing it. Like to an extent it's almost disposable." – P10: male, 40.

<u>Cultural symbols</u>: Although blood was viewed in a functional and pragmatic way, it was also considered a symbol of 'family' and 'heritage', and in that sense it acted as a common thread connecting people:

"blood symbolizes your heritage...it binds people...I do think blood does in some ways define you, beyond it's functional value" – P9: male, 23. This participant also mentioned the phrase 'blood brothers', and in this sense, blood represents a bond of loyalty between two people not limited to family.

An idiom in Gujarati was also identified in the discussion when a participant (P3m: male, 37) made a passing comment to his mother. Literally translated, the son asked, "I'm drinking your blood too much, aren't I?". The phrase "lohi pivu" was used, and this can be literally translated into "to drink blood", and the closest English idiom to this would be 'to get on one's nerves': it is a metaphor where by the person 'drinking the blood' is annoying or irritating the other person who is figuratively losing blood. In this instance, the phrase was used light-heartedly by a son teasing his mother. However, the phrase also alludes to the possibility that lack of blood signifies lack of calmness and self-composure, and therefore indicates the negative connotations attached to blood loss.

Theme 2: BLOOD DONATION AS 'A GOOD THING'

This theme describes the positive attitudes towards blood donation and explores the reasons behind this.

<u>Benefit to others</u>: There was a unanimous understanding that blood donation could save the life of the recipient. Donation was considered a selfless act of charity, for which repayment to the donor was not necessary:

"If someone needs blood, then it's a matter of life and death, not a matter of 'is it worth 20 quid?' so it should be given without money" – P9: male, 23

<u>Benefit to self</u>: There was the belief that, in carrying out this charity work, the donor would then feel good about themselves. For one participant, this 'feel good factor' was seen as a personal benefit and believed to override the selflessness of the act:

"I think it's a big feel good factor...yeh you're helping the world... but I think the bigger factor is that you feel nice about yourself for doing something which you think is right and charitable" – P9: male, 23.

Another aspect of personal benefit of blood donation arose from the belief that after giving blood, the body could then create new blood, which would have health benefits for the donor:

"blood donation is useful for us also in creating more for later... it helps us make more blood, fresh blood" "your body feels good because you get new blood" – P6: male, 37

<u>Effortless</u>: The donation process was perceived as easy, which acted as an incentive to donate blood:

"It's something that requires very little effort because it's not like you're pulling out the blood from your veins by yourself ... you just sit there. There's no strain on the person giving blood" – P10: male, 40

Religion: Among participants who identified themselves as Hindu or Moslem, religion did not provide any specific advice on blood donation, but it was widely believed that blood donation, as an act of charity, would be encouraged. There was also the belief their good deed would be rewarded later by God:

"there's probably nothing to say that you should do it [give blood] but I think as an act of goodwill, it is something that religion would promote" – P9: male, 23

However, for one participant who identified themselves as Jain, religion also provided him instruction to refrain from donating blood where his own health was at risk:

"Non-violence is another key principle of ours, and I guess if you were harming yourself in the process of giving blood, well then that would go against the non-violence rule" – P7: male, 26

Theme 3: DONATION DISCINCENTIVES

This theme describes the various factors that acted as obstacles or deterrents, preventing participants from donating blood. It explores the views of those who did not want to donate, as well as those who expressed a desire to donate but had not done so yet.

<u>Fears and concerns</u>: The donation process was viewed as frightening by some: The fear of needles and low standards of hygiene were some of the worries expressed:

"they are irresponsible towards using hygienic syringes... so that fear is always there in the back of the mind" - P4f: female, 29.

There was a lack of knowledge and uncertainty about what the process entailed which made the procedure daunting:

"It's always quite intimidating...you don't know how the process goes" - P7: male, 26

There was a concern amongst participants over the potential negative effects that donation would have on their own health:

"...there is fear that if that blood goes from our body, then what will happen to us, if that blood goes down?... then the fear is here and real... makes me think 'no I don't want to give blood'" – P1: female, 58.

Some participants felt they would be discouraged to donate by their family members who were concerned about the impact that the loss of blood would have on their health. In one case, the participant's parents were willing to donate themselves but felt that it would be too much of a risk for their children. The reasons for this were ascribed to paternal instinct and the desire to protect their children who they regarded as more vulnerable:

"I think my mum would be worried... probably because she doesn't understand that you can regenerate blood... I think any parents are always a bit worried... like you want your child to stay healthy and have the best in

life... I don't think they themselves would mind giving, but they just want to protect their children from everything" – P9: male, 23

Discussion also revealed that some participants felt that their own blood would be inadequate for donation, due to the concern of passing on their own medical conditions to the recipients:

"And another thing that I'm scared of about giving blood, is that in giving blood we don't know what illness we have in our body that we would end up giving to other people" – P1: female, 58

<u>Lack of awareness</u>: There was a general awareness of the high demand of blood, however the majority of participants believe that transfusions were only required in emergency situations and surgery: Participants were unaware of the need for transfusions for people with chronic conditions.

"I only know about blood transfusions for people who have lost blood... in surgery or gun wounds... those kind of emergency situations" – P9: male, 23 Furthermore, there was a lack of awareness of the need for human donors: one participant explained the view of a family member who believed that human donors were unnecessary as blood used in transfusions was made artificially in a laboratory:

"I know some family who think that... yeh, they just have a misperception that blood can be made in a pharmacy lab" - P10: male, 40

<u>Lack of accessibility</u>: Participants who expressed a desire to donate identified a lack of accessibility as an insurmountable obstacle in donating. This included: lack of knowledge where to donate and the steps to initiate the donation process; inconvenient times available for donation (which meant missing time at work). Overall, it was regarded as a long and inconvenient process, which deterred them from donating.

"It just always seems like an inconvenience to doing it [donating blood]...I don't really know how to make that step to actually give blood. It doesn't seem like it's very clearly explained" – P10: male, 40

<u>Lack of impetus</u>: Participants expressing a desire to donate found that it often just 'slipped their mind' and they forgot about it, mainly due to their busy lifestyles. Public media and advertisements were identified as effective reminders, however they were too infrequent and their message was soon forgotten:

"...it's not so much that I'm anti-donation, it's more that I haven't had the chance to. So like 'out of sigh out of mind' type of thing, you know" – P9: male. 23

"I think the advertisements like on the TV, television, there should be more. That is what makes me want to go, but I don't see them anymore and I forget. Too many things in my life" – P6: male, 37

For one participant, the desire to donate blood was diminished by the preference for other acts of selflessness considered more challenging, such as feeding the homeless. This stemmed from the belief that selflessness could only be achieved through performing demanding tasks, and blood donation was considered too effortless:

"I wouldn't feel good if I gave blood because I've not put that effort in...In my opinion there's no quick way to do a good deed. If it's quick, then it's not good enough. You're sort of cheating by doing that... selflessness can't come so easily" – P7: male, 26

<u>Social norms</u>: Participants acknowledged that donation was uncommon amongst Indians and attributed this to the culture: blood donation was not considered the 'normal' thing to do. Although this did not prevent participants from donating, it also did not act to promote donation:

"I guess you learn things from your family and those around you... you end up doing as they do. It's inevitable. I don't think my family would stop me from donating blood, but you know, it's just not something they've ever done themselves" – P5: male, 27

Theme 4: RECIPIENT MATTERS

This theme explores the participants' views on what would be important to them should they donate blood in the future.

<u>'Seeing the fruits of your goodwill'</u>: There was a widespread preference to know about how their blood had helped someone else, and knowing how one's blood had helped was considered an incentive. There current system, whereby the recipient would be unknown to the donor was seen as a disincentive:

"...your blood goes off and you never find out about it, well that's just a bit... disheartening I guess. Maybe lose the importance and actual relevance of it" – P10: male, 40.

<u>'Family comes first'</u>: For some participants, the needs of their family came before the needs of others – an attitude that was attributed to Indian culture by the participants. It meant that participants were willing to donate blood for their family where they otherwise would not have donated (e.g. due to the fear of needles):

"Well I guess the main thing is the family, close-knit tradition of Indian people – your family would come first before the general population ... if it's the case that your family would require something, then yes, you'd give it up for them" - P7: male, 26

<u>Help for all</u>: Some participants held a view which contrasted those aforementioned: they believed that blood should be given regardless of who the recipient is, because anyone who is in need of help should receive it:

"...not just friends and family. Anyone who's come into trouble needs help" – P1: female, 58

Theme 5: DONOR MATTERS

This theme explores how participants anticipated they would feel about receiving a blood transfusion should they need one in the future.

<u>Preference for family donors</u>: Participants expressed a preference to receive blood that was donated by a family member over blood donated by a stranger, mainly because it felt more natural and safer.

"with family I'd feel like it'd be more safe and natural" – P9: male, 23. "stranger's blood seems more dangerous" – P1: female, 58.

<u>Donor's health matters</u>: There was concern about the health of the donor, in part due to the fear of acquiring a blood-borne disease. Moreover, there was the desire to know that the donor's health had not been adversely affected by the donation; that the recipient had not benefitted at the cost of the donor's health.

"If someone I knew wanted to give it [blood], I'd just feel more accepting from them than from someone I didn't know... More just because I know them, I know that they're ok with it, and that they're still healthy and ok after the donation" – P9: male, 23

<u>Donor's character matters</u>: Participants expressed a preference for 'a good person' as the donor of the blood they were receiving: They did not want to associate themselves with someone of 'bad' character, even through the means of a blood transfusion.

"it just wouldn't sit right with me to have their parts in me... I wouldn't want to associate my life with that type of badness" – P5: male, 27.

This participant regarded donor anonymity positively, as the recipient would not know if the donor was 'bad', and therefore could feel comfortable with the blood they received, following the 'ignorance is bliss' proverb.

<u>Feelings towards the donor</u>: Participants expressed that they would feel grateful towards the donor, and disliked that donor anonymity prevented them from expressing their gratitude to the donor.

"... I actually think I'd feel more indebted to them because they're a stranger who owes me nothing, and get's nothing out of it apart from the knowledge that they're helped save a stranger. In a way that's [donor anonymity] a bit annoying because you'd want to know who they are so you could do something for them, even if it was just to say thank you and tell them you appreciated it." – P9: male, 23

DISCUSSION

Discussion of results

Participants had a pragmatic view regarding the function of blood: it was seen to serve a functional purpose, carrying nutrients around the body, but not individual character or personality. In previous studies, it was found that those who viewed blood in a functional manner ('body as machine') were more inclined to donate organs (13), which raises the question as to why this view was so common amongst Indian non-donors, (albeit that in this case the donation was of blood not organs). This could be explained by the phenomenon of cathexis, which Belk (1990) describes as "the charging of an object...with emotional energy": those who placed greater cathexis on their body parts felt a greater attachment to these parts and so were less willing to donate. It could be that Indian non-donors, despite seeing blood as having a mainly mechanical function, place greater cathexis on blood, thus rendering them less inclined to donate. This greater cathexis could be accredited to the large role of culture in influencing the attitudes of participants in this study toward blood: it was a symbol of familial connections and extra-familial kinship. This would explain the emotional attachment and value placed on blood, and therefore the lack of willingness to donate.

The findings within the second and third themes, *blood as a 'good thing'* and 'donation disincentives', correspond with many of the positive and negative motivators for donation identified in previous studies (9, 11, 14, 15). Interestingly, this study found that some non-donors believed that blood donation could have benefits to their own health. Previous studies have found such belief in personal benefit to be a significant predictor of blood donation (16) which suggests that this population contains an untapped pool of potential donors.

It is important to highlight that this study did not uncover the same false beliefs which were reported in the study carried out in India (accelerated ageing; infertility and loss of vitality; permanent weakness and anaemia) (9). Although one participant in this study identified lack of blood after donation as a disincentive due to the negative health effects, it was acknowledged that this was only temporary. This could be the result of a difference in cultures, as Indians living in England will have a different culture to those in India as a result of 'enculturation' (17). Another possibility is that the small sample size of this study did not reveal these false beliefs held by a very small minority.

Overall, blood donation was regarded in a very positive manner, which raises the question of why participants had not donated. Although all participants agreed that blood donations were necessary, there was a lack of knowledge as to why they were necessary, who could donate, where to donate and what the process entailed: This, combined with lack of accessibility to donation services, and social norms favouring not donating, explains in part why these participants were non-donors. Amongst the participants who were keen to donate, advertisements were identified as positive influences and helpful reminders. However it was noted that these were too infrequent and so participants' desire to donate blood would 'slip from their mind' as their busy lifestyles and other commitments took over. This suggests that there is a need for more advertisements about blood donations in order to: raise awareness

 about why donations are necessary; inform the population about how to donate; and also to serve as a reminder.

Interestingly, two opposing views emerged in discussion: a preference for donations to be given to family members, and the belief that blood should be given equally to all without discrimination. For those holding to the former stance, the current system, whereby blood is donated into an anonymous 'pool' and then redistributed amongst the population, would be undesirable as they would not be able to influence whom the recipient would be. This ties in with the desire amongst participants to see or know about the results of their donation, i.e. how their donation has helped save a life, as the current system would be undesirable to them in this respect also, as no such information is available about individual donations.

The role and influence of the family with regards to blood was a recurrent concept throughout the core themes: blood symbolised family; family created the behavioural norm; family members' concerns acted as disincentives to donate; there was a preference to donate blood to family, and receive blood from family too. Previous studies had also found a connection between family influence and blood donation (10, 18), but tended to focus on the family's positive impact on encouraging a person's decision to donate. This study identified that family could have a negative impact too, dissuading the participant from donating by expressing their concerns about the participant's wellbeing. According to previous research about the Theory of Planned Behaviour, the subjective norm (i.e. the perceived social approval of an action or non-action) is one of the major determinants of intention to donate (19) – it may be that family members' concerns contribute significantly to the subjective norm of this population and this has a great influence on their decision.

Limitations

The convenience sampling techniques and small sample size mean that views of groups not included in the sample may not have been identified, especially as the term 'Indian' includes people of a diverse mix of races, religions and beliefs. It is also important to mention that all participants were recruited when they came into the practice, and so this sampling technique will not have included the beliefs of people who do not consult their GP. It is possible that these members will have had different characteristics, such as differences in their perceived vulnerability to illness, health seeking behaviours and their "locus of control" (20), which could have led to a different beliefs . Furthermore the lack of translation facilities may have resulted in the study not capturing the beliefs of non-English speaking Indians who may have different beliefs.

It is also important to mention that the DJ was also Indian. In some ways this proved to be advantageous for this study: the researcher had a working understanding of the culture so this aided interpretation; some participants mentioned that they felt more comfortable to express culture-bound views freely; participants occasionally unintentionally conversed in their native language which DJ understood. On the other hand, this could have also had negative implications: the participants may have felt it necessary to give answers that they thought were 'culturally correct'.

Conclusion

This research suggests that there is a positive attitude towards blood donation in this sample of the population of Indian origin living in the UK. However, it uncovered a variety of factors (including lack of awareness and accessibility, a high degree of 'emotional charge' on blood, the preference to donate blood to known recipients) previously unidentified in the literature which may been important in helping to understand why donation rates are lower in this population. This suggests a need for further quantitative research to be undertaken to explore their generalizability among Indians living in the UK.

ACKNOWLEDGMENTS

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Footnotes

Contributors: DJ and RM were both involved in all of the following stages: design of the study; analysis and interpretation of the data; writing up the report; final approval of the version to be published. DJ carried out the interviews.

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Competing interests: None declared.

Ethics approval: Ethical approval was granted by East of Scotland Research Ethics Service. Written and verbal informed consent was obtained from participants. The interviews were conducted privately and the participants' transcripts were anonymised.

Data sharing statement: No additional data are available.

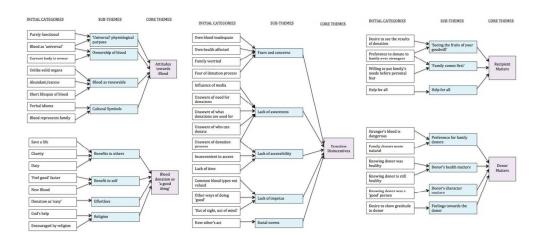


Figure 1. Coding Tree

113x50mm (300 x 300 DPI)

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Item No. Guide Questions/Description	
			Page No.
Domain 1: Research team			
and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	5
Relationship with			
participants			
Relationship established	6	Was a relationship established prior to study commencement?	5
Participant knowledge of	7	What did the participants know about the researcher? e.g. personal	5
the interviewer		goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator?	5
		e.g. Bias, assumptions, reasons and interests in the research topic	3
Domain 2: Study design			•
Theoretical framework			
Methodological orientation	9	What methodological orientation was stated to underpin the study? e.g.	
and Theory		grounded theory, discourse analysis, ethnography, phenomenology,	6
		content analysis	
Participant selection			•
Sampling	10	How were participants selected? e.g. purposive, convenience,	E
		consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail,	5
		email	
Sample size	12	How many participants were in the study?	5
Non-participation	13	How many people refused to participate or dropped out? Reasons?	5
Setting			•
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	6
Presence of non-	15	Was anyone else present besides the participants and researchers?	5
participants			5
Description of sample	16	What are the important characteristics of the sample? e.g. demographic	7
		data, date	/
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot	6
-		tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	N/A
Duration	21	What was the duration of the inter views or focus group?	6
		Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or	6

Торіс	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and	•		•
findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	6
Description of the coding	25	Did authors provide a description of the coding tree?	6, figure 1
tree			o, ligure i
Derivation of themes	26	Were themes identified in advance or derived from the data?	6
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?	7-13
		Was each quotation identified? e.g. participant number	7-10
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-13
Clarity of major themes	31	Were major themes clearly presented in the findings?	8
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	8
	ı		1

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Views & Attitudes towards Blood donation: A Qualitative Investigation of Indian non-donors living in England

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Views & Attitudes towards Blood donation: A Qualitative Investigation of Indian non-donors living in England

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ABSTRACT

OBJECTIVE:

To explore the views and attitudes of Indians living in England on blood donation.

BACKGROUND:

In light of the predicted shortages in blood supply, it is vital to consider ways in which to maximise donation rates. This includes addressing the issue of lower donation rates amongst ethnic minorities, including Indians. However research specifically amongst minority ethnicities in UK is sparse.

SETTING:

General Practice in North London

PARTICIPANTS:

A convenience sample of 12 non-donor Indians living in England.

METHOD:

A qualitative investigation involving semi-structured interviews. Themes derived were analysed using thematic framework analysis.

RESULTS:

Five key themes emerged from the data, and these concerned participants' perspectives regarding: Attitudes towards blood; Blood donation as a 'good thing'; Donation disincentives; the Recipient matters; the Donor matters.

CONCLUSION:

A variety of attitudes presented, but were generally positive and blood was conceptualised in a manner previously found to be consistent with donation. However, lack of awareness and accessibility were prominent barriers, indicating the need for improvement in these capacities. In contrast to this, blood was also greatly associated with family and acted a symbol of kinship: such degrees of 'emotional charge' often act to dissuade one from separating with their blood through donation. Possibly due to this, there was also a strong preference for donated blood to be distributed within the family, as opposed to strangers: This presents a potential barrier to blood donation for some Indians within the current system in which donations are given to unknown recipients.

ARTICLE SUMMARY

Strengths and Limitations of the study:

- Both authors independently analysed the data and the themes identified by DJ and RM were compared and agreed upon.
- The convenience sampling techniques and small sample size mean that views of groups not included in the sample may not have been identified.
- Although there were only 12 participants, there was a diverse range, from 18-80 years old, at least 3 ethnic groups and 3 religions.
- Lack of translation facilities may have resulted in the study not capturing the beliefs of non-English speaking Indians who may have different beliefs.
- The interviewer (DJ) was also Indian which may have had some negative implications, however in practice was found to be advantageous as participants commented that they felt more able to express culture-bound views.

INTRODUCTION

With the ageing population, the demand for blood products has been predicted to increase dramatically (1) with a 29% increase in demand for blood products within the NHS between 2004 and 2029, principally because the elderly have a 9-fold higher demand for blood transfusions than those younger (2). The ageing population also means that the proportion of the population eligible to donate blood will decrease, due to the national age limit placed on first-time donors (3). This increasing disparity between the supply and demand of blood products indicates imminent shortfalls in provision.

Current donation rates are sufficient to meet the existing demand (4) but ethnic minorities are greatly underrepresented amongst those donating: Indians account for 2.5% of the population of England and Wales, yet only contribute 0.74% of all donated blood (5, 6). To the best of our knowledge, no studies have been carried out to investigate the reasons behind the disparity in donation rates amongst different ethnicities in the UK.

Lower donation rates amongst ethnic minorities are common outside the UK also, and there have been studies investigating to that effect. These revealed beliefs of perceived social exclusion and distrust in the governing systems to be amongst some of the factors contributing to the lower donation rates (7, 8). Although useful in highlighting potential beliefs of ethnic minorities in the UK, the results cannot be extrapolated to account for neither the situation in the UK, nor the beliefs of its population.

A study in North India found nearly 23% of non-donors reported false-beliefs about blood donation, including views that blood donation could lead to: accelerated ageing; infertility and loss of vitality; permanent weakness and anaemia (9). It is necessary to investigate whether these views also exist within the UK population of Indians because, if so, these false beliefs could be addressed through education programmes aimed at this population, which may lead to increases in donation rates.

A study carried out in South India investigated the factors influencing voluntary blood donation, and reported the vast majority had been prompted to donate by religious leaders (92.5%) or family members (57.1%) (10). This contrasted with results from a study carried out in USA, which had the same investigative focus, but found only 20.7% of blood donors who self-identified as 'Asian' were encouraged to donate by a family member (11) - although admittedly the term 'Asian' encompasses many more ethnicities than 'Indian' alone. This gives some indication as to the differences which exist amongst Indians living in different countries, supporting the case for an investigation into the beliefs of Indians within the UK.

In this study, we aimed to investigate the views of non-donor Indians living in the UK towards blood and donation, to shed some light as to why the blood donation rates are lower amongst Indians than the national average. In turn, this may provide useful information which could be used to encourage donations among Indians living in the UK in the future, and help alter the unfavourable trajectory of predicted blood supply in the UK, narrowing the gap between supply and demand.

MATERIALS AND METHODS

The study design was a qualitative investigation involving semi-structured, private, face-to-face interviews examining the beliefs of non-donor Indians living in the UK concerning blood transfusion. The principal researcher (DJ) was at the time a third year female medical student of Indian descent who carried out the research as part of an intercalated bachelor of science. RM supervised the research.

Before the recruitment process was commenced, Ethical approval was sought from East of Scotland Research Ethics Service and granted in February 2015.

Participant Recruitment

Patients were recruited through a General Practice in Northwest London, as a large proportion of registered patients had already self-identified as 'Indian'. Convenience sampling was carried out and all potential participants were previously unknown to the researchers, and were approached about participating in the study when they came for an appointment with the GP or nurse. Participants were included if they were over 18 years of age and self identified as 'Indian' or 'British Indian' (in order to mimic the ethnicity identification process employed by donation services). Patients were excluded if: they had donated blood before; had previously tried to donate blood and been rejected due to medical reasons; or already knew they could not donate blood due a medical reason. The purpose for this was that the study aimed to investigate the views of the 'untapped resource' of potential donors. Unfortunately, patients also had to be excluded if they could not speak English – this was due to lack of funding for interpreters. The aims of the research were explained to the participants prior to the interviews.

In total, 12 participants were recruited between February – April 2015. Recruitment was carried out alongside data collection, and ended when DJ felt that data saturation had been achieved. 8 patients were approached who met the participant criteria, but refused to participate (see Table 1).

Rejection	Sex	Age	Occupation	Reason for
no.				declining
1	M	unknown	unknown	unknown
2	M	43	unknown	Did not have time
3	F	49	Teacher	Did not have time
4	M	unknown	unknown	unknown
5	F	23	Supermarket cashier	Did not have time
6	F	37	Housewife	Did not have time
7	F	unknown	unknown	unknown
8	F	unknown	unknown	unknown

Table 1. *Patients who declined participation in the study*

Data collection

Interviews were carried out by DJ in a room at a North London GP practice and recorded for transcription later on. An interview schedule was used which included prompts for conversation topics based on existing literature and two pilot interviews. The audio recordings of the interviews were transcribed verbatim, and then checked twice to ensure accuracy by the researcher, but were not returned to participants for checking. Interviews lasted 20-30 minutes.

Data analysis

The 'Thematic Framework' method of analysis (12) was used and therefore, in accordance with this, analysis occurred in five steps:

- 1. *Familiarisation with the raw data,* achieved by re-reading the transcripts and field notes to create a list of recurrent concepts.
- 2. *Identification* of the thematic framework, which entailed identifying recurring subthemes.
- 3. *Indexing* the transcripts according to the subthemes identified.
- 4. *Charting* and rearranging the data into the area of the thematic framework to which they related.
- 5. *Mapping and interpreting* the data. This involved the interpretation and categorisation of the charts of data collected, in order to create broader themes from the subthemes.

Analysis began soon after the first interview. By carrying out data collection and analysis concurrently, it was possible to employ an iterative approach to the investigation, such that findings were used to shape the discussion in subsequent interviews. As the interviews progressed, data was analysed in comparison to the initial findings, and new themes added where necessary, in line with the 'constant comparison' method (12). The second author (RM) independently analysed the data. The themes identified by DJ and RM were compared and found to be similar. After minimal discussion a final list of themes and subthemes was agreed (see Figure 1 for coding tree)

RESULTS

Sample characteristics As four participants expressed a wish to be interviewed as pairs, there were 10 interviews in total. The demographic characteristics of the sample are given in Table 2.

Interview	Participant	Gender	Age (years)
no.	identification		
1	1	F	58
2	2	F	80
3	3f	F	61
	3m	M	37
4	4f	F	29
	4m	M	33
5	5	M	27
6	6	M	37
7	7	M	26
8	8	F	18
9	9	M	23
10	10	M	40

Table 2. Sample characteristics

Five participants identified themselves as Gujarati, two as Marathi and one as Punjabi. The ethnicity was not available for 4 participants. Eight participants identified themselves as Hindu, one as Moslem and one as Jain. The religious identity was not available for 2 participants.

Themes

Five core themes were identified, each with their own subthemes (Table 3).

Core Theme	Subtheme
THEME 1:	'Universal' Physiological purpose
Attitudes towards Blood	Ownership of blood
	Blood as renewable
	Cultural symbols
THEME 2:	Benefit to others
Blood donations as 'a good thing'	Benefit to self
	Effortless
	Religion
ТНЕМЕ 3:	Fears and Concerns
Donation Disincentives	Lack of awareness
	Lack of accessibility
	Lack of impetus
	Social norms
THEME 4:	'Seeing the fruits of your goodwill'
Recipient Matters	'Family first'
	Help for all
ТНЕМЕ 5:	Preference for family donors
Donor Matters	Donor's health matters
	Donor's character matters
	Feelings towards the donor

Table 3. Results: 5 Core themes and their respective subthemes

Theme 1: ATTITUDES TOWARDS BLOOD

This theme addresses how participants conceptualized blood; what they understood to be the functions and properties of blood; the significance and meaning they attributed to it.

<u>'Universal' Physiological Purpose</u>: All participants stated that blood had a functional purpose to deliver nutrients around the body, and did not carry any characteristics specific to the person.

"I think the fact that my blood can work in another person's body – for me that just proves that there isn't much to it. It's just there to do a job. It's quite a universal substance" – P10: male, 40

<u>Ownership of blood</u>: Generally, participants believed that they had ownership over the blood in their body, and that ownership was transferable i.e. through transfusion:

"It belongs to the person ...the house essentially that is carrying it" – P5: male, 27

However, there was a contrasting belief that blood was a universal substance that everyone had a right to, hence could not be subject to claims of ownership:

"There is no point going into it whether it is yours or mine... it's just universal like water" – P4f: female, 29.

<u>Blood as renewable</u>: Blood was widely viewed as temporary and renewable, which led to a sense of indifference about blood loss:

"...something like my heart, my brain, I carry a bit more emotional attachment to it. But your blood, your body is constantly reproducing it. Like to an extent it's almost disposable." – P10: male, 40.

<u>Cultural symbols</u>: Although blood was viewed in a functional and pragmatic way, it was also considered a symbol of 'family' and 'heritage', and in that sense it acted as a common thread connecting people:

"blood symbolizes your heritage...it binds people...I do think blood does in some ways define you, beyond it's functional value" – P9: male, 23. This participant also mentioned the phrase 'blood brothers', and in this sense, blood represents a bond of loyalty between two people not limited to family.

An idiom in Gujarati was also identified in the discussion when a participant (P3m: male, 37) made a passing comment to his mother. Literally translated, the son asked, "I'm drinking your blood too much, aren't I?". The phrase "lohi pivu" was used, and this can be literally translated into "to drink blood", and the closest English idiom to this would be 'to get on one's nerves': it is a metaphor where by the person 'drinking the blood' is annoying or irritating the other person who is figuratively losing blood. In this instance, the phrase was used light-heartedly by a son teasing his mother. However, the phrase also alludes to the possibility that lack of blood signifies lack of calmness and self-composure, and therefore indicates the negative connotations attached to blood loss.

Theme 2: BLOOD DONATION AS 'A GOOD THING'

This theme describes the positive attitudes towards blood donation and explores the reasons behind this.

Benefit to others: There was a unanimous understanding that blood donation could save the life of the recipient. Donation was considered a selfless act of charity, for which repayment to the donor was not necessary:

"If someone needs blood, then it's a matter of life and death, not a matter of 'is it worth 20 quid?' so it should be given without money" – P9: male, 23

Benefit to self: There was the belief that, in carrying out this charity work, the donor would then feel good about themselves. For one participant, this 'feel good

factor' was seen as a personal benefit and believed to override the selflessness of the act:

"I think it's a big feel good factor...yeh you're helping the world... but I think the bigger factor is that you feel nice about yourself for doing something which you think is right and charitable" – P9: male, 23.

Another aspect of personal benefit of blood donation arose from the belief that after giving blood, the body could then create new blood, which would have health benefits for the donor:

"blood donation is useful for us also in creating more for later... it helps us make more blood, fresh blood" "your body feels good because you get new blood" - P6: male, 37

<u>Effortless</u>: The donation process was perceived as easy, which acted as an incentive to donate blood:

"It's something that requires very little effort because it's not like you're pulling out the blood from your veins by yourself ... you just sit there. There's no strain on the person giving blood" – P10: male, 40

<u>Religion</u>: Among participants who identified themselves as Hindu or Moslem, religion did not provide any specific advice on blood donation, but it was widely believed that blood donation, as an act of charity, would be encouraged. There was also the belief their good deed would be rewarded later by God:

"there's probably nothing to say that you should do it [give blood] but I think as an act of goodwill, it is something that religion would promote" – P9: male, 23

However, for one participant who identified themselves as Jain, religion also provided him instruction to refrain from donating blood where his own health was at risk:

"Non-violence is another key principle of ours, and I guess if you were harming yourself in the process of giving blood, well then that would go against the non-violence rule" – P7: male, 26

Theme 3: DONATION DISCINCENTIVES

This theme describes the various factors that acted as obstacles or deterrents, preventing participants from donating blood. It explores the views of those who did not want to donate, as well as those who expressed a desire to donate but had not done so yet.

<u>Fears and concerns</u>: The donation process was viewed as frightening by some: The fear of needles and low standards of hygiene were some of the worries expressed:

"they are irresponsible towards using hygienic syringes... so that fear is always there in the back of the mind" - P4f: female, 29.

There was a lack of knowledge and uncertainty about what the process entailed which made the procedure daunting:

"It's always quite intimidating...you don't know how the process goes" - P7: male, 26

There was a concern amongst participants over the potential negative effects that donation would have on their own health:

 "...there is fear that if that blood goes from our body, then what will happen to us, if that blood goes down?... then the fear is here and real... makes me think 'no I don't want to give blood'" – P1: female, 58.

Some participants felt they would be discouraged to donate by their family members who were concerned about the impact that the loss of blood would have on their health. In one case, the participant's parents were willing to donate themselves but felt that it would be too much of a risk for their children. The reasons for this were ascribed to paternal instinct and the desire to protect their children who they regarded as more vulnerable:

"I think my mum would be worried... probably because she doesn't understand that you can regenerate blood... I think any parents are always a bit worried... like you want your child to stay healthy and have the best in life... I don't think they themselves would mind giving, but they just want to protect their children from everything" – P9: male, 23

Discussion also revealed that some participants felt that their own blood would be inadequate for donation, due to the concern of passing on their own medical conditions to the recipients:

"And another thing that I'm scared of about giving blood, is that in giving blood we don't know what illness we have in our body that we would end up giving to other people" – P1: female, 58

<u>Lack of awareness</u>: There was a general awareness of the high demand of blood, however the majority of participants believe that transfusions were only required in emergency situations and surgery: Participants were unaware of the need for transfusions for people with chronic conditions.

"I only know about blood transfusions for people who have lost blood... in surgery or gun wounds... those kind of emergency situations" – P9: male, 23 Furthermore, there was a lack of awareness of the need for human donors: one participant explained the view of a family member who believed that human donors were unnecessary as blood used in transfusions was made artificially in a laboratory:

"I know some family who think that... yeh, they just have a misperception that blood can be made in a pharmacy lab" - P10: male, 40

<u>Lack of accessibility</u>: Participants who expressed a desire to donate identified a lack of accessibility as an insurmountable obstacle in donating. This included: lack of knowledge where to donate and the steps to initiate the donation process; inconvenient times available for donation (which meant missing time at work). Overall, it was regarded as a long and inconvenient process, which deterred them from donating.

"It just always seems like an inconvenience to doing it [donating blood]...I don't really know how to make that step to actually give blood. It doesn't seem like it's very clearly explained" – P10: male, 40

<u>Lack of impetus</u>: Participants expressing a desire to donate found that it often just 'slipped their mind' and they forgot about it, mainly due to their busy lifestyles. Public media and advertisements were identified as effective reminders, however they were too infrequent and their message was soon forgotten:

"...it's not so much that I'm anti-donation, it's more that I haven't had the chance to. So like 'out of sigh out of mind' type of thing, you know" – P9: male, 23

"I think the advertisements like on the TV, television, there should be more. That is what makes me want to go, but I don't see them anymore and I forget. Too many things in my life" – P6: male, 37

For one participant, the desire to donate blood was diminished by the preference for other acts of selflessness considered more challenging, such as feeding the homeless. This stemmed from the belief that selflessness could only be achieved through performing demanding tasks, and blood donation was considered too effortless:

"I wouldn't feel good if I gave blood because I've not put that effort in...In my opinion there's no quick way to do a good deed. If it's quick, then it's not good enough. You're sort of cheating by doing that... selflessness can't come so easily" – P7: male, 26

<u>Social norms</u>: Participants acknowledged that donation was uncommon amongst Indians and attributed this to the culture: blood donation was not considered the 'normal' thing to do. Although this did not prevent participants from donating, it also did not act to promote donation:

"I guess you learn things from your family and those around you... you end up doing as they do. It's inevitable. I don't think my family would stop me from donating blood, but you know, it's just not something they've ever done themselves" – P5: male, 27

Theme 4: RECIPIENT MATTERS

This theme explores the participants' views on what would be important to them should they donate blood in the future.

<u>'Seeing the fruits of your goodwill'</u>: There was a widespread preference to know about how their blood had helped someone else, and knowing how one's blood had helped was considered an incentive. There current system, whereby the recipient would be unknown to the donor was seen as a disincentive:

"...your blood goes off and you never find out about it, well that's just a bit... disheartening I guess. Maybe lose the importance and actual relevance of it" – P10: male, 40.

<u>'Family comes first'</u>: For some participants, the needs of their family came before the needs of others – an attitude that was attributed to Indian culture by the participants. It meant that participants were willing to donate blood for their family where they otherwise would not have donated (e.g. due to the fear of needles):

"Well I guess the main thing is the family, close-knit tradition of Indian people – your family would come first before the general population ... if it's the case that your family would require something, then yes, you'd give it up for them" - P7: male, 26

<u>Help for all</u>: Some participants held a view which contrasted those aforementioned: they believed that blood should be given regardless of who the recipient is, because anyone who is in need of help should receive it:

"...not just friends and family. Anyone who's come into trouble needs help" – P1: female, 58

Theme 5: DONOR MATTERS

This theme explores how participants anticipated they would feel about receiving a blood transfusion should they need one in the future.

<u>Preference for family donors</u>: Participants expressed a preference to receive blood that was donated by a family member over blood donated by a stranger, mainly because it felt more natural and safer.

"with family I'd feel like it'd be more safe and natural" – P9: male, 23. "stranger's blood seems more dangerous" – P1: female, 58.

<u>Donor's health matters</u>: There was concern about the health of the donor, in part due to the fear of acquiring a blood-borne disease. Moreover, there was the desire to know that the donor's health had not been adversely affected by the donation; that the recipient had not benefitted at the cost of the donor's health.

"If someone I knew wanted to give it [blood], I'd just feel more accepting from them than from someone I didn't know... More just because I know them, I know that they're ok with it, and that they're still healthy and ok after the donation" – P9: male, 23

<u>Donor's character matters</u>: Participants expressed a preference for 'a good person' as the donor of the blood they were receiving: They did not want to associate themselves with someone of 'bad' character, even through the means of a blood transfusion.

"it just wouldn't sit right with me to have their parts in me... I wouldn't want to associate my life with that type of badness" – P5: male, 27.

This participant regarded donor anonymity positively, as the recipient would not know if the donor was 'bad', and therefore could feel comfortable with the blood they received, following the 'ignorance is bliss' proverb.

<u>Feelings towards the donor</u>: Participants expressed that they would feel grateful towards the donor, and disliked that donor anonymity prevented them from expressing their gratitude to the donor.

"... I actually think I'd feel more indebted to them because they're a stranger who owes me nothing, and get's nothing out of it apart from the knowledge that they're helped save a stranger. In a way that's [donor anonymity] a bit annoying because you'd want to know who they are so you could do something for them, even if it was just to say thank you and tell them you appreciated it." – P9: male, 23

DISCUSSION

Discussion of results

Participants had a pragmatic view regarding the function of blood: it was seen to serve a functional purpose, carrying nutrients around the body, but not individual character or personality. In previous studies, it was found that those who viewed blood in a functional manner ('body as machine') were more inclined to donate organs (13), which raises the question as to why this view was so common amongst Indian non-donors, (albeit that in this case the donation was of blood not organs). This could be explained by the phenomenon of cathexis, which Belk (1990) describes as "the charging of an object...with emotional energy": those who placed greater cathexis on their body parts felt a greater attachment to these parts and so were less willing to donate. It could be that Indian non-donors, despite seeing blood as having a mainly mechanical function, place greater cathexis on blood, thus rendering them less inclined to donate. This greater cathexis could be accredited to the large role of culture in influencing the attitudes of participants in this study toward blood: it was a symbol of familial connections and extra-familial kinship. This would explain the emotional attachment and value placed on blood, and therefore the lack of willingness to donate.

The findings within the second and third themes, *blood as a 'good thing'* and 'donation disincentives', correspond with many of the positive and negative motivators for donation identified in previous studies (9, 11, 14, 15). Interestingly, this study found that some non-donors believed that blood donation could have benefits to their own health. Previous studies have found such belief in personal benefit to be a significant predictor of blood donation (16) which suggests that this population contains an untapped pool of potential donors.

It is important to highlight that this study did not uncover the same false beliefs which were reported in the study carried out in India (accelerated ageing; infertility and loss of vitality; permanent weakness and anaemia) (9). Although one participant in this study identified lack of blood after donation as a disincentive due to the negative health effects, it was acknowledged that this was only temporary. This could be the result of a difference in cultures, as Indians living in England will have a different culture to those in India as a result of 'enculturation' (17). Another possibility is that the small sample size of this study did not reveal these false beliefs held by a very small minority.

Overall, blood donation was regarded in a very positive manner, which raises the question of why participants had not donated. Although all participants agreed that blood donations were necessary, there was a lack of knowledge as to why they were necessary, who could donate, where to donate and what the process entailed: This, combined with lack of accessibility to donation services, and social norms favouring not donating, explains in part why these participants were non-donors. Amongst the participants who were keen to donate, advertisements were identified as positive influences and helpful reminders. However it was noted that these were too infrequent and so participants' desire to donate blood would 'slip from their mind' as their busy lifestyles and other commitments took over. This suggests that there is a need for more advertisements about blood donations in order to: raise awareness

 about why donations are necessary; inform the population about how to donate; and also to serve as a reminder.

Interestingly, two opposing views emerged in discussion: a preference for donations to be given to family members, and the belief that blood should be given equally to all without discrimination. For those holding to the former stance, the current system, whereby blood is donated into an anonymous 'pool' and then redistributed amongst the population, would be undesirable as they would not be able to influence whom the recipient would be. This ties in with the desire amongst participants to see or know about the results of their donation, i.e. how their donation has helped save a life, as the current system would be undesirable to them in this respect also, as no such information is available about individual donations.

The role and influence of the family with regards to blood was a recurrent concept throughout the core themes: blood symbolised family; family created the behavioural norm; family members' concerns acted as disincentives to donate; there was a preference to donate blood to family, and receive blood from family too. Previous studies had also found a connection between family influence and blood donation (10, 18), but tended to focus on the family's positive impact on encouraging a person's decision to donate. This study identified that family could have a negative impact too, dissuading the participant from donating by expressing their concerns about the participant's wellbeing. According to previous research about the Theory of Planned Behaviour, the subjective norm (i.e. the perceived social approval of an action or non-action) is one of the major determinants of intention to donate (19) – it may be that family members' concerns contribute significantly to the subjective norm of this population and this has a great influence on their decision.

Limitations

The convenience sampling techniques and small sample size mean that views of groups not included in the sample may not have been identified, especially as the term 'Indian' includes people of a diverse mix of races, religions and beliefs. It is also important to mention that all participants were recruited when they came into the practice, and so this sampling technique will not have included the beliefs of people who do not consult their GP. It is possible that these members will have had different characteristics, such as differences in their perceived vulnerability to illness, health seeking behaviours and their "locus of control" (20), which could have led to a different beliefs . Furthermore the lack of translation facilities may have resulted in the study not capturing the beliefs of non-English speaking Indians who may have different beliefs.

It is also important to mention that the DJ was also Indian. In some ways this proved to be advantageous for this study: the researcher had a working understanding of the culture so this aided interpretation; some participants mentioned that they felt more comfortable to express culture-bound views freely; participants occasionally unintentionally conversed in their native language which DJ understood. On the other hand, this could have also had negative implications: the participants may have felt it necessary to give answers that they thought were 'culturally correct'.

Conclusion

This research suggests that there is a positive attitude towards blood donation in this sample of the population of Indian origin living in the UK. However, it uncovered a variety of factors (including lack of awareness and accessibility, a high degree of 'emotional charge' on blood, the preference to donate blood to known recipients) previously unidentified in the literature which may been important in helping to understand why donation rates are lower in this population. However, the heterogenous nature of the sample interviewed and the small sample size suggests the need for further qualitative research to identify additional factors that may not have arisen in this study. In addition further quantitative research needs to be undertaken to explore their generalizability of these beliefs among Indians living in the UK. This may enable community based initiatives to address these and encourage members of these communities to become donors.



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Footnotes

Contributors: DJ and RM were both involved in all of the following stages: design of the study; analysis and interpretation of the data; writing up the report; final approval of the version to be published. DJ carried out the interviews.

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Competing interests: None declared.

Ethics approval: Ethical approval was granted by East of Scotland Research Ethics Service. Written and verbal informed consent was obtained from participants. The interviews were conducted privately and the participants' transcripts were anonymised.

Data sharing statement: No additional data are available.

Figure 1. Coding tree depicting how the themes and sub-themes were formed from the initial categories found on analysis of the data.

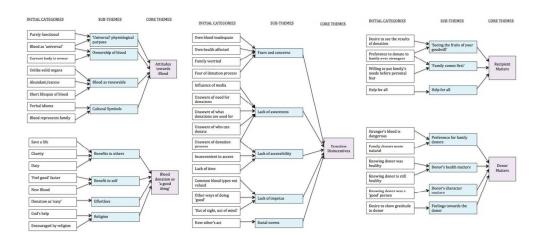


Figure 1. Coding Tree

113x50mm (300 x 300 DPI)

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Item No. Guide Questions/Description	
			Page No.
Domain 1: Research team			
and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	6
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	5
Relationship with			
participants			
Relationship established	6	Was a relationship established prior to study commencement?	5
Participant knowledge of	7	What did the participants know about the researcher? e.g. personal	5
the interviewer		goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator?	5
		e.g. Bias, assumptions, reasons and interests in the research topic	3
Domain 2: Study design			•
Theoretical framework			
Methodological orientation	9	What methodological orientation was stated to underpin the study? e.g.	
and Theory		grounded theory, discourse analysis, ethnography, phenomenology,	6
		content analysis	
Participant selection			•
Sampling	10	How were participants selected? e.g. purposive, convenience,	E
		consecutive, snowball	5
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail,	5
		email	
Sample size	12	How many participants were in the study?	5
Non-participation	13	How many people refused to participate or dropped out? Reasons?	5
Setting			•
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	6
Presence of non-	15	Was anyone else present besides the participants and researchers?	5
participants			5
Description of sample	16	What are the important characteristics of the sample? e.g. demographic	7
		data, date	/
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot	6
-		tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	6
Field notes	20	Were field notes made during and/or after the inter view or focus group?	N/A
Duration	21	What was the duration of the inter views or focus group?	6
		Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or	6

Торіс	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and	•		•
findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	6
Description of the coding	25	Did authors provide a description of the coding tree?	6, figure 1
tree			o, ligure i
Derivation of themes	26	Were themes identified in advance or derived from the data?	6
Software	27	What software, if applicable, was used to manage the data?	N/A
Participant checking	28	Did participants provide feedback on the findings?	N/A
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?	7-13
		Was each quotation identified? e.g. participant number	7-10
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7-13
Clarity of major themes	31	Were major themes clearly presented in the findings?	8
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	8
	ı		1

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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