Attitudes and beliefs among high- and low-risk population groups towards β -thalassemia prevention: a cross-sectional descriptive study from India

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Abstract β -thalassemia is an autosomal recessive blood disorder caused by gene mutations that affect all aspects of β -globin production. In majority of Asian countries including India, the frequency of β -thalassemia is closely intertwined with social, cultural, and religious issues of the respective country. Several national level screening programs imparted education regarding β -thalassemia, but follow-up evaluation revealed that education was not effective. It has been hypothesized that the beliefs and attitudes, carrier screening, and education among “high risk communities” will have far-reaching implications towards β -thalassemia prevention in the country. The present study is aimed to investigate attitudes, intention, and behavior of β -thalassemia high- and low-risk ethnic groups towards carrier screening and education. A structured questionnaire on knowledge, attitude, and practice regarding β -thalassemia was administered on 926 individuals belong to Arora, a high-risk ethnic group for β -thalassemia (347 rural (AR) and 202 urban (AU)) and 377 cosmopolitan commoners (CC) aged above 18 years of both sexes. To understand the relationship between various questions, Pearson’s correlation test and factor analysis was performed. The responses were further categorized into the theory of planned behavior (TPB) constructs with the measures of the

main constructs reported as a mean. Various dimensions of knowledge, attitude, and practice reveal that the urban groups (AU and CC) are better aware of the disease “ β -thalassemia” than the rural group (AR) who witness suffering at close quarters. The AR group is more positive for preventive measures than the urban groups. Significant correlations and factor analysis show “intentions” for premarital and prenatal screening highly loaded as outcome behaviors. The Ajzen’s “Theory of planned behavior” support that the “intention” and “perceived behavior control” are better predictors of “outcome behavior” compared to “attitude” and “subjective norm.” As this study is cross-sectional and descriptive in nature, the constructs of the theory should be considered as perceptions. However, we believe the patterns observed are indicative of “predicting behavior” that has far-reaching implications on health planners and administrators in designing β -thalassemia screening and prevention program.

Keywords β -thalassemia · Attitude · Belief · Screening · Prevention · Theory of planned behavior

Introduction

β -thalassemia is an autosomal recessive blood disorder caused by gene mutations that affect all aspects of β -globin production. The frequency of β -thalassemia is high in populations in the Mediterranean, Middle-East, Trans-Caucasus, Central Asia, Indian subcontinent, and Far East. Worldwide, there are annually about 56,000 β -thalassemia major conceptions or births (Modell and Darlison, 2008). In India, it is estimated that there are 1:2700 β -thalassemia major births with about 9000–10,000 added each year (Verma 2000). The carrier frequency for β -thalassemia varies from 0 to 5% in general Indian population (Verma et al. 1992; Mohanty et al. 2007). However, higher carrier frequency of 8–15% was documented in certain

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communities in India, such as Sindhi and Arora (Punjabi) from northern India; Bhanushali, Kutchi, and Lohana from Gujarat; Mahar (Neobuddhist), Koli, and Agri from Maharashtra; and Gowda and Lingayat from Karnataka (Madan et al. 2010; Marwaha and Lal 1994; Verma et al. 1992). Arora (Punjabis) has reported higher carrier frequency of 9.3% (Marwaha and Lal 1994). State-wise frequency of β -thalassemia major revealed that children of Punjab origin showed the highest frequency of 7.6% (Ghotbi and Tsukatani 2005). Screening for β -thalassemia trait in Punjab region revealed that 47.8% affected population belongs to Khatri and their sub-caste Arora (Garewal and Das 2003). Although two all India ICMR-task force carrier screening and education programs were undertaken among school children in metropolitan cities (Sood et al. 1993; Mohanty et al. 2007), there is no national β -thalassemia prevention program in the country. A follow-up study conducted after 20 years of the carrier screening program in Mumbai showed that the education and awareness imparted were ineffective (Colah et al. 2007).

In the majority of the developing countries of Asia, including India, the frequency of β -thalassemia is closely intertwined with the social, cultural, and religious issues of the respective country. It has been reported that attitude towards prenatal diagnosis and termination of pregnancy affected with β -thalassemia major are associated with religious practices, particularly among Muslims where prenatal diagnosis is often declined on religious grounds (Zahed and Bou-Dames 1997; Alkuraya and Kilani 2001; Ngim et al. 2013). Lack of knowledge among the general population, including high-/low-risk communities and health care professionals, about the disorder, its manifestations, survival rate, treatment availability, and psychosocial and cultural issues may cause barriers to optimal health care of the affected as well as to carrier testing of β -thalassemia (Chattopadhyay 2006).

However, high-risk communities exhibit a positive attitude for premarital screening and couple with an already affected child for prenatal diagnosis (Al Sulaiman et al. 2008). In the present study, based on the application of the “theory of planned behavior” on beliefs and attitudes, it has been hypothesized that carrier screening and education among married and premarital individuals belonging to “high risk communities” will have far-reaching implications towards β -thalassemia prevention in the country.

Materials and methods

Participants and procedures

A cross-sectional study was carried out using a structured questionnaire for the investigation. About 926 individuals of both sexes aged 18 years above were included in the study. Out of them, 549 belong to Arora, a high-risk group for β -

thalassemia (347 rural (AR) and 202 urban (AU)) and 377 cosmopolitan commoners (CC). The AR and AU subjects were recruited from house to house visits in Kalanur village of Rohtak District, Haryana state in north India, and New Delhi, respectively. CC were from hostels and colleges in New Delhi and does not belong to any high-risk populations. The questionnaire was developed and tested by us in West Bengal population in East India (Shrivastava et al. 2011) to evaluate knowledge, attitude, and practice regarding β -thalassemia, and was used in the present study. Before administering, the questionnaire was pretested on 20 subjects of each group for cultural sensitivity, to misinterpretation of questions, ambiguity of words, and modified accordingly. A positive “Yes” response to any one of the questions “have you seen a child to whom blood is given frequently?” or “have you heard the word β -thalassemia?” qualifies the subject for further administration of the full questionnaire. After evaluating the responses to qualifying questions, the sample sizes were 307, 181, and 310, respectively, for the AR, AU, and CC groups. The questionnaire comprised of five dimensions (Table 1); each dimension has a set of questions and each question was answerable with “Yes or No.” The first dimension obtained participants demographic profile, the second gathered knowledge and awareness about β -thalassemia, the third comprised of beliefs of the participants related to premarital carrier screening and prenatal diagnosis, and the fourth raised questions on social discomforts. The fifth dimension of the questionnaire dealing with practice had been administered after giving knowledge through pamphlets and presentations regarding β -thalassemia and its prevention. The questionnaire was administered in a face to face interview method by single investigator (SC). The power of the study for each group was found to be 90% (AR), 80% (AU), and 90% (CC) with a type I error of 5% ($\alpha = 0.05$) at 95% level of significance.

Institutional ethical committee of Delhi University approved the study protocol. A written informed consent was obtained before the interview. To apply the “theory of planned behavior” (Ajzen 1991), responses were accordingly grouped into respective constructs of the theory (Fig. 1 and Table 3).

Statistical analysis

All the questionnaire data were analyzed using SPSS 16 (SPSS Inc., Chicago, USA). For each dimension which was measured by multiple questions, internal consistency was determined by Cronbach’s alpha. Scoring was given for each response as NO = “0” and YES = “1” and averaging in each theoretical construct and knowledge for an individual. Pearson correlations (r) were computed on these average scores of individuals between theoretical constructs and knowledge. Factor analyses were conducted on the 21-item scale, and the principal component analysis with varimax rotation provided the clearest results to interpret.

Table 1 Responses of various dimensions of questionnaire on knowledge, social belief, social distance, and practice among the three populations studied

Z test value													
		Arora rural (AR)		Arora urban (AU)		Cosmopolitan commoners (CC)		AR × AU		AR × CC		AU × CC	
		(N = 347)		(N = 202)		(N = 377)							
S. No.	Statements	Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)	Yes	No	Yes	No	Yes	No
Qualifying													
1	Do you know anyone getting blood transfused frequently?	292 84% 18*	55 16%	74 37% 5*	128 63%	55 15% 19*	322 85%	11*	11*	19*	19*	6*	6*
2	Have you heard the word β-thalassemia?	146 42% 4*	201 58%	184 91% 17*	18 9%	339 90% 22*	38 10%	11*	11*	14*	14*	0.4	0.4
1 (a): Knowledge and awareness													
A	Do you know β-thalassemia is treatable but not curable?	64 21% 14*	243 79%	148 82% 12*	33 18%	159 51% 0.6*	151 49%	14*	13*	8*	8*	7*	7*
B	Do you know about genetic diseases?	285 93% 21*	22 7%	164 91% 15*	17 9%	253 82% 16*	57 18%	0.8	0.9	4*	4*	2*	3*
C	Do you consider β-thalassemia is genetic disease?	87 28% 11*	220 72%	148 82% 12*	33 18%	200 65% 7*	110 35%	12*	12*	9*	9*	10*	4*
D	Are you aware of β-thalassemia major?	108 35% 7*	199 65%	66 36% 5*	115 64%	37 12% 19*	273 88%	0.2	0.2	7*	6*	6*	7*
E	Are you aware of β-thalassemia minor? Do you think minor is normal?	102 33% 8*	205 67%	49 27% 9*	132 73%	38 12% 19*	272 88%	1	1	6*	6*	4*	4*
1 (b): Social belief													
F	Do you believe β-thalassemia is caused because of sin committed by parents?	38 12% 19*	269 88%	33 18% 12*	148 82%	23 7% 21*	287 93%	2*	2*	2*	2*	4*	4*
G	Do you think β-thalassemia is caused because of the defect in mother?	151 49% 0.4*	156 51%	49 27% 9*	132 73%	49 16% 17*	261 84%	0.5	5*	9*	9*	4*	3*
H	Do you think β-thalassemia is caused because of the defect in father?	65 21% 14*	242 79%	49 27% 9*	132 73%	43 14% 18*	267 86%	2	5*	2*	2*	3*	4*
I	Do you believe the β-thalassemic child makes the family life miserable?	199 65% 7*	108 35%	33 18% 12*	148 82%	49 16% 17*	261 84%	10*	10*	12*	12*	0.6	0.6
J	Do you think family is unlucky where the β-thalassemic child is born?	215 70% 10*	92 30%	32 18% 12*	149 82%	35 11% 19*	275 89%	11*	11*	15*	15*	2*	2*
K	Is it better to die than to live with a deadly disease like β-thalassemia?	81 26% 11*	226 74%	32 18% 12*	149 82%	15 5% 23*	295 96%	2*	2*	8*	7*	5*	5*
1 (c): Social discomfort													
L	Do you feel discomfort from the neighbor having β-thalassemia?	11 4% 23*	296 96%	33 18% 12*	148 82%	18 6% 22*	292 94%	5*	5*	1	1	4*	4*

Table 1 (continued)

Z test value													
S. No.	Statements	Arora rural (AR)		Arora urban (AU)		Cosmopolitan commoners (CC)		AR × AU		AR × CC		AU × CC	
		(N = 347)		(N = 202)		(N = 377)							
		Yes (%)	No (%)	Yes (%)	No (%)	Yes (%)	No (%)	Yes	No	Yes	No	Yes	No
M	Do you feel discomfort living with a person suffering from β -thalassemia?	5 2% 24*	302 98%	50 28% 9*	131 72%	56 18% 16*	254 82%	9*	9*	7*	7*	3*	3*
N	Do you feel discomfort establishing a marriage relation where someone is suffering from β -thalassemia?	280 91% 20*	27 9%	98 54% 2*	83 46%	106 34% 8*	204 66%	9*	9*	15*	15*	4*	4*
O	Do you feel discomfort accepting a life partner who is β -thalassemia minor/carrier?	301 98% 24*	6 2%	132 73% 9*	49 27%	174 56% 3*	136 44%	8*	8*	12*	12*	4*	4*
1 (d): Practice													
P	Have you ever tested for β -thalassemia?	11 4% 23	296 96%	49 27% 9*	132 73%	6 2% 24*	304 98%	8*	7*	1	1	9*	8*
Q	Would you like to go for β -thalassemia test?	285 93% 21*	22 7%	148 82% 12*	33 18%	246 79% 15*	64 21%	4*	4*	5*	5*	0.8	0.8
R	Would you like to go for a genetic test with your fiancé before marriage for β -thalassemia?	248 81% 15*	59 19%	82 45% 2*	99 55%	220 71% 10*	90 29%	8*	6*	3*	3*	6*	6*
S	Prenatal diagnosis—Would you like to adopt for this procedure if you and your spouse are β -thalassemia minors/carriers?	301 98% 24*	6 2%	165 91% 16*	16 9%	241 78% 14*	69 22%	4*	4*	8*	8*	4*	4*
T	Would you like to abort a baby when it would be diagnosed with β -thalassemia major?	296 96% 23*	11 4%	132 73% 9*	49 27%	195 63% 6*	115 -37%	7*	8*	10*	10*	2*	2*
U	Would you like to share knowledge about β -thalassemia with others?	172 56% 3*	135 44%	115 64% 5*	66 36%	271 87% 19*	39 13%	2	2*	9*	9*	6*	6*

Z scores are computed on % between and within populations based on responses of each question

Columns on the right indicate Z scores between populations (AR × AU, AR × CC, and AU × CC)

Last row of each question indicate Z scores within population

*Significance at $p \leq 0.05$

Results

Table 1 reveals responses for questions on various dimensions among the three populations studied. The measures of Cronbach's alpha for different dimensions of the questionnaire indicate good internal consistency or reliability of each dimension in all the groups except for the social discomfort (0.457) and practice (0.692) dimensions in AR (Table 2). Although a large proportion of AR does not know the word “ β -thalassemia,” they are more familiar to persons needing frequent blood transfusions, whereas the AU and CC groups are

more aware about “ β -thalassemia” disease and its nature. In our study, a fraction of the participants failed to differentiate the major and minor forms of β -thalassemia. Approximately 50% of the AR group believe that defect in mother is the main cause, and also think that the family is miserable and unlucky with a β -thalassemia major child. The majority of respondents from all the groups are assertive that there is no discomfort living as neighbor to or with a β -thalassemia major person, but expressed strong reservation in terms of establishing marriage alliance or marrying from a family with β -thalassemia major sufferer. It is indeed alarming to find that a large number of AR

Fig. 1 Diagrammatic representation of various constructs of the “Theory of planned behavior” with knowledge as external variable. Note: The responses of questions given in the Table S1 that are included in different constructs of the theory of planned behavior are as follows: R, N, and O (subjective norm); P and Q (perceived behavioral control); F, G, H, I, J, K, L, and M (attitude towards behavior); T and U (intention); and R and S (outcome behavior)

Note: The responses of questions given in the table S1 that are included in different constructs of Theory of planned behavior are: R N O (Subjective Norm), P Q (Perceived Behavioral Control), FGH I J K L M (Attitude towards Behavior), T U (Intention) R S (Outcome Behavior).

(96.4%) and CC (98.1%) are not tested for β -thalassemia carrier status, whereas among AU (72.9%), the number is moderate, though all of them in large percentages are willing to be tested. Positive attitude towards premarital and prenatal screening and to abort the affected fetuses is found in all sections of the population. Higher proportions of AU (54.7%) are not willing for premarital screening compared to those of AR and CC. Further, preference for abortion is the highest in AR (96.4%) followed by AU (72.9%) and CC (62.9%). Furthermore, large numbers of CC are willing to share knowledge about β -thalassemia with others, whereas half of the AR and AU groups are not willing to share the same.

Significant correlation coefficients between responses of almost all questions within and across dimensions in the three studied populations (Table S1) reveal underlying relationships of social behavior patterns. Factor analysis conducted on the

21 items with varimax rotation produced four distinct and coherent factors explaining 77.8% of the variance (Table S2). The weightings and details on factor loading show factor 1 intention to outcome behaviors like premarital and prenatal screening, factor 2 social discomfort, factor 3 practice, and factor 4 knowledge.

Responses categorized into various theoretical constructs of the theory of planned behavior and correlation values (r) indicate that, “intention” predicts “outcome behavior” in all the population groups. However, the correlation is slightly weak in AR (0.647) compared to that in AU (0.727) and CC (0.863). Similar trend was also found with respect to prediction of “outcome behavior” by “perceived behavioral control.” The contention of resources and opportunities gains strength with very weak and negative correlation values of “attitude” (personal factor) and “subjective norm” (social factor; in the present case, social stigma) with “intention” in all the populations. Correlation values obtained with knowledge as external variable to the theoretical constructs is the least or negative in all the population groups studied (Table 3).

Table 2 Reliability analysis between the responses of different dimensions of the instrument

S. No.	Sections	AR	AU	CC
1	Knowledge	0.891	0.817	0.801
2	Social belief	0.874	0.974	0.946
3	Social discomfort	0.457	0.809	0.769
4	Practice	0.692	0.864	0.891

All values are Cronbach’s alpha values

AR Arora rural, AU Arora urban, CC cosmopolitan commoners

Discussion

In the present study, the relative acquaintance of β -thalassemia major is more in the high-risk population group (AR) than that in the low-risk groups. The factor analysis between different questions on various dimensions validated

Table 3 Correlation values (*r*) between different constructs of the “Theory of planned behavior” and “knowledge” as external among the three populations studied

Variables	Arora (rural)	Arora (urban)	Cosmopolitan
Theory			
Outcome behavior			
Intention	0.647*	0.727*	0.863*
Perceived behavioral control	0.565*	0.767*	0.870*
Intention			
Attitude towards behavior	0.152*	0.054	−0.148*
Subjective norm	0.129*	−0.848*	−0.371*
Perceived behavioral control	0.490*	0.717*	0.774*
Attitude towards behavior			
Subjective norm	0.189*	−0.024	0.252*
Perceived behavioral control	−0.110*	0.102	−0.260*
Subjective norm			
Perceived behavioral control	−0.203*	−0.521*	−0.189*
External			
Knowledge			
Outcome behavior	−0.408*	−0.854*	−0.778*
Intention	−0.636*	−0.765*	−0.829*
Perceived behavioral control	−0.445*	−0.963*	−0.732*
Attitude towards behavior	0.261*	−0.089	0.278*
Subjective norm	−0.123*	0.562*	0.590*
Gender	0.875*	0.712*	0.835*
Age	0.611*	0.849*	0.360*
Education	0.765*	0.808*	0.659*
Occupation	0.704*	0.858*	0.410*
Family income/month	0.698*	0.792*	0.876*

Note: The scoring of all responses in constructing theoretical variables are taken as positive

For example, in subjective norm, the construct “no stigma” is taken as positive

*Significance at $p \leq 0.05$

objective of our study questionnaire with heavy loading on factor 1 for intention towards outcome behavior followed by social discomfort, practice, and knowledge. This has been corroborated by other studies in multi-ethnic Asian society (Wong et al. 2011a), Bahrainis (Al Hajeri and Al Arrayed 2012), and rural West Bengalis of India (Shrivastava et al. 2011). Further, in rural settings, the disease etiology is mainly depending on the orthodox feelings such as sins committed by the parents (Shrivastava et al. 2011).

The national β -thalassemia minor screening programs around the world have provided a platform for increased awareness and education in screened populations. Confusion over differences between β -thalassemia minor and β -thalassemia major, inheritance patterns, and specific physical and psychological effects underscores lack of true understanding (Wong et al. 2011b). Peer education is an effective means of disseminating health information throughout the community, and it has been a cornerstone of effective HIV prevention programs (Comish and Campbell 2009).

Preference to prenatal diagnosis and termination of pregnancy are mainly determined by perceived religious and cultural restrictions of the society (El-Hazmi 2009). In Chinese and Indians, termination of pregnancy is not taken into consideration due to complex web of moral, cultural, and traditional religious values of family and community (Wong et al. 2011a). South Asian and socioeconomically disadvantaged women with positive attitudes towards undergoing the prenatal screening for Down syndrome were less likely to make an informed choice than other women (Dormandy et al. 2005).

Strong correlations between questions of various dimensions and factor analysis showed the importance of “intentions” for premarital and prenatal screening as outcome behaviors. Further, the relation between intentions and outcome behavior is examined in light of the theory of planned behavior. For the purpose of understanding, we have added “knowledge” dimension as external variable. The correlation values obtained for predicting “outcome behavior” is much higher for “intention” and “perceived behavioral control” in this study due to perceived

social context and psychological implications of this genetic disease. Investigation of attitudes, intention, and behavior of general practitioners and midwives in the Netherlands revealed the differences in their attitude towards the ethnicity-based registration (Jans et al. 2012). On the other hand, “attitudes” and “subjective norm” are found to be better predictors of “intention,” in case of clinical screening for cancer risk (Devellis et al. 1990), breast and testicular self-examination (McCaul et al. 1993,) and mammography (Montano and Taplin 1991).

In summary, application of the “theory of planned behavior” reveals “intention” as important predictor of “outcome” in urban groups compared to rural group. The intention is not influenced by “attitude” and “subjective norms.” Further, perceived behavioral control is predicting the “intention” and “outcome behavior” independently. As there exists a gap between intentions and actions, altering “intentions” may not be sufficient to change the actual behavior (Orbell and Sheeran 1998). Creating facilities and strong education and awareness programs with more emphasis in rural areas will have positive effect in the prevention of the disease. Cross-sectional and descriptive nature of the study has limitations in terms of the constructs of the theory that are considered as perceptions. However, we believe that the patterns observed both by factor analyses and determinants of the Ajzen’s “Theory of planned behavior” ingrained in social psychology of human behavior (Liska 1984) are indicative of predicting behavior that has far-reaching implications in β -thalassemia prevention. The conclusions of the study, we hope, will have a bearing on health planners and administrators.

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Conflicts of interest The authors declare that they have no conflict of interest.

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