‘Rakter dosh’—corrupting blood: The challenges of preventing thalassemia in Bengal, India

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Abstract

Thalassemia is an inherited blood disorder that has been receiving increasing attention in India. However, prevention of thalassemia in India continues to be difficult despite efforts of public health professionals and the government. Using West Bengal as a case study, this paper attempts to unravel some of the barriers to the prevention campaign and the consequent under utilization of the program. Lack of access, low awareness, low-risk perception and poverty are all important proximate constraints; however, one of the greatest barriers to the program is rooted in cultural notions of blood, marriage, identity, personhood and kinship in Bengali society. Blood is so deeply valued in the Bengali kinship system that this genetic mutation is perceived to be corrupting the blood (rakter dosh). Being a thalassemia carrier (i.e., having thalassemia minor) renders an individual unfit as a suitable marriage partner because of beliefs related to purity of blood, its association with the continuity of the lineage, and subsequent transmission of desirable traits to future generations. The risk of non-marriage affects women disproportionately, and parents are not inclined to test their daughters because of the possibility of not being able to marry them off to eligible suitors. The stigma associated with having thalassemia minor (TMI) is a deterrent to the disclosure of thalassemia status as well as to testing. Using anthropological theories and ethnographic methods, this paper focuses on the gendered process by which the diagnosis of a thalassemia carrier ‘spoils’ identities, thereby creating a disjuncture between the goals of the prevention program and people’s need for social conformity, and ultimately between medical desirability and social desirability. The paper also suggests policies for enhancing the utilization of the program. Finally the conclusions from this study have potential applications for public health prevention programs that confront problems of stigma in program acceptability.

Keywords: India; Thalassemia; Marriage; Gender; Genetic screening; Public health program

Main text

Thalassemia is a hematological disorder that belongs to a heterogeneous group of single gene disorders occurring due to an absence or reduction of hemoglobin synthesis. Thalassemia can be categorized into three classes depending on clinical expression: thalassemia major (TMA), a severe disorder leading to transfusion dependence; thalassemia intermedia (TI), relatively milder involving less transfusion dependence; and thalassemia minor (TMI), where individuals carry the heterozygous mutation but do not exhibit any of the symptoms and usually do not require blood transfusion.1 If both parents have TMI there exists a 25%

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probability in each pregnancy that their child will have TMA, a 50% probability that the child will have TMI and a 25% probability that a child will have neither mutation (Weatherall & Clegg, 1981, 2001). The classification of TMA or TMI also depends on the age of onset of symptoms, degree of anemia, age when first transfused, transfusion requirements per year, and growth or enlargement of the spleen (Colah et al., 2004).

Thalassemia is not uncommon among people of Asian descent, occurring at a higher rate among certain communities including Punjabis, Assamese, Gujaratis, Sindhis, Marwaris and Bengalis. It is estimated that globally there are 200 million people with thalassemias or similar hemoglobinopathies, primarily in the Mediterranean countries, Asia, parts of North and West Africa, and parts of Eastern Europe. India has nearly 30 million thalassemia carriers and of the 100,000 children born with thalassemia annually, 10,000 are born in India. Though there are many variants of thalassemia, beta thalassemia is most commonly found in the Indian subcontinent. Thalassemia cannot be cured, only managed; bone marrow transplantation has been successful in the management of TMA and reduces (sometimes eliminates) dependency on transfusions. However, this procedure is expensive, risky, and difficult to perform, and success rates are discouraging in India. Excess iron deposited in the body during transfusions needs to be chelated with the aid of injections of drugs like desferal, through a pump for up to 12 h each day sometimes up to seven nights a week. This is a very burdensome, painful (and expensive) procedure and premature deaths result from inadequate chelation. Complications from TMA include diabetes, delay or failure to enter puberty, and infections acquired through blood transfusions such as hepatitis C and HIV/AIDS. Even with the advantages of good medical care and a high standard of living, patients cannot expect to have the full life expectancy of an average adult, and premature deaths are not uncommon.

A literature review of the social and cultural issues associated with thalassemia screening and prevention reveals that most of the studies focus on immigrant populations living in Europe or in the Mediterranean region (Anionwu & Marteau, 1996; Angastiniotis & Hadjiminas, 1981; Atkin, Ahmed, & Anionwu, 1998; Firdous & Bhopal, 1989; Giordano, Dihal, & Harteveld, 2005; Gill & Modell, 1998; Henneman et al., 2001; Modell et al., 1998; Streetly, 2000) with the notable exceptions of Iran (Samavat & Modell, 2004), Thailand (Hartwell, Boonraksa, Kongtalwert, Christian, & Grudpan, 2004) and Pakistan (Ahmed, Mohammed, Modell, & Petrou, 2002). A majority of these studies have been conducted in hospital settings with small groups of people seeking genetic counseling or during prenatal check-ups. The findings from these studies underscore practical issues like organization and delivery of services, lack of awareness both on the part of the communities as well as their health service providers, ethics of genetic screening and abortion, and psychological and social impacts of screening, principally because the study populations belong to minority groups in their host countries. A discussion of the ethical concerns that emerge from a prevention program that emphasizes prevention over informed consent, while extremely interesting, is beyond the scope of this paper, as is a discussion of the political economy of genetic counseling (Chadwick, 1993; Clarke, 1991; Green & Statham, 1996; Holtzman & Shapiro, 1998; Marteau & Croyle, 1998; Michie & Marteau, 1996; Modell et al., 2000; Rapp, 1988, 1990; Richards, 1993; Streetly, 2000). Atkin and Ahmed (1998) in their excellent paper on the ethics, politics and practice of screening have identified a gap in the literature on genetic testing.

Some authors have suggested that carrier status for genetic conditions may constitute a spoiled identity which becomes especially salient at particular times in the life cycle, such as the early stages of a new relationship, marriage, or when planning a pregnancy. There is little research assessing the consequences of people’s responses to such damaged identity, and the impact is likely to be context specific (p. 455).

This paper will attempt to fill this particular gap in the literature by focusing on the process by which being diagnosed as a ‘carrier’ marks a person, thereby ‘spoiling’ his or her identity. There is an inherent conflict between the medically desirable course of action and cultural desirability of an ‘unblemished, whole person’. The process of thalassemia screening on the surface appears to be relatively easy and innocuous; besides, TMI is not really viewed as a ‘problem’ by the medical establishment. But because of the cultural importance of blood in Bengal, the genetic mutation is perceived to be corrupting the blood (rakter dosh);
in the social imagination this departure from normalcy is stigmatizing in and of itself (Goffman, 1963). The social meanings and constitution of ‘disability’ or ‘impairment’ involve a dialectical exchange between the individual and society and in this particular case, supersede the medical understandings of impairment. Oliver (1996) argues that the social connotation of disability is as debilitating as the physical impairment; it is therefore unsurprising that in a society that deeply values blood an individual with a hematological disorder is likely to be marginalized.

At the outset I must clarify the use of terminologies in this paper. The terms ‘thalassemia minor’, ‘thalassemia major’, ‘carrier’ are all terms used by the medical community in Calcutta in their interactions with thalassemia patients and when talking to me. While these may not be internationally recognized or standard biomedical terms, they are used by medical practitioners in India, and in order to retain linguistic authenticity I have used them in this paper.

The approach employed in this paper draws from the field of critical medical anthropology loosely defined as

a theoretical and practical effort to understand and respond to issues and problems of health and illness, and treatment in terms of the interaction between the macrolevel of political economy, the national level of political and class structure, the institutional level of the health care system, the community level of popular and folk beliefs and actions, the microlevel of illness experiences, behavior and meaning, human physiology and environmental factors (Singer, 1998).

The aim of this paper is to illuminate the factors contributing to the low uptake of the prevention program, particularly with reference to the cultural emphasis on marriage, construction of personhood and identity, and the cultural significance of blood, including its associations with caste and the growth of the patrilineal line in Bengali society. This paper will outline the prevention program; explore how the program is subverted by investigating the cultural and moral economies that make thalassemia prevention problematic; and thirdly, recommend possibilities that might enhance the utilization of the program.

A bird’s eye view of West Bengal

West Bengal is located in eastern India, has a population of over 80 million, and is bordered on the north and east by Bhutan, Nepal and Bangladesh. Seventy-two percent of the population is rural, sixty-nine percent is literate, and sixty-eight percent is engaged in agriculture (Indian Census, 2001). The capital, Calcutta (Kolkata), is the largest city in West Bengal and played a distinguished role in India’s struggle for independence. The social reform movement in India, which began in the middle to late 1800s at the behest of progressive Bengalis, abolished child marriage, Sati (the immolation of widows) and prohibition of widow remarriage. On account of these early social reforms Bengali women typically had higher levels of literacy and were politically more active and less secluded than women living in northern India (Bandopadhyay, 2004; Fruzzetti, 1982; Inden, 1976; Lamb, 2000; Nicholas, 1995). West Bengal is one of the two states in India where the Communist Party of India (Marxist) has a strong foothold3 (Franda, 1971; Samanta, 1984). Despite the communist agenda of the state government, there is widespread poverty, malnutrition and high infant mortality among the poor (National Family Health Survey, 1995). It is popularly believed that the only successful reform has been the network of public hospitals, which provide free and relatively good quality medical care to the poor. While land reforms, including the abolition of Zaminndari (an exploitative land tenure system) have been implemented, they have not led to the expected developments, particularly in the rural areas (Bergmann, 1984; Bhaumik, 1993; Mallick, 1996; Sengupta & Gazdar, 1997). Poor labor-management relations have shut down many industries leading to high rates of unemployment especially among young men (Chakrabarty, 1989; Mallick, 1996). The caste hierarchy in Bengal is similar to the systems observed in northern India: Brahmins are at the top followed by Kayasthas and Baddis, Vaishyas and Artisan castes, and finally the Shudras/Dalits (Inden, 1976). Although barriers of caste have diminished to a very large extent in urban areas they still exist in rural areas. Marriages are usually arranged, but in both urban and rural areas, there are increasing instances of ‘love’ marriages or marriages not arranged by parents. Nuclear and extended households are more common in cities

3The second state is Kerala in southern India.
while joint families are more common in the villages.

Methods

I chose West Bengal as my primary field site because of high levels of prevalence of thalassemia, an active prevention program, and my own familiarity with the area, its culture, history and language. I have primarily employed ethnomethodological methods, including in-depth and semi-structured interviews and participant observation to gather data; one focus group discussion with 12 women in the village in the initial stage of the study was conducted for rapport building and to gain an understanding of whether thalassemia was perceived to be a local ‘problem’. I interviewed a total of seventy-two people, of whom forty-one were relatives/caregivers of patients with thalassemia, fifteen were connected to the prevention program either because they were doctors or medical social workers or involved with Non-Governmental Organizations, five were not connected with the prevention program and represented that part of the population that has no direct contact with patients or the campaign. I also informally interviewed eleven people from the village (District North 24 Parganas) where many of the respondents lived. All interviewees were recruited from the hospital (using snowball sampling), while they waited for relatives to be transfused. I approached them and explained the topic of the study and obtained oral consent. A convenient time and day were worked out for interviews, which were either conducted at the respondent’s home or during their subsequent visits to the hospital.

The interviews were conducted in Bengali and then translated into English. Data were collected on key socioeconomic indicators such as income, residence, occupation and education. Questions were asked pertaining to current and prior knowledge of thalassemia, place and time of diagnosis, consequences of diagnosis including stigma, use of alternative/complementary care to manage TMA, use of contraception, genetic counseling and selective abortion to prevent future births with the same condition, family history of thalassemia, whether the respondent had asked other family members to get tested, barriers to both screening and management of thalassemia, specific knowledge about the prevention program, the role of media, and mental health of caregivers and patients. In cases where patients were schoolchildren, questions were asked about attitudes of teachers and peers towards the child, and accommodations made by the school to ensure the continuity of education. Further, specific questions were asked to understand each respondent’s attitudes towards premarital testing, its effects and possible consequences after the diagnosis. I spent most of my time at the two bases of the program—Nil Ratan Sarkar Hospital (NRS) and Calcutta Medical College (CMC). I also conducted interviews at Maniktala Thalassemia Welfare Center in Calcutta and the Bordhoman Thalassemia Welfare Center, the only clinic outside Calcutta devoted to the management of thalassemia. I spent two weeks in Helencha village in North 24 Parganas where some of the respondents lived to investigate village-level efforts directed at thalassemia prevention. At the King Edward Memorial (KEM) hospital I interviewed some of the staff engaged in prevention with pregnant women, as well as students of a local college where KEM was conducting an awareness campaign.

The prevention program

In 1998, the governments of West Bengal, Maharashtra, Punjab, Gujarat and Karnataka in collaboration with the Indian Council of Medical Research (ICMR) launched thalassemia prevention campaigns. These states have a particularly high incidence of thalassemia, with official estimates of TMI ranging from 5% to 10% incidence in the general population (Indian Council of Medical Research Bulletin, 1993). An ICMR pilot study conducted during 1998 with schoolchildren revealed that 2.7 percent of 5682 tested in Bombay, 5.5 percent of 5408 tested in Delhi and 10.4 percent of 952 children tested in Calcutta had beta TMI. Based on these figures, the pilot study concluded that thalassemia was sufficiently prevalent to warrant a prevention program in the study areas. In West Bengal the program is called ‘Joi Vigyan: Community Prevention of Thalassemia’ which literally means ‘Victory to Science’. This project aims to test 10,000 people, focusing on college students and pregnant women, within the next five to seven years (using electrophoresis). These two groups were targeted based on the assumption that engaging young, unmarried people in the program would
instill awareness in them encouraging caution during partner selection and before pregnancy; pregnant women are targeted to prevent the birth of TMA children by terminating the pregnancy within the first trimester. The project conducts camps in colleges and tests students free of charge (Table 1 for details). At the time of the study (May–August 2002) 3000 people had been screened in the two target groups. In the Outpatient Department of NRS hospital each week hundreds of patients arrived from different parts of West Bengal to consult with hematologists; in CMC, pregnant women are screened for thalassemia as part of their antenatal check-up. Those with a positive TMI diagnosis are requested to bring in their husbands. If there is a positive TMI diagnosis for the husbands, the hospital sends them to other centers in Calcutta or to Bombay for amniocentesis for the husbands, the hospital sends them to other centers in Calcutta or to Bombay for amniocentesis for the husbands. If there is a positive TMI diagnosis for the husbands, the hospital sends them to other centers in Calcutta or to Bombay for amniocentesis for the husbands. If there is a positive TMI diagnosis for the husbands, the hospital sends them to other centers in Calcutta or to Bombay for amniocentesis for the husbands. If there is a positive TMI diagnosis for the husbands, the hospital sends them to other centers in Calcutta or to Bombay for amniocentesis for the husbands. If there is a positive TMI diagnosis for the husbands, the hospital sends them to other centers in Calcutta or to Bombay for amniocentesis. Dr. Kanjakshya Ghosh, a leading hematologist in India and the chief of the prevention program in Bombay, reported that a majority of the people seeking prenatal counseling are families with past experience of thalassemia or other hematological disorders (Ghosh, Shetty, Pawar, & Mohanty, 2002); a fraction of the people seeking genetic counseling are those with no experience but who have recently discovered their carrier status. He also indicated that in CMC as in other antenatal centers in India, women do not seek prenatal care until they are well into their second or third trimester of pregnancy when little can be done to terminate the pregnancy without grave risks to the mother and fetus. Other studies have confirmed this finding (Pallikadavath, Foss, & Stones, 2004). NRS hospital also screens young people at a subsidized fee of 12USD (450 Rupees).

Caste, kinship, marriage and identity

Before we venture into a discussion of marriage in Bengal, it is important to gain an understanding of the caste system, which was (and in some places still is) the primary means of social organization. The words jāti and kula refer to castes and clans as social units. Two key features that define castes and clans are shared substances (dhātu) and code for conduct (dharma). The coded substance that defines a caste is bodily substance, and this differentiates clans from other social units. Other coded substances like livelihood (jītvika), country (desa) and worship (yajña, pūjā), along with bodily substance yield different social classes and occupational categories, territorial categories and religious categories (Inden, 1976). Between the 15th and 19th century, the Hindu community in Bengal underwent several important transformations, and during each of these stages the accompanying historical changes firmly established the importance of marriage in Bengali society. In the final stage in the transformation of the Hindu community that began with the Muslim conquest of Bengal, many Brāhmans and Kāyasthas, including Kulīnas (the highest among the Brahmins), sought wealth from the Muslim conquerors and made improper marriages with low-caste Hindus and thus fell from grace. In order to establish proper community relationships with the Muslims, Brāhmans and Kāyasthas narrowed their standard of good conduct primarily to marriage (Bandopadhyay, 2004; Nicholas, 1995). The renewed emphasis on marriage for enhancing or maintaining social status firmly established the centrality of marriage in Bengali society. Proper marriage (vivāha, biyā), the gift (dāna- pradāna) or acceptance (grahana-ādāna) of a daughter was the chief of the 10 sacraments (samskāras) that purified a person’s body (śarīra śuddhi) (Inden & Nicholas, 1977; Nicholas, 1995). The primary purpose of marriage was to provide a caste and its clans with children, especially sons, embodying the coded substance of their parents’ caste and clan and enabling them to follow the caste-specific occupations and the final rites (śrāddhā) of parents and ancestors. The caste rules of marriage prohibited men and women from marrying partners who possessed the same bodily substances (savarna) and prescribed marriages outside one’s clan (gotra) but within the same caste (Ostor, et al., 1982; Srinivas, 1987; Bandopadhyay, 1995).

Blood or rakta is considered to be an important substance, one that is enduring and persistent and
shared among people in the same kin group. It is transmitted along the male line through women who establish his bangśa by transmitting his blood to the children. Āttiya, the native term for relatives in Bengal, are further divided into close and distant based on blood ties, ties by marriage or code of conduct or through shared space (pārā āttiya). However, the most primary ties are blood ties and therefore even today blood defines personhood, determines relationships, and categorizes ranks and differentiates people in Bengal. It is believed that purity of the blood is important because blood condenses to form semen in male and sexual fluids in the female, which fuse during sexual union enabling conception. A child inherits whatever purity—or flaw—is contained in parental blood. So it is critical that women in particular be complete and blemish-free and possess desirable traits, passing them on to the next generation (Ostor et al., 1982). Traditionally marriages have been a collective activity, contractual in nature, that establish permanent relations between two kin groups. Love marriage is not viewed very favorably because it often precludes the involvement of parents in the marriage and is perceived to be determined not by cultural and collective considerations like jati, bangśa and hierarchy but solely by the transience of physical attraction (Mitra, 1946; Fruzzetti, 1982). Arranged marriages are not devoid of love, but the love between the husband and the wife is expected to flower as part of their being together and having children together.

Given the centrality of marriage and criteria that establish desirable attributes in a future marriage partner, it is evident why the thalassemia Prevention Program is problematic. In a society where marriage is still an important rite of passage, behaviors that jeopardize the prospects of finding a good marriage partner are likely to be condemned and avoided. One of the obstacles in convincing people of the importance of thalassemia prevention is that the dangers of not testing are neither immediate nor certain, but the highly undesirable possibility of being burdened with an unmarried daughter for life if she is a carrier seems imminent. For many women marriage is synonymous with financial, emotional and physical security, and parents feel obligated to marry their daughters to respectable and responsible families (Uberoi, 1993).

Discussions with parents of children with thalassemia expose the conflicts experienced by them with regards to screening and disclosing the results of the test to future families of their children. Maya, 41 years old and college educated with two daughters, the younger one with thalassemia and the one with TMI, was tentative and vague about whether she would disclose her daughter’s carrier status at the time of marriage. She said:

We don’t want our daughter to suffer like the way I am suffering (because she did not know both she and her husband carried the mutation). I would really want to rule out that her (daughter’s) husband is a carrier. But if circumstances are such that we cannot disclose then I do not know what our reaction is going to be.

She added that her 20-year-old daughter did not have any strong opinions in this regard. When I prodded further and asked her if it might be difficult to hide it, especially because her younger daughter
had thalasemia, she responded that this was all the more reason not to disclose (her status) because having an ill sibling would already put her in a disadvantageous position in the marriage market. If the truth might seal her daughter’s fate for good (by not being able to marry), it was a price that neither she nor her husband were willing to pay. Sheela, a 35-year old housewife, appeared more certain about getting her 10-year-old daughter as well as the suitor tested; however, she added the disclaimer: ‘…not at the cost that my daughter remains unmarried for the rest of her life’. Only one respondent, a school-teacher from rural Bengal, indicated that he would want his daughter to get tested even if it meant ‘…she stays obibahita (unmarried) for the rest of her life’. Most of the respondents found testing after marriage or prenatal counseling to be a more palatable idea because it would not jeopardize their daughters’ chances of finding suitable partners. Pranab, a Brahmin engineer in his mid-fifties and not involved with the prevention program, was candid about his unwillingness to get his son married off to someone with TMI. The following is an excerpt from our conversation:

S: If at the time of your son’s marriage you get a proposal of marriage from a family that is equal in all respects except that the daughter is a thalassemia carrier, will you mind getting your son married in such a place?

P: Yes definitely. Why should I get my son married to a girl who has some kind of flaw? Especially when I would have so many choices?

S: Why do you think it is a flaw? Any one could be a carrier and being a carrier does not mean the person is diseased, it just means that if he/she gets married to another carrier they should be careful when having a child.

P: In my family all the girls who have come in have come from good families (bangsā), are beautiful and don’t have any hidden diseases. I do not want to take such a risk for my son.

These conversations not only highlight the dilemmas faced by parents who have at least one child with TMA and other healthy children, but also delineate two important aspects related to popular perceptions about marriage and testing. Firstly, this particular group of people, the parents of children with thalassemia are in a unique position to be convinced of the merits of premarital testing because of the traumatic experience of being the caregiver of a very sick child. Notwithstanding that they continue to be hesitant and tentative about getting their healthy children screened for fear of endangering their marriage prospects. Secondly, arranging one’s children’s marriages is a gendered process, with parents of daughters expressing concern that their daughters will not be accepted into their future families because they are ‘flawed’ as individuals with TMI, and parents of sons believing that it is their right to have a healthy, unblemished woman who can further the lineage. Interestingly in colloquial Bengali there is no specific term for a spinster. The term obibahita is telling because it indicates the negation of marriage (O = no or non, Bibahita = married), as if it were a transient stage, which would be duly completed with marriage. This is in sharp contrast to the term widow (Bidhoba), which though marginal, is never liminal like obibahita. It appears as if there is no appropriate social space that an unmarried woman could possibly inhabit. In my conversations with the parents of thalassemic children I frequently heard parents express grief, anguish and concern for their children, but I also heard disbelief and denial with parents often saying, ‘I do not know where she got this disease from! No one in my bangsā has it.’ It is natural to experience a sense of pride in one’s origins but this pride is accompanied by the belief in the incorruptibility of one’s bloodline. A blood disorder like thalassemia affects people’s notion of the enduring and pure nature of blood. TMI is an asymptomatic genetic mutation that is normally undetected; however, the stigma associated with it is exacerbated because of the cultural interpretation of Rakter Dosh. Blood that is corrupted is a non-negotiable attribute in a future wife or daughter-in-law because of her prescribed role in the flawless reproduction of the family line.

**Proximate barriers to the screening**

The reasons for the underutilization of the prevention program are not only limited to the fear of not finding suitors for one’s children but also include proximate determinants such as lack of awareness about the existence of the program, risk that is not internalized at the individual level, and lack of access to the program.

**Lack of awareness, low-risk perception and access**

Low awareness and low knowledge of prevention is not only restricted to those who have never had
any personal experience with the disease but also to those exposed to prevention messages. Many rural people lack access to television and print media, and therefore may not be exposed to the prevention messages. The awareness posters (designed so that it is easily understood why thalassemia should be cause for immediate concern) typically present a situation where a family with a relative who is thalassemic is asking the audience to get tested so that they do not end up suffering as they have. One poster showed a couple about to exchange garlands during the marriage ceremony with a thick red line cutting the poster diagonally and the following caption: ‘Have you had your blood screened for thalassemia?’

Despite such efforts, most of the respondents who did not have a relative with thalassemia did not consider themselves to be at ‘risk’ for being a carrier, and many believed that carriers are found only among the poor or people belonging to a certain caste or religion—the ‘others’. These beliefs are not atypical, and the concordance between low risk perception and/or absence of family history and low participation in screening programs have been reported in other studies also (Becker, Kaback, Rosenstock, & Ruth, 1975; Atkin & Ahmed, 1998; Henneman et al., 2001).

When parents and relatives of thalassemic children were questioned if they asked their friends and acquaintances to get tested, less than one-third of them reported they did, explaining that they ‘did not want to be seen as interfering’ or ‘if I told them they would tell me just because my child is sick it does not mean other people also have sick children’ or ‘it is really not my business’. Even among college students (whom I spoke to informally while shadowing the implementation of the awareness campaign) exposed to the awareness messages in Bombay, there was great reluctance to testing and the idea that they might be carriers. In the college, the blood test was preceded by a presentation highlighting the etiology, prevention and management of Thalassemia and followed by a debriefing of the medical form and implications in case of a positive result. Despite the best efforts of the program managers efforts, turnout was usually less than 50%. When a group of young men who had refused to take the test (and were amusing themselves with carom and chess instead) were questioned regarding their refusal, they responded with skepticism about the process, fear of the blood test and indifference. When I spoke to some of the respondents from urban upper-middle-class families in Calcutta I received similar responses. Most people did not know and did not care, and those who knew would not want their daughters to be screened lest they jeopardize their chances of finding an eligible suitor. The following conversation with Gopal illustrates why risk is not internalized, particularly in the absence of family history.

G: I do not think it is important to get this test done.
S: Why not? You have two children—one son and one daughter—why would you not want to get either of them tested before they get married?
G: No I will not; it does not figure in my list of priorities.
S: What if your son or daughter has thalassemia minor and gets married to someone with the same condition. Could one not prevent bringing a thalassemic child into the world by knowing one’s status?
G: These things do not happen to people like us. I do not believe that anyone in my family is flawed, and when I get my son married I will make sure their bangsa is as good as ours.

His most immediate reaction was resistance to the test followed by his firm belief in his (and his lineage’s) purity. A majority of the respondents related to thalassemic patients revealed that they had never heard of the disease prior to their personal experience with it. The few who claimed that they had heard it in passing, lived in the city and additionally had young children who had recently been diagnosed. In the last five years there have been intensified efforts to familiarize people, particularly through the involvement of local celebrities at fundraising programs for children with thalassemia. However in the village, only one of the 15 women who participated in a focus group discussion had heard about thalassemia because she was training to be a nurse; but she too did not have complete information about prevention. Dr. M. Ghosh, Professor of Hematology at CMC argues that the attitudes of the young boys and the well-educated are a function of the general lack of awareness regarding public health, and he commented:

Health awareness is not a result of literacy but education. Awareness about the disease is tied up with long-term goals of education and develop-

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8 Exchanging flower garlands is one of the important rituals associated with Bengali marriages.
ment. While we can try to make a short-term impact on people’s awareness levels by these mass campaigns, ultimately it is public health education that will make people understand and take action in this (public health) area.

Many within the biomedical world believed that education and economic reforms were critical for the success of public health campaigns like the thalassemia program. They conveyed the difficulties of translating scientific information to an audience that was largely semi-literate; even for a literate population, translating technicalities like genetic mutations was a challenge. A study in Greece reinforces this impression of the doctors with its findings that education has the strongest influence on awareness of thalassemia and the belief that people with thalassemia can be productive members of society and can be socially integrated (Politis, Richardson, & Yfantopoulos, 1991). Preventing thalassemia is fairly problematic because of a lack of public health knowledge and people’s inability to access the scientific and medical vocabulary that frequently accompanies public health messages.

Physical and financial access posed problems with regard to both screening and management of thalassemia. The two major government hospitals in Calcutta, NRS and CMC, provided subsidized treatment for all and free treatment for people earning below 2000 Rupees a month. But located in central Calcutta, they were difficult to access for the rural population. A majority seeking care here were indigent and from some of the most remote areas in the state, sometimes traveling several hours by trains, buses and boats to get to the hospitals. The fact that more than half of the 42 respondents came to the hospital from at least a hundred kilometers away indicates that people living in rural areas have to depend on hospitals in the city for thalassemia care. With the exception of Bordhoman, which has a thalassemia center of its own, none of the other districts in West Bengal currently have provisions to diagnose, treat and manage thalassemia. During the Thalassemia Outpatient Department Days of NRS, there were easily 300 people crammed into one room waiting to consult with the doctor. Patients had an average waiting time of one hour and frequently more. The department, while very dedicated and motivated, was chronically understaffed. A private two-year-old center in Calcutta, Chetala Thalassemia Center (CTC), appeared to be less crowded, consisting of mostly very young children and a clientele that did not appear to be as impoverished since treatment here was neither free nor subsidized. The center was also particularly attractive to young people and middle-class families because it could provide facilities for discreet screening by having technicians collect blood samples from people’s homes. The center’s administrator claimed that many families who wanted a confidential test for their daughters chose this center. However, what was deeply disconcerting was that the proprietor of the clinic who doubled as the attending ‘doctor’ had PhD in life sciences but was not a medical doctor; medically qualified nurses and physicians were largely absent here. Despite this, some patients preferred it to the government hospitals for its shorter waiting period, promise of confidentiality and the promise of clean rooms and particularly for children the toys and bunk beds. KEM (Bombay), also a government hospital, has an excellent department of immunohematology with a research center, a state-of-the-art laboratory and clinicians. However, the cost of transportation and lodging in Bombay is prohibitive for many families, and this hinders the utilization of the facilities at KEM.

Conclusion

Through an ethnographic approach, privileging Bengali constructions of personhood, we have unraveled the process by which a medically desirable action becomes socially and culturally undesirable, thus complicating the prevention of thalassemia in Bengali society. Blood is a critical cultural construct that acts as a parameter for categorizing desirableness in potential marriage partners. While marriage is especially significant for Indian women because a woman’s relationship to a man defines her identity, it is also gendered, which disadvantages women in the marriage market. A woman graduates from being a daughter, to a wife, to a mother, and at each of these stages it is her relationship with a male, either the father or the husband or the son, which is instrumental in establishing her status and rank in society. This explains the stigmatization of states such as orphanhood, definitive celibacy or widowhood and infertility for Indian women (Fruzzetti, 1982; Sen, 1999; Wadley, 1995). Men’s identities and status in society on the other hand are rarely, if ever, derived from their associations with women. There exists a spectrum of possibilities for them to establish their
position in society, including professional success, spiritual enlightenment and scholarship. Marriage is thus an overarching concern for parents of daughters because frequently it is the only way to secure the futures of young women, particularly if they have little or no formal education and professional skills. Unmarried women are believed to bring dishonor to their families because their unmarried state is assumed to be a product of their parent’s failure to secure a husband as well as their own imperfections. Some of the doctors were aware that stigma associated with being a carrier might inhibit people from utilizing the program, and they suggested targeting young men instead of women because even if they were to be diagnosed with TMI, it would not significantly jeopardize them in the marriage market. However, the problem with this strategy is that it might be difficult to persuade young men who are frequently convinced of their own invincibility to have a blood test for an asymptomatic condition.

Some of the most insightful suggestions regarding more effective thalassemia prevention strategies emerged (unsurprisingly) from discussions with parents of thalassemic children. One of the respondents, a 36-year-old fish farmer from Hoogly district, believed that street plays or Jatra presented during the harvest and festive seasons were better approaches than TV or newspapers because they were likely to reach a wider audience. Street plays have become a fairly popular method for raising consciousness especially since HIV/AIDS has assumed epidemic proportions in some parts of India. Jatra offers the advantages of being a pre-approved medium of entertainment that is cost effective, employs local talent and can reach a large audience efficiently. Krishnakant, a 40-year-old man actively involved with street plays to spread awareness about social themes, claimed that when he performed plays related to thalassemia prevention during or before a detection camp, the number of people who took the test was significantly higher than when the plays were not staged. He had organized and acted in two plays related to thalassemia: one dealt with the issue of blood donation and the other dealt with premarital testing. The second, more interesting, play ‘Rakta Bidhan’ is about a girl whose wedding is called off by the groom’s side, because her physician father requires the future husband to get tested and reveals to him that his daughter has TMI. However, all ends well when the girl finds another eligible suitor (another doctor) who agrees to marry her and get himself tested for TMI.

Many of the respondents felt a community-based approach might work best in their villages and towns because community leaders command respect from people and are likely to have wider influence. One of the respondents, a 25-year-old Muslim man, said:

The best way to stop this disease among us (Muslims) is to involve the Maulavis in the prevention campaigns and ask them to spread the word. People are more likely to listen to his recommendations than the health educator from the clinic because he commands greater respect and has more control over us.

Attitudes regarding women’s status and roles do not change overnight, but the stigma associated with being a carrier can be reduced significantly through greater awareness by involving community leaders. Involving people who are associated with the process of arranging the marriage (locally called ghatak) could be an effective strategy to reduce the mystery and stigma surrounding thalassemia. A ghatak is typically a family priest and traditionally arranges marriages in West Bengal. However, not all families have ghatak, hence community leaders like the head of a village or the local government should be engaged in the prevention program. Some of the respondents, especially those in the medical community, believed that legislation was likely to help: for instance, mandating that there be a blood test before issuing a marriage license. While a similar process may have succeeded in Greece, Italy and Cyprus in curtailing thalassemia it is unlikely to succeed in India because the process of marriage and the norms associated with marriage are very different in the Indian context, and marriages need not be registered in India to be valid (Angastiniotis & Hadjiminas, 1981).

Two good examples of culturally sensitive strategies that have worked in developing countries such as Pakistan and Iran can be found in the work of Ahmed et al. (2002) and Samavat and Modell (2004), respectively. In the Pakistani study, Ahmed and colleagues suggest that given the cultural acceptability and desirability of consanguineous

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9I have used a pseudonym because he did not want to reveal his identity.

10Rakta Bidhan means Judgment by Blood, significant given the premise of the play.
marriages, identifying a child with TMA and getting his extended family tested might work as the best strategy for preventing thalassemia. Although exploratory in nature, the merits of this strategy lie not only in its cost-effectiveness but in its recognition of the difficulty of preventing consanguineous marriages given the nature of Pakistani society. In Iran, coverage of couples under the National Thalassemia Prevention Program by 2000 had lowered the birth of children with Thalassemia by 30% of the expected rate since the inception of the program in 1997 (Samavat & Modell, 2004, p. 1135). The key to the success of the program lay in its holistic approach, which was preceded by widespread public education and public health surveillance. The services of the program were sensitive to Islamic norms relating to abortion and even co-opted Islamic scholars, making an argument for medically necessary termination of pregnancies (Christianson, Streetly, & Darr, 2004, p. 1116). One could argue for a similar strategy in India where the prevention program is integrated with the existing reproductive health programs and is not just limited to a few select hospitals. This will not only reduce the costs of implementation by the utilization of extant infrastructure but the program will be able to reach young women who are not currently pregnant but may want to be mothers in the near future. A peer-based strategy might work well for youth, especially those in college. Most colleges have a social work component as part of their academic curriculum. Hospitals, with the help of the college authorities, could recruit volunteers from the students (as part of their social service requirement) and then enlist their support to get their friends tested in their communities and neighborhood. This would not only ensure a greater turnout in colleges but also reach those who may not be attending college and thus may not be exposed to the prevention program. While the program currently calls itself a community-based prevention program and means to be one, it is not entirely embedded within the local community. By enlisting the support of students, community leaders and local doctors within the framework of a more decentralized approach, the prevention program might potentially have better outreach.

Through this paper I have attempted to demonstrate the importance of recognizing local norms and conceptions in the implementation of public health program such as the thalassemia prevention program. The conclusions from this study are applicable to other prevention programs such as for HIV/AIDS, tuberculosis or leprosy, where the complexities of social stigma introduce the possibility of underutilization of these programs. A combination of culturally situated understandings of blood, kinship, marriage and personhood, and proximate barriers such as restricted access, low-risk perception and awareness, and financial constraints pose major obstacles to the prevention program. Though a formidable task, thalassemia prevention is not entirely impossible; with the correct mix of strategies, support of local communities and determination it is possible to reduce the incidence of thalassemia major and concurrent mental and physical suffering.

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