

**GENETIC DISORDERS AND
ISLAMIC IDENTITY AMONG
BRITISH BANGLADESHIS**

Santi Rozario

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SERIES EDITORS' PREFACE

CAUSATION, COUSIN MARRIAGE, AND PERCEPTIONS OF RISK: BANGLADESHI FAMILIES IN BRITAIN

*Andrew Strathern & Pamela J. Stewart**

What causes illness? This is a universal question, to which many different answers are given. One of the reasons for variability in this domain is that people have contrasting ideas of what makes up, or constitutes, the body. Another is that people set these ideas of the body into a wider cosmos of understanding of powers and influences, especially the power of spirits or deities. Such classic factors enter sharply into the ethnographic context of Santi Rozario's finely nuanced study of how Bangladeshi families in Britain deal with illness conditions in their children that are a product of genetic factors, specifically recessive genes for certain relatively rare conditions that have serious health consequences and place significant burdens both on the families and on the national health care system. The likelihood of such conditions emerging is influenced by the extent of consanguineous marriage between classes of cousins in a given population; and cousin marriage, in turn, in some populations, such as those that Rozario has worked with both in Bangladesh itself and in Britain, is frequent enough that it creates a crucial ethnographic context for enquiry. This was the rationale for Rozario's entry into the field in Britain, and in doing so her understanding was greatly strengthened by the fact that she had already carried out fieldwork in Bangladesh itself.

Two other factors are also worth noting here. The first is that the study was explicitly envisioned in a comparative context along with another study by a senior academic on Pakistani families in Britain. Alison Shaw reports on this

study in an engaging Afterword to the present book. Rozario notes that while there are many similarities between Pakistanis and Bangladeshis there are also cultural and historical differences. She notes further that the Bangladeshis she worked with in two different locations in Britain came largely from a single part of Bangladesh, Sylhet, and this is not a minor factor in her study, because it influences the marriage patterns and the reproduction of a kind of bilocality with concomitant tensions of living patterns. The wider comparison with Pakistanis reveals a strategic context of decision-making that is shared between Bangladeshi and Pakistani people: Because cousin marriage is practiced in both cases, people reason about its possible connections with illness in similar ways, balancing their own religious ideas of causation about the ultimate source of all things in life with the explanations offered by biomedical health services and popular notions and practices based on ideas about blood or the activities of jinn spirits. The shared framework of analysis used by Rozario and Shaw is that decision-making about illness is based on multiple factors of life experience. Illness conditions in children that are an outcome of genetically influenced patterns pose a special problem for parents and their wider families. Admission of the genetic factors implies their continuing potentialities, and hence the status of the families themselves. A minefield of difficulties opens up, and both the people and the researcher have to pick their way delicately through this field. Bringing in explanations other than genetics ushers in the prospect of contingencies and exculpatory matters that would deflect attention away from genetics and towards the arena of moral choices. Rozario skillfully teases out the implications of this point, following for example the ramifications of an idea that a woman might have been assaulted by hostile jinn spirits in a public park where a female should perhaps not have been walking alone.

The second factor of note is that it was very difficult for Rozario to gain bureaucratic permission to carry out the specific interviews with individual families that were important for her research. In Chapter 1 she recounts this process. When she began as a researcher on the ESRC funded project of which her own study was a part she notes that she already had local and national clearances, but now had to get approval from two separate NHS Trusts in the two cities where she proposed to work—something she was not aware of in advance. In pursuing this approval she spent nine months of the research time allocated for the project. She comments: “It appeared to me to be wholly out of proportion to any risks involved in the kinds of social science research I was undertaking ... I am sure that the present situation has successfully deterred many good researchers from undertaking research within the NHS.” The kind of observation made here must surely find echoes in the feelings of research workers in other contexts. One instance is where rules derived primarily for medical re-

search are mistakenly applied to social science work. Internal Research Board regulations either reflect this kind of pattern or become the site of intense discussions and attempts to ameliorate what Rozario, citing another researcher in the NHS, characterized as a “bureaucratic nightmare.”

Yet, out of this situation something good came. While waiting for official permission to do structured interviewing work Rozario was able to make good use of her time in unstructured ethnographic observation and experience. Indeed, it is arguably this experience that in the end gives the depth of understanding which she is able to bring to the overall study. This process was facilitated further by the fact that she had previously conducted research in Bangladesh herself and that she knows the Sylhet area from which the Bangladeshi migrants whose lives she studied in Britain originally came. The advantage of understanding both areas shows particularly in the crucial context of cousin marriage. Such marriages do not spring simply from a cultural preference. They are products of a mutual interaction between diaspora circumstances and frameworks of alliance and reciprocity in the field of marriage over time. Cousin marriages in effect are sometimes used as ways to sponsor people from the home area to come to the U.K. Both men and women migrants already established in the U.K. expressed a preference for spouses from Bangladesh on the grounds that these would be more morally tractable than those acculturated into contemporary local ways. All kinds of cousin marriages were contracted and amulets were sometimes used in order to magically change the feelings of a potential partner who expressed reluctance to enter an arranged marriage. Traditional ideas entered in the notion that wives who did not bear children would find their marriages in trouble and there was a preference for sons. In spite of the significance of marital alliances, there were many tensions in diaspora marriages, related to educational disparities, and in the supposed tendency of husbands recruited from Bangladesh to send money back home while their British-born wives might wish to spend money on themselves, i.e. on the spot with their immediate family.

Several other important ethnographic points come up in this background ethnography. Rozario noticed a tendency for younger Bangladeshis in Britain to stress their Islamic identities as a mark of difference. Historically in Bangladesh this process stemmed from the time of the Partition and self-conscious differentiation between Hindu and Muslim customs, which has accelerated with moves to “purify” Islam. It has led women to wear the burqa veil, and people to go on the Hajj pilgrimages to Mecca. There is a sense of influence also among the Muslims from Sylhet of the work of a Sufi saint who is said to have converted the Sylhet people in the fourteenth century C.E.

This intensification of a Muslim identity has influenced attitudes to health and disease in general, to cousin marriage, and to the genetic factors in causing specific debilitating conditions. Basically it has led to seeking religious resolutions to problems, in asking for advice, in seeking the source of all things, including the afflictions of illness, and in listening to advice from imams, who might not be well versed in biomedical matters. Islamic senses of identity also include, for these Bangladeshi people, ideas about the hostile activities of jinn spirits, which are said to be able to blend into the blood and to cause sickness. Such an attribution of sickness to jinns is accompanied by an imputation of moral fault because the person must have allowed herself to be open to the incursions of such spirits. ('Herself' here is written, because women are considered more vulnerable than men to attacks by jinns.) The outcome of all these notions is that they provide a means of discourse about risk that can appeal to causes outside of the mysterious realm of genetics. With this careful ethnographic grounding Rozario proceeds to a detailed and sympathetic rendering of case histories of families with affected children, in which ideas of risk, stigma, morality, and purity / pollution of blood are all mixed. The moral scenario here is the same, *mutatis mutandis*, as the pre-Christian idea in Mount Hagen, Papua New Guinea, that persons are under the protection of their ancestral spirits, but if they do wrong these spirits will withdraw their protective fence around their living kin, allowing hostile wild spirits to attack them and make them sick. Slot in the supreme deity for the ancestors, and jinns for wild spirits, and you have the identical syndrome. Add the evil eye and you have the equivalent of ideas of witchcraft in Hagen (see Stewart and Strathern 2004). Ideas about kinship also share some features with those found in Mount Hagen and other areas in Papua New Guinea. Not only is the idea of sharing blood important within the patrilineage, but in a broader sense substance is thought of as shared with people of one's locality, and such substance is said to be the basis of moral relationships. In Mount Hagen the mediating idea here would be that people who share food coming from the same soil share substance (cf. Stewart and Strathern 2001). Duna ideas, also from the Highlands of Papua New Guinea, are the same: *rindi* for the Duna means the kin based local parish and its land or territory (Stewart and Strathern 2002, Strathern and Stewart 2004). Perhaps it is these ideas, which are ultimately about ecology and the constitution of groups, that provide the key to a much debated concept, first introduced by McKim Marriott for South Asia, to effect that in these societies persons are seen as part of a wider whole rather than as individuals (Marriott 1976). Of course, to some extent persons are everywhere seen as part of wider wholes, for example the nation, if not the tribe or lineage. However, this does not pre-

clude them from being in another sense individuals in terms of their strategies, proclivities, choices etc. in relation to their kin and others. Rozario astutely notes that it does not make sense to argue that South Asians (a very broad category) have no sense of individuality, but she suggests that South Asians do have stronger sense of being a part of a family group than some others. We remark on this point here for two reasons. First, we have extensively commented on the issue for Papua New Guinea over many years of writing (e.g. Stewart and Strathern 2000, Strathern and Stewart 2008). Second, if we triangulate senses of commonality among kinship (blood), locality (soil), and agency as a kind of universal model of personhood components, it is clear that it is in agency that individuality is expressed, while McKim's concept of "dividuality" belongs to ideologies of blood and soil. From Rozario's case histories it is very clear that all three elements of personhood are present. People feel tied together by kinship and locality, but they come into conflict through choice and the exercise of agency. Rozario notes that many of her interlocutors saw their health problems as linked to being in the U.K., away from their home place and foods, and at risk of pollution as well as moral corruption. Often, the people we work with as anthropologists are very keen analysts of their own circumstances, and this is certainly so here. A disjunction between kinship and home locality is seen as bringing on sickness.

Rozario's study in this book is embellished and enriched by many background insights as well as by the solid and nuanced case histories she was eventually able to amass. Her findings are highly significant for medical anthropology generally, and must surely assist both the Bangladeshis she worked with and the biomedical specialists who offer them diagnosis and treatment in coming to significant mutual understandings of how their explanatory models may mesh in with, or conflict with, one another. Indeed, in many cases, no effective treatment can be offered regardless of the precise diagnosis of a condition, and the people are left to cope with, and rationalize, events as misfortunes that perhaps only religious ideas can be appealed to in the search for their meaning. Thus, an intractable condition that is an "affliction" may be seen as a form of "punishment" or, per contra, as ultimately a "gift" that is a test of faith on the part of those who care for the sick person.

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Notes

* A.J. Strathern and P.J. Stewart are a husband and wife research team in the Department of Anthropology, University of Pittsburgh, and were the 2012 DeCarle Distinguished Lecturers at the University of Otago, Dunedin, New Zealand. They are also Research Associates in the Research Institute of Irish and Scottish Studies, University of Aberdeen, Scotland, and have been Visiting Research Fellows at the Institute of Ethnology, Academia Sinica, Taipei, Taiwan during parts of every year from 2002-2012. Their long-term, diverse, and creative research work has been published in over 40 books and over 200 influential articles on their research in throughout the Pacific, Asia (mainly Taiwan), and Europe (primarily Scotland and Ireland, also on the European Union). Their most recent co-authored books include *Witchcraft, Sorcery, Rumors, and Gossip* (Cambridge University Press, 2004); and *Self and Group: Kinship in Action* (Prentice Hall, 2011). Their recent co-edited books include *Exchange and Sacrifice* (Carolina Academic Press, 2008), *Religious and Ritual Change: Cosmologies and Histories* (Carolina Academic Press, 2009) and *Ritual* (London: Ashgate Publishing, 2010). They have broad interests which embrace and engage with global issues, utilizing their cross-cultural linguistic skills, a powerful comparative and interdisciplinary approach, and a uniquely engaged scholarly gaze. Their current research and writing is on the topics of Political Peace-making and the new arena that they are developing on Global Disaster Anthropology Studies. Their webpages are:
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 (<http://www.pitt.edu/~strather/>) and
 (<http://www.StewartStrathern.pitt.edu/>)

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FOREWORD

Sophie Gilliat-Ray

This important new book represents the first in-depth qualitative study of the way Bangladeshi Muslims in Britain are affected by, and respond to, genetic disorders. Amid the growth of new scientific knowledge and rapid medical advance, the opportunity to appreciate how distinctive communities are affected by these changes, particularly in the sphere of genetic science, provides an opportunity to appreciate the lived reality of both disease and, for some, curative potential. The contested place of religion within this dynamic—in this case Islam—adds to the complexity of the issues, particularly in the accounts we read in this volume about hope and suffering, and the contested place of religious healing practices.

It is a testament to the value of the research that underpins this book that we not only gain a richer understanding of genetic disorders, as they impact on a distinctive ethnic/religious group, but a much wider array of questions also come to light. For example, we come to appreciate the fact that genetic disorders often compound other socio-economic difficulties related to employment, housing, and poverty. They might also be a catalyst for problems of mental health, perhaps made worse by ill-informed and poorly-trained *imams* on the one hand, and by limited health service resources for explaining genetic disorder, on the other. The narratives in this book offer a powerful and challenging commentary on questions of health service provision, information flow between medical professionals and the assumptions that underpin “non-directive” counselling discourse. The careful research which underpins this volume means that Rozario provides us with a lens through which much broader issues around health and well-being, health communications, and the meaning of illness and suffering, come into view.

Rozario’s book is valuable for other reasons also. Her work offers insight into changing socio-economic and religious dynamics within Bangladeshi fam-

ilies in the UK, who because of their unique experiences are well-placed to comment on questions of honour, “stigma” and shame, purity and kinship, relationships and “belonging,” power relations within marriage and family life, and the continued practice of transnational marriage. We come to see how religious perspectives inform decision-making in difficult circumstances, and the way in which Islam is displayed and performed in Bangladeshi households in the UK. Given the increasing importance of religion as a reference point for identity among many young Muslims in Britain—Bangladeshis included—a study which placed Islam at the centre of research questions was timely and consonant with the significance that is attached to religion, especially by a demographically “young” and increasingly British-born population group.

Rozario was exceptionally well-placed to undertake the research upon which this book is based, personally and biographically, as well as academically. The insights we read about in this volume arise from the careful labours of an experienced anthropological fieldworker who has navigated a complex and ethically sensitive subject with care and respect. Because of the relationships Rozario formed with the families involved in her study, they become more than just “case-studies.” We gain a real appreciation of their worldview, their struggles, and their hopes, and this signifies the quality of the research relationships that underpin this book.

Arising out of these relationships, important questions surrounding the tension between conventional medical advice and action, and “Islamic” medicinal approaches and courses of action, become clear. Whilst scientific medical intervention is clearly sanctioned in Islamic tradition, among devout Muslims there is also an awareness of the ultimate source of cure, who for them is God. This book explores some of these questions, tensions, and challenges.

As Alison Shaw’s afterword suggests, the issues faced by the Bangladeshi families in Rozario’s study both resemble and differ from those among other South Asian populations. This study is thus of value not only for what it tells us about British Bangladeshis, but as a contribution to a wider exploration of how South Asian migrant populations in the UK and elsewhere deal with serious illness. I hope that it will be of value both to those most directly concerned with the delivery of genetics services to Muslims in Britain, especially those of Bangladeshi origins, and to the wider community concerned with similar issues in other contexts.

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Within the Bangladeshi community, I would like to thank various people associated with Bangladeshi associations, including Farida, Rehana, Shahara, Fateha, Rajma, Ruksana, Reha, Rohma and Anwara. Wahida Kent from the ABCD in South Wales also facilitated my research and I would like to thank her. Jasmin Chowdhury and Patricia Gregory provided me with initial contacts within the community and also kept me informed about various functions which became very useful for my ethnographic research.

I thank Eve McKenzie for putting me in touch with her parents, and her parents for their hospitality upon my arrival and for sharing interesting anecdotes about the Bangladeshis in their city, which became my second home for the duration of this project. Alison Shaw extended moral support and shared her own experience of similar research with British Pakistanis; this was especially helpful with my recruitment strategy and later with my writing. I would also like to thank her for reading through the final manuscript and I am grateful for the Afterword she has supplied for the book.

Pnina Werbner's enthusiasm and prodding encouraged me to persevere in writing this book. Thank you Pnina, it meant a lot for me. Other individuals who were supportive of my research for this book directly or indirectly are

Clara Gaff, Linda Connor, Patricia Jeffery, Shelley Feldman, Helen Williams, Marta Bolognani, Des Barry, Pat and Will Johnson and Dawn Collins.

Finally, I would like to specially thank the patients and their family members for sharing their stories, for their hospitality during my visits, and for allowing me to meet their extended family members. Without these families' cooperation, their willingness to share their life stories with me, especially the stories involving their affected children, and their patience with my often-persistent questioning, this research would not have been possible. I am particularly grateful to some of the families who accommodated me in their households during my inter-city visits. For reasons of confidentiality I am unable to name any of the families here. I would like to extend a very big thank you to Runu Simpson, her husband Peter Simpson and their children for opening up their house to me, and for their on-going support and help towards my research in ways that I am unable to go into detail here. I would also like to extend my thanks to Jane Emery who has carefully copy-edited the final manuscript. Last, but not least, I would like to thank my husband Geoffrey Samuel without whose encouragement and confidence in me, and on-going support behind the scene, I would never have written this book. He has also very kindly edited this present book thoroughly.

Chapters 7 and 8 include some material published in an earlier form in two articles, "Allah is the scientist of the scientists: Modern medicine and religious healing among British Bangladeshis" (2009, *Culture and Religion*, 10(2): 177–199) and "Growing up and living with Neurofibromatosis1 (NF1): A British Bangladeshi case study" (2007, *Journal of Genetic Counseling*, 16(5): 551–559). I thank the publishers for allowing me to include this material here in revised form.