Socio-cultural Dimensions of Congenital Adrenal Hyperplasia: An Ethnographic Study from Chennai, South India

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Abstract

Aim: This study aims to provide a medical anthropological perspective on how congenital adrenal hyperplasia (CAH) is perceived and constructed by parents and doctors in India. It aims to put forth the complexities that are associated with CAH and the various experiences that parents and doctors share as a result, while also exploring the influences that culture and medicine have on each other. Methods: An ethnographic approach was taken to understand CAH in this study, in which families and doctors of children with CAH were interviewed. Fieldwork was done for 2 months in Chennai, Tamil Nadu. Results: A major finding of this study was the faith that parents had on biomedicine in general and doctors in particular. While parents continued to follow the instructions provided by the doctors, they also exercised their agency by questioning the decisions taken by the doctors. The research also revealed that there is constant worry and fear in parents about the future of their children due to the stigma attached to CAH. Conclusion: A constant discourse between medicine and culture can be noticed while analyzing the complexities associated with CAH. The study tries to show that medical decisions that doctors take in matters concerning CAH are culturally driven. Surgical corrections done in order to categorize the child into one of the two sexes is an example for the same. Similarly, various structures of family, marriage, and kinship have been medicalized owing to the strong influence medicine and culture have on each other.

Keywords: Congenital adrenal hyperplasia, culture, India, society

Introduction

“Intersex” is used to refer to conditions where an individual is born with atypical reproductive and/or sexual anatomy, making it hard to categorize the individual into either of the two “true” sexes. “Hermaphrodite,” in reference to a character from Greek mythology[1] who was half-man, half-woman, was the term used to refer to individuals with ambiguous genitalia until the 20th century, when it was replaced with “intersex.” The medical term is disorders of sexual development (DSD). Several conditions come under DSD. Congenital adrenal hyperplasia (CAH) is one of the commonly occurring one. Research on intersexuality in India is essential largely to generate awareness about it, which would in turn help people make choices accordingly. An anthropological research might provide a perspective different from that of a medical one, for it will bring out the socio-cultural realities of how ideas of gender, medicine, and culture impact health conditions such as CAH.

Methods

This is an ethnographic study on CAH that was conducted in Chennai, Tamil Nadu over a period of 2 months. An Institutional Ethics Committee approval was obtained for the study and oral consent (audiotaped) was taken from each respondent. Doctors and families of children with CAH were the primary and sole respondents of this research. The sampling for the research was purposive and the total number of respondents for this study were 18. Five doctors and 13 families of children with CAH were interviewed. Out of the five doctors that were interviewed, four were endocrinologists and one was a pediatrician. Twelve families with CAH children were interviewed. Out of these 12 families, seven families have male children with CAH and five families had female children with CAH. The research also revealed that there is constant worry and fear in parents about the future of their children due to the stigma attached to CAH. Conclusion: A constant discourse between medicine and culture can be noticed while analyzing the complexities associated with CAH. The study tries to show that medical decisions that doctors take in matters concerning CAH are culturally driven. Surgical corrections done in order to categorize the child into one of the two sexes is an example for the same. Similarly, various structures of family, marriage, and kinship have been medicalized owing to the strong influence medicine and culture have on each other.

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Access this article online

Quick Response Code:

Website: www.ijem.in

DOI: 10.4103/ijem.IJEM_177_18

How to cite this article: Pellur M, Narasimhan H, Mahadevan S. Socio-cultural dimensions of congenital adrenal hyperplasia: An ethnographic study from Chennai, South India. Indian J Endocr Metab 2019;23:227-31.
female children with CAH [Table 1]. In addition, out of the five families with female children diagnosed with CAH, two families had more than one daughter diagnosed with CAH and one other family was expecting another child with a definite CAH condition [Tables 2 and 3]. Additionally, an adult female with CAH was also interviewed. A clinic in Chennai was the field site where most of the interviews with the respondent families were conducted. Two families, however, were interviewed in their respective houses. Each of the doctors who participated in this research gave their interviews in their respective clinics.

An ethnographic study is largely based on qualitative methodologies and places importance to the narratives of individuals involved in the concerned area of research.[2] Qualitative methodologies such as interviews were used in the process of data collection. Semi-structured interviews that were aided by a question guide were used throughout the research to gather details on intersexuality. Interviews were conducted by the first author and were held in privacy. Two separate question guides with a list of questions that could possibly be asked to doctors and families of intersex children were prepared. While the question guides for doctors focused on queries relating to how they would explain this condition to the parents, the treatment protocol, and the best available solution for this medical condition, the question guide for the parents focused on queries that paved the way for understanding their experiences and emotions in the process of identifying, accepting, and treating their child with CAH. Questions were not, however, posed verbatim as they were in the question guide but were asked in accordance to the response of the respondent. Apart from conducting interviews, observation as a tool for data collection was used wherever possible. Since this is a medical anthropological study, socio-cultural domains were given prominence.

| Table 1: Gender of children identified with CAH |
|-----------------------------------------------|
| Socially identified gender of the child with CAH | Number of informants |
| Boys                                       | 7       |
| Girls                                      | 6       |
| Total                                      | 13      |
| CAH: Congenital adrenal hyperplasia         |         |

| Table 2: Number of CAH children in house |
|------------------------------------------|
| CAH children in households               | Number of informants |
| Single child with CAH                    | 3       |
| Siblings with CAH                        | 4       |
| Sibling without CAH                      | 6       |
| Total                                    | 13      |
| CAH: Congenital adrenal hyperplasia      |         |

| Table 3: Gender of child with CAH and child’s sibling with CAH |
|---------------------------------------------------------------|
| Gender of CAH child with CAH sibling | Number of informants | Gender of sibling |
| Boy                                  | 0                     | N/A               |
| Girl                                 | 4                     | Girl              |
| Total                                | 4                     |                   |
| CAH: Congenital adrenal hyperplasia, N/A: Not applicable       |         |
some parents had built a knowledge base of their own, separate from that provided by their doctor, because of which they were able to play an active role in the decision-making process of their child’s treatment, thereby putting the “authoritative knowledge” of the doctor in question. One of the fathers while talking about the side effects of the tablets given for CAH said:

“And we cannot share these issues with anybody […]. Society is a big (pause) problem for us. Social barriers are a very very big thing. When he goes to school, I have spent a lot of time thinking, how he will be or feel in that school. We (wife and him) still have that feeling.”

Parents also expressed their concern for their child’s future, which they feared might be affected by the stigma attached due to CAH. Living in a heteronormative, patriarchal society parents of a girl child worried more about her future in terms of marriage and reproduction. While the parents of girls with CAH worried about her marriage and ability to reproduce, parents of boys with CAH feared the consequences that their child might have to face in the age of puberty when he might have to articulate and understand the difference in his physical appearance from other boys of his age, if there is any. Additionally, the very idea of considering CAH a shortcoming reveals that there is a set notion about what is normal and what is not. Such notions most often result in pathologizing what we do not regard as the “normal.”

Though, on the one hand, parents considered CAH a shortcoming, they were on the other hand relieved that it could not be purely identified from the child’s physical attributes, barings the ambiguity in the child’s external genitalia (that may or may not occur). They unanimously believed that CAH was rather “internal” than “external” and this belief made it easy for them to tackle the notions of stigma. As the sociologist Erving[5] writes in his seminal work “Stigma,” visibility of the factors that may cause stigma and the capacity of the viewer to decode it is to be kept in mind when addressing issues of stigma. That is why one can often hear parents state something similar to what this father of a CAH boy said “[…]physically he looks very active, he has more energy. Everything is good, but the only thing is some internal[…]. As I said earlier, the growth and all is the problem.”

Cultural impact
Parents and doctors try everything at hand to ensure that the child with CAH grows up with a “normal” childhood and the decision to not disclose the details of this condition to anyone is a measure taken to ensure the same. Although nondisclosure may help their child’s life and future, it will not prevent this genetic condition from being transmitted to the next generation. Hence, when consanguineous marriages were identified as a possible reason for the occurrence of CAH, doctors advised parents to forgo consanguineous marriage practices in the future. With the advent of new genetics, family and kinship have become medicalized. And this medicalization, which brings about an awareness of the medical history of one’s family, helps individuals deal better with hereditary medical conditions. Once individuals are aware about their hereditary medical condition, they scout for options that can stop or at least minimize its effect on the body and mind of the next generation. Avoiding consanguineous marriages, which has been the cornerstone of the Dravidian kinship system, is one such attempt to prevent CAH from affecting the next generation.
of the family/lineage. Isabelle Clark-Decès[7] in her book “The Right Spouse” talks about something similar where Tamils, among whom the consanguineous marriage practice is believed to be common, have slowly forgone marrying within close kin stating scientific reasons for the same. She writes about how Tamils now believe that 50% of the genetic makeup is derived from the father and the other 50% from the mother and that brothers and sisters share 50% of their genetics, thereby stating that if close kin marry, their offspring will have to face medical defects.[6] One of the grandparents interviewed said, “in the future we should not get our children married within relation/relatives. Apart from that there is nothing.”

**DISCUSSION**

Anthropological studies on CAH or intersexuality have not been conducted in India as far as we could find, though similar researches have been done in the West. Katrina,[8] an American anthropologist, writes in her book on the history of intersex, the current treatment protocol that is followed by doctors, and the experiences they share in the process of the treatment. Although in certain cases surgical corrections are done to avoid medical complications, in most cases the desire and compulsion to categorize children with CAH into the heteronormative structures of the society has been prominent. Like Katrina states the term intersex is in itself heavily laden with the heteronormative ideas of gender and sex, for it is derived from the “natural” binary model of gender with the term “intersex” falling perfectly between the two “true” sexes.[9] Both parents and doctors feel it is essential for the child to be “normalized” and fit into one of the two sexes in order to avoid a life with much stigma and pain. However, is gender necessarily a binary? If so, then why do some scholars including the biologist Anne Fausto-Sterling[10] state that sex is a continuum? Philosopher Judith Butler[9] states that “a body’s sex is simply too complex. There is no either/or. Rather, there are shades of difference.” If there are true shades of differences then why does gender binary cloud the presence and existence of other genders and sexes? The culture and the norms of the society can be identified as possible reasons for the same. The idea of average that eventually becomes the norm could be recognized as one major reason for this insistence on categorization into the gender binaries. Georges,[10] a philosopher and physician, in his book “The Normal and the Pathological” talks about how the average is used to form norms which in turn influences the categorization of normal and pathology. Focusing largely on the influence of social norms on medicine, Georges writes that “normal” for physiologists is determined by an average and establishing a norm in purely biological terms is hard, for each one’s biological condition is different and forming an average in biological terms will only lead to variations going unnoticed. This eventually paved the way for social determinants to be used in forming the average.

A number of scholars who have worked on intersexuality have addressed the socio-cultural influence on the medical constructions of many biological conditions. Such an influence can be distinctly seen in the treatment protocol followed for treating CAH. Using surgical corrections to “normalize” the child is a result of this socio-cultural influence. When physicians take to surgical corrections, when there is no medical complication otherwise involved, to ensure the child grows “normally” with little or no stigma attached, they are allowing the socio-cultural factors to influence their medical decisions. The one interview with an adult with CAH exemplifies the main arguments of this article, about the role of social and cultural factors in accessing treatment for CAH. The young woman discussed her inability to talk about the condition with anyone openly due to the stigma attached. In Tamil culture, menarche is celebrated with a public ritual announcing a girl’s coming of age. Not having attained puberty is therefore a huge problem for the woman. However, she expressed confidence in being able to help her sisters with similar conditions, through biomedicine. Currently undergoing treatment for late menarche, she even contemplated suicide at one point, prevented by support from a male friend who is also planning to marry her, after knowing her condition.

At the same time, various social structures of the society have also been medicalized, an example of which is the possible change in the Dravidian marriage systems. This constant discoursing between the society, culture, and medicine has resulted in each influencing the other largely. Isolating one from the other will therefore only result in establishing partial reality. Decisions on treating intersexuality have to be taken keeping in mind this interaction of medicine and culture. As one of the doctors said, in a nation like India, where power of gender binaries is intense, categorizing the intersex child into one of the two sexes is probably the easiest/best choice available for the parents, doctors and maybe the child as well. She said:

“There (in UK) they do not have to put gender in everything. Here, right from your LKG admission form you are asked to mention your sex including father’s name, mother’s name. Everything is optional there. So they do not bother about what has been documented and whatever the child prefers they assess….”

This paper takes a medical anthropological perspective to understand how CAH is perceived by parents and doctors and how that might help unravel the complexities that are experienced by people with CAH and their care givers, in this context, the parents. Using ethnographic methods is a helpful way to explore issues that otherwise get hidden from public domain, whether it is the extended family, or the larger society. There is hardly any study done on CAH from a social science perspective as far as our research could find, especially in India. Through the findings of this research a close connection between medicine and culture can be drawn that shows the influence each have on the other. The constant discourse between medicine, society, and culture has to be acknowledged and understood in order to establish multiple ways of treatments for DSD or intersexuality, as well as for the
process of diagnosis of the same. Further in-depth research, exploring the socio-cultural aspects associated with CAH, can in turn provide a better understanding on CAH and initiate a possible awareness among people on the socio-cultural and medical complexities surrounding this condition.

**Financial support and sponsorship**
Nil.

**Conflicts of interest**
There are no conflicts of interest.

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