Artifacts of Care: The Collection of Medical Records by Families in North India

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Abstract

In India, where there is no centralized medical records system, biomedical care providers rely on families to explain their child's illness and to carry records of any previous treatment the child may have received. Drawing on discussions of documentation, I argue that in the context of medical treatment for pediatric seizures (1) families collect medical records to enable and shape their child's medical treatment, and (2) such a merging of medical and familial care is necessitated by the nature of their child's illness and the structure of the Indian healthcare system. Based on ethnographic fieldwork in Meerut and New Delhi, this paper attends to practices of record keeping to understand the demands biomedical institutions place on families for the treatment of their child's seizures. I examine the creation, maintenance and movement of medical records to suggest that documents are a point of intersection between medical and kinship practices. They are artifacts of care that can narrate parallel histories of a patient's illness and family-clinician efforts to alleviate a child's suffering.

Keywords

Documents, Medicine, India.

Introduction

In spending time with families whose children suffer from seizures in the north Indian state of Uttar Pradesh, I was struck by the range of care providers and treatment regimens families availed for their children. This entailed regularly travelling long distances, collecting and creating records of treatment, and expending considerable financial resources to seek out opinions, diagnostic tests and medicines. This article focuses on the medical records families maintained about their child's seizures. I delve into the creation and circulation of medical documents to understand the role families play in the biomedical treatment of chronic illnesses among children in India. Like many countries, India does not have an electronic medical records system that physicians can use to access the medical history of a patient. In hospitals and clinics in the north Indian cities of Meerut and New Delhi I found that medical care providers relied on family members to explain their child's condition and to carry records of any previous treatment the child may have received. The time doctors gave to family members to share the history of their child's seizures varied across doctors and institutions. Similarly varied was the import a doctor gave to prescriptions written and diagnostic tests ordered by other doctors. Nevertheless, both these histories—oral and written—were critical components of patient-doctor interactions in outpatient settings where the onus was on family members to collect documents relevant to their child's illness and treatment, and to bring these records along when visiting a doctor. Past prescriptions, discharge summaries, the results and reports of diagnostic tests were generally kept and carried by families in a sturdy plastic bag. If the child had had an MRI done, the large bags of thick plastic in which the MRI film and report came were often used to store other documents

related to the child's treatment. Some private clinics gave clients hardbound folders in which to keep prescriptions accumulated with each consultation at their clinic. Some doctors stapled all their prescriptions together, adding one page for every visit. Some families included in these records bottles and strips of medicine their child had previously been prescribed. Some created photographs and videos of their children having a seizure and showed these to doctors.

How important documents can be in the treatment of pediatric seizures was brought home to me one afternoon in the pediatric intensive care unit (PICU) of a public hospital. Having arrived at the hospital after its outpatient department had closed for the day, a mother walked into the PICU with her daughter, who looked to be around four years old. The mother approached the young doctor manning the PICU and informed him that her child had recently experienced a seizure. She requested him to write a prescription for medicines she should give her daughter. The doctor asked the mother about the girl's medical history and it emerged that the child was already on an anti-epileptic drug. However, the mother could not recall the name of the drug. Neither had she brought the prescription on which it was written. I asked whether she had brought bottles or strips of medicine to show to the doctor, as I had seen families sometimes do. She had not and this left the doctor in a fix. He could not treat the child because he did not know the child's recent treatment history. The mother pleaded with him to write a prescription, citing the cost of travelling to the hospital for her and her daughter, but the doctor asked the family to return to the hospital with the prescription the next day.

It is likely that in a different treatment setting, for instance in a private clinic where the family would have paid to see the treatment provider, the child would have received treatment in the form of medicines or a prescription for them. This paper, however, is concerned with

situations like the one described above, wherein medical documents are used by families and biomedical personnel to communicate with each other about a child's illness and coordinate medical care for them. There is a rich literature in the social sciences on documents, and on medical records in particular. The latter are considered central artifacts of biomedical knowledge and practice (Berg and Bowker 1997) and include all documents created about individual patients for their biomedical care. Medical records adhere to philosopher Suzanne Briet's definition of documents being objects that are "preserved or recorded toward the ends of representing, of reconstructing, or of proving a physical or intellectual phenomenon" (quoted in Hull 2012, 253). Briet's definition highlights the productive and evidentiary aspects of documentation. Documents are crucial components of bureaucratic institutions (Weber 1958) and knowledge-producing endeavors such as modern medicine (Foucault 2003). They are essential for the performance of biomedicine in the clinic where written texts tend to be privileged over other forms of recollection and recording (Berg and Bowker 1997). Medical documents also work as "boundary objects" that both coordinate the activities of teams and separate insiders from outsiders (Bowker and Star 1999; Heimer 2006). They can reveal how alliances to collect, record and share information create a disease (Mol 2002). Conversely, records can be left incomplete and vary in the extent to which they adhere to scripts and protocols (Street 2011). Furthermore, a record's use of a specialized language replete with abbreviations and jargon can make the activities of the clinic opaque to individuals not conversant in the language (Martín 2016). These characteristics make medical records useful for understanding how the boundaries of biomedical practice are established and negotiated in a particular setting.

Scholars have shown medical records to be generative at multiple levels and crucial for the constitution of diseases, patients and clinics. Berg and Bowker (1997) emphasize that records do not merely represent the body of the patient. The structure of a patient's day—when they are fed, medicated, measured and tested—is shaped by demands made by the medical record. In this way, "the body is materially reconfigured—its flesh is part and parcel of the discursive transformations that convert a body into a medical 'case'" (519). At the same time, documents are an unstable knowledge technology because their social role and purpose changes as they are added to and transported from one setting to another (Street 2011; Breinneis 1994). In the clinic, records can structure thought and actions, making them a part of the apparatus that marks the clinic as a rational space guided by processes of classification and standardization (Riles 2006; Hunt et al. 2017; Newman 2019). Conversely, records can also be used as "artefacts of not-knowing", employed to suspend diagnostic certainty and professional responsibility (Street 2011).

Medical records remain productive outside of biomedical spaces and processes. Their non-administrative and nonbureaucratic significance sits beside their bureaucratic functions and their textual meaning can exist apart from their affective, social and political significance (Street 2011; Martín 2016). Heimer (2006), Seo (2017) and Mariner (2019) have paid attention to the role medical documents play in the production and performance of kinship. Building on their insights, in this article, I study how families in north India use medical records to connect and communicate with the heterogenous mix of medical care providers who diagnose and treat their child's seizures. I argue that (1) families collect medical records to enable and shape their child's medical treatment, and (2) such a merging of medical and familial care is necessitated by the

nature of their child's illness and the structure of the healthcare system in India. The ethnographic material examined below illustrates that biomedical practice in India relies upon families for the creation of medical documents and their collection into a record. Within India's fragmented and privatized medical care system, the records kept and carried by families are the primary means for tracing a child's medical history. Paying attention to instances in which families create, save and share documents about their child's illness shows us that a culture of record-keeping by kin is an intrinsic part of pediatric medicine in India. Studying instances of record collection also helps us understand one of the key ways in which families and medical care providers interact with each other and coordinate care for children suffering from chronic neurological illnesses in the country.

An important facet of the biomedical management of seizures is that they are intermittent, unpredictable episodes that can occur even when the patient is regularly taking medication. At the same time, patients are advised to continue medicines and visits to specialists even when the symptoms of seizures are not present. In current biomedical literature, a seizure is defined as the "clinical manifestation of an abnormal and excessive activity of a set of cortical neurons" (Hauser 2016, 177). Seizures vary in form and severity. As Trostle et al. explain, "seizures may involve electrical activity in the majority of the brain cortex, resulting in generalized convulsions of the whole body (tonic clonic seizures), or momentary lapses in consciousness (absence seizures). They may also involve only a small portion of the brain (partial seizures), resulting in automatic behaviors such as muttering or aimless activities, in sensations of numbness, sound, smell or taste, or in regular contractions of particular extremities" (Trostle 1983, 35). Epilepsy is defined as two or more unprovoked seizures separated by more than 24 hours.[3] A large

proportion of pediatric seizures—between 60 to 80 percent—appear to be idiopathic, i.e. they do not have a cause that can be found and resolved (Hauser 2016). Studies indicate that familial predisposition increases the risk of developing seizures (Miller et al. 1999). In addition, children are most vulnerable to develop epilepsy during the first year of life, with the incidence of seizures decreasing with age. A diagnosis of epilepsy holds for five years, which means that a patient is considered to be epileptic, and in need of medication, until five years from their last seizure. In theory, every seizure restarts the clock.

As biomedicine has changed in the two past two centuries, so has its understanding of seizures. While the term 'seizures' stems from the notion that patients were possessed or seized by spirits, its continued use in biomedical and lay literatures alerts us to the nature of the condition, with its ability to disrupt and take hold. Nordli (2016) explains that biomedical explanation and classification of epileptic seizures have gone through three phases: the pre-twentieth century 'philosophical era' that relied on patient observations to speculate about the nature of the disease; the 'era of the localizationalists and pathologists' in the first half of the twentieth century in which epilepsy came to be located in the nervous system; and the current 'molecular and genetic era' which understands epileptic seizures through lab sciences such as neurochemistry, pharmacology and molecular biology. Despite this engagement, epilepsy remains a difficult condition for biomedicine to diagnose and treat. Ethnographic studies among persons with epilepsy have found that most patients continually assess the appropriateness and effectiveness of treatment regimens suggested by their doctors and willingly seek out opinions and treatments from other care providers (Gaudecker et al. 2017). Discussing the notion of compliance, Trostle et al. (1983) note that while for a physician the ideal process of epilepsy

management would include: "(1) diagnosing a type of seizure, its presumptive case, and/or any remedial factors; and (2) establishing an optimal balance between seizure control and the side effects of anticonvulsant medication" for many persons suffering from epilepsy, explaining and managing their illness necessitates taking into account the haziness of biomedicine's understanding of seizures and the elusiveness of a biomedical cure for them (Trostle et al. 1983, 35).

Thus, for many children and their families seizures are chronic events that begin in infancy or childhood and reoccur in an unpredictable and irregular manner. The biomedical management of seizures requires an understanding of the child's birth history and information regarding the onset of seizures. It further necessitates keeping track of the medications given to the child, their doze and effects. It also requires the use of expensive diagnostic tests such as MRIs and EEGs to track developments in the child's brain as the form, frequency and severity of their seizures changes over time. Medical documents are one of the main instruments through which all this information is materialized. Understanding the maintenance and movement of medical records is thus key to understanding the way that disease is understood and managed, and the way that care is performed. This article contributes to discussions in anthropology about the significance of documents in biomedical practice through an examination of the role families play in the maintenance and movement of records in India. Following Martín's call to analyze medical documents as constitutive of the world of medicine and of "the socio-material world of care", I conceive of the records collected by families as artifacts of care that allow for the coalescence of familial and medical care (Martín 2016, 17). Attention to the physicality and portability of documents helps us delve into the relational and material aspects of biomedical practice in India.

In the following section, I provide details of the setting in which this research was conducted and the methods used for data collection. Next, I analyze particular medical documents created in biomedical institutions to reveal the crucial role families play in their construction and circulation. I show that even though families might not understand the content of these documents and might not be the audience for whom they are written, families are essential for the continued presence and use of these documents in biomedical treatment. Families make these documents portable. Next, I consider the medical document that families themselves create about their child's seizures in order to either constitute or direct its biomedical treatment. The creation of medical documents by families is seen in light of their work maintaining medical records. I delve into the work of maintenance and propose that the medical records kept and carried by families are artifacts of care that result from the merging of familial and medical care, a coalescence that is essential for the continuation of biomedical treatment of a child's seizures in India.

Research setting

It is estimated that each year 5.9 million children younger than the age of five die globally, and of these 1.2 million are in India (Lui et al. 2016). This article is based on an ongoing study on child health in the north Indian state of Uttar Pradesh (UP). It takes pediatric seizures as a doorway to enter conversations about child health, kinship and medicine in north India. UP has been called "one of the most dangerous places in India to give birth" and its infant and child mortality rates are the highest in the country (Das 2019, 1994; India State-Level

Disease Burden Initiative Child Mortality Collaborators 2020). It is one of India's poorest states and home to seventeen percent of its population. More than 200 million people reside in UP's 75 districts, and it is estimated that thirty percent of them are poor (Mohanan 2020). Mirroring national demographic trends, UP is a young state with 34 percent of its population below the age of 15 years (Indian Institute of Population Sciences 2020).

Although people in UP have access to an array of biomedical care providers, the quality of care they receive is poor (Jeffery and Jeffery 2010; Muralidharan et al. 2011; Das et al. 2016; Sharma et al. 2017; Semrau et al. 2017; Mohanan 2020). People are much more likely to visit private, fee-charging medical care providers than public facilities. The latter provide services at highly subsidized rates but suffer from a high prevalence of absenteeism among workers, a shortage of staff and infrastructure, and a strict hierarchy between patients and providers. The private medical sector in UP is largely unregulated and access to it is based on a family's ability to pay.[1] It consists of numerous small and large, individually or corporate-owned hospitals and clinics manned by both qualified and untrained personnel.[2]

Fieldwork for this study began in 2019 and is centered around the city of Meerut, the capital of Meerut district in western UP. Meerut district is home to more than 3.4 million people and is more urbanized than most other districts in the state. To understand the experience of families in western Uttar Pradesh whose children suffer from seizures, I began by interviewing pediatricians and neurologists in Meerut city. These included: three senior neurologists and pediatricians who operate private clinics; a pediatrician, Dr. Ravi, who runs a private clinic and a hospital; and Meerut's sole pediatric neurologist, Dr. Jyoti, who comes to the city from New Delhi once a month to see patient's at Dr. Ravi's clinic. These doctors allowed me to observe

their consultations, which I did for a period of four months. They also gave me permission to reach out to families who had come to them for medical advice. In addition, I interviewed faculty and medical residents at the two medical colleges in Meerut, Netaji Shubhash Chandra Bose Subharti Medical College (Subharti) and Lala Lajpat Rai Memorial (LLRM) Medical College. The former is a private institute and sits on the western border of Meerut city. Here, I met Dr. Dev, a professor of pediatrics, who helped me understand the etiology of pediatric seizures commonly treated at Subharti's teaching hospital and also introduced me to families whose children he was treating. LLRM, commonly referred to as Medical, is a public institute and provides free or highly subsidized outpatient and inpatient services. I was given permission to observe medical practices, follow medical residents and speak with families whose children were being treated in the outpatient ward and Intensive Care Unit (ICU) of Medical's Department of Pediatrics. Among the many families I interviewed, four became my key informants. I accompanied them to hospitals and clinics in Meerut and New Delhi, spent time at their workplaces and homes in Meerut and in villages located in districts adjacent to Meerut, and was introduced to their neighbors and kin. Participant-observation, analysis of medical documents and in-person and telephone interviews were the primary instruments of data collection for this study. I conducted all interviews using either Hindi-Urdu or a mix of Hindi-Urdu and English.

Families and Documents in Biomedical Practice

Prescriptions, diagnostic test results and reports, bills for hospital stays, pharmaceuticals and medical devices, are documents that can narrate a particular history of an illness episode, or a life. In India, where the practice of medicine is dependent on the presence of kin, these

documents can also offer us "histories of care and family life" (Pinto 2014, 20). In following the treatment of children admitted in the ICUs and wards of hospitals in Meerut and New Delhi, I learnt that each hospital had protocols for the making and maintenance of patient files and that families played an essential and particular role in the creation and circulation of these documents. In the pediatric department of Medical's teaching hospital, for instance, files functioned as medical, administrative and legal records. They consisted of pages filled by doctors and residents on a child's medical prognosis and treatment. These pages were interlaced with sections wherein the child's parents had been asked to sign below text that explained the risks associated with their child's treatment. On the first page of a file, for instance, half the space listed the department's name (pediatrics), the ward (ICU), the clinician in charge of treatment (a professor in the pediatrics department), the patient's name, address, gender, age, date of admission, name of their father and a provisional diagnosis. The second half of the page comprised of a section entitled "Risk notes/ Consent" wherein the "pt's father" had signed his name under a paragraph that read, "I have been told about my patient's serious condition I still want my patient's treatment to happen in this hospital if an unfortunate (apriya) event happens then I will be solely responsible for it not any hospital or doctor". Below the father's signature was a note stating the name of the resident who had "verified" the signature. Within the file, pages documenting treatment and test results lay beside pages recording parents' approval of particular treatment procedures, such as lumbar punctures, and their understanding of their child's critical condition.

The use of multiple languages in a file paralleled its various functions and indicated the parties involved in its creation and maintenance. Text about diagnosis and treatment was written

in English and made use of numbers, diagrams and signs. Diagrams, for instance, were used to portray the 'ancestry' of the patient; arrows indicated whether a statistic had increased or decreased since its last measure; dates and vital statistics were in numerical form. Most of this writing was in shorthand; scribbled in with a blue ball-point pen it is difficult to decipher and understand. It is not meant for perusal by families. In the time I spent in the ICU, I never saw a family go through the file of their child. Service providers did not expect them to and most families did not read English. Sections in the file that required consent were written in Devanagari script by residents responsible for conveying this information to caregivers and getting their signatures. It is telling that sometimes these sections would be signed before the text had been written in. Thus, in Sofiya's file, a page entitled "Sofiya [next line] Consent for L.P." is blank except for her mother, Ayesha's, signature in a circle on the right side of the page. On top of this circle is the phrase "Sign of Mother" and on the bottom "Verified by Dr. Aarushi". Similarly, in Sajiya's file, there is a page entitled "Grave Prognosis Explained" with no other text but the date, the signatures of Sajiya's mother and uncle, and the name of the resident who has verified these signatures. The prognosis was explained to family members and verbal consent was sought from them for the continuation of treatment but text that documents the explanation and approval will be written later that day or in the following days when a resident has time to do so. Its current absence points us to conditions under which the file exists, and the purpose it serves. Files were created in an understaffed ICU that required residents to treat and to record the treatment in a particular format. The resultant text was meant for medical, legal and administrative staff at the hospital. Although it was not meant to communicate with families, they were essential for its creation.

Families were also needed for the safekeeping and circulation of documents. In the cases I was following, text given to families included the names of medicines and medical supplies to be bought by them, receipts, bills and discharge sheets. Some of this information was written on blank pieces of spare paper, some was filled into forms designed to relay this information. In all instances, families saved these documents but they were neither the sole nor the ultimate audience for these documents. At Medical, for instance, a form entitled 'Discharge Summary, Department of Pediatrics, [Name of Medical College]' distilled a patient's file into a three-page document. While hospital files remained in the hospital, discharge summaries were meant to be taken home by families. Both texts used language in a similar way. Except for its "Advice" section, the Discharge Summary was in English and used biomedical terminology and abbreviations. For instance, the last page of Sajiya's Discharge Summary consists of four pre-formatted sections. The top-most section is a narrative summary of the treatment, written in shorthand, in English, with the use of symbols such as arrows, equal signs and pluses. In the second section, beside a cell entitled "Treatment Given", the resident has listed three drugs and the number of days they were given to Sajiya. For instance, "- Inj vancomycin x 28 days." The third section is divided into two columns. In the first, under the printed heading 'Advice', the resident has written in Devanagari "Show the patient in number 15 if they have difficulty breathing or run a high (*tez*) fever". Room number 15 is the outpatient clinic of the pediatrics department. The second column reverts back to English; the first-row states, "Diet as advised", and subsequent rows list medication to be given to the child, their dose and duration. In the last row the resident has noted in English that the patient be brought to the department's OPD for follow-up in a week. The final section of the Discharge Summary notes the positions and

signatures of the medical officer, senior resident, and junior residents involved in Sajiya's treatment. These signatures showcase the collaborative aspects of diagnosis and treatment and enable the document to distribute medical authority and legal responsibility.

In addition, the predominance of English and biomedical terminology in Sajiya's Discharge Summary suggests that the audience for this document is not her family alone. Rather, it is primarily meant for perusal by biomedical personnel: doctors and residents at this hospital when Sajiya is brought back for follow-up; pharmacists from whom medicines will be bought; other doctors to whom Sajiya's family might take her for treatment. Families carry and keep the Discharge Summary but may not understand what it says about their child's condition. This is similar to the role served by prescriptions written in outpatient settings and reports accompanying diagnostic tests such as MRIs and EEGs.

Most prescriptions written in the private and public clinics I observed were brief. Doctors noted the name of the child and the date of consultation. The names of medicines they prescribed were often accompanied by diagrams indicating how often in a day they were to be given to the child. Some prescriptions also noted the weight of the child. Doctors' description of the condition afflicting the child ranged from a list of words:

Fever

Seizure

[two undecipherable letters separated by a '/'] cervical right nod

to shorthand sentences about the last episode of seizure and the child's history with seizures. Various factors influenced the amount of information noted in a prescription. Based on my

observations, the following elements could play a role: the size of the prescription pad; how busy the doctor was that day; if this was the first time the doctor was seeing the patient; if the prescription was likely to be perused by a researcher or another doctor. Prescriptions served as memory aids, enabling their writers to recall previous encounters with a patient. They were a medium of communication with other medical professionals, such as pharmacists who sell the medicines listed and often explain to family members when they are to be taken. Prescriptions also acted as material proof that a patient had been seen by the doctor and that advice had been dispensed. Finally, prescriptions became records for families to keep or discard.

The Creation of Medical Documents by Families

In addition to aiding biomedical personnel in the creation and circulation of bureaucratic and routinized medical documents, families also created documents themselves. I was alerted to this practice by Parth's father, Ajit, who had summarized his twelve-year old son's medical history into a three-page document. Ajit teaches at a public, junior college in Meerut and had used the wide sheets of an examination booklet for this purpose. Neatly written with a blue ball-point pen, in small English letters the document notes the diagnoses and treatment regimens given to his son, who has been suffering from seizures since birth. It mentions the names of doctors who have directed Parth's treatment at various stages and the hospitals wherein he has been admitted. I first saw this document when Ajit showed it to Dr. Jyoti during the family's first consultation with her about their son's seizures and hyperactivity. Dr. Jyoti had expressed surprise that Ajit had written this medical history and was impressed by it. She later told me that it was the first time a patient's family had brought such a document to her. Encouraged by Dr.

Jyoti, I followed-up with Ajit and visited him at his workplace a few weeks later to ask him about his experience caring and seeking medical treatment for Parth. Ajit explained that he thought to write this medical history to avoid carrying all the files and reports related to his son's treatment every time they visited a doctor. When I first met them, the family was consulting at least two doctors: a pediatrician based in Meerut and Dr. Jyoti, a pediatric neurologist who visited Meerut once a month. Later, unsatisfied with their initial consultation with the latter, they were considering visiting another pediatric neurologist in New Delhi who had previously directed Parth's treatment. Ajit shared that while some doctors found the medical history he had written to be sufficient for understanding Parth's condition, others insisted on seeing all the reports themselves.

Some families created digital documents. Using cameras on mobile phones, they recorded photos and videos of their child swearing, spitting, shaking, stiffening, weighing more or less than before, looking lighter or darker than before. These were symptoms and events that families found worrying and which they wanted the doctor's treatment to respond to. The recordings were shown to doctors during consultations and shared with researchers interested in learning about their child's condition. Some doctors encouraged families to create such records. Dr. Jyoti, for instance, often asked families to show her videos of the child having seizures so that she could determine the kind of seizures affecting her patient. If families needed to get in touch with her in between consultations, she asked them to share photos of the child's parcha through the free messaging service Whatsapp, along with a video of the child's current condition.

The digitization of paper documents through smart phone photography also enabled families to keep documents related to their child's treatment that were not created for them but

which they thought were important. For instance, Sajiya's father encouraged me to photograph his daughter's hospital file while we were in the ICU because he was not sure if the hospital would allow him to take the file out of the hospital to get it photocopied. He did not have a smart phone on him and said he'd ask me to share these photographs with him when he did. The duplication of Sajiya's file through digitization gave her father the ability to share the file, to circulate it within networks he and his daughter were a part of. For instance, both Sajiya and Mohammad Saad had uncles who were doctors. They couldn't visit their nephew or niece at the hospital but spoke to the child's parents on the phone about the treatment being provided, answering questions and giving suggestions about how best to proceed. Sajiya's father told me that he wanted to share photographs of her file with one such uncle so that they could assess whether Sajiya was receiving appropriate treatment at this hospital.

The Maintenance of Medical Records by Families

There was no script for families to follow in archiving materials resulting from their child's illness and its medical treatment. The decision of which documents to save, which to show and which to discard was largely left to them. The effect of the writing in the documents was thus subject to an arbitrariness (Gupta 2012) that stemmed from the contingent nature of its circulation. There was no system that organized the flow of these documents: what families chose to save and what medical professionals asked to see was arbitrary in that it was determined by individual families and clinicians. Doctors played an influential role: they wanted to read previous prescriptions they had written to decide upon the next course of treatment. But the ability of documents to coordinate treatment across medical care providers and intuitions was not

always called forth. Not all doctors I observed asked families to bring records of treatment regimens prescribed by other doctors that the child was following or had followed in the past. It was assumed that families would bring the documents they wanted the doctor to see and that the doctor would decide how much weight to give these documents. Sometimes families brought the medicines the child was taking, or had taken in the past, to show to the doctor, alongside or instead of prescriptions.

A family's decision to save or discard a document was not based solely on its textual contents. As discussed earlier, the document's use of English and biomedical terms and abbreviations made these texts largely indecipherable. Families were regularly confronted by questions about how to gauge the value of holding on to a document and how to draw distinctions between documents. For instance, one of the questions they faced as the collection of their child's "parchas" (literally, papers) got thicker was if the film of an x-ray or MRI was less, more, or equally important than the report accompanying it? Should both be saved, or would one do? Some doctors might ask for the report, while others chose to read the film alone. There were also instances when a doctor declared "ye jaach theek nahi ki" (this test wasn't done correctly) and asked parents to get a test redone, at their own clinic or from a diagnostic center they trusted. Should the "wrong" test be discarded then? Similarly, tests like EEG might need to be repeated at regular intervals as a child's treatment progressed and their seizures became less frequent. In such cases, families had to decide whether to save past EEGs.

Seizures can be a chronic condition and biomedical treatment can involve years of consultations, medication and tests. The value of a document created in this process fluctuates. It is partly based on whom it was shown to and the value they attribute to it. This instability

prompts families to strategize, to carry what they think a doctor would want to, or should, see. A doctor's request for, and reaction to, a document helps families gauge its relevance. It also helps families gauge whether their child is receiving adequate medical attention. For instance, a father whose daughter had been under the treatment of a neurologist for three years shared with me his surprise that the neurologist had asked to see the film of the x-ray but did not read the report that accompanied it. The doctor's decision to read the film alone—and to not explain to the child's father why he was not referring to the report—made the father wonder whether the doctor was taking all relevant information into account when treating his daughter.

These instances of document creation and record maintenance demonstrate the central role families play in the conceptualization of their child as a medical case. The nature of their child's illness and of the healthcare system in India compels families to collect documents and create a medical record that would otherwise not exist. Although families might not understand the textual content of the documents they collect, they use the resulting medical record to communicate and problem-solve. During consultations with medical care providers, records brought in by families narrate the history of a child's seizures in a language and format that is given precedence in biomedical spaces. The purpose served by documents created and kept by families shifts as their child's condition and treatment changes. Similarly, the value of documents created by doctors and hospitals fluctuates as they are passed on to families and taken to other medical care providers.

Medical Records as Artifacts of Care

Records hold communicative potential in both medical and social settings. They are the materialization of the ill body in that their creation, thickening, and possible devaluation indexes the illness's impact on the wished-for healthy body of the child. Records are also a materialization of the effort families and medical care providers make for a child's recovery. In the context of biomedical treatment for pediatric seizures in north India, families are responsible for financing, creating and carrying records necessary for understanding the nature of a child's seizures and the history of their medical treatment. These records are an artifact of care in that they index both the presence of the disease within the child and efforts to expunge it. They narrate parallel histories of a patient's illness and efforts to alleviate the child's suffering. Approaching the medical records carried by families as artifacts of care illuminates an important way in which the medical documents discussed above are generative. As manifestations of the medical gaze, records make a disease visible by classifying it as a diagnosis or as a set of symptoms that need to be tracked and acted upon (Foucault 2003). They reconstruct the past using particular narrative structures. Following Strauss and colleagues (1985), Berg and Bowker (1997) find that records provide illness trajectories that trace "the course of the illness, the total organization of work done over the period, and the impact of that work on those involved" (523). Records simultaneously produce the object that is acted upon—the patient—and the agent who acts—the clinician. In India, in addition to contributing to the construction of disease, patient and clinician, the medical documents created, preserved and shared by families also fix the position of the family within the network of medical care. From the perspective of biomedical practice, a patient's family is the group of individuals who signs, saves and carries the medical documents created over the course of treatment.

The valence of these artifacts of care is based on their continued relevance for biomedical practice. Medical documents help produce narrative order and uniformity by making certain actors, including clinicians, interchangeable (Heimer 2006). Over the course of this research, I have met multiple families who meticulously save all documents created during their child's biomedical treatment. The parents of ten year old Mayank, for instance, have kept the prescriptions, discharge summaries, diagnostic tests and reports that clinicians in Meerut and New Delhi have created about their child since his seizures began at the age of seven. When I visited their home in Meerut, the first thing Mayank's mother did was to take this thick wade of papers out from a plastic bag and place it on the coffee table in front of me. I had met the family in the outpatient department of a public hospital and had come to their home to learn about their experience accessing biomedical care for Mayank. He had experienced a seizure a couple of months prior to my visit and his parents were keen to learn whether and when his seizures would stop. They visited a public hospital in Delhi every month to get Mayank's prescription reassessed. In between these visits, they refilled Mayank's prescription at the local public hospital. His mother shared that when doctors wanted to know which medicines Mayank has been on and what tests have been conducted on him they refer to the accumulated documents she carriers to the consultations. While the doctors who direct Mayank's treatment at the public hospitals change overtime—leaving the hospitals or graduating to other positions within it—the medical record his parents are creating allows for continuity in his medical care.

Families such as Mayank's create and keep medical records because clinicians find these documents to be essential for understanding and treating their child's condition. This is similar to the experience of Seo's (2017) interlocutors in Thailand, who are able to elicit care and

attentiveness from nurses in a public hospital by, in part, maintaining and carrying the antenatal logbooks that the hospital creates to track the progress of their pregnancies. These logbooks help establish the pregnant women as "legitimate subjects of care" despite their status as migrants and non-citizens (Seo 2017, 22). There is a similar signaling of deservingness that happens through documents in India during the pursuit of biomedical care for children suffering from seizures. Documents collected and carried by a family articulate the family's dedication to the biomedical treatment of their child. When a child's seizures are revealed to be biomedically incurable, however, their family is faced with the decision of whether to continue accruing documents by going for medical consultations and paying for diagnostic tests that appear both expensive and ineffective. A family can stop collecting and maintaining medical records, for a while or forever.

I first met Mohammad Saad and his parents a few weeks into the start of this study, at the pediatric ICU of the public teaching hospital in Meerut. Saad came to Medical in a very serious condition and I remember now the tense face of Des, a first-year medical resident, as he tried to insert a cannula in the back of Saad's hand. It took a long time. Saad's father and I held him down to the bed as Des sat on a stool next to Saad's bed in concentration and frustration. I think a needle broke, blood spilled onto the bedsheet. I remember the tired young resident's angry question to Saad's father, "Kucch kiya kyun nahin?" (Why didn't you do something [to prevent Saad's seizures from getting so bad]?). Saad's father stood mute behind him, at his feet were plastic bags containing prescriptions and diagnostic test reports the family had collected about Saad's illness over the past six months. I had gone through these documents earlier in the day when Saad had been unconscious but not seizing. The bundle of prescriptions was written by doctors in Muzaffarnagar and Meerut. It included a prescription written a few months earlier by a

senior neurologist in Meerut whom I had recently interviewed and whom my mother—a senior gynecologist in the city—considered one of the best doctors in town.

Saad and his parents had come to Meerut from a private hospital in Muzaffarnagar when the hospital told them there was nothing more they could do for Saad. The family had reached Medical in the late morning and Saad was immediately admitted into the PICU. Later that day, after three rounds of anti-epileptic drugs had failed to control Saad's seizures, his parents were asked to take him to a public hospital in Delhi. He was admitted there for a week, after which his parents were asked to take him to the private hospital where he eventually passed away. I had followed the family to Delhi and after a few days of visiting them at the private hospital, Saad's father invited me to join him for the counselling sessions held by doctors treating his son. This invitation was prompted by my interest in learning about Saad's condition and treatment, my experience conversing with pediatricians and neurologists, and my ability to understand English.

'Counselling' at this hospital was done once a day to inform families how their child was doing, to answer questions they might have and to counsel them about how to proceed. It started at around 11am and took place in a small room adjacent to the pediatric ICU. When the doctors were ready, a security guard stationed at the entrance of the ICU would enter the waiting room and call out the names of patients whose families the doctor wanted to meet. Once their child's name was called, a family lined up outside the ICU and waited for the guard to let them in. They then stood outside the room where the counselling sessions took place and waited their turn to be asked in by a doctor.

The room used for counselling was small, longer than it was wide, with wood paneling on the walls. On one end were bookshelves and cabinets and on the other side a small sofa sat tucked under a large window. Families sat on a cushioned, wooden bench that protruded from one of the long walls. Across from them sat the doctor on a similar bench, behind a table he could use to lean on and to place documents. Over the five days I visited Saad and his family in Delhi, I accompanied his father to two counselling sessions. On both days, we returned to the same room in the afternoon to speak with other doctors treating Saad and to learn about the results of tests conducted on him earlier in the day. The first counselling session I attended was the fifth for his father. Once we were seated, Dr. Kero asked me about my relation to Saad's family and enquired whether I was "from the family's side, feeling for them or looking at the scientific side." I replied that I was doing both. Accepting my response, Dr. Kero said he'd explain the scientific side of the case to me and then talk to Saad's father.

Dr. Kero shared with me that Saad was "not ok." He had been suffering from a neuro-degenerative disease for the past six months and was currently on the ventilator. Doctors were conducting tests to "see brain functioning" but he appeared to be "brain-dead." Turning to Saad's father, and switching to Hindi, Dr. Kero explained that the child's future looked bad ("bhavishya kharaab"), that they couldn't see a life for him if he were taken off the ventilator ("zindagi nazar nahin aati"). Dr. Kero recommended that we meet Dr. Sona, the pediatric neurologist who was directing Saad's treatment at this stage, and shared directions to Dr. Sona's chamber. Saad's father and I met Dr Sona that afternoon and he elaborated for us what Dr. Kero had shared in the morning, confirming that Saad's brain and brain stem didn't look to be working, and he no longer had "the basic vital signs." Saad seemed to be suffering from a "neuro-regressive

condition" that had been worsening over the past five, six months. The child had been "symptomatic" for the past two months. Dr. Sona told us that over the next twenty-four hours they would keep testing for "any sign of brain stem, any sign of life in terms of brain activity" in Saad.

Upon leaving the ICU after our meeting with Dr. Sona, Saad's father handed me a parchi, a piece of white paper of the size of a visiting card, on which someone had written "Inj-Valproate" with a blue ball-point pen, underlined it and written "2" in a circle next to it. As he held it out to me, he said, "Maybe this will be of use to you." I accepted the parchi and we went back to the waiting room to Saad's mother.

Saad passed away a week later. The parchi rests in a blue, plastic folder in which I keep paraphernalia I found, was given, or created during fieldwork. I recognize it now as written by a resident at Medical, where families are given such chits of paper when they have to purchase medical supplies from private pharmacies because these are currently unavailable at Medical. Saad's father must have bought the injections by showing the parchi at one of the private pharmacies that line the road across Medical. His handing over the parchi to me in Delhi signaled to me the end of Saad's biomedical treatment. Following the dire prognosis shared by Saad's doctors, the parchi was of no use. Its work connecting Saad's family and doctors was now unnecessary. There was nothing more that biomedicine could do for Saad. Thus, an artifact that once signified the coalescence of medical and familial care and was part of that medical history was now no longer in need of preservation by Saad's father.

Conclusion

Anthropologists studying documentation have drawn attention to the parallels between documentation and ethnography. As Riles (2006) explains, both are discursive and aesthetic exercises that rely on an ability to appreciate pattern and respond to it "with further replications and extensions" (20). Street (2011) uses the term "knowledge effects" to refer to this ability of a document to feed into other documents, including ethnographic texts (830). The term points us toward the reproductive capacity of documents and gives us a measure of their value. By writing about certain documents and records, I have tried to bring to light the critical role families in Uttar Pradesh play in the co-creation of their child as a medical case. Their work enables biomedical practice, as it simultaneously fixes the position of the family in relation to that practice. A family is the entity that carries the medical records. The medical history threaded together using documents also narrates the history of a family's efforts to access biomedical care for their sick child. Homes and hospitals collaborate in constructing documents; and entities like disease, biomedicine and family take physical form in records.

Studying medical decision-making in a Papua New Guinean hospital through the records created over the course of a patient's illness and death, Street (2011) finds them to be 'temporary stabilizations' enforced by actors so as to be able to work despite of, and thus in response to, uncertainty about the cause of an illness. Diagnosis here is a fraught exercise because of its dependence on actors that are often uncooperative or unavailable. Documents become materializations of a hard-fought and variable stability, rather than of a movement towards clarity and "diagnostic closure" (Street 2011, 816). Instead of demarcating boundaries between the medical and the sociopolitical, such documents are messy, holding "excessive potentialities"

that speak to the multiple and contingent ways in which they are used (Navaro-Yashin 2007, 95). A patient's medical history as recorded in their hospital file and death certificate is as much about what was happening within their bodies as it is about the resources and personnel present at the hospital. In the context of this study, families actively create records to constitute the history of an illness and influence its course. Analytically, they blur the line separating familial and medical care, highlighting one of the ways in which they enable clinicians to create knowledge about their child's seizures. Records show the trajectory of an illness (Strauss et al. 1985), the biography of a child (Heimer 2006) and become artifacts signifying the familial and medical care the child has received.

A month after Saad passed away, I visited his family at their home in a village twenty miles north of Meerut city. I spent time with Saad's parents and siblings and met his grandmother, cousins, aunts, uncles and neighbors. I was encouraged to take photographs of and with the people I was meeting. Through the file sharing app, 'Shareit', Saad's brother, Afwan, transferred to my phone five photographs of Saad from his father's phone. Two photographs show Saad sitting indoors on a charpai (rope-bed) and holding an infant. He is not looking at the camera/ phone but smiling at something outside the frame. The remaining three photographs have Saad at their center, sitting on a charpai and looking up at the camera. Taken together in an order that cannot be deduced by looking at them, Saad's mother explained to me that these three photographs show how Saad's right hand would stiffen and turn toward his inner wrist. I was also shown a video of Saad being irate, swearing and spitting, that had been recorded a few months back. By the time the video was made, Saad's parents were concerned about physical and behavioral changes in him and had sought treatment for him from multiple sources. I was

also shown medicines that had been prescribed for Saad by various medical and non-biomedical treatment providers prior to his hospitalizations. A few of them were kept in a cloth bag that hung from a hook in the room where the family sleeps; another cluster of bottles and plastic containers was arranged in one corner of a shelf. As with the parchi Saad's father gave me in Delhi—and the hospital files, discharge summaries, test reports and prescriptions of other children I had met over the course of fieldwork—I took photographs of these medicines. Later, I filed these photographs into the digital folders of my fieldnotes.

In considering this archive as a singular collection and as a multiplicity of objects, I am faced with questions about its history and purpose. Documents that once held the potential to solve Saad and his family's concerns now signify the care Saad was given. They are reminders of effort, showing how families and medical care try to collaborate, and at times fail. In the movement from medicine to memento, the bottles and plastic containers have lost their medicinal worth but acquired a sharper historical and social value. Their presence is neither unwelcome nor celebrated. Originally acquired to save a life, they now enable the reconstruction of one.

Notes

1. Only five percent of households are enrolled in some form of health insurance program (Singh and Kumar 2016). Thus, the majority of expenditures on healthcare are out-of-pocket, dependent on a family's current income and savings.

2. As Das et al. (2016) describe: 'Provider qualifications range from MBBS degrees to no medical training at all, and clinics can range from well-equipped structures to small one-room shops, the provider's residence, or the patients' home for providers that make home visits.'

3. One way of classifying seizures is by type: provoked and unprovoked. Provoked seizures can be traced back to a stimulus, such as flickering light, or activity, such as reading. Unprovoked seizures are divided into symptomatic and idiopathic seizures. The former stem from a particular cause within the patient's body, such as meningitis or encephalitis. Idiopathic seizures, on the other hand, are believed to have a genetic basis.

Compliance with Ethical Standards

Funding:
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Ethics Approval:
All procedures performed in this study were in accordance with the ethical standards of Brown University's Institutional Review Board.

Informed consent:
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