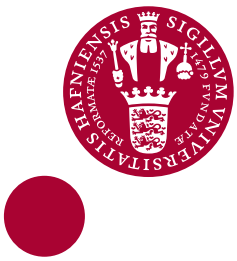

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Sheikh, Zainab Afshan; Jensen, Anja MB

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Channeling hope: An ethnographic study of how research encounters become meaningful for families suffering from genetic disease in Pakistan

Zainab Afshan Sheikh*, Anja M.B. Jensen

Section for Health Services Research, Department of Public Health, University of Copenhagen, Denmark

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ABSTRACT

The Pakistani population has become particularly interesting for international genetic research due to its high rates of consanguinity. Based on 5 months fieldwork in Faisalabad among Pakistani genetic researchers from December 2015–January 2016 and February–April 2017 and interviews with 36 families and 14 researchers, this article focuses on research encounters. It demonstrates how genetic research figures in the lives of families affected by genetic medical conditions in light of their everyday struggles with disease, and considers their perspectives on destiny and hope. Through examining the potentials of the research encounter, we ask *how research becomes meaningful* in the lives of Pakistani families affected by genetic disease: how these families and individuals enable different modes of sharing tragic stories, contemplating hope and contesting logics of consanguinity. International genetic research depends on human raw material. If we wish to understand the precarious lives this research relies on, then the everyday struggles with disease, and the perspectives of families must be methodologically and theoretically engaged.

1. Introduction

According to biomedical knowledge, the offspring of consanguineous relationships are at greater risk of both rare and common genetic disorders due to the higher chance of inheriting identical copies of one or more detrimental genes (Fareed and Afzal, 2017). Since Pakistan has high rates of consanguineous marriage, the Pakistani population has become relevant and particularly interesting for international genetic research (Erzurumluoglu et al., 2016). As a result of increased international studies and funding, a growing number of impoverished families suffering from severe genetic conditions provide biomaterial and health data for internationally funded research through a local laboratory in the Punjab Province of Pakistan. This study provides ethnographic insights into the particular encounters between Pakistani families and Pakistani researchers taking place in the complex intersection between global research agendas, local traditions and human suffering.

In the social science literature on research subjects' participation in and donation to life sciences, immense attention has been given to how people become available to research, with thorough studies of how notions of 'altruism', bioavailability and consent practices facilitate recruitment-participation (Cohen, 2007; Healy, 2006; Svendsen and Koch, 2011). Focusing specifically on the "off-shoring" of biomedical research to low-income countries, other studies have argued that recruitment-participation, especially in clinical trials, may be seen as a form of exploitation for commercial purposes, or for research only benefitting high-income populations (Petryna, 2009; Rajan 2006; Waldby and Cooper, 2008). In this contribution, we wish to widen the discussion on recruitment and participation from the question of *how people become available* for research, to the question of *how research becomes meaningful* in the lives of the people affected by genetic disease who are participating in international genetic research. For this purpose, we are inspired by studies that focus on how people living precarious lives make sense of their everyday struggles (cf. Eggerman and Panter-Brick, 2010; Huniche, 2011). Thus, we situate our study in the intersection between an anthropological interest in meaning-making, destiny and hope and a STS-inspired focus on what sociotechnical infrastructures of data collections both produce and rely on. As such, we set out to provide insights into the personal stories and hopes of those providing genetic data for global research.

Sheikh [henceforward referred to as Zainab] followed a group of researchers travelling across Pakistan to collect samples, medical pedigrees and other clinical tests for different international projects, from families suffering from recessive genetic conditions, most of which incurable, as part of international collaborations with Sweden, Germany, Denmark and the US. She conducted ethnographic interviews with both

* Corresponding author.
E-mail address: zash@sund.ku.dk (Z.A. Sheikh).

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the affected families and the genetic researchers, and observed multiple encounters between the researchers and research participants. These research encounters are indeed about making "research subjects" available: for example, researchers would ask families detailed questions to secure useful data. Previous publications based on the same fieldwork have focused on how the research subjects relate to the rigorous requirements of formal procedures for donations in Pakistan (Sheikh and Høyer, 2018a; 2018b). However, the encounter is also about more than merely fostering access to human raw material; especially in the context where researchers visit the houses of people who most often do not have access to public health care (WHO, 2013). Based on this, we ask how genetic research becomes meaningful in the precarious lives of families affected by genetic conditions in Pakistan through the entry-point of the genetic researchers visiting these families.

Previous ethnographic studies have exposed the limits of bioethical discourses when biomedical research is conducted in low-income settings, for example by showing that 'blood-stealing' is a worry in some communities (Fairhead et al., 2006; Geissler, 2005). Indeed, this research is unequal in terms of its output. Genetic research participants in Pakistan do not benefit from research results. Rather the results contribute to research agendas defined by high-income research laboratories aiming to understand human biological differences. The question of how this matters for people in low-income countries is widely discussed in literature on benefit-sharing (Schroeder and Lucas, 2013).

Other recent studies have argued that people in low-income settings use research participation as one of many strategies to establish and maintain social relations and gain access to services and goods (Bruun, 2016; Geissler et al., 2008; Kingori, 2015). By directing attention to the research encounter between local genetic researchers and affected families, we will show how families use the encounters in different ways to communicate fear, care, hope and longing. Our objective is to explore what research encounters *do* for the families: We argue that they provide a context for sharing tragic stories, contemplating hope and contesting logics of consanguinity. We unpack this argument by providing some family cases and by conceptualizing the meaning-making practices of families in light of a theoretical understanding of suffering, destiny and hope derived from the social sciences.

2. Channeling hope: making sense of suffering

Theoretically, we take inspiration from meaning-making as a concept, as it allows us to focus on people's interpretations rather than justifications of research participation (Dewey, 1947). Following Evans-Pritchard (1937) classic example, along with other groundbreaking ethnographic studies (Livingston, 2005; Scheper-Hughes, 1993; Whyte, 1997), we explore how, in order to deal with adversity, people employ meaning-making practices embedded in local beliefs for what might otherwise seem like random misfortune. Families living with genetic diseases employ a range of logics to make sense of their suffering. When focusing on suffering, anthropological attention has been given to what political, economic and institutional power does to people, and how people react to this (Davis, 1992; Kleinman et al., 1997; Wilkinson and Kleinman, 2016). Perceiving the suffering related to genetic diseases as a result of a specific social organization (cf. Davis, 1992) our approach is based on an interest in how individual experiences of suffering manifest themselves.

The theoretical framework for understanding the different ways of meaning-making was developed in close dialogue and interaction with the empirical material. Most of the affected families Zainab interviewed and observed referred to *kismat* (translated 'destiny' or 'fate') when describing their difficulties in living with or caring for close family affected by genetic disease. Similar observations have been made in studies of how Bangladeshi families understand a genetic diagnosis (Rozario, 2013). For the Pakistani families, dealing with destiny was never a passive conduct, but rather provided agency and meaning to suffering. Several studies have argued against the notion that 'destiny' in Muslim contexts connotes the passive acceptance and restraining fatalism that social theorists have repeatedly identified (Elliot, 2016; Hamdy, 2009; Qureshi, 2013). Conversely, notions of destiny are intimately related to the concept of hope. 'Hope' was also a word, commonly used by the families. Using Weber's argument about the relationship between divine destiny and earthly action, Alice Elliot (2016) has argued that "destiny triggers a complex 'labor of hope', wherein one feels compelled to act in the human world in specific, hopeful ways, in view of a future that has already been written" (p. 487). Destiny works both retrospectively and prospectively, and as such, it becomes a central feature in staging stories of suffering and practices of hope (Jackson, 2002; Mattingly, 2010). Hope has been identified as an integral part of social life that can be resilient, but also lost, gained, cultivated and transformed under different circumstances (Jensen, 2016; Mattingly, 2010). Mattingly explains that "hope most centrally involves the practice of creating, or trying to create, lives worth living even in the midst of suffering, even with no happy ending in sight" (Ibid: 6). We use these takes on destiny and hope as the basis for our understanding of how Pakistani families affected by genetic disease articulate suffering, and of the different ways research encounters become meaningful for them. Paraphrasing Arthur Frank (2013), the stories unveiled during research encounters are not only about suffering, they are an opportunity to search for healing and a call for recognition. In the absence of patient organizations and political activism (Novas, 2006), research encounters in Pakistan became a context in which the individual family could share their stories and longings. However, for some families the encounter and the research itself also raised a hope for immediate cure or a specific solution to their sufferings.

3. Methods

Zainab did five months of ethnographic fieldwork among genetic researchers based in a laboratory in Faisalabad in two periods from December 2015–January 2016 and from February-April 2017. The empirical material discussed in this paper comprises observations of 45 research encounters. Furthermore, 36 families were interviewed in their homes, and 14 researchers at the laboratory on a campus where most of them (and Zainab) lived. These interviews were conducted and planned according to trips to collect DNA samples and family history data that genetic researchers already had scheduled during the fieldwork period. Many encounters took place in poor rural areas and in financially deprived households. Despite some socio-economic differentiation among the families, lack of access to resources, financial or medical, were mentioned in all encounters. The genetic researchers doing collections were all born and raised in different areas of Pakistan, hence sharing religion, culture and tradition with the affected families. Zainab also has a Pakistani background and speaks Urdu, but is born and raised in Copenhagen. Most of the researchers were collecting the above mentioned samples and data in order to do their PhD-research in one of the collaborating laboratories in Germany, Sweden, Denmark or the USA.

Interviews with families were conducted primarily in Urdu or Punjabi and lasted up to 3 h, and in some cases, the entire day was spent with the family. As such, this is an ethnography of encounters; an engagement across difference, that focus on the relational dynamics of these engagements and involves an imbalance in social status and power that produce new cultural meanings (Faier and Rofel, 2014). There were mainly two types of research encounters: The research participation primarily consists of donating blood samples and providing personal information about intra-family marriage and disease, which the researcher draws as a pedigree (a family tree illustrating genetic lineage). This would normally take less than an hour. In order to trace relevant disease-specific genes, genetic researchers in Pakistan collect blood samples from families practicing intra-family marriages

with at least two cases of affected children or adults in at least two generations. Other research encounters were referred to by genetic researchers as 'resampling trips', meaning a revisit that could take place one – two years after the initial encounter. A revisit usually implied that the researchers in the collaborating countries had found a novel mutation in the family and needed clinical tests and further investigation. This could take several days. The social dynamics between genetic researchers, Zainab and the families became a relevant part of the analysis, since the efforts and reactions of researchers always influenced the family encounters.

The research laboratory Zainab followed is involved in various international genetic research collaborations and keeps pedigrees from over 1300 families organized in 61 different disease categories such as Microcephaly, Ataxia, Schizophrenia, Infertility and Recurrent Pregnancy Loss. Zainab joined researchers in their quest to find and visit these families in the Punjab Province of Pakistan and in the Province of Khyber Pakhtunkhwa. In Pakistan, there are no formal registers to support centralized identification of families with genetic diseases. Thus, practices of recruitment emerge from the researchers themselves: Personal contacts and snowball sampling facilitate the collections of health data and samples used for global genetic research, so when following the researchers in their endeavors, this method also became the way Zainab recruited families for this ethnographic study. Zainab obtained ethical clearance from the institutional committee of the host-institution of the local laboratory. Besides this, the research has been approved by the Danish Data Protection Agency and the European Research Council.

Zainab's meetings with families were structured by researchers 'dropping-by' the families at home, either to collect samples and pedigrees, to revisit for further clinical investigations or with the sole purpose of establishing access for an ethnographic interview. Based on the differences between asking questions for genetic research and ethnographic interviewing, we suggest that genetic researchers might be 'dropping-by', but ethnographers are 'dropping-in' to the lives of families. Sometimes the 'dropping-in' (ethnographic interview) happened simultaneously with the 'dropping-by' (research encounter), and other times these were temporally different: Zainab could visit a family up to one year after they had participated in the research to ask how they had experienced the encounter. Following Mol's approach to studying patients living with atherosclerosis in their clinical encounters, we argue that we can still learn some of the things we would have seen if we had followed people living with disease in their daily routine (Mol, 2002, p. 15). The stories and lives Zainab faced are indeed able to provide us with much-needed ethnographic detail about the people participating in genetic research, and about what research participation enables for them in that particular situation. As we shall see, facing the sufferings of families also constituted a wide range of ethical challenges and reflections regarding the role of both genetic and ethnographic research practices. After fieldwork, Zainab was emotionally affected by the individual destinies of families. Discussing this with the second author sparked a shared interest to describe this suffering and led to the development of the analytical framework for this article.

Zainab interviewed men, women and some adolescents, sometimes together and sometimes separately. Overall, approximately half of the interviews with families were one-on-one with women, and half of them with couples. Very few interviews were with men. The majority of the families were living with parents or parents-in-law in so-called 'joint-family' units. This reflects the common family structure and gendered propriety in Pakistan. As many interviews were done in rural settings and poorer households, the ideals of *parda* (segregation by sex, (cf. Shaw, 2009)) were often something Zainab had to carefully bear in mind. All interviews and observations from the fieldwork were transcribed and coded and underwent thematic analysis (Attride-Stirling, 2001). The analysis was done by both authors and guided by the following questions: What do research encounters enable for the families affected by genetic disease, and what kind of reactions do these encounters create among researchers?

We have chosen six cases that represent the multitude of sufferings and hopes encountered in the 36 interviews. The cases are structured in three sections to show the different significance placed on three aspects of what the encounters are about for the people participating. These three aspects are: sharing tragic stories, contemplating hope, and contesting logics of consanguinity. As we will show, the encounters create and channel hope that are intimately related to very specific life-situations, while, with different intensity, articulating reliance on divine will and destiny.

4. Sharing stories of living with disease

In the following cases we will depict how research participants are much more focused on how to live with disease than on their participation in the research. Research encounters, however, still do something for them: creating a platform to share their stories.

On a hot day in April 2017, Zainab drove with the researchers Fatima and Mariam from the local laboratory to the outskirts of Faisalabad to meet and interview Aisha. Aisha was a diminutive woman in her 60s, with a kind wrinkled face. Aisha and her family were very poor and lived on a plot consisting of a small yard with only a pipe to tap water and a clay building consisting of a single common room where the whole family slept. This one-roomed building had no electricity. The *charpoys* (traditional woven beds commonly used in Pakistan) were stacked in the corner ready to be used when nighttime arrived. Aisha had given birth to nine children in her lifetime. Four of her children had died of a medical condition which she described as having a combination of symptoms including fits and "a lacking sense of *dunya* (the world)". The disease had an onset from the age of two – three years, with worsening symptoms over time, until they died. Of the five children that were still alive, two of them had the same condition as their deceased siblings: Tallat, in his 20s, and Ali, 11 years old. Over the years, Aisha had tried taking her children to several *peers* (spiritual guides), medical doctors and *hakeems* (alternative therapists), but unfortunately, she had been unsuccessful in curing her children. When asking her about participation in the genetic research project, she explained: "They (the genetic researchers) came to my door and asked about us. They can have a go if they want, I have done what I could. Let the young ones try now." The medical research basically figured as an insignificant feature in her life. When asked why, then, she had wanted to take part in the research, she answered: "You come, you ask, you listen. That is enough for me." In this way the research encounter became an opportunity for her to articulate her life story and family sufferings, and to be recognized (Frank, 2013). In contrast to what other studies have found (Bruun, 2016; Geissler et al., 2008), participation in research was for Aisha not a strategic way of getting access to goods or practical help. She had stopped seeking out people to help her:

> "My husband recently died, so I have no source of income anymore. Everything I have is what my oldest son brings, and that is for food. I have accepted their *kismat* (destiny). Allah gave me sick children, and he also gave me healthy children. *Sabr* (patience) is what really matters."

For Aisha, who had longed for a cure for her children for most of her life, reliance on a divine will and kismat, gave her a new type of agency: one related to steadfastness and endurance in suffering (cf. Hamdy, 2009). At one point, Aisha looked at the researcher Mariam with a serious expression on her face. "I hope Tallat and Ali die before me," she stated with a firm voice. Aisha worried how her children would manage if she was not there to care for them and therefore hoped for a specific end-of-life for them. Both sons were in a bad condition. Tallat did not share a room with the rest of the family. In the yard, there was a small passage to a shed where he lived. As he was unable to walk, sit and communicate with words, he laid on a charpoy daylong where he both ate and defecated. Aisha had to feed him, wash him and clean him

every day. During the visit, Ali ran around the yard without pants but only a long robe on. With small intervals he would scream loudly when he had fits. Anytime he would come near Zainab, Aisha would hit him. With a sad voice, she explained: "I can only hope for them to die in peace before me, so that they will never be alone in the world." From Aisha's perspective, there was no life worth living for her children, if she passed away before them (cf. Mattingly, 2010). These statements depict the lack of access to any type of care from a health sector, network or family, and also Aisha's state of acceptance: She joined the research project to give others a chance and to share her own story. She had exhausted all her options to cure her children, and was only occupied with providing them with relief.

In another case, Amir, a 24-year-old man, was also eager to explain his story. He did not see the research project as something that could benefit him, as he strongly believed in an etiology involving *jinns* (spirits). This did not leave space for any biomedical explanation. Right from the moment Annam, a genetic researcher, and Zainab stepped into his living room, he had a very clear goal from the research encounter: to convince the researchers that what they called psychiatric diseases were actually *jinns* possessing people. Jinns were haunting his family and himself. For Amir, this etiology overruled any genetic explanation:

> "I want to tell you what is really happening in my family. You do this research but waste your time. You see, my father used to mix chemicals in water and sell it to local stores as eye-drops and my mother supported him. My mother always said that it was good medicine. She is also possessed."

In this way, the genetic research figured in his life as something he opposed. Instead he blamed his parents for the state of affairs and was seeing several *peers* in his longing for salvation from the bad deeds of his father, who had now passed away. Following this encounter Zainab and Annam received several emails from Amir, with a long explanation about what had happened in his family. In these letters he stated that his point was to get the "real" story out to the world.

When Zainab observed and took part in encounters where families believed that research could do very little for them, it was always based on a personal story and a longing that did not involve the researchers. Many encounters like these left significantly different impressions on Zainab and the genetic researchers. The epileptic attacks and loud screaming of Ali, and Amir's insistence on jinns possessing his family reoccurred in many of Zainab's dreams following the fieldwork. However, the researchers said that they were used to this. Maria, one of the researchers also visiting Aisha, would later explain: "We live in a society where this is our daily life, sometimes I react, but we are so used to this: All the stories." For her, and other local researchers, the many encounters with families, pain and suffering was normal (cf. Davis, 1992). The routinization of sample collections in some ways neutralized their response to suffering. The local researchers, who experienced these circumstances in their daily lives – both in their own families and during collection trips – were often surprised, and sometimes rather empathetic to see Zainab's emotional reactions after meeting people like Aisha and Amir. For them, it was evidence that Zainab was born and raised among *gore* (whites), where a social healthcare system took care of families in this kind of need. Now, moving on to different cases, we will see how researchers and research participants get involved in a 'labor of hope' in research encounters, and how genetic researchers can also have difficulty responding to questions and situations.

5. The labor of hope, longing for a change of fate

A majority of the research participants (30 of the 36 families) longed for some kind of 'change of fate'. In the following, we will introduce cases where the encounters, in different ways, and with different intensity, became opportunities for research participants to express their hopes towards specific futures.

On a fieldtrip to Islamabad, the capital city of Pakistan, Zainab followed Annam, a researcher with extensive experience of collecting samples and health information, to the home of Subhan and Raheela. The couple were in their 40s and parents to a five-year-old boy, Bilal, suffering from ataxia, a rare genetic disorder. They lived in a house with Bilal and their other child, a daughter, who was unaffected by the disease. Zainab and Annam were invited to sit on a couch, in a nicely decorated living room, in front of a table arranged with biscuits and tea. Serving tea is a common ritual of Pakistani hospitality, used to welcome guests. Being welcomed with tea always made Zainab a little uncomfortable: The blank expressions on the faces of Subhan and Raheela testified to the fact that the visit was not a regular 'guest-visit' and she worried if the family even knew what the researchers were there for. Bilal was curled up in his father's lap, looking around with frightened eyes and salvia running uncontrollably out of his mouth. Visibly affected by the disease, he was very small, weak and could not control his movements or facial muscles. Bilal got several fits during the visit. His body would stiffen and his jaw fall to one side. He was not able to communicate but made strange noises and could suddenly burst into laughter.

Initially, Annam was busy asking personal questions about family ties and disease in order to create the pedigree. Subhan and Raheela were cousins and both their parents were also related as cousins. They had lost three sons to ataxia. Speaking of their deceased sons was visibly difficult for them. All three of them had been through the same disease trajectory with an onset around two years of age. Before they reached the age of seven they had died during seizures. Subhan explained:

> "The very first sign of disease is when their teeth start to rot no matter how much we brush them. Then they suddenly start falling, having more and more difficulty walking, sitting, eating and speaking. They just can't keep balance (…) After this they have fits, a type of attack. Bilal has not been able to walk for nine months, and his bones are getting weaker."

Annam nodded eagerly during these descriptions and looked at Zainab explaining: "So the disease involves a degeneration of the body, including intellectual disability leading to mental retardation." As a reaction to this, the parents looked at each other with sorrowful eyes. Situations like these testify to the friction that arose in many of the research encounters between genetic researchers' agenda of getting sufficient and 'interesting' data, and the reality of what families were going through. Later during the visit, when Zainab asked the couple how they dealt with the difficult time they were going through, Subhan replied:

> "In the beginning we couldn't accept that this was Allah's will. We assumed that what He gave us (the disease) would be a test of some sort and then disappear again. Just in the same way that it came suddenly."

For Subhan, believing that the genetic disease was a product of divine will had provided meaning to his life-situation. As mentioned above, believing in a divine predestined will is never a passive conduit, but a meaning-making process that provides agency in one way or the other (Elliot, 2016). Subhan had spent a lot of energy trying to get through the "test" by approaching doctors in Pakistan, America and other countries. As described in a different paper (Sheikh and Høyer, 2018b) the chance of getting help from resourceful distant actors motivated some Pakistani research participants' involvement in this project. The genetic research project figured in his life *as one of many ways* of pursuing help for their child. During the encounter, Raheela asked Zainab and Annam: "Have you ever seen any examples like my son who got better and recovered? Do you think my son will survive?" Asking these questions was more than just a way to satisfy curiosity or doubt. Both parents were looking at Zainab and Annam with eyes begging for a positive answer. For Raheela and her husband, the research encounter had provided them with a platform to involve a specific 'labor of hope'

towards a future they longed for, merely by asking questions about potential survival. The question created tension in both Zainab and Annam, and as Zainab could not hold her tears back, she remained silent, unable to state that Bilal was going to die. After a long pause Annam said: "So recovery … in reality … it depends. If this disease is *marusi* (hereditary) then the chances are slim." Soon after, Zainab ended the interview due to her discomfort with Bilal's hopeless condition. Early in the encounter with Subhan and Raheela, Zainab had found it astonishing that Annam was able to ask very intimate and difficult questions in such a formalized and curious manner. After the research encounter however, Annam told Zainab: "Sometimes I have difficulties sleeping – some families really touch my heart." This shows that genetic researchers also could not always react neutrally during and after a research encounter.

In a similar case, the couple Asia and Imran from Faisalabad, proclaimed that the longing to have children was their main reason for joining the research project. As a result of infertility problems, the couple was enrolled in the genetic research project by Omar, one of the staff members of the laboratory and a relative of Imran. However, for them it was important to articulate that the chance of getting what they longed for was not controlled by their actions alone, but by divine will. During the research encounter, Asia stated: "Of course I want children. That is why we enrolled in the project. I hope it will give us some positive news. See, we have been married for 16 years now, but whatever happens it is by Allah the almighty's will." For Imran, having a low sperm count meant that he had turned to 'ruhani ilaaj' (spiritual treatment). Practically, *ruhani ilaaj* was about reading specific parts of the Quran, a specific number of times each day prescribed to him by a *peer*:

> "We believe in the Holy Quran, and in the Quran, there is a cure for every condition, disease of the body and the heart. But it is all Allah's will. I believe that the only one who can give me shifaa (healing) is Allah. Not you (pointing at Zainab) or other researchers or whatever they will discover."

Research participation was still a way of taking hopeful action, trying to resolve a difficult life-situation, but should be understood within a religious framework where reliance is first and foremost limited or guided by divine will. In this way, research encounters became significant moments in the families' labor of hope (Elliot, 2016) by providing an opportunity for expressing and channeling their hope towards a better future. This reliance on the spiritual also controlled belief in the potential of scientific findings or technological innovation. When Zainab asked Imran how he found comfort in ruhani ilaaj, he replied: "Religion helps me in dealing with everything, like exercise helps the English people." Zainab had joined four genetic researchers for this visit. One of them, Tanya, nodded appreciatively. Turning to Zainab, she explained: "It has even been proved by research that recitation of Quran has positive cardiac effects." In this way religion figures as a way not only of coping with a difficult life-situation, but also of providing potential cure. Tanya, who visited Asia and Imran, shared their religious rationale and belief in specific healing powers of reciting the Quran. This co-existence, not commonly seen in a Western biomedical context, was an inbuilt part of many researchers' and research participants' rationale.

In another case of infertility, a different level of intensity can be identified in both the research participants and the researchers. Here Farooq and Nosheen, who were dealing with recurrent pregnancy loss, were expecting concrete medical answers to their condition from the genetic researchers. The couple was highly educated and in their 30s, living in suburban Kamoke, 30 miles north of Lahore. Annam, the genetic researcher from the local laboratory, was following Zainab on this trip to visit the couple for an interview on their research participation as they were struggling with recurrent pregnancy loss. For Farooq and Nosheen participating in research was not a minor issue. In fact, they had placed immense expectation on the genetic research. Nosheen explained that she had been pregnant four times until the fourth month of pregnancy. She stated: "The doctors tell me that my fetus spreads out in my womb and then expires." After doctors confirmed that her fetus was "not growing properly" she had needed assisted abortion each time. She had donated one of her dead fetuses to the research laboratory. She continued to explain that she was desperate to get any type of result based on this donation: "I am in my thirties now, and I am running out of time. I need children, my life is nothing without it. People are also talking about me and I need answers. Why do I keep losing my child?" The social dimension of dealing with infertility as a "medical problem" was difficult for the couple to cope with. Studies in Pakistan have shown a strong societal perception of failure on a personal, interpersonal and social level when it comes to infertility (Ali et al., 2011). Nosheen's articulation of her situation reflected this and was accompanied by a sense of disappointment towards the genetic researchers for not having provided her with medical answers to *why* she was continuously losing what she herself identified as her "babies". The research encounter thus became a context for channeling hope, but also disappointment when researchers as 'hope-givers' do not fulfill the longings of research participants. Nosheen articulated a disappointment that was so strong that she had not wanted to meet the researchers again:

> "I haven't heard about the test results. That is why I didn't want to speak with you. You come whenever you need something. What about what I need? I hope you will change the fate of my next baby, but I am still very worried."

Note here, that Nosheen placed responsibility of 'changing the fate' of her next baby onto the researchers, which implies that she believed that they could do more than they were currently doing to help her. While the situation of Bilal and his parents was difficult to handle for the researcher Annam, this latter situation turned out to be even more challenging, as the research participant was expecting concrete answers related to Nosheen's condition. As elaborated elsewhere (Sheikh and Høyer, 2018a), many research participants awaited "reports" on their conditions. These reports contained information about carrier status; however, many understood it as if they could use the reports in an action-oriented sense towards relief of their current suffering. They longed for answers to medical questions of disease-causality and ultimately some kind of treatment. Sometimes this longing, and assumption related to the medical reports, were used by genetic researchers to escape an uncomfortable situation. For example, Annam at one point took out her cell-phone to call a colleague at the local laboratory. Nosheen, Farooq and Zainab were quiet, while listening to the conversation between Annam and her colleague, who was in charge of the handling of dead fetuses in Pakistan: "Listen, this family really needs the initial reports you promised them." Had the miscarriages been due to chromosomal defects, which was what the initial investigations were about, Annam would have known. Thus, she already knew what was in the report, namely that there were no findings yet. However, the phone-call had one reaction: Nosheen and her husband seemed more at ease. This type of action, what we might call a type of "performa care", – a reaction or a human need of both parties to feel like they are doing 'enough' or 'what they can' – could often take place in situations where families were desperate for findings and no actual healthcare was within reach. Strikingly, Pakistani researchers sometimes found they could not state their inability to resolve the medical problems of families suffering from difficult conditions, where these families expected answers. From one perspective this act could be viewed as an act of deception. From the researchers' perspective, however, this "false hope" was their way of limiting harm to the research participants. We see this "performa care" as a response to the moral distress of not knowing how much to disclose and how to help. As Latimer's ethnographic study of dysmorphology in the UK has shown, genetic researchers shift between definition and deferral and families of children with suspected congenital conditions are often "held in a space of motility" for years

within clinical genetics hoping that the service will one day deliver something clinically useful (Latimer, 2007: 113, 130). When Zainab asked the Pakistani researchers critically about their practices regarding family hope, one researcher answered: "What is better in the long run? That we kill their hope, or keep it alive, and by that make it easier for them to live?" The genetic researchers' actions were basically built on a rationale of caring for these families, although (and partly because) they were not able to provide the families with actual physical healthcare. Genetic researches experienced several of the family encounters as morally distressing (e.g. Epstein and Delgado, 2010), especially those where family stakes and hopes were high and unable to be accommodated.

Genetic research encounters became a way to create and channel hopeful ways of dealing with suffering with more or less expectation of concrete help from the researchers. Subhan had sought multiple medical doctors for his children; Imran had pursued spiritual treatment for his condition, while Nosheen and Farooq primarily articulated their reliance on the research project as their most central point of hope. In the following section we will address how the research encounters were not only about sharing hope or expectations. At the same time, they were also about contemplating and contesting logics of consanguinity, which is the fundamental premise for their enrollment in the research project.

6. Negotiating genetic and social risks of consanguinity

The genetic disease understandings that research participants were exposed to included specific biotechnological narratives about kinship and family, namely that of risks related to having children in consanguineous marriages (Prainsack et al., 2016). Even though the research encounter was not the first encounter between the families and these narratives, the research encounter became a way of talking about their worries related to the risks.

Nida and Ahmed, both in their 60s, were weak and marked by age but did what they could to take care of their three disabled children, suffering from microcephaly. Ahmed sold fruit *chaat* (spiced fruit salad) at the local market earning around 7000 rupees (55 USD) monthly for his family of six. The research encounter with them was based on a request from genetic researchers from a collaborating laboratory in Germany for further clinical tests on their children, in order to confirm a diagnosis and a mutation. This meant that the family was taken from their village, located 3 h away from the laboratory, to Faisalabad for tests. This took the whole day. The family earned compensation of around 2–3000 rupees for a trip like this, which was a very large amount of money for Nida. She saw it as a concrete way of contributing to the household. Medical research thus figured in her life as a source of income. However, it was not only the compensation that mattered to her. During the day, she spoke of the importance of marriage and the issue of consanguinity with a spirit of resignation. Nida explained:

> "I am devastated that my sick children will never get married or build their own families. I only have one healthy girl, Shabana. You saw her, she is beautiful. I want her to get the things the other kids cannot and marry her off soon."

Nida was longing to see her daughter Shabana get married and explained that she was obligated "give her daughter" to her sister's oldest son. Traditionally marriages in Pakistan have been arranged by the elderly in the family and up to 60 percent of marriages are consanguineous (Khan and Mazhar, 2018). Nida had accepted the genetic risks related to consanguineous marriage. But despite dealing with immense desperation in the face of her own marriage, changing practice was not a choice for her family. There were too many social risks involved. Nida continued with a sad voice:

> "We said no to our own family at first, because of our own situation (the disease). Then we found another man for her. But they lived so far away. And we didn't want to send her far away. So, we stopped the engagement. Then the cousin asked again. Now we can't say no, because it would cause problems in the family."

Due to poverty, living too far from their daughter's family in-law was an important consideration for Nida and Ahmed. Marrying within or outside their family was not only a genetic issue, it was also a social issue. Thus, this was neither about the family not understanding the information given about consanguinity, as would be the main focus from a health-literacy point of view, nor about them passively accepting intra-family marriage as a necessary part of their destiny. Likewise, in many conversations with other families, local customs and cultural practices were demonstrated as being at odds with the normative underpinning of genetic disease causation which stipulates that people should marry outside their own family. Basically, people in communities like these rarely experience the choice to act differently: ownership to land, promises made between kin, fear of how other families will interact with them, and financial necessity (and fear of high dowries) all create barriers preventing them from changing the sociocultural practice of intra-family marriages. Returning to the case of Aisha, she gave her perspective on why she had a difficult time reacting to what she had heard from several doctors over time:

> "They tell me that my marriage has been fragile and that is the reason my children turned out this way. My husband was my mother's aunt's son. When they explain this, I just shut up. I can't change my *rishta* [relationship] now can I? The same man gave me healthy children."

Note that the fact that she had both healthy and sick children was a source of ambivalence for her, as she could not entirely 'blame' her (consanguineous) marriage for her suffering (e.g. Mozersky, 2012). Similarly, other families also explained that the fact that they had both healthy and sick children, was ambivalent for them: "My destiny is not all bad. We can't change anything now, can we?" explained one mother of three diseased and two healthy children, providing retrospective meaning to her life-situation. These understandings often confused or collided with research participants, who felt pressured to act in specific ways based on the information they were given by the researchers, yet also felt the urge to push back. Genetic explanations do not redefine kinship relations but can 'enrich' relationships with genetic meaning (Fairhead et al., 2006). Thus, the information on genetic risk can rearrange ideas of guilt and shame (Arribas-Ayllon et al., 2008; Prainsack et al., 2016; Shaw, 2009). When understanding why some families had a difficult time coping with their situation (that is, understanding and/or accepting the hereditary factor) one must recognize that this cannot simply be made into a question of 'health-literacy' as, due to the sociocultural practices that people like Nida and Aisha are embedded in, families are obviously not able to abandon practices of cousin marriages merely as a result of being given information. Such tensions between biomedical genetic disease causality and local belief have also been described among British Pakistani families (Shaw & Hurst 2008; Shaw & Raz 2015).

The genetic researchers were no exception to the sociocultural practices, and also had a difficult time adjusting into a strict biomedical rationale. Many of them were themselves married with their cousins or other close kin – despite the fact that their work also included providing families with genetic counseling in order to prevent marriages among close kin. One male researcher, Hassan, explained to Zainab after a research encounter:

> "I tell them that they should not marry within their family. This is my main advice, when we are dealing with inherited diseases. But you know, it's part of our society so we have to develop appropriate diagnostic tools instead of expecting people to change their ways. We want to combat it, but it's difficult. Even in my own family."

The sociotechnical infrastructure for genetic research indeed

produces and facilitates specific ways of understanding and communicating about intimate aspects of life, such as who one should marry. However, both for the Pakistani researchers and the research participants, the focus on consanguinity in the genetic research figures as a dilemma that needs to be handled in a manner appropriate to the longstanding cultural practices in the society. As also reported by Shaw (2015) studying British Pakistani, British researchers would advise against marrying within the family due to health risk for the children. Knowing that the risk is not the marriage as such but the carrier status of the couple, Pakistani researchers often gave the same advice, based on the difficulties of the Pakistani families getting access to carrier testing and screening. That is why researchers spoke of looking into diagnostic tools, such as prenatal screening, in order to limit the cases of children born. Thus, it is easier to limit the choice of children, when they are knowingly affected by genetic disease, than to change the marital practices of society.

7. Concluding reflections

How can the multifaceted sufferings and destinies of human beings that are usually described in genetic and social science literature as "research participants" be unfolded and investigated without simply describing one tragic story after another? Resisting the tempting option to emerge into merely theoretical discussions of genetic research and ignore the pain-ridden faces appearing in Zainab's nightmares, our ethnographic contribution came to focus on what the *research encounters do for* families involved in international genetic research. Our paper has shown that the encounter creates a context for creating and channeling different longings and hopes, where families can articulate living with disease and how the genetic research and their concerns and choices figures in their lives. Thereby, through an ethnographic perspective, our study contributes to the social studies of global genetic research where the everyday sufferings and longings of families participating do not always take center stage.

By focusing on the research encounter as a particular moment in time, we have shown that families use these meetings as vehicles to articulate their own longings for specific futures. The encounter provides a platform for some to allow the expression of hope for the survival of their children, even if they have realized that this survival is not actually an option, while others demand concrete answers and help from the researchers. Even if the genetic research itself might be misleading with regard to finding a cure, the encounter constitutes a potential space of relief through the articulation of destiny and hope. In this space, the opportunity of sharing one's own suffering and alternative views on disease etiology that are based on local traditions and spiritual aspects of human life become possible and meaningful.

In the field, genetic researchers reacted differently to these ways of using the encounter as a context for creating and channeling hope. Mostly, listening to and witnessing extreme poverty and suffering was common for the genetic researchers, and they had a neutralized response to the suffering. To routinize is to reduce complexity (Wahlberg, 2018). Furthermore, families and researchers share not only ethnicity: in most cases they also share religion, tradition and culture, so that they had no significant differences in attitudes and perspectives. In other situations, where the researchers had authority as 'hope-givers', coping with the family encounters were difficult and led them to handle family expectations according to their own individual moral standards, sometimes not always revealing the futile reality. We have called this aspect of the research encounter "performa care" –reacting to the human need of both parties to feel like they are doing 'enough' or 'what they can'.

In the context of a failing and weak Pakistani healthcare system, emphasis could have been given solely to discussing whether poor people are being exploited in global research collaborations. However, we must consider that local researchers operate under circumstances characterized by global structural inequalities in health and wealth. They themselves lack clinical skills and emotional resources in terms of handling the suffering they face in research encounters. We argue that research encounters not only provide samples, pedigrees and clinical tests; they provide space for families' stories and longings thereby enabling a way to understand the human suffering that fundamentally underlies this type of international genetic research. If we wish to recognize the lives that bio-prospecting for international genetic research interacts with, we suggest that future studies pay attention to the sufferings and hopes of families, and to how they are articulated in research encounters.

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