The London School of Economics and Political Science

Making "Healthy" Families: The Biomedicalization of Kin Marriage in Contemporary Turkey

Maria Kramer

A thesis submitted to the Department of Sociology
of the London School of Economics for the
degree of Doctor of Philosophy, London, September 2019

Declaration

I certify that the thesis I have presented for examination for the MPhil/PhD degree of the London School of Economics and Political Science is solely my own work other than where I have clearly indicated that it is the work of others (in which case the extent of any work carried out jointly by me and any other person is clearly identified in it). The copyright of this thesis rests with the author. Quotation from it is permitted, provided that full acknowledgement is made. This thesis may not be reproduced without my prior written consent. I warrant that this authorisation does not, to the best of my belief, infringe the rights of any third party. I declare that my thesis consists of **88,935** words.

Acknowledgements

Like all PhD projects, this one has been a journey, enrichening, challenging, at times frustrating and then again rewarding, with opportunities aplenty to go astray and lose sense of direction. So many different people have helped me along throughout this journey, putting me back on track, giving encouragement and inspiration, sharing their time and insights with me and contributing in manifold ways to this research project which I could never have realized without their support. I am deeply grateful to the women and couples as well as to the medical and genetic professionals who offered to tell me about their private and professional lives, their experiences, memories and thoughts. I am also greatly indebted to the team members of the genetics clinic who hosted me during my fieldwork stay, giving me fascinating insights into their work and facilitating my research. Without the generosity, patience, trust and kindness of all of these people this thesis would have remained unwritten.

I cannot imagine this research project to ever have taken shape or become completed without the excellent mentorship that I have benefitted from as a graduate and PhD student. First and foremost, I would like to thank my truly wonderful supervisors Dr Carrie Friese and Dr Suki Ali whose continuous encouragement, inspiration, scholarly guidance and support have guided me so safely through the PhD. Seeing their never-ending commitment, innumerable stimulating comments and genuine interest in my project as well as their sincere sense of care, I could not have wished for better academic mentors. I am also greatly indebted to Prof Dr Belgin Tekçe for her invaluable support, feedback and intellectual insights during my time as a guest research student at the Sociology Department of Boğaziçi University. Pointing me to relevant readings and important sources of archival data, sharing her always inspiring thoughts on my drafts, and helping me gain access, she greatly supported me in navigating a particularly challenging period of the research project. Both Dr Ayşecan Terzioğlu and Dr Dikmen Bezmez have been truly inspiring teachers, mentors and friends. Having first sparked and nurtured my interest in the sociology of health and illness during my time as a graduate student at Koç University, they have kept offering constant advice and support since then, accompanying me through the PhD. I would like to thank İbrahim Demir for his long-standing support and valuable advice on interview transcriptions and the legal aspects of governmental health and family policies in Turkey. I would also like to thank Hande Güzel who has been a remarkable friend and intellectual companion over the last years, not only listening and re-listening to my research ideas, giving insightful feedback and advice, but also standing by my side supporting me tirelessly during the most difficult periods of the PhD process.

Getting to know and spending time with my fellow PhD students at the LSE Sociology Department has been one of the most profound joys in being a PhD student. I am grateful to them for providing me with an intellectual home and safe haven at LSE, being generous both in their emotional support and constructive feedback at so many occasions throughout the years.

They have reminded me time and again what academia can be like at the best of times by being such an incredible community of interested, curious, stimulating and caring people. My particular thanks go to Birgan Gökmenoğlu, Dominika Partyga, Kristina Kolbe, Linda Lund Pedersen, Martha McCurdy, Nabila Munawar, Niamh Hayes, Maria-Christina Vogkli and Rong A for not only helping me get through the PhD but also giving me plenty of reasons to enjoy the experience. I would also like to thank the PhD and departmental writing groups for offering helpful comments on earlier versions of chapters 5 and 3 as well as Dr Ayça Çubukçu, Prof Dr Bridget Hutter and Dr Don Slater for their constructive and insightful feedback on the outline of the research project and early chapter drafts. I also presented parts of what became chapter 3 at the conference "Remaking Reproduction: The Global Politics of Reproductive Technologies" at Murray Edwards College, University of Cambridge, and at the BSA Postgraduate Event "Nation Building, Family (Un)Making and Genetic Technologies" at LSE, both in 2018, where I received valuable feedback.

This research has been granted generous funding in the form of an LSE PhD Studentship and the Abdullah Mubarak BRISMES Scholarship. This crucial financial support enabled me to fully concentrate on my research, conduct fieldwork in Turkey and travel repeatedly between London and Istanbul. My fieldwork stay in Turkey was furthermore supported by the Orient-Institute Istanbul (OIIST) which hosted me as a PhD Fellow between October 2016 and February 2017, providing me with an opportunity to present my research and fieldwork plans in front of the Institute's affiliated researchers and receive helpful feedback. My thanks go in particular to Dr Melike Şahinol who, as head of the OIIST's research field "Human, Medicine and Society", introduced me to other scholars working in the fields of health, illness, science and technology in Turkey and who regularly offered her time to discuss the progress of my fieldwork. I would also like to thank Dr Ayfer Bartu-Candan for supporting my stay as a guest research student at the Sociology Department of Boğaziçi University during the 2016/17 academic year as well as Prof Dr Nükhet Sirman and Dr Kızılca Yürür for their inspiring and helpful comments regarding my research project when it was still at a rather fledgling state.

While this thesis talks a lot about families, it was rendered possible in the first place by my own family. I would like to thank my grandmother Ellen Krell and her partner Jürgen Ehrenpfordt, my mother's partner Friedhold Praetorius and my friend and newly found sister Sophia Saftien as well as my uncle Uwe Kramer and my cousin Shraddha Spörl. All of them have been consistently by my side, supporting me throughout this journey. Most of all, I am deeply grateful to my parents, Kathrin Praetorius and Jörg Kramer, whose unconditional love, trust and encouragement have accompanied me on all my paths, including the PhD one, being a never-ending source of strength and motivation.

Abstract

This thesis focuses on the impact of reproductive genetic health services on the making of "healthy" families in Turkey by exploring how kin marriage is being conceptualized, managed, and negotiated as a genetic risk factor and reproductive health concern within intersecting biomedical and genetic spaces in contemporary Turkey. It asks how notions of "healthy" reproduction and "healthy" family making inform the health policies, discourses and practices surrounding the biomedical management of kin marriage, and how couples practicing kin marriage respond to and negotiate concepts of "risky reproduction" and "genetic risk" in their experiences with genetic services. Although kin marriages as close as first cousin marriage are legally accepted and comparatively frequent in Turkey, these marriage patterns have long occupied a contested position within Turkey's society. Modernist nationalist discourse depicted kin marriages as a remnant of the Ottoman past signifying the lingering presence of internal "non-modernity", "traditionalism" and "Oriental" otherness. These existing legacies of otherization and stigmatization of kin marriage have gained a new biomedical quality with the emerging re-conceptualization of kin marriage as a reproductive health problem following the spread and routinization of reproductive genetic health services in Turkey from the 1980s onwards. This "biomedicalization" (Clarke et al. 2003) of kin marriage has shifted the question of how future citizens should be brought up in a socially and politically desirable familial environment to the question of how these future citizens should be conceived and born in the first place. Based on a critical reading of relevant government issued texts on reproductive health, family making and kin marriage, 19 qualitative interviews with medico-genetic professionals as well as 18 qualitative interviews with lay participants practicing kin marriage, and observations during a two-and-a-half months stay at a public genetics clinic in Istanbul, this thesis explores the (bio)political implications of this biomedicalization process.

Table of Contents

Introduction

> "By now, we have internet and television. There we can see that it [kin marriage] is risky (*riskli*) but back then there were no such things. If I got married now, I would be scared but we didn't know about it back then. Nowadays I wouldn't take that risk (*şimdi olsa o riski almazdım*). We learned that over time. [...] I don't know exactly why but as far as I have seen on TV, there is a high risk for becoming impaired (*sakat olma riski yüksek*). But our parents and we ourselves, we didn't know; if we had known, we could not have put our children at risk (*bilseydik çocuklarımızı riske atamazdık*)."[1]

> "When you tell a close friend of yours, for instance, quite a lot of them said 'Dilba, have you thought well about that? Once you get married in the future, your children will have a very high risk of being impaired (*senin çocuklarının sakat olma riski çok yüksek olacak*)' and things like that. I was staying at a student hall at university and my friends at the student hall knew about it [Dilba's ongoing relationship with her cousin] and when they said things like that I got really sad and I thought I wish I hadn't told them because some people went so far as to directly say 'you are clearly not thinking of yourself but you will have children in the future, do you not care about them?'."[2]

While kin marriages, especially first and second cousin marriages, are a relatively common practice in Turkey with a national rate of 23% (TUIK 2016), the recent decades have seen a growing concern across the medico-scientific and public realms regarding this form of marriage alliance as giving rise to the birth of genetically affected children. The above quotations illustrate the generational differences in experiencing kin marriage as a reproductive health problem. They make apparent how the concern for the health of future children has emerged as a moral and – as I will argue – also political stake in making decisions about marrying "close". This thesis is interested in this shift in conceptualizing and managing kin marriage as a genetic risk factor which has coincided with major transformations in the reproductive health sector in Turkey form the 1980s onwards. It particularly seeks to highlight the (bio)political qualities of this incorporation of kin marriage into genetic and reproductive health care, a process which I understand as part of what Adele Clarke et al. frame as "biomedicalization", namely "the increasingly complex, multisited, multidirectional processes

[1] Çiğdem (name has been changed), woman in her 60s who comes originally from a village in the Eastern Black Sea region of Turkey. She is married to her maternal uncle's son. The interview took place at Çiğdem's daughter-in-law's home; I recruited her through my circle of personal acquaintances. Interview conducted in Turkish by author, 08 June 2017, Istanbul.

[2] Dilba (name has been changed), woman in her 30s who comes originally from a town in South Eastern Anatolia. She is married to her paternal aunt's son. The interview took place at Dilba's home; I recruited her via my circle of personal acquaintances. Interview conducted in Turkish by author, 30 May 2017, Istanbul.

of medicalization that today are being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine" (Clarke et al. 2003, 162). Recognizing the centrality of the family as a symbolic figure and social institution within changing imaginations of state, nation and society, this thesis approaches the biomedicalization process of kin marriage as an expression of a newly emerging management of "healthy" family making at the genetic or genomic level in contemporary Turkey, thus contributing to the biomedicalization scholarship.

The relative frequency of kin marriage (Turkish: *akraba evliliği*)[3] among Turkey's population has placed Turkey in line with other countries much researched by mostly Western anthropologists and sociologists with a pronounced interest in "Middle Eastern" kinship structures. Existing anthropological and sociological studies on kin marriage in the Middle East have extensively discussed the functions, meanings and structural patterns of these marriage alliances, especially the so-called "patrilateral parallel cousin marriage", focusing either on the utilitarian or symbolic and emotional dimensions of marrying "close" (Bourdieu 1977, Holy 1989, Kressel 1992, Murphy and Kasdan 1959, Tillion 1983). This marked focus on cousin marriage, turning it into a key concern of "Middle Eastern ethnography" (Holy 1989), emerged from and continued classical anthropology's interest in kinship systems and structures. Concentrating on kinship organization not only offered an intimate way of knowing and classifying (former) colonial populations; it also served as a reaffirmation of the discipline's self-understanding as being concerned with the study of "non-modern" and "non-Western" societies (Featherstone et al. 2006, 2). This thesis largely departs from the aims and perspectives of this main body of scholarly work on kinship and kin marriage. It does not take kin marriage per se as its primary field of interest. Rather, it explores how kin marriage emerges as an object of interest within another field of discourses and practices, namely Western biomedicine, while tracing how contestations over "modernity" and "(non-)Westernness" retain salience in shaping this biomedical reconceptualization of kin marriage.

[3] As a remark of clarification, I use the term "kin marriage" throughout instead of "consanguineous marriage", which is predominantly used in the biomedical literature, as the best approximation to the Turkish term *akraba evliliği* (literally meaning „marriage between relatives"). For a detailed discussion, see the section "A Note on Translation" in chapter 2.

More specifically, this thesis asks the central research question of how kin marriage is being conceptualized, managed, and negotiated as a genetic risk factor and reproductive health concern within intersecting biomedical and genetic spaces in contemporary Turkey. It makes sense of this re-conceptualization process from within the framework of "biomedicalization" theory (Clarke et al. 2010, Clarke et al. 2003) and understands this biomedicalization of kin marriage to hinge upon multiple stakeholders, actors, institutions and policies. Consequently, it approaches the overarching research question by tracing the following sub-questions: How do biomedical and genetic professionals (henceforth "medico-genetic" professionals) frame and approach kin marriage in Turkey? How do government bodies concerned with issues of family making, reproduction and health respond to and contribute to the biomedical reconceptualization of kin marriage; how do they incorporate kin marriage into (public) health infrastructures and policies? And finally, how do couples practicing kin marriage negotiate the biomedicalization of kin marriage, how do they make sense of notions of "genetic risk" and "risky reproduction" in their encounters with genetic health care infrastructures?

Significantly, this thesis seeks to explore how the biomedicalization of kin marriage rests upon a complex interplay of new and old modes of reproductive governance, unprecedented technological innovations in reproductive and genetic health care as well as a particular articulation of the state, the family and biomedicine in Turkey which has historically placed "healthy" families at the heart of the nation. "Healthy" stands in quotation marks here because I employ it as a term which does not only refer to the seemingly unpolitical good of family members' physical and social wellbeing; I also understand it in its biopolitical sense indicating how the population's health constitutes a prime matter of political state concern, the management of which is inseparably tied to the reproduction and maintenance of state governance and hegemony in the modern nation state (Foucault 2003, 1978). This thesis is thus interested in how the biomedicalization of kin marriage not only links up with processes of "healthy" family making in Turkey but also adds a new genetic quality to them.

Taking into consideration the heterogeneous and multi-sided character of biomedicalization processes, this thesis is based on multiple strands of qualitative data

collection, namely (a.) 19 qualitative semi-structured interviews with medico-genetic professionals working in the fields of genetics and family health, (b.) 18 qualitative semi-structured interviews with individual persons or couples practising kin marriage, (c.) observations during my two-and-a-half months stay at a public hospital's genetics clinic, and (d.) a textual analysis of state issued documents and legal texts concerning kin marriage, family making, and reproductive health. These methodological pathways are discussed in detail in chapter 2.

While I conceive of the biomedicalization of kin marriage as an entry point to address larger questions surrounding (de-)alignments between medicine, specifically medical genetics, the state, and the family which hold a strong fascination for me as a social scientist, I am conscious that all research interests have their own biographies. What elicits interest and feeds one's fascination is neither innocent nor arbitrary. The academic pathway leading to a specific research site is, unsurprisingly, contingent upon personal experiences and stakes. I was drawn to this exploration of kin marriage and its biomedical reconceptualizations as a result of my own affective entanglements and the academic trajectory which they have stimulated.

Born as a citizen of a state that ceased to exist shortly after my birth, I grew up in a family who had experienced the former Eastern German regime as an intrusive presence governing both intimate and public moments of everyday life during uncountable instances. Familial memories of state repression, retold on numerous occasions, revealed not only how such repression gained efficacy through the seemingly banal and mundane workings of bureaucratic infrastructures rather than through unmasked violence; they have also lent themselves to eclipse more disturbing and uncomfortable memories of another not too distant German past. The atrocities of the Third Reich were deeply entangled with the evolvement of modern medicine and hygiene (Weindling 2004, Weindling 2000), not only relying on but also driving medical expertise and technologies. Growing up in East Berlin, both familial and public memories of Germany's multi-layered pasts have impressed me with a sense of state and medicine being far from inherently beneficial sites and shaped my interest in the socio-political implications and potentially repressive effects of their alignments.

However, this account of the research project came about remains partial without reference to other familial narratives and memories which bring me closer to genetics and the vexed question of genetic risk as well as to the lived experience of disability. As this PhD was drawing to a close, I lost one of my close cousins, her life untimely ended by the consequences of cystic fibrosis, a genetic condition which progressively damages the respiratory and digestive systems of the body. Another close cousin of mine is boldly defying the statistical prognosis of life expectancy which was given to her parents when she was diagnosed in her infancy with a severe and very rare genetic condition. This condition has been affecting her body's muscular functioning and development since her early childhood and requires her to use a wheelchair for mobility. The presence of these as well as other milder conditions in my family has given rise to a variety of narratives about how such genetic conditions are passed on and who is likely to be (not) affected which draw on lay and scientific notions of relatedness and heredity; it has generated profound solidarities but also lines of tension, feelings of guilt and the presence of silences among family members. With genetic conditions and genetic risk thus being a constant reality in my, as in so many others', families, I could not but be intrigued by questions surrounding the social life of genetics and the reverberations of genetic risk regarding the making of families. Both my cousins are among the most inspiring people I have had the chance to know. Living their lives while managing the requirements of their conditions has often been hard work for them and their immediate families, but these conditions have far from rendered their lives worthless or unfulfilling despite being also undeniably a source of hardship, pain and, thinking of my late cousin, grief and mourning. Both the affective entanglements and analytical stakes which undergird this thesis have been shaped by the impact of their presence in my and my family's life.

A final strand of attachment shaping this thesis project connects me to Turkey, specifically Istanbul, where I had spent a year as an exchange student during my undergraduate studies and where I received my two-year postgraduate training as a masters' student. Influenced and shaped by Turkish scholarship and the invaluable mentorship of my former teachers in Turkey which together have significantly formed my ways of thinking and doing

research, I was eager to stay in a scholarly relation with Istanbul at exactly the moment when I was preparing to leave its higher education landscape to embark on a PhD in the UK. During my studies in Turkey, I had become aware of kin marriage as a relatively common but also socially contested practice in Turkey. However, it was not until I read Can Açıksöz's short but insightful reflections on kin marriage as an emergent genetic risk factor in Turkey which form a minor side-strand of his published master's thesis on the uptake of prenatal diagnosis among affluent and upwardly mobile women in Turkey (Aciksoz 2012, 58-62) that I seriously considered exploring the biomedical reconceptualizations of kin marriage in Turkey as the focus of my PhD research. Guided by Açıksöz's reflections, which I will come back to in more detail later in this chapter, I sensed that this reconceptualization process of kin marriage was highly complex in character, bringing to the fore multiple interconnections and (mis)alignments between medicine, genetics, risk, disability, reproduction, the family and the nation state in Turkey which so much intrigue me as a social scientist. And put simply, after many years of living in Istanbul, I wasn't fully ready to leave. I wished for a reason to come back. This thesis thus became a story about Turkey, about family making and reproduction in an age of genetic risk and its technoscientific management. What it offers is a narrative about recent developments in the field of reproductive genetic health care which have allowed for the rise of new genetic sensibilities informing the conceptualization of the family as a key social institution securing the "healthy" future of nation, state and society.

The Biomedical Reconceptualization of Kin Marriage in Turkey as a Case of Biomedicalization

The Emergence of Kin Marriage as a Health Concern

The notion of kin marriage resulting in children with disabilities has become increasingly dominant in the popular imagination in contemporary Turkey. This idea is constantly reproduced by sensationalist media reports highlighting the dramatic impact of kin marriage on reproductive health. Headlines such as "The Great Danger in Kin Marriage" (2012, 9 Nov), "33% of Infant Deaths Occur due to Kin Marriage" (2017, 14 June), or "Kin Marriage: A Genetic Threat to the Health of the Çukurova Region" (2016, 31 Aug) are no rarity in Turkish

newspapers. However, the popular idea of kin marriage as medically "problematic" is a relatively recent phenomenon in Turkey which dates back no further than the 1980s. It was preceded by and emerged out of a proliferation of public health and demography studies by Turkish scientists focusing on the impacts of consanguinity on population health over the 1970s, 1980s and 1990s (Başaran 1973, Başaran et al. 1988, Güz, Dedeoğlu, and Lüleci 1989, Tunçbilek and Koç 1994). This medico-scientific interest in consanguinity did not appear out of nowhere in Turkey; it reflected and was shaped by a debate on genetic inheritance, risk and consanguinity which had originated in Western medicine and public health but has by now gained global currency (Shaw and Raz 2015).

Biomedical discourses highlighting the reproductive risks of consanguinity began to circulate and proliferate in Turkey's medico-scientific and public realms in the 1980s, at a time when reproductive policies and health care were undergoing major changes. Following the shift from pronatalist to antinatalist population policies in the 1960s, an amendment of the abortion law occurred in 1983 which legalized abortion under the new Population Planning Law (Gürsoy 1996, Toksöz 2011). Only two years later, in 1985, the first medical genetics department in Turkey was founded at the public Çapa Istanbul University Hospital under the roof of the Child Health Institute (Aciksoz 2012, 40-41). The following introduction of prenatal diagnostic technologies at Çapa Hospital in 1989 marked the beginning of a rapidly growing expansion of genetic and reproductive health services throughout public and private health care in Turkey over the 1990s and 2000s (Aciksoz 2012, 40-41, Gürtin 2016, 2011). The spread of reproductive genetic health services, which only gradually moved under government regulation, thus coincided with a period of increasing commercialization and privatization of the health sector in Turkey (Günal 2008).

Undoubtedly, the effects of these transformations in reproductive health care have not been felt equally across society as they intersect with stratified access to health care services in the country. For instance, a report on reproductive health care seeking behaviour issued in 2007 within the framework of the joint EU and Turkey led "Reproductive Health Programme" highlighted how non-medicalized experiences of pregnancy and birth continue to be very

common among women from rural and urban poor areas in Eastern, Southern and Inner Anatolia (Conseil Santé, SOFRECO, and EDUSER 2007). In contrast, major cities like Istanbul, Izmir and Ankara as well as larger Anatolian urban centres nowadays boast an ever growing health service infrastructure allowing for the management of genetic disease and reproductive health before, during and after pregnancy, thus revealing the highly uneven development and distribution of biomedical institutions.

Global biomedical discourses stating an increased risk for recessive genetic disorders in children born to consanguineous parents have found entrance into the public and medical realms in Turkey within the wider context of this changing landscape of reproductive health care. This is not an accidental co-incidence but stems from the ways through which "risks get embedded in technology as technologies evolve" (Hilgartner 1992, 43). These emergent genetic risk discourses have not entailed legal sanctions against kin marriage in Turkey but have rather initiated new prevention strategies and health policies singling out couples with kin marriage as a distinctive reproductive risk group. This proliferation of risk discourse which mostly promotes individualized responsibilization and "voluntary" risk management instead of directly coercive measures has occurred on multiple levels. Since the 1980s, public media organs have repeatedly reported on the health risks of kin marriage. Similarly, educational programs have sought to inform school children or the adult population about the genetic consequences of consanguinity (Delaney 1991, 155, Bellér-Hann and Hann 2001, 145). These educational campaigns have not been launched within any nation-wide government initiative but have rather resulted from civil society organizations' or individual politicians' initiatives and remained of local or regional outreach. Most significantly, medical professionals themselves have driven this reconceptualization of kin marriage as genetically risky by publishing widely on the prevalence of kin marriage in Turkey and its links with reproductive health problems (Başaran et al. 1988, Hancıoğlu and Tunçbilek 1998, Tunçbilek and Koç 1994) while emphasizing consanguineous couples' need for reproductive risk management through genetic health services (Akbaba et al. 2012, Çiçeklioğlu et al. 2013, Güz, Dedeoğlu, and Lüleci 1989). Many genetics centres' websites nowadays list "couples with kin marriage" among the primary risk groups who should

opt for preconceptional genetic counselling and testing, thus revealing the crucial role kin marriage has played and continues to play with regard to the expansion and consolidation of genetic health services in Turkey.

A significant exception to this risk management approach based on voluntary participation and individual responsibility exists due to the relatively recent incorporation of kin marriage as a risk factor within obligatory premarital health screening. Whereas premarital health examinations testing couples' mental and physical "fitness" for marriage have been institutionalized as an obligatory part of legal marriage procedures in Turkey since the 1930s, the recent years have seen a shift in focus towards the unprecedented inclusion of genetic risk management within the examination framework. Not only are incoming couples to be informed about the reproductive risks of kin marriage, the examination procedure itself has also changed and now requires testing for certain inherited blood disorders in specially designated high-risk areas (Ministry of Health 2013b). Over the 1990s, kin marriage has become strongly associated with the generational transmission of the genetic blood disorders (haemoglobinopathies) β-thalassemia and sickle cell anaemia (Canatan et al. 2003) which are considered to be among the most pressing public health issues in the country (Erdem and Tekşen 2013). Based on the 1993 Law for the Fight against Inherited Diseases and the Haemoglobinopathy Prevention Programme launched in 2002, the government has overseen the establishment of a treatment and prevention infrastructure which includes obligatory premarital testing for thalassemia and sickle cell anaemia in originally 33 and by now 41 so-called "high-risk" provinces across the country. Couples tested positively with carrier status are referred to genetic counselling and recommended prenatal diagnosis in case of pregnancy (Canatan et al. 2003, Erdem and Tekşen 2013). Although these premarital examinations are directed at all forms of marriage, the close association of haemoglobinopathies with kin marriage (Gülleroğlu, Sarper, and Gökalp 2007) furthers the conceptualization of consanguineous couples as a primary target group for genetic reproductive health services.

From Biomedical Discourse to a Theoretical Framework of Biomedicalization

The biomedical reconceptualization of kin marriage as a reproductive health concern hinges upon an interplay of discursive shifts, infrastructural and political changes as well as transformational changes in the management of reproduction and health. I make sense of this interplay from within the theoretical framework of "biomedicalization" (Clarke et al. 2010, Clarke et al. 2003). The concept of biomedicalization was developed by Adele Clarke and her colleagues to capture late 20th century transformations of biomedicine which they conceived of as being insufficiently accounted for by existing medicalization concepts (Conrad and Schneider 1992, Conrad 1992, Zola 1972). Biomedicalization theory both builds on and extends the concept of medicalization. Whereas medicalization theory describes the extension of medical authority over ever increasing aspects of everyday life (Zola 1972), biomedicalization theory argues that biomedicine itself is being transformed from its very organization to its practices, or "from the inside out", as a consequence of the growing significance of technoscience and the engagement with life itself within biomedical organization, practices and institutions. Biomedicalization thus describes "a shift from enhanced control over external nature (i.e., the world around us) to the harnessing and transformation of internal nature (i.e., biological processes of human and nonhuman life forms), often transforming 'life itself'" (Clarke et al. 2003, 164).

Clarke et al. identify five major interactive processes upon which biomedicalization hinges: (1) the rise of a new biopolitical economy of medicine, health and illness which is marked by the growing salience of corporatization, commodification and privatization processes; (2) an intensified focus on health itself and the emergence of risk and surveillance biomedicines; (3) the increasingly technoscientific nature, or "technoscientization" of biomedical practices and interventions; (4) transformations of biomedical knowledge production, information management, distribution, and consumption; and (5) transformations of bodies and the production of new individual and collective technoscientific identities (Clarke et al. 2010, Clarke et al. 2003, Clarke et al. 2009). As Clarke et al. argue, the processes described by biomedicalization are not necessarily new in themselves but – and here lies the major

contribution of biomedicalization theory – they need to be understood as historically interconnected and cumulative rather than separate trends and it is this interconnectedness which "biomedicalization" as a concept seeks to grasp (Clarke et al. 2010, 56). Significantly, despite its encompassing scope, biomedicalization must not be conceptualized as a "tsunami of biomedical power" (ibid., ix); it does not constitute a predetermined process but a heterogeneous multiplicity of contingent and uneven processes which are also marked by resistances, push-backs and contradictions (Clarke et al. 2010, 14, Clarke et al. 2003, 166).

Although Clarke et al. developed their theory of biomedicalization with regard to the context of US biomedicine, which has also been the predominant contextual focus of subsequent biomedicalization scholarship (Clarke et al. 2010, Fosket 2010, Mamo 2010, Shim 2010), I consider biomedicalization as a useful concept to capture processes of biomedical transformation beyond the US. I argue that the incorporation of kin marriage within Turkey's infrastructures of reproductive health care is shaped by interrelated shifts in biomedical infrastructures and practices which turn it into an incidence of "biomedicalization in its transnational travels" (Clarke et al. 2010, 380ii). These shifts consist in the growing technoscientization and molecularization of reproductive health care, the rise of an increasingly commodified and privatized health care sector, and the emergent emphasis on reproductive surveillance, optimization, and risk management over the last decades in Turkey which have rendered the biomedical reconceptualization of kin marriage both conceivable and practically implementable. Before turning to a discussion of these shifts, it needs pointing out that biomedicalization does not displace but rather extend medicalization, with "traditional" medicalization processes often occurring alongside more technoscientifically based biomedicalization processes (Clarke et al. 2003, 166). Thus, while I argue that the targeting of kin marriage as a reproductive health concern constitutes an unfolding process of biomedicalization, it nevertheless also presents familiar elements of medicalization. It perpetuates and consolidates the extension of medical authority and control over family making, reproduction and pregnancy by affirming the need for expert surveillance of these areas. It also marks the emergence of a couple's "relatedness" as a new reproductive and genetic health

concern which draws a formerly non-medicalized socio-cultural practice of family making into the biomedical realm, opening up a new space for biomedical scrutiny and control.

As detailed earlier, the biomedical reconceptualization of kin marriage coincided with and hinged upon the growing technoscientization and molecularization of reproductive health care in Turkey from the mid-1980s onwards. The introduction of new technologies such as ultrasound, prenatal screening, in vitro fertilization (IVF), preimplantation genetic diagnosis (PGD), and increasingly refined methods for analysing genetic and genomic data has shifted the management of reproductive processes and emergent life to the molecular level. Thus, clinical practices have been expanded through the emergence of a "molecular gaze" (Rose 2001) which rests on a close collaboration between the clinic and the laboratory. The growing significance of these collaborations points to another unfolding key process of biomedicalization, namely the rise of an increasingly commodified and privatized health care sector and the blurring of boundaries between public and private health care infrastructures and practices. Although they were initially introduced within public health care infrastructures, the expansion of reproductive and genetic technologies has subsequently been driven by the burgeoning sector of private health care facilities with new technoscientific innovations such as PGD or whole genome sequencing techniques being foremost or even exclusively available through private institutions, as the following chapter will discuss in more detail. The production, analysis, communication and consumption of complex genetic information as well as the availability of and demand for reproductive genetic technologies rely on extended national and transnational networks encompassing clinics, medical and genetic professionals, laboratories, universities and research centres as well as patients and their families, which span the public and the private realm. It is exactly these networks of different stakeholders and institutions which in between themselves produce the knowledge and practices required for reproductive risk management that render possible the conceptualization and management of kin marriage as a genetic risk factor.

The biomedical reconceptualization of kin marriage probably most clearly indicates a process of not only medicalization but also biomedicalization by how it transforms kin marriage into a genetic risk factor, thus turning it into a site of technoscientifically mediated surveillance

and risk management monitoring emergent life at the molecular level. As Clarke et al. point out, a key process of biomedicalization consists in how "health itself and the proper management of chronic illnesses are becoming individual moral responsibilities to be fulfilled through improved access to knowledge, self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self-help/biomedical goods and services" (Clarke et al. 2003, 162). The incorporation of kin marriage within genetic health care infrastructures as a risk factor hinges upon biomedical interventions which aim less at treating illnesses than at identifying, managing and minimizing risks to achieve the "best possible futures" (Rose 2001, 7) by working towards reproductive outcomes deemed "healthy". Undoubtedly, a significant part of the clinical work done by geneticists in their encounters with families experiencing reproductive genetic risk revolves around the identification, classification and ultimately long-term management of genetic conditions after the birth of an affected child (Latimer 2013b). However, the rise of a growing array of technologies facilitating prenatal or preconceptional testing for genetic traits has entailed an increasing channelling of couples "genetically at risk" towards risk identification and minimization (Shaw 2009, 2011, Franklin and Roberts 2006). Such risk management strategies approach "risk" as "a family of ways of thinking and acting, involving calculations about probable futures in the present followed by interventions into the present in order to control that potential future" (Rose 2001, 7).

Public media discourses concerning kin marriage in Turkey are driven by a sense of moral panic in how they present kin marriage as a threat to the well-being, health and happiness of families and their future children as indicated by the newspaper headlines cited earlier. Government policies and biomedical discourse similarly produce this sense of threat by emphasizing consanguineous couples' need for medically managed reproduction and risk management (Canatan et al. 2003, Ministry of Health 2014, 2013b). These discursive practices approach health and healthy reproduction as a moral and social good while holding couples individually responsible for achieving this good. They generate a strong sense of moral obligation and responsibility to become pro-active vis-à-vis one's risks and enrol in self-surveillance strategies such as genetic counselling, screening or selective reproductive

technologies. This sense of moral responsibility is rendered all the more acute because what is at stake is not so much the health of the couple as such but the health of their future children. In light of the growing public hegemony of biomedical framings of kin marriage in Turkey and the responsibilization they entail, couples practicing kin marriage have to respond to their "genetic identities" (Novas and Rose 2000) and negotiate their respective "burdens of genealogy" (Konrad 2003). As this thesis will show, these negotiations are far from straightforward, revealing the contradictions and push-backs inherent in biomedicalization processes.

Biomedicalization thus captures how the remaking of biomedicine and the management of life at the molecular level unfold within Turkey's landscape of health care and biomedicine. As a concept, it helps to see as interconnected the rise of commercialized health care, the increasing salience of technoscientific innovation and knowledge production within reproductive health contexts as well as the rise of surveillance medicine in the form of risk management aiming at future-oriented reproductive optimization. The transformation of kin marriage from a non-medicalized socio-cultural practice to a genetic risk factor is rendered possible by these larger historical and qualitative shifts. Exploring the conceptualization and management of kin marriage as a reproductive health concern thus provides a pathway towards studying how biomedicalization processes take shape in contemporary Turkey.

The Biomedicalization of Kin Marriage at the Intersection of Contestations over "Healthy" Family Making, Modernity, and Nation Building

Any attempt to approach the biomedicalization of kin marriage in Turkey as a target of sociological inquiry needs to take into account the historical legacies which have shaped and continue to inform the interrelations between state infrastructures, biomedical landscapes and the processes of family making and reproduction in Turkey. This section will thus detail how my thesis needs to be contextualized in relation to the family and biomedicine as biopolitical sites of state governance and nation building in modern Turkey. It traces (1) how the founding of the Turkish Republic and the perpetuation of state governance through changing regimes of power has hinged upon the propagation of the "modern" nuclear family as the primary social unit, turning the family and reproduction into significant sites of state intervention; (2) how Western biomedicine has played a crucial role in expanding state infrastructures, consolidating state legitimacy and crafting the "modern family" as the cornerstone of state and society, thus building a new "modern" citizenry; and (3) how kin marriage occupies an ambiguous positionality within Turkey's society, being both a normalized practice and a site upon which contestations regarding modernity, traditionality, Turkishness and internal "otherness" are being played out. It finally argues that the biomedicalization of kin marriage has not unfolded within a socio-political vacuum but has been deeply informed by these three trajectories.

The following discussion will concentrate on dynamics of social change that have succeeded the foundation of the Turkish Republic and been decisive in producing those discursive practices that render the current biomedicalization of kin marriage conceivable and realizable. However, any prioritization of a historical "starting point" will always remain arbitrary to some degree and it is important to keep in mind that many of the changes brought about by the founding of the Turkish Republic, which have affected a subsequently closer articulation of state, family and medicine, have significant precedents reaching back to the socio-political conditions of the late Ottoman Empire. Limiting the discussion to the period of the Turkish Republic thus constitutes a pragmatic choice guided by feasibility concerns and the scope of this thesis.

The Propagation of the "Modern" Nuclear Family as the Primary Social Unit: Family Making and Reproduction as Sites of State Intervention and Biopolitical Governance

The emergence of the modern state is intrinsically bound up with a transition from the extended to the conjugal family as a privileged site of state intervention (Donzelot 1980), as a consequence of which the formation of the modern Turkish nation state cannot be discussed in separation from the role of the family within it. The family has occupied a key strategic position in modern Turkey's society, acting as a normalizing institution through which changing regimes of state governance have been rendered hegemonic. It stood at the heart of those processes of socio-political change which resulted in the transition from the Ottoman Empire to the Turkish Republic following World War I. Already in the late Ottoman Empire, familial relations (and specifically the status of women) started to emerge as a touchstone for relative "modernity", "civilization" and "progress" achieved (Duben and Behar 1991, Sirman 2007). Throughout the history of the Turkish Republic, the family and familial relations have continued to constitute a highly politicized ground upon which "tradition" – "modernity" relations are being played out in Turkey (Kogacioglu 2004, Parla 2001), mirroring similar dynamics in other socio-political contexts shaped by colonial encounters with the West (Abu-Lughod 1998, Chatterjee 1993).

Following the War of Independence, the proclamation of the Republic of Turkey under the leadership of Mustafa Kemal Atatürk in 1923 initiated the rapid and violent transformation of the multi-lingual, multi-religious and multi-ethnic empire into a nation state. The Kemalist nation building and modernization programme focused on the family as a primary site for the realization of social transformation and the anchoring of loyalty to the newly founded state (Yilmaz 2015). Severing any remaining links with sharia law[4], a major part of social reforms in the 1920s and 1930s aimed at secularizing the regulation of marriage and family life. Propagating what Şirin Tekeli has referred to as "state feminism" (Tekeli 1992), the government initiated a transformation of the public status of women while simultaneously harnessing this state-concerted "liberation" of women to the nationalist course (Kandiyoti 1991, Arat 1994).

[4] The passing of an Imperial edict in 1838 seeking to formulate a consistent state policy to prevent abortion, which was followed by the 1858 Penal Code, had already marked the first incursions of state power into realms of family life previously under sole religious authority (Demirci and Somel 2008).

The “new modern woman” was to be liberated and educated yet loyally serving husband, family and nation.

Modernizing elites sought to re-craft the relation between the state and its subjects through the propagation of the nuclear family as the new basis of socio-political order which was to replace the previous kinship networks and alliances upon which governance in the Ottoman Empire had hinged. Instead, loyalty to the new nation state was to be anchored in the conjugal couple (Sirman 2005). The mutual affection (*sevgi*) between husband and wife was endorsed as a model for naturalizing citizens’ love for and gendered duties towards the nation, as a consequence of which citizenship became conceived in “familial” rather than individualistic terms (ibid.). As Nükhet Sirman argues, “it was through the forms of intimacy pertaining to the nuclear family that the morality of the proper citizen was to be produced and citizens turned into the subjects of the modern nation-state” (ibid., 149). Familial relations became thus conceptualized in early Republican discourse as a primary marker of distinction between the “Oriental” Ottoman past and the modernity of the Republican present and as a benchmark for evaluating the process of modernization and civilization separating the present from the past. As Sirman succinctly frames it, “the production of an imaginary of the nuclear family took place in tandem with the creation of the nation-state as modern” (Sirman 2005, 148). Diverging family making arrangements such as kin marriage practices which revealed the lingering salience of kinship relations and loyalties were recast as remnants of the past and turned into signifiers of “traditionality” and “non-modernity” (ibid., 165).

Notwithstanding nationalist imaginations, the hegemony of the nuclear, conjugal family has remained shaky and contested throughout the history of modern Turkey as is illustrated by the continuing tension between the narrow legal definition of “the family” in conjugal terms and the de-facto significance of extended kin-relations in regulating everyday life (Sirman 2004, 2005). However, this complex everyday salience of kinship norms, including notions of familial honour (*namus*), has been pushed to the margins of public visibility through the nationalist language of modernization and civilization. Such language safely locates practices perceived as pertaining to “the law of kinship” either within the domestic sphere or interprets them as a

characteristic of "traditional" parts of the population situated at the periphery of the "modern" nation state, thus masking how "the law of kinship" and the notion of honour remain central to the gendered framing of citizenship and the working of the modern nation state in Turkey (Koğacıoğlu 2011, Kogacioglu 2004, Parla 2001, Sirman 2004).

The experience and legacy of the Kemalist reforms and nation building process during the first half of the 20th century remain central to the understanding of how family, state governance and nationhood are framed in Turkey until today; however, the very principles of Kemalism as the foundational ideology of the Turkish Republic have become increasingly contested over the last decades. Especially the ruling Development and Justice Party (AKP), the first political party with an explicitly religious political agenda to form a single-party government since the establishment of the Republic, has since its rise to power in 2002 embarked on a major ideological and institutional re-conceptualization of the state which breaks with the Kemalist tradition of state rule (Kaya 2014, Özyürek 2006, Tuğal 2009, White 2002). In line with its pronounced endorsement of pronatalism and its particular biopolitical governance of sexuality and reproduction in the name of creating a "strong nation", the AKP and its party leader Recep Tayyip Erdoğan, former prime minister and now president of the country, propagate the extended, three-generational family as the true bearer of "Turkish" cultural-religious values and as a marker of distinction from an imagined other "West" (Yazıcı 2012). However, this departure from the ideal of the nuclear conjugal family and the corresponding reification of the "West" as the epitome of modernity is in itself expressive of how the family continues to occupy a key position regarding the realization of socio-political transformation. The family once again constitutes the major institution through which state power seeks to secure and anchor its political hegemony (Öztan 2014a, Yilmaz 2015). The strategic familialism of the ruling party equates citizens with families and citizenship rights with family responsibilities. It depoliticizes and individualises issues of social inequality, such as poverty or gender inequality, as "family matters" while endorsing traditional gender roles and family values. Particularly expressive of this shift towards familialism were the founding of the Ministry for the Family and Social Affairs in 2011, replacing the previous ministry responsible

for women's affairs and women's rights (Öztan 2014a, Yilmaz 2015), as well the propagation of welfare provision as a primary family responsibility (Akkan 2018, Buğra and Keyder 2006, Yazıcı 2012). Such policy shifts and rhetorics treat the family as a discursive figure and social institution which deflects and absorbs threats to the legitimacy of state power. They are undergirded by discursive framings of the nation as "one big family" which naturalise the party leader's claim to be representing the true "head" or "father" of the nation (Öztan 2014a).

The "Healthy" Family at the Heart of a Strong Nation: Intersecting Biomedical and State infrastructures

Medicine has historically functioned as a mechanism of social control, facilitating state governance of the emergent conjugal family which was attributed a key role in linking the health of the social body and the individual in the forming nation states of the 18th and 19th centuries (Foucault 1984, 280-81). A delineation of the articulation of state and family in Turkey thus needs to take into consideration the significant role which Western biomedicine has played in the regulation of family life and reproduction. As the following discussion will illustrate, changing state regimes in Turkey have devoted significant effort to the biopolitical management of the population's (reproductive) health as a means to further the crafting of a strong and "healthy" nation.

Procreative imagery is central to Turkish nationalist discourse and nation founding narratives which draw on the gendered binary of the "seed" and the "soil". This binary evokes a symbolic analogy between masculine procreative power and the (Father) State's authority to rule and convey citizenship on the one hand and feminine fertility and the Motherland's nurturing capacity to raise the future citizenry on the other hand (Delaney 1991, Delaney 1994). With its privileged access to the body and the body's reproductive capacities, Western biomedicine has provided the modern Turkish state with unprecedented means to harness reproduction and family making to the realization of nationalist agendas. Within the context of the transition from the Ottoman Empire to the Turkish Republic, Western medicine emerged as a significant "political technology of social reform" assisting in the crafting of a new relationship between the bodies of the citizenry and the body politic of the Turkish state (Dole

2012, 38). In the early Republican years, the medical infrastructure was greatly expanded. Many leading physicians of the founding years, who often came from former elite Ottoman families with access to Western education, acted self-consciously as representatives of the state. They regarded themselves as pioneers of the Republic, responsible both for the health of population and nation (İlikan 2006, Terzioğlu 1998). Following the passing of the Law of Public Hygiene in 1930, various hygiene and medical education campaigns and policies were launched which reveal a new concern for a scientific management of family life and reproduction (Günal 2008). Mandatory premarital examinations were introduced, childcare institutions founded and education programmes for mothers launched to teach them the requirements of "modern" motherhood in line with medico-scientific principles (Öztamur 2004). These efforts to educate and train the population in terms of modern, scientific citizenship were underpinned by contemporary influential eugenic discourse which established a link between healthy individuals, healthy families and a healthy nation (Alemdaroglu 2005). The intersection of state and biomedical infrastructures was not restricted to the early Republican period. Reflecting the global reach of emerging governmentalities directed at "economic modernization" and "population control" after World War II (Ali 2002, Connelly 2008, Greenhalgh 1994, Murphy 2010), changing governments during the 1960s to 1980s engaged in efforts to reform and expand biomedical health facilities throughout the country as a means to drive the modernization of "under-developed" regions and further their integration into the state apparatus (Günal 2008, 220ii). "Population control" was identified as a pathway towards national growth, economic stability and social progress, initiating a shift in Turkish population policies towards antinatalism and the propagation of birth control (Günal 2008, Gürsoy 1996, Toksöz 2011).

Family health and reproduction continue to constitute a core area of governmental interest under the current rule of the AKP with its decided familialist agenda. The ruling party's 2012 programme presents the married heterosexual couple as the primary social unit for nurturing "the mentally and physically healthy citizens with strong moral and ethical values that the new Turkey needs" (quoted after Öztan 2014, 32-33). Consequently, the programme

promises to implement a social policy that "strengthens the institution of marriage, protects the unit of the family and maintains family values" (ibid., 32-33). The discursive language of this party programme is expressive of the AKP's new "politics of the intimate" which glorify the Turkish family and demonize birth control (Acar and Altunok 2012). This shift towards "patriarchal pronatalism" (Gürtin 2016) constitutes a departure from the previous antinatalist policy stance advocated by Turkish governments in the second half of the 20th century. The legal regulation of new reproductive technologies, which had started emerging in Turkey in the 1980s but only became widely routinized from the early 2000s onwards, has been significantly shaped by this socio-political environment of "patriarchal pronatalism". Heralded as a powerful "weapon" against infertility, reproductive technologies in Turkey have been geared towards heteronormative reproduction and the protection of the hegemonic family (Gürtin 2016, 2011, Mutlu 2011). As this thesis details, the AKP has furthermore consolidated and expanded the existing infrastructure for compulsory premarital health examinations dating back to the early Republican Period, thus re-emphasizing the state's targeting of reproductive health as an integral part of biopolitical population management. In particular, the expansion of premarital genetic carrier screening for inheritable blood diseases was actively pursued under AKP governance (Canatan 2011, Canatan et al. 2006). Taken together, the growing routinization of genetic health services and new reproductive technologies suggests the presence of an emergent genetic quality which has come to inform the existing legacies of the biopolitical management of healthy family making in Turkey. The result is a shift from the question of how future subjects should be brought up in a socially and politically desirable familial environment to the question of how they should be conceived and born in the first place.

Ambiguous Significations: Kin Marriage as a Site of Normalcy and Otherness

Although kin marriages as close as first cousin marriage are legally permitted in Turkey (article 129, Turkish Civil Code; Official Gazette no. 24607), kin marriage has historically occupied an ambiguous and contested position within modern Turkey's society, constituting both a site of "normalcy" and internal "otherness". With a national rate of ca. 23% of all marriages in Turkey being officially categorized as "kin marriage" by the Turkish Statistical

Institute (TUIK 2016), kin marriage constitutes a comparatively common socio-cultural practice. Ethnographic research conducted in various regions of Turkey such as the Black Sea area (Bellér-Hann and Hann 2001), Central Anatolia (Delaney 1991), the Eastern Mediterranean (Prager 2015, 2010) or Western Turkey (Sirman 1995, 1990) all refer to it as a valorised form of marriage commonly practiced among the rural, urban or semi-urban communities studied. In that sense, it would be wrong to generally describe kin marriage as a marginalized and socially largely unaccepted form of family making in Turkey.

However, the statistics also indicate an uneven pattern of kin marriage practices across different regions in Turkey. For instance, the Turkish Statistical Institute's 2016 Family Structure Survey gives a kin marriage rate of 8.9% for the West Marmara region in contrast to a rate of 42.6% for the region of South Eastern Anatolia (TUIK 2016). It is in relation to such discrepancies that the potency of kin marriage as a means for discursive constructions of "self" versus "other" takes shape. Based on her ethnographic work in a Western Turkish village in the 1980s, Sirman for instance points out how people in the village claimed that kin marriage was only practiced by Yuruk[5] families living in the village whereas villagers whose families had originally migrated from the Balkans decidedly emphasized their disapproval of the practice (Sirman 1990, 35). Conducting fieldwork, I encountered numerous similar instances during interviews with lay and professional participants when my interlocutors discursively evoked "kin marriage" as a practice which they considered to be only common among certain groups or families while being strictly avoided by others. Some stressed how kin marriage had always been considered rather "weird" (*garip*), "taboo" (*tabu*) or even "shameful" (*ayıp*) by their own family. Others, in contrast, who practiced kin marriage remarked on how their marriages were absolutely ordinary, accepted and endorsed within their social circle of family or village community but had been looked at disapprovingly by others outside of this circle.

For instance, one woman I interviewed who had grown up in a village in the Eastern Black Sea region of Turkey emphasized how her cousin marriage which reflected the commonness of kin marriage practices in her village was considered an expression of

[5] The Yuruk (or *yürük*) are a Turkish speaking people in Anatolia whose distinct socio-cultural practices have been shaped by their (now largely abandoned) nomadic way of life.

"backwardness" and "rurality" among the social circle she started frequenting upon moving to Istanbul with her husband in the late 1970s.[6] During another interview, one of the women quoted at the beginning of this chapter, who also came from the Eastern Black Sea region, told me how kin marriage had been widely practiced among her family as well as many other families in the village where she had grown up but was decidedly not practiced by her current neighbours. Reflecting on their rejection of kin marriage, she remarked that these neighbours were probably Georgian (*Gürcü*) or Circassian (*Çerkez*), implying that their identity explained their marriage preferences.[7]

"Kin marriage" was consistently used in conversations like those conveyed above as a means to do draw distinctions between one's in-group and outsiders. However, the group-level at which a line of demarcation between "self" and "other" was drawn remained fluid and varied in character. At times speakers referred to their "family" in opposition to "other families" or to their "village" practices being different from those encountered in an urban environment. Thus, while considered perfectly normal and acceptable in one context, kin marriage practices could easily become a social misfit in other ones, marking those practicing it as stigmatized "outsiders". As Goffman has argued, stigma is not a given attribute but emerges within relationships; what is conceived of as a discrediting quality or marker of "undesired differentness" in one situation may not be so in another (Goffman 1968). The changing potency of kin marriage to act as a signifier of stigmatized "otherness" does thus not come as a surprise but is inherent in the discrepancies regarding its varying acceptability as a form of marriage making. Sometimes during conversations with participants the lines of differentiation drawn with reference to kin marriage assumed a clear ethnicist dimension reminiscent of the pattern narrated by Sirman or the women quoted above when kin marriage became framed as a cultural particularity decidedly (not) practiced by certain ethnic groups in Turkey. As I will discuss in

[6] Meryem (name has been changed), woman in her 50s who comes originally from a village in the Eastern Black Sea region of Turkey. She is married to her paternal aunt's son. The interview took place at the home where Meryem was working as a babysitter; I recruited her through my circle of personal acquaintances. Interview conducted in Turkish by author, 06 July 2017, Istanbul.

[7] Çiğdem (name has been changed), woman in her 60s who comes originally from a village in the Eastern Black Sea region of Turkey. She is married to her maternal uncle's son. The interview took place at Çiğdem's daughter-in-law's home; I recruited her through my circle of personal acquaintances. Interview conducted in Turkish by author, 08 June 2017, Istanbul.

the following, that "kin marriage" as a concept can be used to make such distinctions is not arbitrary but has to do with how it has historically emerged as a signifier of internal "otherness" vis-à-vis the imaginary of Turkish modernity.

Although kin marriage has continuously remained a legal practice in modern Turkey, it has historically sat uncomfortably with the alignment of nationhood, state and family, concisely captured by Sirman's above discussed concept of "familial citizenship". Contradicting the model of the nuclear family propagated by modernizing state representatives, kin marriage emerged as a divergent practice of family making, expressing unfulfilled modernity and "Oriental" backwardness. Building on Sirman, Can Açıksöz has remarked on how the propagation of the conjugal couple as a representative symbol of the new republic went hand in hand with a recasting of kin marriage as "a signifier of backwardness, ignorance, and the peasantry, the others of Turkish modernist imaginary" (Aciksoz 2012, 61). Turkish social science and medical publications often make use of such framings of kin marriage as a failure of modernity which exposes the lingering "tradionality" of parts of Turkey's population (Ayan et al. 2002, 2001, Aydoğan 1995, Başaran et al. 1988, Başaran 1973, Bilgel et al. 1991). Often these texts are guided by developmentalist paradigms approaching kin marriage as a social problem and measuring its validity as an indicator of low socio-economic standing, limited upward mobility, lacking education, female gender oppression and "traditional" family structures.

Significantly, as Açıksöz himself points out, the representation of kin marriage as a signifier of internal "otherness" has a certain ethnicist quality to it (Aciksoz 2012, 136, footnote xxv). "Kin marriage" not only denotes a sense of "non-modernity"; it is often, though not consistently, evoked in discursive ways which turn this alleged lack of modernity into an essential "cultural trait" of some parts of the population who thus become marked as internal "others" vis-à-vis Turkish modernity. Kin marriage thus emerges as a site of internal "otherness" through its intersection with the legacies of state formation, nation building and the construction of Turkishness. Due to a complex logic of inclusion and exclusion shaped by factors such as religion, ethnicity and perceived loyalty to the state, Turkish citizenship had

explicitly been extended following the foundation of the Republic to some former subjects of the Ottoman Empire such as the Kurdish population, Muslim migrants from the Balkans or parts of the Arab population living in Anatolia who were not "Turkish" in terms of ethnicity (Cagaptay 2006, Yeğen 2004). However, this inclusion hinged upon the subjectification of these new citizens to Turkification policies which rested on the denial of ethnic heterogeneity and the affirmation of "Turkishness" as the hegemonic and exclusive national identity (Turkyilmaz 2016, Yeğen 2007). Practices which ran counter to or aimed at resisting these Turkification attempts were recast by the government as expressions of "backwardness" and the inability to adapt to "modernity" (Yegen 2009, Yeğen 2007). Such framings represented "Turkishness" as the epitome of modernization while turning "non-modernity" into a placeholder for internal ethnic "otherness". Notwithstanding the early 21st century departure from the denial of Turkey's ethnic heterogeneity on part of the government, such ascriptions of "non-modernity" and "backwardness" continue to occupy a key strategic position in the increasingly ethnicized "otherization" of the Kurdish population today (Ergin 2014, Koğacıoğlu 2011). With regard to these legacies, it becomes apparent that "kin marriage" as a signifier of "non-modernity" easily slips into becoming a signifier for internal ethnic "otherness".

Transporting a sense of extended kinship networks and loyalties, kin marriage has been evoked alongside polygamy and "honour killings" as a signifier of the Kurdish population's essential "backwardness" and as proof of the Kurds' inability to emancipate from the pre-modern structures of their "tribal system" (*aşiret*) (Ergin 2014, Koğacıoğlu 2011). Here it is important to know that the *aşiret* system has been historically cast by Turkish nationalist discourse as a reactionary threat to the Republican project of modernity. Kurdish uprisings against state governance were thus strategically depoliticized as an expression of "tribal backwardness" and as a failure to adapt to the requirements of modernity (Ergin 2014, Yeğen 2007). Consequently, assimilationist policies employed by the Turkish state have targeted and sought to systematically disrupt Kurdish kinship networks which were seen as a potential source of danger to the hegemony of the emerging state (Turkyilmaz 2016, Ülker 2008, Yegen 2009). Once brought in association with the *aşiret* system, kin marriage thus suggests a disquieting

internal threat to the promise of Republican modernity. However, notwithstanding a strong association of kin marriage with Kurdishness, it would be wrong to argue that it is exclusively or consistently framed as an essentially "Kurdish" practice. For instance, kin marriage in Turkey has also been described as commonly being practiced among the country's Arab population, thus accounting for the significantly higher rates of kin marriage in the East and South East of Turkey (Altuntek 2001).

This argumentation has also found entry into genetic health campaigns and discourses which highlight the comparatively high rate of kin marriages among the Alawi population in Turkey, linking it with incidences of sickle cell anaemia and thalassemia, two inheritable blood disorders, among the community (Çiçeklioğlu et al. 2013, Tosun et al. 2006). Clinicians and epidemiologists involved in these campaigns which have sought to reduce the prevalence of these blood disorders through the expansion of systematic premarital carrier screening have been described by Kızılca Yürür and Laila Prager as referring to kin marriage practices as an "ignorant" and "backward" practice, blaming it as a major factor for the persistence of these diseases among Alawi families (Prager 2015, Yürür 2005). Both have critically remarked upon the stigmatizing effects of such framings which target an already socio-politically and economically marginalized group in Turkey (ibid.).

It is the paradox circumstance of kin marriage being variously evoked as a signifier of internal "otherness" as well as socio-cultural "normalcy" in Turkey which I refer to when speaking about the "ambiguous significations" of kin marriage. The biomedical reconceptualization of kin marriage as a health problem has not displaced existing legacies of contestation regarding kin marriage but rather added a new biogenetic quality and scientific authority to them as this thesis contends. Exploring the socio-political implications and biopolitical reverberations of this biomedicalization process, this thesis argues that Turkey constitutes a particularly rich context for such an exploration process due to the shifting and overlapping conceptualizations of kin marriage as a signifier of non-modernity, internal "otherness", and genetically risky reproduction as well as the ongoing processes of change

under AKP rule concerning the health sector, the state and the position of the family within the state.

Reproduction and Family Making as Sites of Political Intervention, Biomedical Risk Management and Technoscientific Enhancement

This thesis is situated within a theoretical terrain delineated by three main strands of scholarship that have explored reproduction, biomedical genetics and the rise of the so-called "new reproductive technologies" as sites of sociological enquiry. More specifically, it builds on (1) feminist scholarship politicizing reproduction, (2) STS and medical sociological scholarship concerning the growing salience of genetics and risk management within biomedicine, as well as (3) sociological and anthropological scholarship focusing on reproductive technologies both in terms of their transformative impacts and their potential to perpetuate existing forms of stratification and exclusion. The following discussion will introduce these strands of scholarship before focusing in detail on existent social science studies concerning genetic risk and kin marriage in the Middle East and outlining the contribution of this thesis to the existent literature.

The Politics of Reproduction

This thesis is in dialogue with feminist sociological and anthropological scholarship conceiving of reproduction and family making as a site of politics which belongs at "the centre of social theory" (Ginsburg and Rapp 1991). It builds on the insight that reproduction unfolds within an unequal and contested social terrain which is deeply "stratified" in character (Colen 1995, Ginsburg and Rapp 1995b). Physical and social reproductive tasks are differently accomplished, experienced, valorised, empowered or disempowered across differences of class, race, ethnicity, gender and other sites of inequalities, turning reproduction both into the outcome and driving factor of stratification. Thus, as Ginsburg and Rapp argue, analyses of reproductive technologies must not only focus on the technologies themselves but take into account the nexuses of power shaping reproduction and interrogate how the interests of states and other powerful institutions impact on reproductive relations in a given context (Ginsburg and Rapp 1995a, 5).

With state power hinging directly and indirectly upon "defining normative families and controlling populations" (Ginsburg and Rapp 1991, 314), women have been cast historically as "reproducing biologically, culturally, and symbolically their ethnic and national collectivities" (Yuval-Davis 1996, 17). Consequently, especially women's reproductive capacities have been harnessed to the realization of nationalist agendas and state programmes (Anagnost 1995, Das 1995, Kligman 1995) as nationalist projects "locate the site of political contest in women's wombs" (Kanaaneh 2002, 17). Nationalist myths and rhetorics have relied on the suggestive power of the "biological" as a signifier of what is deemed "natural". They are often couched in deeply gendered terminologies which co-naturalise women as the biological reproducers of the nation and the nation body as an organic entity (Bryant 2002, Delaney 1994). Highlighting how traditional family values, systems of gender, race, and the nation constitute intersecting systems of oppression, Patricia Collins points out how such co-naturalization of reproduction, nation formation and family making masks and perpetuates hierarchies and inequalities both within the family and the nation (Collins 1998a, b). States have historically sought to control family planning, fertility and reproduction differentially across the population and monitor motherhood in line with nationalist interests and racial anxieties which have translated into eugenics and eugenic attempts at forming the nation body through selective control and disciplinarization of female sexuality (Collins 1998b, 75, Davis 1982, Roberts 1999). Thus, the "right" to give birth to citizens has been unequally distributed and shaped by exclusionary regulations and migration restrictions which favour and encourage the reproductive agency of some groups as a "national interest" while pathologizing the reproduction of others as a "threat to the nation" (Roberts 1998, Stern 2005).

Significantly, intervention into reproduction and the control of fertility have not only unfolded within national but also transnational contexts shaped by imperialist interests, developmentalist sensibilities and global inequalities. Developmentalist programmes and international institutions have especially targeted the fertility of women in the Global South as a hindrance to economic growth and modernization, promoting population control under the relatively thin veil of "humanitarian concerns" (Connelly 2008, Morsy 1995). In the face of

such powerful national and transnational discursive practices identifying reproduction, fertility and family making as potent vehicles for securing and naturalizing political interests and sensibilities, women have not remained passive victims. Rather, as "pragmatic agents", they have engaged in strategies of circumnavigating, negotiating or resisting these interests (Greenhalgh 1994, Kaufert and O'Neil 1993, Lock and Kaufert 1997).

Biomedical Genetics, Risk Management and the "Molecularization" of Life

This thesis is in dialogue with another body of scholarship which explores the management of genetic disease, reproductive risk and the biopolitical management of life and life processes at the "molecular level" (Rose 2008). The rise of the "new genetics" has generated the category of those who find themselves "genetically at risk" and confronted with a new "genetic responsibility" which requires the adoption of "life strategies" and responsible choice-making to minimize these risks and optimise their futures (Rose 2001, Novas and Rose 2000). Such strategies of risk minimization and self-actualization link up with the late modern emphasis on the "autonomous self" as well as forms of "enterprising, responsible personhood" (ibid.). New subjectivities are formed through processes of genetic testing and counselling which may produce genetic information affecting a reconstruction of a person's past and future identity (Armstrong, Michie, and Marteau 1998) or initiating the emergence of new forms of "biosociality" (Rabinow 1992). A genetic diagnosis may entail significant "burdens of genealogy" (Konrad 2003) which implicate existent family members who might be sharing the same genetic risks as well as future offspring who become exposed to these risks via the transmission of genetic substance. As Kaja Finkler has argued, the identification of genetic susceptibilities leads to the "experience of a new vulnerability which draws healthy members of families into the biomedical realm" (Finkler 2000, 183). She sees this "drawing in" of the apparently healthy into the ever expanding scope of genetic risk and the search for "faulty" genes across the pedigree as giving rise to a new "geneticization" of kinship and family ties which become increasingly defined in terms of genetic inheritance and the transmission of genetic substance indicating certain susceptibilities and shared genetic risks (Finkler 2005).

Other scholars have been more sceptical regarding such rather sweeping arguments of "geneticization". For instance, based on ethnographic research among Welsh families facing genetic risk and disease, Kate Featherstone et al. have emphasized that everyday mundane beliefs about kinship and heredity are often under-determined by scientific understandings (Featherstone et al. 2006). The families in their study have not succumbed to a biological essentialism in their understandings of kinship and relatedness as a result of their contact with genetic medicine; rather, they have responded to and negotiated genetic risk information by assimilating it into established notions of kinship and relatedness (ibid., 150). Thus, they side with Carlos Novas and Nikolas Rose in arguing that genetic identity is "rarely hegemonic" but becomes located in a "complex field of a bewildering array of other identity claims and identificatory practices" (Novas and Rose 2000, 144, Featherstone et al. 2006, 144). Based on her ethnographic research in a UK dysmorphology clinic, Joanna Latimer has similarly sought to "trouble simple stories about the geneticization of medicine and life" (Latimer 2007b, 99). Describing the genetics clinic as a "space of deferral in which the genetic itself is performed very much still as open, and its categories as revisable" (Latimer 2013b, 203), she traces the often tentative and provisional rather than determinating or essentializing character of genetic diagnoses. Owing to the frontier character of clinical genetics as a discipline, the genetic basis (or genotype) of many conditions is far from given and self-evident but needs to be rendered evident or "see-able" through the accumulation and alignment of different forms of "evidence" (such as pedigrees, test results, scans, family photographs etc.) in clinical space (Latimer 2007a, b). Rather than juxtaposing "lay" and "expert" perspectives, Latimer demonstrates how the parents of children with (suspected) genetic conditions become actively involved in this diagnostic process, thus participating in the "epistemological processes of objectification" (Latimer 2007b, 109) through which classifications of genetic conditions are generated. Instead of declining and losing its significance vis-à-vis the laboratory in an era of "new genetics" and "molecularization", the clinic thus asserts its significance as a crucial interface between the lab and society. It constitutes the space where the genetic aspects of syndromes are made visible by

being located across different family members and therefore acts as a key site where genetic knowledge is both produced and becomes embedded within wider society (Latimer 2013b).

Whereas rare genetic conditions or those with an as yet unclear genotype offer limited opportunities for reproductive risk management, carrier screening programmes for some more common genetic conditions such as thalassemia, sickle cell anaemia or Tay-Sachs disease exist. Such testing schemes may be implemented at population level by health authorities under state supervision, as in the case of the well-documented premarital thalassemia screening in Cyprus (Hadjiminas 1994, Hoedemaekers and Ten Have 1998), or be located at community-level under the authority of social or religious institutions as the case of the Dor Yeshorim carrier matching programme among the Haredi in Israel illustrates (Raz and Vizner 2008). Family arrangement policies, gender inequalities and strategies for carrier information communication all influence the highly heterogeneous impact of such testing schemes on match-making and the social (non)stigmatization of affected individuals and carriers (Chattopadhyay 2006, Prainsack and Gil 2006, Raz 2010). Emphasizing the need for comparison across different local contexts, Barbara Prainsack and Siegal Gil have pointed out how the Dor Yeshorim screening programme does not rest on individualized responsibilization with regard to genetic risk; rather than generating a new kind of individualized genetic selfhood, it conceives of risk as a matter of "genetic jointness" between potential spouses who are revealed to be either genetically "compatible" or "incompatible" (Prainsack and Gil 2006). Such a communication of risk in terms of (in)compatible "genetic couplehood" deflects the effects of stigmatization associated with individual carrier status (ibid.). If the delineation of "genetic communities" (Raz 2010) found to be "genetically at risk" overlaps with the lines along which race and ethnicity are constructed, it may add a new genetic "quality" and sense of genetic vulnerability to the identity of certain ethnic and/or religious communities (Raz and Atar 2004, Raz 2010) and contribute to the racializing as well as stigmatizing of those same groups through practices of surveillance and exclusion (Duster 2003, Tapper 1999, Wailoo and Pemberton 2008).

Overall, scholars working on genetic disease, reproductive risk and the shift of bio politics to the molecular level have contributed to a more complex understanding of how the

growing salience of genetics within medicine and the life sciences has far from entailed a turn to fatalist determination and genetic essentialism; rather, it has generated new ambiguities and uncertainties, offered up new spaces of intervention and regulation which vary greatly according across different national and social contexts, and elicited highly heterogeneous responses to and negotiations of biogenetic information on part of those classified as being at risk. At the same time, they have shown how the rise of the so-called "new genetics" has not necessarily displaced established ideas about relatedness, kinship and inheritance and how it has not only transformed but also often perpetuated existing legacies of stratification, surveillance and stigmatization.

New Technologies and Old Constraints: the Rise and Routinization of New Reproductive Technologies

Both the management and the experience of reproduction and family making have undergone significant change since the late 20th century due to the rise and expansion of the so-called "new reproductive technologies" which make use of technoscientific innovation to not only exercise control and surveillance over reproductive processes but also transform them, giving rise to new conceptualizations of selfhood, kinship, family and community. At the same time, old socio-political constraints and biases continue despite these transformations. Existent lines of stratification, exclusion and marginalization are often perpetuated, enhanced and cast into sharper relief rather than abolished by the spread of these new technologies. This thesis is theoretically greatly indebted to scholarship exploring these unfolding dynamics.

Technoscientific innovation over the last decades has been directed both at facilitating reproduction and at rendering it more selective. Assisted reproductive technologies (ARTs) have elicited much interest from feminist STS scholars who have approached these technologies as a site for problematizing the nature-culture-opposition. Building on David Schneider's work on "American kinship" (Schneider 1980, Schneider 1984), Marylin Strathern has famously argued that nature can no longer function as a grounding for culture in an age of assisted reproduction. With technology and medicine assisting "the natural facts of procreation" while "the social facts of kin recognition" now require assistance via legislation, kinship as "the social construction of

natural facts" becomes itself destabilized (Strathern 1995, 1992). The very meaning of what constitutes a "natural fact" undergoes transformation when intervening technology becomes conceptualized as giving nature a "helping hand" (Franklin 1997, 1995). As the kinship patterns emerging out of ART clinics can no longer be accommodated by the modern nature-culture-divide, future parents, donors and clinicians engage in co-existent processes of strategic socialization and naturalization to achieve a disambiguation and stabilization of these kinship patterns (Thompson 2005, 2001).

Technoscientific transformations of medicine and reproductive health services have also rendered reproduction more selective in character, offering ever more refined possibilities to screen for and detect "abnormalities" at the molecular and genetic level. The routinization of prenatal screening methods such as ultrasound, amniocentesis and chorionic villus sampling throughout the 1980s to early 2000s as well as the more recent rise of non-invasive blood tests, all designed to detect genetic conditions at the prenatal stage, have transformed the experience of pregnancy (Rothman 1988) and reshaped the woman-foetus-relationship (Ivry 2009, Petchesky 1987, Taylor 2000, 2008). The expansion of these technologies has been driven by a language of choice and reassurance which downplays their selective potential and masks how the exercise of choice creates the moral obligation to choose what is considered socially acceptable and normative (Lippman 1991, Browner and Press 1995). As "moral pioneers" (Rapp 1999), women have come to navigate newly emerging ethical terrains which are however deeply informed by existing legacies of stratification that impact on and delineate their processes of decision-making. Significantly, the routinization of "selective reproductive technologies" (Gammeltoft and Wahlberg 2014) does not unfold as an even process. Not all women engage in "moral pioneering"; some refuse to be tested, thus expressing their understanding of responsible parenthood by "choosing not to choose", as Susan Kelly's research among women in less privileged, rural areas of the US has shown (Kelly 2009). Neither do all women experience reproductive decision-making necessarily as a process of individualized responsibilization; rather, in deciding on their reproductive futures they may act as moral members of their respective communities, engaging with genealogical, spiritual and national

responsibilities as Tine Gammeltoft has argued with regard to women in Vietnam (Gammeltoft 2007, Gammeltoft 2014).

Recent years have furthermore seen the rise and routinization of preimplantation genetic diagnosis (PGD) which makes use of IVF technology to test embryos for specific genetic conditions prior to implantation. While PGD allows for the avoidance of pregnancy termination, its use is nevertheless fraught with (bio)ethical and political questions – specifically with regard to the creation of so-called "saviour siblings" (Hashiloni-Dolev and Shkedi 2007) - and dilemmas due to the essentially selective nature of this technology. However, as Sarah Franklin and Celia Roberts have shown in one of the first ethnographic studies of PGD, public perceptions and media discourses of PGD "designer babies" stand in stark contrast to the harrowing and difficult experiences of couples who opt for PGD following the loss of a child due to genetic disease. These couples often feel driven by "a painful and expensive sense of obligation to act responsibly" to minimize future children's suffering (Franklin and Roberts 2006, 18).

The selective nature of prenatal and preconceptional screening technologies has generated a debate as to whether or not these technologies mark a "return" to eugenics. "Eugenics" constitutes a loaded and ambiguous concept (Raz 2010, 3). Coined by Francis Galton to describe "the science which deals with all influences that improve the inborn qualities of a race" (Galton 1909, 35, cited after, Raz 2010, 6), it is now often referred to by scientists as expressing the idea of "improving the gene pool of a population" by means of genetic enhancement or selective reproduction preventing the birth of offspring deemed undesirable (Raz 2010, 3). With the expansion of reproductive genetics over recent decades, there has been a shift in the perception of eugenics as linking up with "liberal and utopian" rather than "authoritarian and dystopian" agendas, pointing to an increasing social and moral acceptability of eugenics as a means to reduce suffering and enhance individual freedom (ibid., 1, 3). In light of these debates, Nikolas Rose has emphasized the transformative and unprecedented character of technoscientific interventions which drive the "molecularization" of life (Rose 2008, 2001). He argues that the current biopolitical management of life is marked by a "new will to health"

which sees state intervention give way to new modes of individualized self-management of health and illness. The "relation between the biological life of the individual and the well-being of the collective", he contends, no longer rests on the identification and elimination of those deemed defective "in the name of overall fitness of the population, nation, or race"; rather, "it consists in a variety of strategies that try to identify, treat, manage or administer those individuals, groups or localities where risk is seen to be high" (Rose 2001, 7). According to Rose, what is at stake in light of these shifts is not a "return" to the eugenics of the past but rather a biopolitical paradigm shift regarding the management of life and life processes.

Other scholars have in contrast stressed what they perceive to be tendencies of continuation and troubling parallels with eugenic sensibilities which they fear are being reintroduced "through the backdoor" (Duster 2003) via genetics and genetic technologies. Anne Kerr has argued that the fascination with the "new-ness" of current genetic technologies masks continuities with or links with the past and its history of eugenics and genetics and she has criticized Rose's emphasis on the transformative aspects of these technologies to be eschewing comparisons with the past (Kerr 2004, 4-5). Although selective reproductive technologies are not homogenously condemned by disability activists as for instance in the context of Israel (Raz 2004), disability scholars have pointed out how selective reproductive technologies perpetuate the "long and unsettling history of discrimination against people with disabilities" (Gammeltoft and Wahlberg 2014, 5). They have argued that these technologies contribute to the medicalization, devaluation and marginalization of people with disabilities (Kaplan 1994, Parens and Asch 2000, Shakespeare 1995, 1998, 2005). Capturing the complex interplay of individualized choice, commercialization, socio-political constraints and eugenic legacies, Taussig, Rapp and Heath have coined the term "flexible eugenics". While the proliferation of old and new technologies offer new choices concerning the modification of biological qualities and assets, these technologies nevertheless exert a strong push towards genetic normalization in how they become employed within contexts marked by long-standing bias against "atypical bodies" (Taussig, Rapp, and Heath 2005).

Dorothy Roberts in turn has made a strong case in highlighting how even the so-called "assisted reproductive technologies" are highly selective in character, embedded as they are within structures of racial inequality (Roberts 1999). The marketing, accessibility and use of these technologies in the US intersect with eugenic legacies. They reflect the devaluation of black women's reproduction, which is seen as problematic and in need of fertility control and regulation through welfare policy, contrasting with the great value placed on white women's reproduction whose infertility becomes channelled towards high-tech intervention and treatment (ibid.). The transnational economy of surrogacy services and arrangements similarly reveals how the infrastructures of assisted reproduction are marked by and generative of racial stratification which privileges white reproductive desires and needs (Dasgupta and Dasgupta 2015, Vora 2012, 2010).

"Fertile Ground": Reproductive Technologies in the Middle East and Turkey

Reflecting the initial socio-geographical expansion of new reproductive technologies and genetic health services, the majority of existing research has focused on the US and Western Europe in exploring the social dimensions and political implications of these technologies. However, scholarship has increasingly responded to the need for further comparative analyses and shifted the focus to other national contexts, often following particular technologies in certain contexts. This expansion of scholarly interest has generated prolific research on assisted reproduction in Israel (Birenbaum-Carmeli and Carmeli 2010, Hashiloni-Dolev and Weiner 2008, Hashiloni-Dolev and Shkedi 2007, Kahn 2000, Teman 2003, Vertommen 2016), surrogacy arrangements in India (Vora 2013, 2012, 2010, 2009), or assisted and selective reproductive technologies in Asian countries such as Vietnam (Gammeltoft and Nguyen 2007, Gammeltoft 2014), Japan (Ivry 2006, Lock 1994) or China (Wahlberg 2018, 2016) . These studies make evident the necessity to contextualise the routinization of these technologies and people's varying responses in relation to respective "local moral worlds" (Kleinman 1997) as well as changing national health care systems. The Middle East and Turkey have emerged as "fertile ground" (Thompson 2002) for scholars seeking to explore and think through the socio-political implications of reproductive technologies and genetic health services, especially with

regard to their intersections with local religious norms, kinship practices and legal-governmental structures.

Marcia Inhorn has conducted pioneering research on infertility, reproductive technologies and family making practices in the Muslim Arab world. Her research looks at how religious practices, gender norms and state regulations in different Arab countries intersect with the expanding sector of new reproductive services, knowledges and technologies, together forming a complex assemblage or "reproscape" which is "traversed by global flows of reproductive actors, technologies, body parts, money, and reproductive imaginaries" (Inhorn 2011b, 90). Following on from her earlier ethnographic work on technoscientifically mediated infertility management in Egypt (Inhorn 2003a, b), Inhorn has devoted much scholarly effort, often in fruitful collaboration with other scholars working on reproduction and technoscience in the Middle East, to exploring the heterogeneity of Islamic bioethical and legal responses to new reproductive technologies across the Sunni-Shi'i divide as well as across state boundaries (Inhorn 2011a, Inhorn et al. 2017). Her work contributes to the significant insight that there are no uniform socio-cultural as well as legal responses to the introduction of new technologies. Religious norms and practices rather than strong state intervention have emerged as the primary regulatory frameworks regarding the regulation of technoscientifically mediated (in)fertility, donation practices and third-party involvement in many Middle Eastern states. This has given rise to different trajectories of restrictions and permissions which in turn have engendered a lively reproductive tourism (Inhorn 2011b) as well as varying bioethical implications and challenges for kinship reckoning (Inhorn and Tremayne 2016, Inhorn et al. 2017). Inhorn furthermore sets the expansion of reproductive technologies in the Arab world in relation to what she terms new "emergent masculinities" (Inhorn 2012) and changing family ideals (Inhorn 2018) which hinge upon a transition to the small, nuclear family and a pronounced commitment to the notion of conjugal love and commitment. By tracing this changing family model with its orientation towards fewer children, Inhorn's work speaks to Rhoda Ann Kanaaneh's significant work on changing reproductive ideals among Palestinians (Kanaaneh 2002).

Complementing Inhorn's work on the intersection of technoscience and Islamic practices, Morgan Clarke has explored the expansion of reproductive technologies in Lebanon, focusing particularly on legal responses to these technologies as well as their impact on socio-legal conceptualizations of kinship (Clarke 2009). He cautions against Eurocentric or Western-centric assumptions of how "natural" or "biological" kinship is conceptualized, arguing that local kinship notions only map partially onto bioscientific ones. Understandings of "closeness", "milk kinship" or "legitimate descent" which are crucial to Islamic regulations of kinship are difficult to accommodate within concepts of biogenetic relatedness but have profound impact on how reproductive technologies are regulated, rendered (in)accessible or stigmatized in Lebanon (Clarke 2007a, b). He also challenges the assumption that anxieties and legal concerns regarding reproductive technologies travel evenly, arguing that in contrast to predominantly Western concerns coalescing around the mixture of substances and the propriety of gametes, questions of maintaining sexual propriety or securing the "purity" of the kin group have a more decisive impact on the regulation of these technologies in Lebanon (Clarke 2008). Like Inhorn, his work details the highly heterogeneous approaches to reproductive technologies across and within various religious communities, thus refuting notions of a monolithic Islamic response.

Being home to a rapidly expanding infrastructure of selective reproductive technologies turning prenatal screening into an increasingly routinized pregnancy ritual (Aciksoz 2012) and harbouring one of the largest IVF sectors in the world (Gürtin 2016), Turkey has emerged as another significant site of scholarly interest, with studies exploring the management and experience of (in)fertility (Mutlu 2011, Göknar 2015, Göçmen and Kılıç 2018, Gürtin 2012b, Kılıç and Göçmen 2018) as well as sex selection in the context of assisted reproduction (Mutlu 2017, 2015). Situating assisted reproductive technologies in Turkey within the context of governmental reproductive policies and ideologies, Zeynep Gürtin has traced how these technologies unfold within a governmental environment of "patriarchal pronatalism" which secures the reproduction of the heteronormative, married family (Gürtin 2016). While not being "shrouded in secrecy, angst and shame", IVF technologies in Turkey are legally regulated in ways which treat the conjugal couple as "legally central and clinically indispensable" to the

process of assisted reproduction (Gürtin 2011). The protection of conservative, heteronormative family values thus achieved is further enhanced by the banning of third-party reproductive assistance both in Turkey and since 2010 also abroad for Turkish citizens. However, these legal restrictions mirror neither the heterogeneity of lay attitudes towards third-party donation in Turkey, nor the existing demand for such services (ibid.).

The Medicalization of Kin Marriage as an Emergent Site of Research

A subsection of the scholarship on reproductive technologies and genetic health services in the Middle East and Turkey addresses the issue of kin marriage or consanguinity as an emergent (public) health concern. Both Inhorn and Clarke reflect on the prevalent practice of cousin marriages as part of their wider interest in assisted reproduction, kinship and family making in the Arab world without placing the issue at the centre of their research agendas. Inhorn discusses these marriage forms in relation to changing marriage practices among young Arab couples who increasingly eschew arranged marriages (Inhorn 2012). She also highlights the significance of consanguineous marriage patterns as a factor contributing to infertility incidences in Arab societies which feed the demand for assisted reproductive technologies (ibid.). Clarke in contrast reflects on the socio-medical implications of "closeness" in marriage which continues to be a "key social strategy" regarding family making while having become "medically suspect" in recent times (Clarke 2007a). He describes cousin marriages as a site of ambivalence and "cultural intimacy" (Herzfeld 1997) which constitutes a source of public "embarrassment" due to its association with "backwardness" and "traditionality" while being valorised as a socio-culturally preferred form of marriage which enhances the "closeness" of the family and kinship relations. As he points out, the growing awareness of the medical implications of cousin marriage among the Lebanese public has not rendered the practice redundant. Rather, it has led to genetic counselling becoming a standard practice for couples undertaking such a marriage who, like all couples planning marriage, are also required to undergo mandatory premarital health checks for some genetic diseases such as thalassemia (Clarke 2007a, 388-390). While Clarke's observations are highly fascinating, they do not constitute the central concern of his article and are not explored in detail. Thus, questions are

left open concerning the apparently smooth acceptance of biomedical discourse and risk management practices among Lebanese society as well as about the intersection of medicalization and existing legacies of stigmatization of cousin marriage.

Few studies exist which are centrally concerned with the medical management of kin marriages from a social science perspective. Substantive work has been done by Alison Shaw and Aviad Raz. Shaw has conducted extensive ethnographic research on genetic risk and cousin marriage among British Pakistani families (Shaw and Hurst 2009, Shaw 2009, 2011). Although her work is situated within the UK context, it has influenced scholars working on similar questions in the Middle East. Shaw criticizes stereotypical depictions of kin marriage and exaggerated accounts of cousin-marriage-induced medical harm in the British public media and foregrounds the complex socio-cultural significance of these marriage patterns (Shaw 2006, 2009). Refuting notions of "religious fatalism", she traces through her ethnographic work based on counselling observations and interviews with couples the heterogeneity of British Pakistani couples' responses to and adoptions of genetic risk management (Shaw and Hurst 2009, Shaw 2009). She argues that couples' active engagement with as well as their resistances to medico-scientific definitions of genetic risk are culturally mediated, drawing on established lay and religious notions of inheritance, disability and illness among British Pakistani families.

Significantly, Shaw points out how genetic risk may be only one among many concerns which have to be taken into account and counter-balanced as couples seek to build a family in a (post)migratory environment in which they often face hostility and stigmatization for their marriage choices. Drawing on Mary Douglas' insight that risk perception is socially shaped, Shaw thus highlights how the condemnation of kin marriage in the British public and its singling out as a particularly problematic practice of "risky behaviour" is intrinsically linked to the wider socio-political marginalization of British Pakistani families within the UK (Shaw 2009, 4-5). She contemplates that these dynamics may play out differently in countries where cousin marriage is commonly practiced such as in Pakistan or in the Middle East (ibid.). As this thesis will suggest, a complex dynamic of intersecting medicalization and stigmatization may also unfold in societies where kin marriage constitutes a socially common practice, exactly

because these societies, like all societies, are marked by their own trajectories of internal stratification, marginalization and exclusion which impact on how risks are made (in)visible.

Aviad Raz's ethnographic and interview-based work on cousin marriage and genetic risk shifts the focus to Israel, concentrating specifically on the implementation of a carrier screening programme among the Bedouin of Negev (Raz and Atar 2005, Raz 2005, Raz 2010). Targeting certain prevalent genetic conditions among the community, such as congenital deafness, which are associated with the community's high rate of cousin marriage, this screening programme has been initiated by the Israeli health authorities in the late 1990s to promote "healthy consanguinity". Somewhat reproducing oversimplified juxtapositions of "modern" Western science and "traditional" belief systems, Raz directs his interest at how the contact between biomedical discursive practices and lay Bedouin notions of heredity, illness and disease gives rise to emerging processes of hybridization of local beliefs and biomedical genetic knowledge. He states that "traditional communities are not passively modernized" (Raz 2010, 109), but rather actively participate in and negotiate the biomedical screening programme, sometimes conforming to it as envisaged by the programme initiators, sometimes rejecting it and sometimes using the programme for their own agendas in ways which contradict the programme's rationale (ibid., 109).

Other scholars have taken up this interest in biomedical reconceptualizations of cousin marriage or kin marriage, focusing on a variety of contexts. They concentrate mainly on Arab countries, namely Qatar (Kilshaw, Al Raisi, and Alshaban 2015, Kilshaw 2018), Saudi Arabia (Panter-Brick 1991) and the United Arab Emirates (Parkhurst 2014). Reminiscent of Shaw's and Raz's approaches, these studies foreground what they frame as discrepancies and negotiations between biomedical conceptualizations of genetic risk on the one hand and established local ideas about kinship, disease, inheritance and disability on the other hand. Focusing on South Eastern Turkey, Leila Prager (Prager 2015, 2010) and Kızılca Yürür (Yürür 2005) adopt a similar approach which contrasts "Western" biomedicine with local conceptualizations of kinship, disease, and illness management. They explore how members of the Alawi community, a religious and ethnic minority in Turkey among whose members kin

marriages are frequently practiced, respond to the medicalization of kin marriage as a risk factor for the prevalent inheritable blood disorders thalassemia and sickle cell anaemia by adopting risk explanation and management strategies with do not necessarily conform to biomedical discourse. Significantly, their work draws attention to the political implications of the medicalization of kin marriage and blood disorders by highlighting how governmental policies and health campaigns regarding kin marriage, thalassemia and sickle cell anaemia in South Eastern Turkey have had particularly stigmatizing effects for the Alawi community.

Thesis Contribution and Outline

Thesis Contribution

Exploring the biomedical reconceptualization of kin marriage in Turkey, this thesis brings into dialogue multiple strands of scholarship, namely the literatures on (1) biomedicalization, (2) reproductive and genetic technologies, and (3) the state, reproduction and family in Turkey. It thus contributes to the sparse scholarship on (bio)medicalization processes of kin marriage or cousin marriage, enrichens the debate about the family and the state in Turkey by tracing how the management of "healthy" families has assumed a new genetic quality, and broadens the scope of biomedicalization as a concept of transnational significance by following the unfolding of biomedicalization processes in Turkey.

As the discussion of scholarship on reproductive technologies and genetics in the Middle East and Turkey has revealed, few studies exist which focus on the emergence of kin marriage as a reproductive health concern from a social science perspective. This thesis does not simply seek to add another case story to the existent literature. It rather offers not only an empirical and but also a qualitative contribution by adopting an approach which largely departs from existent studies' predominant focus on what are framed as discrepancies or tensions between the global biomedical discourse of inheritance and genetic risk on the one hand and "local" or "traditional" beliefs about relatedness, heredity and illness on the other. Instead, it foregrounds the biopolitical dimensions of the incorporation of kin marriage into medico-genetic infrastructures by bringing in the question of state governance and asking how the

family, the health sector and the state come together when consanguinity becomes attached to genetic risk. Thus, the thesis does not restrict the focus to the interface between the biomedical realm, specifically the field of reproductive health care, and the family, but extends it by asking how this encounter between the family and the clinic is shaped by the processes of biopolitical state governance targeting the family as a key social institution.

This thesis furthermore stands in dialogue with the earlier discussed rich body of scholarship which has politicized the family and reproduction as primary areas of state intervention upon which the realization of changing agendas of socio-political transformation has hinged in Turkey. As detailed, a fascinating and growing body of research on technoscientific transformations of family making and reproduction in Turkey has emerged within this larger field of scholarship. In contrast to these studies which have predominantly focused on new reproductive technologies, this thesis primarily directs its attention to the far less studied issue of genetic risk management in Turkey, arguing that the governance of "healthy" family making and reproduction in contemporary Turkey is taking a genetic turn which has not displaced state intervention but rendered it more sublime through an emphasis on individualized responsibilization, voluntary enrolment and choice.

Finally, approaching the biomedical reconceptualization of kin marriage as a process of biomedicalization unfolding in Turkey, this thesis departs from the largely US American focus of biomedicalization scholarship. It thus traces how biomedicalization extends beyond the US while intersecting with local trajectories of state governance and biopolitical family making as well as local significations of biomedicine as a vehicle of modernization and Westernization. It furthermore contributes to the insight that biomedicalization unfolds as a partial and uneven process as the biomedical reconceptualization of kin marriage encompasses resistances and push-backs against the attachment of kin marriage and genetic risk. Significantly, this thesis also argues that biomedicalization does not necessarily entail a shift towards (partial) de-stigmatization as often observed by work on (bio)medicalization (Boreo 2010, Clarke et al. 2003, Conrad and Schneider 1992). Rather than "neutralizing" or "normalizing" the contested

character of kin marriage, biomedicalization has perpetuated and invested with a new scientific authority the stigmatization of these marriage practices.

Thesis Outline

The remaining chapters of this thesis are structured as follows. The second chapter offers a methodological framing of this thesis. It outlines the landscape of genetic health services in Turkey and especially Istanbul, clarifying how kin marriage is positioned within this landscape. Detailing the methodological pathways I adopted to manoeuvre through this landscape, this chapter furthermore reflects on the ethical challenges and implications of this research as well as my positionality within the field as a researcher affiliated with a Western university who entered Turkey during a period of increased political instability.

The third chapter approaches the biomedicalization of kin marriage by tracing the question of how kin marriage and genetic risk have become incorporated into public health infrastructures and government supervised public health policies. It explores the changing regulations regarding the mandatory requirement of premarital health examinations in Turkey by tracing how genetic risk, consanguinity and genetic carrier screening for the blood disorders thalassemia and sickle cell anaemia have emerged as intrinsic elements of the examination procedure at the turn of the 21st century. Foregrounding how notions of "genetic risk" and "genetic quality" constitute significant axes of stratification shaping the "selective" nature of the government's pronatalist discursive practices, it traces how these practices perpetuate a long-standing systematic devaluation of bodies deemed a threat to the "quality" of the population and "health" of the nation.

The fourth chapter explores the coming together of genetic risk, kin relatedness, family making, moral blaming and the significations of kin marriage as a socio-politically contested practice in Turkey by exploring first geneticists' and second couples' engagements with the question of "closeness" becoming a "risk" in terms of reproduction. It traces how medico-genetic professionals and families in their conceptualizations of the relation between kin marriage and genetic risk variously foregrounded or downplayed what they considered to be the biogenetic or social aspects of kin marriage. While geneticists' pushed for a "geneticization"

(Lippman 1991) of kin marriage, presenting it as a primarily biogenetic problem requiring technical intervention through genetic health services, this geneticization of kin marriage remained partial and incomplete. Moments of "non-geneticization" repeatedly emerged in the clinical realm, brought about by geneticists' own discursive practices, families' pushbacks against biomedical attachments of risk and biogenetic relatedness, as well as infrastructural constraints regulating what kind of families did (not) have access to genetic health services. Building on the insight of Clarke et al. that biomedicalization constitutes a site of contestations and resistances (Clarke et al. 2003, 166), this chapter discusses families' push-backs against biogenetic framings of their marriage choices as "risky" and contextualizes these push-backs with regard to families' concerns about stigmatization and blaming.

The fifth and final substantive chapter has a closer look at how reproductive risk, kin marriage and genetic disease become managed within medico-genetic space. It unpacks how kin marriage occupies an ambiguous position within medico-genetic space. On the one hand, it is conceived of as constituting a threat to healthy reproduction which renders difficult medico-genetic professionals' efforts to facilitate healthy family making. On the other hand, kin marriage simultaneously emerges as a valuable research resource offering highly cherished opportunities for ground-breaking genetic research. This chapter traces how medico-genetic professionals seek to facilitate what they consider to be "healthy reproduction" by channelling families towards the prevention of the birth of children with genetic conditions while detaching their professional practices from the troubling spectre of eugenics. These detachments are affected through an emphasis on the alleviation of suffering as well as the promotion of individual choice. While this recourse to the language of reproductive choice and rights allows the geneticists to position themselves in critical antagonism vis-à-vis the government and its repressive reproductive policies, it easily obscures convergences in medico-genetic and governmental discursive practices. This chapter explores these convergences. It discusses how the individualizing language of reproductive choice and responsibility resonates strongly with governmental modes of privatizing and individualizing care responsibilities. It furthermore traces how the language of reproductive choice is undergirded by the perpetuation of eugenic

and ableist sensibilities, finding expression across the realms of state and society, which frame genetic disease as a burden and threat to the state and society. Finally, returning to the question of kin marriage and its ambiguous positionality within medico-genetic space, this chapter unpacks how kin marriage helps expand the very frontiers of genetic knowledge production which it simultaneously exposes by eschewing complete risk management. This expansion of genetic knowledge and the pushing back of the unknown is marked, as this chapter argues, by a noticeable continuation in the way how governmental and technoscientific infrastructures mutually depend on and extend each other as newly emerging technoscientific spaces and practices become infused with governmental sensibilities and interests which coalesce around the management of genetic disease and healthy family making.

The chapters of this thesis thus present a narrative about the biomedicalization of kin marriage in Turkey which sets out with methodological and ethical reflections, moves on to a delineation of the historical dimensions of the infrastructural anchoring of this biomedicalization process within Turkey's health care landscape and finally explores how its discursive practices unfold within medico-genetic space. Together, these chapters illustrate how a historically grounded co-production of governmental and biomedical infrastructures which place biopolitically heathy families at the heart of the nation become extended into the 21st century through newly emergent genetic technologies and health services which relocate the (self)management of healthy subjects to the genetic level.

Chapter Two: Researching Kin Marriage in Medico-Genetic Space in Turkey/Istanbul

This thesis is based on one year of fieldwork in Istanbul between September 2016 and August 2017 for which I had obtained ethical approval from the LSE Ethics Committee. Various considerations influenced me in my choice of Istanbul as the main field site. Previous prolonged stays in Istanbul for education and work purposes had rendered me familiar with the city as a site and had allowed me to establish academic and personal networks. Furthermore, sociological studies on kin marriage in Turkey exploring biomedical and lay discourses on consanguinity as "risky" have mainly concentrated on rural areas or on the Southern Mediterranean region around the cities of Adana, Mersin and Hatay (Prager 2015, Yürür 2005). Shifting my focus to Istanbul thus enhanced the contributory value of my work. Characterized by a great number of both private and public hospitals and universities, Istanbul has a highly diverse and stratified health sector. As I will discuss in more detail in this chapter, it has played a pioneering role regarding the introduction of reproductive genetic health services in Turkey and continues to be one of the primary areas in Turkey experiencing a rapid proliferation and commercialization of these services. The diversity of Istanbul's genetic health sector thus promised the possibility of contacting many different professionals working across the public-private divide in the fields of reproductive health and genetics while offering multiple starting points for getting access. This was of crucial importance seeing the volatile situation in Turkey during my stay which required me to think about alternative options in case of closing doors. As a result of its particular location and history and due to several decades of inner Turkish migration, Istanbul today has a highly diverse population which mirrors the complexity and diversity of Turkey's population as a whole. Furthermore, kin marriage is comparatively frequent in Istanbul with a rate of 20% (TUIK 2016) which is relatively close to the national average. Taken together, the diversity of Istanbul's population, the diversity of its health sector and the relative commonness of kin marriage in the area rendered Istanbul a promising site to grasp the socio-political contestations over kin marriage in relation to its increasing biomedicalization.

Moving through the landscape of genetic health care in Istanbul, I encountered a highly stratified and heterogeneous sector of health care provision. Interviewing medico-genetic professionals throughout Istanbul and spending considerable time within a public genetics clinic, I constantly crisscrossed the boundary dividing public and private health care institutions in Turkey, thus manoeuvring through very different clinical environments. These environments spanned the range from exclusive, private hospitals emanating an air of luxury to public health care settings marked by naked functionality which often highlighted rather than hid the run-down character of the facilities. I remember once whiling away my time in a very prestigious private hospital, waiting for an interview while sitting down in one of the mostly unoccupied plush sofas in a softly illuminated waiting room which sported state-of-the-art interior design and a piano player offering live entertainment. Later that same week, I found myself in a public hospital's packed and noisy waiting room where people ran to and fro contributing to the hectic atmosphere of the space within which I had difficulty finding a spare uncomfortable chair to sit down. While these two experiences formed a particularly stark contrast, they do give an idea of the profound inequalities involved in how health care services can be accessed in urban Turkey.

This chapter seeks to map out the landscape of genetic health services in Turkey while discussing and reflecting on the terms of engaging in social science research within and through this landscape. The first part of this chapter starts from a discussion of how the sector of genetic health services has emerged and unfolded in Turkey, before then detailing how kin marriage is conceptualized within the medico-genetic realm as a reproductive risk factor requiring supervision through genetic health services. The realm of medico-genetic space in Turkey is subjectively evoked throughout this thesis as it emerges from my relational encounters with it. Consequently, any descriptive framing of this space needs to take into consideration the methodological pathways I adopted to navigate through it as well as the ethical implications of these methodological choices. Thus, the second part of this chapter concentrates in detail upon the main methodological pathways which I chose to move through medico-genetic space in Turkey. It discusses in detail data collection which consisted of (a.) 19 qualitative semi-structured interviews with medico-genetic professionals working in the fields of genetics and

family health, (b.) 18 qualitative semi-structured interviews with individual persons or couples practising kin marriage both within and outside of the clinical realm, (c.) observations during my two-and-a-half months stay at a public hospital's genetics clinic, and (d.) a textual analysis of state issued documents on kin marriage, family making, and reproductive health. This chapter problematizes my role and identity as a researcher, who enters Turkey's health care landscape while being affiliated with a powerful Western academic institution, and explores how this identity impacted upon my relation with medico-genetic professionals, complicating my desire to "study up". It furthermore describes the particularities of the genetics clinic I stayed in, highlighting the temporal, spatial and ethical constraints which delineated the boundaries of what kind of data I could and would collect as a simultaneous "insider" and "outsider" within clinical space. Finally, it details how I analysed and "read" across the heterogeneous data streams which I had gathered while moving along my adopted pathways through medico-genetic space in Turkey.

The Landscape of Reproductive Genetic Health Services in Turkey

The landscape of reproductive genetic health services in Turkey presents itself both as a comparatively recent and rapidly expanding, dynamic field. Given the highly politicized nature of reproductive health care, the emergence and unfolding of this landscape has not only been informed by profound technoscientific innovation leading to the introduction of ever more refined technologies for the management of reproduction and genetic risk. It has also been shaped by shifts in biopolitical government policies targeting the population and its reproductive capacities. Following on from the decidedly pronatalist stance of the early years of the Turkish Republic, which had been characterized by a great emphasis on a need for population growth in the aftermath of the devastating effects of the years of war and displacement characterizing the Turkish struggle for independence, the period of the 1960s to 1980s marked the emergence of concepts of "family planning" (*aile planlaması*) and "population planning" (*nüfus planlaması*) on the political agenda of the state (Gürsoy 1996, Günal 2008, 229-230). Fuelled by global developmentalist discourse, the Turkish government turned to embracing antinatalist population planning strategies with the passing of the 1965 Law

on Population Planning which advocated population control as a means for economic growth and political stability (Altıok 2013, 49). Within this context of antinatalist government sensibilities, abortion regulations underwent a major change in the early 1980s. Prior to 1983, abortion had been banned as an illegal practice except in cases when it was deemed medically necessary to protect the mother's life or prevent the birth of a severely disabled child as stated by the 1965 Law on Population Planning (Official Gazette no. 11976). The passing of the 1983 Law on Population Planning (Official Gazette no. 18059a) introduced a significant change by rendering abortion legal independently of any existing medical preconditions until the 10th week of pregnancy, requiring married women to present documentation regarding their husbands' consent. Pregnancy terminations beyond the 10th week continued to be permissible in case the child was diagnosed with a "severe invalidity/disability" (*ağır maluliyet*)[8] or the pregnancy constituted a life threatening situation for the pregnant woman (Official Gazette no. 18059a; Official Gazette no. 18255). These regulations are in place until today, delineating legal boundaries within which the expansion and consumption of reproductive genetic health services unfolds.

The legalization of abortion constituted a major policy shift which contributed to levelling the path for the expansion of genetic and non-genetic prenatal diagnostic services in Turkey. Genetics units had existed in Turkey at Hacettepe Medical Faculty, Ankara, and Cerrahpaşa Medical Faculty, Istanbul, since 1964, where they had been situated in the Departments of Paediatrics (Tunçbilek and Özgüç 2007, 355). While their focus had been mainly on clinical and cytogenetics, the 1980s saw the rise of molecular genetics in Turkey's medical landscape. Two significant cornerstones of this development have been the introduction of medical genetics at the Child Health Institute of the public Istanbul University Hospital in Çapa in 1985 and the foundation of the Centre for Prenatal Diagnosis and Research (*Prenatal Tanı ve Uygulama Araştırma Merkezi*, short PRETAM) as part of the same Child Health Institute in 1989 (Aciksoz 2012, 40ii, Apak et al. 1999). PRETAM was aimed at "identifying families/pregnancies at risk for genetic disease" and offering "newly emergent prenatal

[8] A discussion of Turkish terms related to "disability" and their translation into English takes place at the end of this chapter.

diagnostic services and methods" while driving "research into the newest technologies and their application possibilities" (Apak et al. 1999, 171). It acted as a pioneer in the field of reproductive genetic health services, being the first institution in Turkey to conduct and routinize amniocentesis and related prenatal diagnostic services. However, PRETAM did not hold its monopole position for long. The 1990s saw the expansion of medical genetics and prenatal diagnostic centres, many of which were operating from within the private health care sector which had started to expand from the 1980s onwards as a result of increasing privatization and commercialization of health care in Turkey (Ağartan 2012, Günal 2008). Signalling the performance of modern and rational pregnancy, the reproductive (genetic) health services offered by these centres soon evolved into a desired "consumer good" and "middle class ritual" (Aciksoz 2012, 41).

These newly emergent centres were initially situated in a legal vacuum as it took the government time to catch up with regulating and controlling this quickly expanding sub-sector of the health care landscape. In 1998, the Ministry of Health introduced a licensing procedure for cytogenetic and molecular genetic testing laboratories (Tunçbilek and Özgüç 2007, 355) as part of a larger regulatory framework concerning genetic diagnostic centres (Official Gazette no. 23368). The situation was somewhat different with regard to assisted reproductive technologies the practical application of which had been preceded by legislative action in Turkey. Already in 1987, two years prior to the birth of the first IVF baby in Turkey, a regulatory framework concerning assisted reproduction had been introduced which prohibited the use of donor eggs, donor spermatozoa as well as surrogacy arrangements (Gürtin 2011, 555-56). Initially only a marginal practice, assisted reproduction underwent a phase of remarkable expansion following the initiation of partial government and insurance scheme funding for IVF practices in 2005 and 2006. By now, IVF has morphed into a "large and lucrative industry", turning Turkey into one of the biggest IVF markets worldwide (Gürtin 2016, 40).

The creation of such large technological infrastructures specializing in the management of fertility, reproductive genetic risks and health concerns rested on the parallel emergence of scientific institutions and networks as well as laboratories dedicated to genetic knowledge

production and the analysis of genetic data. A two-year specialization training in medical genetics became recognized in 1972 which was increased to four years in 2003 (Tunçbilek and Özgüç 2007, 355), heralding the growing significance of the discipline. Genetics departments proliferated at Turkish universities as have genetics clinics and laboratories in the early 2000s (Ministry of Health 2013a). However, at the time of my fieldwork, many of the clinical geneticists interviewed still felt this expansion of medical genetics to be of a relatively recent character. They experienced the professional boundaries of their discipline as being constantly contested or challenged by their colleagues in other specialization areas of medicine. As they put it, many biomedical professionals had not yet fully internalized the idea of genetics as a separate branch of medicine which had emancipated from its previous confinement to laboratory work or university biology departments and which necessitated direct patient contact and patient work in the form of counselling and treatment. This process of still ongoing institutionalization also becomes apparent with regard to genetic counselling which forms the backbone of much of the patient work done in a genetics clinic. Genetic counselling still constitutes "a new terrain of medical expertise" and has not yet been established as a specialized sub-field of medical genetics (Aciksoz 2012, 45). Unlike in the US or UK where genetic counsellors are trained in specific programmes, genetic counselling in Turkey is conducted by specialists in medical genetics and medical biology as well as by physicians and specialists working in gynaecology, perinatology or obstetrics departments (Erdem and Tekşen 2013, 860).

At the time of my fieldwork, the sector of genetic health services was burgeoning. Between 2007 and 2014, the Ministry of Health had registered an increase from 11 to 18 private genetics clinics solely in Istanbul (Ministry of Health 2013a). A wide array of services and technologies designed to identify and manage genetic risks at the preconceptional, pre- and post-natal levels are institutionalized across the public-private divide of health care in Turkey and, depending on their socio-economic circumstances and insurance schemes, available to individuals or couples to varying degrees. The landscape of genetic reproductive health services in Turkey provides couples facing genetic risk with the opportunity to make use of genetic carrier testing for many common and known genetic diseases, to access invasive and non-

invasive prenatal diagnostic screening or to opt for preimplantation genetic diagnosis (PGD) as a means to try and manage genetic risk at the preconceptional stage. Non-invasive prenatal screening tests include the triple test and ultrasonographic examinations and invasive ones chorionic villus sampling (CVS), amniocentesis, cordocentesis and foetal biopsy (Erdem and Tekşen 2013, 861). Couples who have given birth to a child suspected to have a genetic condition can apply to a tertiary level genetics clinic for medical supervision and diagnosis. Within these clinics, a team of clinical geneticists and molecular or cytogenetic specialists would provide genetic counselling, conduct examinations and long-term observations of a child's development, decide upon appropriate tests together with the families and evaluate test results (ibid., 861). Furthermore, several newborn screening programmes have become institutionalized since the 1980s. In 1986, a nationwide screening programme for phenylketonuria was started which was followed by the initiation of screening for congenital hypothyroidism in 2006, for biotinidase deficiency in 2008 and congenital deafness in 2009 (ibid., 861-862).

This landscape of services is in constant flux. Already during the period of my fieldwork, new technoscientific approaches to genetic health management were on the rise, which increasingly shift their focus away from the identification of specific genetic variations to the simultaneous screening of large masses of genetic or genomic data for multiple variations potentially signalling genetic risk or "abnormalcy". Several public and private genetics clinics I had attended for interviewing geneticists were in the process of acquiring new or "next generation" whole exome or genome sequencing technologies, allowing for the rapid sequencing of large amounts of DNA, or were regularly collaborating with laboratories in Turkey and abroad offering these technologies. A private genetics clinic I visited for interviewing had recently added "package tests" to their list of genetic services. These package tests promise to screen couples for several hundred known recessive genetic conditions at the same time. They seek to render possible encompassing screening in the absence of a clearly known history of genetic risk, a situation often encountered by couples practicing kin marriage prior to the birth of any affected children.

Contingent upon state regulated health policies, insurance schemes and the unequal distribution of genetic health services within public and private health institutions, couples and families in Turkey experience different layers of contact with and access to genetic health services. Due to recent health policy reformations, discussed in more detail in the third chapter, prospective spouses seeking to get married in areas designated as "high-risk" provinces with regard to the blood disorders thalassemia and sickle cell anaemia have to undergo compulsory premarital genetic carrier screening for these diseases. While screening is mandatory, couples can decide for themselves what to do with the information gained and whether or not to opt for further genetic health services to minimize identified risks at the reproductive level. Significantly, couples' socio-economic situation, their place of living in Turkey and their respective social insurance schemes, if existent, greatly inform how they may choose to act or not act upon their reproductive genetic risks.

The landscape of genetic health services is concentrated in the urban centres of the country and unequally distributed across the public – private divide in health care. In 2013, 41 centres in Turkey were offering genetic counselling as well as molecular and cytogenetic diagnostic services for genetic diseases, 7 of which were governmental and 11 university-based whereas the rest was located in the private sector (Erdem and Tekşen 2013, 859). Prenatal diagnostic technologies such as ultrasound, amniocentesis or CVS have been routinized in public and private hospitals and were largely covered by public health insurance schemes at the public genetics clinic where I conducted research. In contrast, PGD, which has been used in Turkey for the management of reproductive risks associated with chromosomal and some molecularly diagnosed conditions since 1999 (Tunçbilek and Özgüç 2007, 355), remained exclusively confined to private health care institutions at the time of my fieldwork. Similarly, routine genetic carrier testing for common genetic diseases such as thalassemia or routine cytogenetic tests like karyotyping were accessible through public health insurance at the clinic where I was situated for fieldwork. However, more refined cytogenetic and molecular tests were either only partially covered by social insurance or were not available at all, necessitating collaboration with external private laboratories. Access to genetic health services thus is clearly

stratified. Those who live in the major urban centres of the country and have the financial means to make use of private health facilities experience a pronounced advantage of access vis-à-vis families who live in areas with limited access to specialized health care facilities and who are unable to access genetic health services left uncovered by social insurance schemes. There also remains a part of the population, especially among those working in the agricultural or informal sector, who are left outside any form of health insurance and whose access to both basic and specialized health care provided within public health institutions is significantly constrained (Conseil Santé, SOFRECO, and EDUSER 2007, 65ii). As of 2011, 5 to 8% of women were estimated to have no access to prenatal care during pregnancy and 30% to have no opportunity to access prenatal diagnostic screening tests (Erdem and Tekşen 2013, 861).

In addition to state enforced genetic carrier testing and voluntary but stratified engagement with genetic health institutions spanning the public-private divide in Turkey, couples may have, under certain circumstances, the opportunity to enrol in research projects by providing DNA samples as research data. At the clinic where I conducted fieldwork, this pathway was particularly being chosen for couples whose children had remained without a genetic diagnosis but whose (suspected) conditions or genetic data were matching the research agendas of scientific research projects. Cultivating connections to national and international genetic research communities, the medical geneticists at the clinic facilitated the enrolment of patients in such research projects if the genetic conditions in question exceeded the diagnostic capacities of the clinic and its associated laboratories or if the couple or family could not financially access private genetic diagnostic services.

What thus emerges is a highly heterogeneous landscape of varying pathways bringing families into contact with the infrastructures of genetic health care and knowledge production, with health policy regulations, access restrictions, the distribution of services across the highly stratified health care landscape in Turkey, and families' respective genetic conditions and risk management aspirations all together shaping individual families' trajectories through medico-genetic space.

Kin Marriage, Genetic Reproductive Risk and Recessive Inheritance

Couples with kin marriage represented a significant share of the couples and families medical geneticists worked with in their daily professional activities during my fieldwork stay at the clinic. Not all families practicing kin marriage presented at the clinic with a condition that could be brought in relation to consanguinity. However, there exists an association between the accumulation and transition of recessive autosomal genetic conditions within a family and the practice of consanguinity or kin marriage. Contrary to reductionist presentations of kin marriage in public media and popular discourses in Turkey which tend to portray kin marriage as a direct cause of disability and reproductive health problems, the link between consanguinity and genetic risk is complex and far from straightforward (ten Kate et al. 2015).

According to Mendelian genetics, every child inherits a copy for each autosomal gene both from the genetic mother and father. In case of an autosomal recessive condition, only a person inheriting two altered copies of the respective gene involved, one from each genetic parent, will be affected. Those who receive one altered copy from one parent and an unaltered "normal" copy from the other parent will not be born affected but as "carriers" of the condition. They will usually not present any of the symptoms of the condition (or only very mild ones) but can still pass on the trait for the condition to their own children. Two people who are both carriers for the same recessive condition thus have a 50% chance of having a child being a carrier, a 25% chance of having an affected child and a 25% chance of having a child who is neither a carrier nor affected. These probabilities remain unchanged with every pregnancy. Consanguinity affects not the probabilities of risk involved in recessive inheritance as such. However, as genetic relatives share a greater percentage of common genes, which increases the closer the genetic relation is, they have a greater likelihood of being carriers for the same kind of genetic conditions. Consequently, consanguinity in reproduction, especially when practiced over subsequent generations, facilitates the accumulation of genetic traits within a family network and thus results in a heightened risk of the birth of a child with recessive genetic conditions. Consanguineous couples are often referred to as having on average a risk of 4 – 6 % regarding the birth of a child with a congenital genetic condition in contrast to a non-

consanguineous couple's average risk of 2 – 3 % (Bittles 2003, 2015, Shaw 2009, Shaw and Raz 2015). However, these macro-level statistics have little meaning for individual couples whose actual risk may be much lower or higher depending on their specific genetic make-up, the degree of their relatedness and the frequency of kin marriage in the family (ten Kate et al. 2015).

To further complicate this picture, genetic conditions adhering to the Mendelian laws of inheritance may well be the best researched and understood genetic conditions which continue to occupy a prominent position within genetic health care but they are not the only existent ones. So-called multifactorial conditions, which result from a complex interplay of genetic and environmental factors, are responsible for many health issues associated with genetics but the effect of consanguinity with regard to these conditions is as yet insufficiently understood. An impact of consanguinity on the risk for multifactorial conditions cannot be ruled out while the specificities of that impact so far remain little known (ten Kate et al. 2015, 47).

The complexity of the link between genetic risk and consanguinity results in very different risk scenarios for individual families practicing kin marriage who consequently experience the exposure to genetic risk in starkly heterogeneous terms. Their pathways into and through genetic health care infrastructures depend not only on whether or not they were encountering reproductive disruptions and health problems in the first place, but also – if existent - on the nature of the genetic risk issues in question. Significantly, although couples practicing kin marriage are highly visible as a prominent genetic risk group requiring medical supervision in the popular imaginary and public discourse, few genetic health services exist which are tailored specifically to consanguineous couples within medico-genetic space. In practice the experiences of couples with kin marriage overlap greatly in technical terms with the experiences of other non-consanguineous couples applying for reproductive genetic health services. This is because of the unpredictable nature of kin marriage associated recessive conditions which may lie dormant in a family over generations being passed on by non-symptomatic carriers. As repeatedly emphasized by the geneticists interviewed, most couples practicing kin marriage first came in contact with medical genetics after the birth of a child with

a (suspected) genetic condition entailing the family's referral to a genetics clinic. Working with these families, medical geneticists proceeded to establish whether or not the child's condition was genetic in character and, relying on a mixture of clinical observation and genetic testing technologies, sought to arrive at a classification and diagnosis of the condition in question. While treatment remains impossible for most genetic conditions, diagnosis offered the possibility to medically monitor the child's condition. If the underlying genetic variation involved in bringing about the condition could be identified, the path was furthermore levelled towards genetic carrier testing for other members of the family as well as for prenatal or preconceptional risk management in case the child's parents desired another pregnancy.

According to the geneticists interviewed, a substantial share of couples seeking out genetic health services did so out of the desire to achieve a healthy pregnancy following the birth of one or multiple affected children, miscarriage, or genetic infertility problems. In contrast, couples practicing or planning kin marriage who decided to apply to a genetics clinic out of the desire for preventive genetic counselling in the absence of any genetic risk manifestations constituted a clear minority among their patients. The geneticists described in similar terms how they approached such couples' desire for advice, emphasizing the difficulty of risk management in such cases due to the absence of "kin-marriage-specific" services. As in counselling sessions with other, non-consanguineous patients, geneticists proceeded by first creating a pedigree, searching for hints indicating known or suspected inherited and genetic conditions in the family. However, in the absence of such hints, there were few starting points for intervention and in such situations the geneticists would resort to recommending genetic carrier testing for common, known recessive genetic conditions as well as prenatal diagnosis with the option of pregnancy termination in case of detected anomalies. As they kept pointing out, with recessive conditions often being passed on undetected, the only guarantee they could offer these couples was the absence of any guarantee regarding the birth of a healthy child.

Moving through Medico-Genetic Space, Interviewing Medico-Genetic Professionals and the Question of "Studying Up"

As a means to explore how the biomedicalization of kin marriage unfolds, I adopted different pathways of moving through the heterogeneous landscape of genetic health services in Istanbul. In addition to a textual analysis of governmental documents concerning reproductive health, (kin) marriage and the family, I interviewed medico-genetic professionals working in the areas of molecular or clinical genetics, family health and reproduction to gain perspectives across the institutional and infrastructural boundaries dividing the health care sector in Istanbul. I also conducted longer term field work at one public genetics clinic to better understand the daily work of clinical geneticists and to recruit incoming couples and individual women practising kin marriage. The discussion of this clinical space and my ethical and methodological strategies in moving through this specific space will be the topic of the next sub-section. First, I will here discuss my approach to interviewing professionals.

I specifically interviewed geneticists and family doctors[9] because both genetics and family medicine constitute disciplines that are intimately concerned with the issues of consanguinity, genetic risk and reproductive health. I recruited these professionals through personal contacts, their institutions' websites or snow-balling. Out of a total of 19 interviews with health professionals, I conducted 17 in Istanbul and 2 in Adana. All interviews took place with individual participants with the exception of one interview in Adana which was a group interview with four participants. In Istanbul, I interviewed 1 female family doctor, 5 male geneticists working in clinical genetics and 11 female geneticists who mostly specialized in clinical genetics while a few of them had a background in molecular genetics. The majority of these participants in Istanbul (11 out of 17) were employed in the public health sector or public universities whereas the remaining participants worked in private health care or private universities. In contrast, interview participants in Adana were exclusively family doctors working in public health care. The decision to talk to medical professionals in Adana arose out

[9] Comparable to GPs in the UK, family doctors in Turkey treat patients of all ages. They are important primary care contacts for concerns relating to reproductive health and are also responsible for conducting the obligatory premarital health examinations in Turkey.

of my initial consideration to extend field work beyond the context of Istanbul and include a prolonged field work stay in Southern Turkey for comparative purposes. Pragmatic concerns, however, subsequently led to the restriction of field work to Istanbul. I decided that an in-depth exploration of one site rather than a necessarily more superficial focus on two different sites was eventually more fruitful in the face of limited time for field work. The interviews in Adana were done out of the desire to test "new ground" and are situated outside of the Istanbul context. However, they nevertheless offered valuable insights in addition to the narratives of Istanbul-based professionals because concepts of Western biomedicine and similar framings of consanguinity as "risky" formed an overarching frame of reference. Apart from the four participants of the group interview in Adana, who were in their late 20s and still in the process of specialization training following their graduation from university, all other professionals were fully trained specialized physicians or university professors in their early 40s to late 60s.

Interview questions concentrated on professionals' career developments and motivations, their conceptualizations of kin marriage as a medical concern and social practice in Turkey, their experiences in working with consanguineous couples, and their reflections on existing as well as possible future health policies regarding kin marriage in Turkey. Interviews lasted on average 40 to 70 minutes. With the exception of one interview that was done partly in English and partly in Turkish due to the participant's preference of English for communicating genetic knowledge, all interviews were done in Turkish. I audiotaped the majority of them with the explicit permission of the interview partners but took detailed notes in case of 4 interviews because audio recording was not wished for.

The geneticists and medical professionals whom I interviewed in the context of this research worked on both sides of the public – private divide characterizing the health care sector in Turkey. The overtly visible discrepancies concerning public and private health care infrastructures and facilities did not straightforwardly translate into hierarchies of professional prestige and expertise. Many renowned and established senior geneticists had themselves been educated and were still positioned in public hospitals associated with well-known public universities. However, while the medico-genetic professionals I interviewed and talked to were

usually positioned either within a private or public genetic health care setting or university, some had at one point during their careers transitioned from the public to the private sector, a trend which they considered to be on the rise. The majority of geneticists interviewed had specialized in clinical genetics, working with couples and families facing genetic reproductive risk on multiple levels. Offering genetic counselling, prenatal (and in the private realm also preconceptional) diagnostic health services, genetic testing and carrier screening as well as the diagnosis and long-term supervision of genetic conditions, these professionals encountered couples and families at different stages of their reproductive lives. Their engagement with families thus ranged from premarital and preconceptional advice, pregnancy related medical supervision all the way to diagnosing and monitoring potential genetic conditions among the members of a given family. While not specifically offering genetic health services, the family doctors interviewed for this research project were similarly positioned across the public-private divide. Trained as general health practitioners, they offered medical counselling for various stages of the life circle, with reproduction and reproductive health constituting a major area of their expertise. In contrast, the molecular geneticists whose narratives found entrance into this thesis were not situated in clinical but rather research focused and laboratory environments. However, as many of their research projects required the enrolment of families being affected by the genetic conditions being researched, they nevertheless often collaborated closely with medical professionals and had direct contact with families.

In devoting a significant share of data collection to interviewing medico-genetic professionals, I made a deliberate decision to foreground their narratives and practices. This approach allowed me to stay close to and focus on the stake holders positioned at the centre of those processes driving the biomedicalization of kin marriage. It constituted a conscious move to "study up" (Nader 1972), to study those in positions of power setting the stakes of how reproduction, risk and genetic health become (in)conceivable, manageable and regulated within Turkey's overlapping infrastructures of health care and the state. This move entailed entering into a potentially charged relationship which did not fit easily into the usual binary between the researcher and the researched, between the "knowing inquirer" and those who "are considered

to be the resources or grounds for knowledge production" (TallBear 2014b, 2). Reaching out to medico-genetic professionals introduced a twist to this binary as those being "researched" were themselves academic professionals who were either actively participating in and driving research projects or had done so at one point in their past. However, interviewing medico-genetic professionals and observing their work did not exactly amount to a form of "gazing back" (TallBear 2014a, 187) either as I myself did not enter the research relationship from a marginalized position but as a privileged social scientist affiliated with a powerful and prestigious Western academic institution. The ensuing dynamic thus did not constitute an unequivocal case of "studying up" but was more complex and relative in character.

Some professionals showed themselves decidedly at ease, happily meeting and sharing their insights and experiences with me and treating me as a student desiring to learn from a senior teacher or professor. Such encounters unfolded on the basis of what could be termed a mentoring relationship and the unusual combination of my identity as a UK based researcher who was simultaneously fluent in Turkish often intrigued these professionals' interest without overriding the hierarchically clearly delineated relation of teacher and student. However, other professionals appeared to feel decidedly less at ease when being interviewed by me, staying reserved, asking detailed questions about the research and requesting the interview transcripts after the interview, sometimes adding changes retrospectively. Such caution is absolutely understandable and respecting it forms part of the principles of ethical research. Yet I often felt during these situations that the professionals' unease was closely connected with my own identity and affiliation. Often these professionals were high achievers in their own respective areas of expertise who were positioned within prestigious universities and/or hospitals, had studied at well-known research centres abroad and participated in international research projects while driving pioneering innovation with regard to reproductive health care in Turkey. I often had a sense that these professionals, being highly sensitive of global hierarchies in research and the stratified nature of academia, felt put on the spot to demonstrate and emphasize the advanced status of the genetic health service landscape in Turkey and its significance as a site for technoscientific innovation in genomics.

The relationship arising during such encounters, thus, took primarily the form of established gatekeepers in the field of genetic health care in Turkey who wished to engage with a foreign research student while guarding against any possible moment of undesired "exposure" in the potentially judgemental, biased and prying eyes of a Western academic. While being supportive of my research by granting me their often valuable time for an interview, they simultaneously appeared to me to sense a potential threat emanating from the ambiguous nature of the hierarchy informing our mutual encounter. It did not matter that I felt nervous and anxious before, and sometimes also during the interviews, being myself highly conscious of the intimidating task in front of me: to venture into the centres of genomic knowledge production in Turkey as a social scientist and PhD student in training in order to enter into conversation in Turkish with some of the most renowned and established geneticists in the country, holding academic titles and being many years my senior. At least for some of these very same geneticists being interviewed by me presented an unpredictable risk as they were effectively disclosing aspects of their work and professional experience to somebody associated with the Western centres of knowledge production. As scientists seeking to maintain their position of expertise within the global ranks of academia, they were probably well aware of the pronounced legacy of conjoined Eurocentrism and developmentalism of these Western institutions which have historically displayed a pronounced tendency to discard knowledge production and innovation emanating from beyond their own infrastructures as negligible or even "suspect".

The question of how Western Eurocentrism and its twin Orientalism shaped the site of my research, informing the encounters between my participants and me does not only arise as a result of my institutional affiliation but also my own positionality within the field. Participants as well as the staff at the clinic commented repeatedly on the oddity of my "coming to Turkey" and staying in the country as a "foreigner" at a time of political turmoil when as they claimed many "Westerners" rather chose to leave the country. In contrast, I experienced my return to Istanbul for fieldwork as a coming back to "familiar" ground which I felt emotionally and physically attached to as a consequence of having lived and studied in the city for several years. It was within the medical context of the clinic that I felt acutely as a "stranger" in "foreign"

land. While this may be telling in terms of the fluidity of boundaries between what counts as ”familiar” or “unfamiliar” or between “self” and “Other”, it does not render the politics of my own identity within this research field insignificant. Notwithstanding my language abilities and “groundedness” in Istanbul as a site which after all had been the centre of my life for several years, my decided “non-Turkishness” was often of course noticed and commented on by the people I engaged with during fieldwork. It definitively opened some doors while closing others as it acted as a constant presence undergirding my heterogeneous relationships with professionals as well as my encounters with families.

This identity of mine, as a Western outsider approaching Turkey and in particular the local practice of kin marriage as a site offering material for research and academically backed knowledge production, did not only charge with tension at least some of my relations with medico-genetic professionals due to the ways in which hierarchies of academic rank coincided with geopolitical and institutional hierarchies during our encounters. My own identity as a researcher and the topic of my research also produced a troublesome epistemological and ontological proximity with the Orientalist and colonial legacies of Western sociological and anthropological research on “kinship” which has codified “kin marriage” into a primary marker of “Middle Eastern” identity. This thesis seeks to avoid the pitfalls of these legacies by turning them into the very lenses which allow for a problematization of the biomedicalization of kin marriage by setting it in relation to what Meltem Ahıska has termed “Occidentalism”, the “reified image of the West as a marker of modernity” (Ahıska 2006, 25). Running through this thesis is a continuing exploration of such “Occidentalism” which is not so much a counterpart to but rather a complimentary of the workings of Orientalism. As detailed by the introduction chapter, the reification of the West forms an intrinsic part of the construction of internal “others” along the lines of “non-modernity”, “traditionalism” and “Easternness” which continue to inform contestations over kin marriage within Turkey’s heterogeneous society. Thus, rather than negating the unsettling proximity of this research to the problematic legacies of Western scholarship in Turkey, this research treats it as a target for sociological inquiry. It approaches

my own encounters within the field as focal points revealing the axes along which constructions of "Turkishness", internal "otherness" and "Westernness" crystallized.

Entering Clinical Space: Gaining Access to and Learning to Make Sense of a Genetics Clinic

While conducting interviews with geneticists from all over the health care landscape in Istanbul, I restricted my fieldwork stay to one public university hospital's genetics clinic which specialized primarily in paediatric and reproductive genetics, making families and their usually very young children their main patient group. This fieldwork stay which lasted for two and a half months between May and August 2017 allowed me to observe the work of clinical geneticists first hand and to recruit couples with kin marriage who were actively engaging with genetic health services for interviews. Gaining access to a closed site such as a hospital or clinic necessitated due preparation as it relied on cooperation with gatekeepers whose consent to my presence was indispensable for entering the site and collecting data. Further complicating this process, my negotiations of access roughly coincided with a period of increased political instability in Turkey following the July 2016 coup attempt. In the immediate aftermath of the coup, my affiliation with a UK university was seen as a potential threat by those very same gatekeepers who, out of all the medico-genetic professionals whom I had contacted, eventually proved most supportive of my research and who were ultimately willing to offer access. It was my status as a guest research student at the Sociology Department of Boğaziçi University, one of the country's leading public universities, which levelled the path towards entrée. Following submittal of a research permission application, written with the explicit support from my local advisor at Boğaziçi University, I eventually gained permission for fieldwork from the directory of the university which the hospital was affiliated with.

There was no separate procedure regarding ethical approval apart from the one I obtained at LSE. While I had initially planned to conduct parallel fieldwork at a public and a private genetics clinic in Istanbul, access constraints and time pressures required prioritization and the concentration on one field site only. Although final access always depends up to a certain degree on elements of chance and happy coincidence, the actual field site opportunity

materializing in the end was fortunate in many ways with regard to the design of the PhD project. It was not only a genetics clinic with a considerably high rate of patients practicing kin marriage due to its pronounced focus on paediatric genetics and reproductive genetic risks. Seeing the focus of this thesis on the interplay of the state, the family and the medico-genetic realm, the situatedness of the clinic within public rather than private health care infrastructures proved of advantage as it allowed me to trace how state supervised health services found their entrance into the intimacies of family making procedures.

As an established clinic in the field, known to be working with many rare and difficult cases, the clinic saw referrals from all over the country and often new patients had to face a considerable waiting period before getting an appointment. The clinic was staffed by a team of senior clinical geneticists, who had graduated from medical school and then specialized in clinical genetics, and a fluctuating number of assistant doctors undergoing their specialization training in genetics. The team often saw dozens of patients a day within a relatively confined space. Closely cooperating with the clinic was a molecular and cytogenetics laboratory located within the same hospital complex. Patient folders, data and samples moved in between the clinic and the lab and joint meetings between the clinical and the lab teams took place to discuss tricky or interesting patient cases, go through test results and debate further proceedings before information was fed back to the family. As Joanna Latimer has argued, this intermingling of clinical and laboratory work is crucial to genomic knowledge production with the encounter between medico-genetic professionals and the families in clinical space being of central importance to the classification work upon which the expansion of the frontiers of genomic knowledge relies (Latimer 2013b, 60).

During my stay, I concentrated on spending time in the clinic, where the actual patient work took place, rather than the lab. The facilities of the clinic appeared mundane at first glance, suggesting a GP clinic rather than a highly specialized branch of medicine, a fact similarly remarked upon by Latimer reflecting on her initial impression of the UK genetics clinic (Latimer 2013b, 37). The examination rooms consisted mainly of desks, chairs, tables for the examination of patients, computers and shelves for the storage of numerous patient folders.

Basic equipment for the taking and storing of blood samples, weighing scales, measuring tapes, photo cameras as well as pen and paper appeared to be the most "sophisticated" and most commonly used instruments in the clinical geneticists' daily activities. This seeming lack of sophistication has not only to do with the fact that the more high-tech aspects of genetic health care unfold within the space of the laboratory; it can also be traced back to the nature of clinical geneticists' work which relies strongly on the clinical geneticist's ability to observe and recognise patterns of "abnormality" signalling certain syndromes. This ability arises from the application of a classifying "gaze" (ibid., 36) which necessitates mainly experience and training rather than complicated technology. As Latimer has argued, this clinical encounter between the clinical geneticist and the family turns the clinic into a crucial interface, bringing together laboratory data and families. The clinic mediates not only the translation of lab findings to the family but also enables the process of interpreting and rendering meaningful this data in cooperation with the family, thus emerging as a space of not only knowledge application but also production (Latimer 2007a, b, 2013b).

Time and space constituted precarious resources in the clinic, requiring careful management. With dozens of patients coming in every day, usually couples with their children who were sometimes also accompanied by one or more relatives, the examination rooms often proved packed while serving multiple functions at the same time. It was not unusual for one member of the team to conduct a consultation while another colleague was busy doing paperwork or researching work-related information on one of the computers in the same room. Being situated in a university hospital, visiting students or interns frequently were present as well and sat in on the consultations. Careful room management was also required to ensure that enough space was available to do patient work while making sure that those rooms within which miscarried or aborted foeti were examined remained well shut and sealed off from any patients or outsiders stepping in unawares. Such foeti were sent in nearly every day for the examination of signs indicating a genetic syndrome or condition, a responsibility usually transferred to the assistant doctors in training. Time management proved an equally tricky issue. The high number of patients and the multiple responsibilities of the clinical geneticists, including direct patient

work, sitting in on committees deciding upon cases of medical pregnancy termination, participation in internal meetings, research activities and the cultivation of relations with the community of national and internal geneticists, as well as keeping up with the paperwork and patient files, exerted great time pressures on the medical staff. In contrast, patients coming in experienced time as languid and filled with long periods of waiting. As Sarah Franklin and Celia Roberts in their clinic-based study on PGD succinctly pointed out, the "urgent time of the clinic, in which everything is 'fast', is very different for patients, for whom the waits in between appointments, and in particular the wait for results between procedures, can feel interminably slow" (Franklin and Roberts 2006, 86).

Being situated in the clinic as a researcher, doing observation and conducting interviews with incoming couples, involved a negotiation of not only these time and space constraints but also of the ethical implications of my role as a simultaneous insider and outsider. As a trained social scientist, finding myself in clinical space in a role other than that of a patient (or occasional visitor) proved completely new terrain. Notwithstanding my fluency in Turkish and my previous periods of residence in Istanbul, conducting research in a Turkish genetics clinic added further to my profound sense of moving into unfamiliar ground, turning me into a double stranger. As a guest invited into the team, I felt deeply grateful to the medical and administrative staff of the clinic for hosting and supporting me during the months of my stay. They allowed me to observe their daily activities, helping me contact families, and generally making me feel welcome. The marked hierarchy between hospital staff and incoming patients meant that I as a visiting PhD researcher was automatically placed "as part of the team" by the staff members, easing the process of what Franklin and Roberts describe as the social science researcher "blending in" within medico-genetic space (ibid., 84). On one occasion, one of the medical geneticists even mentioned his plan to organize a white coat for me to emphasize my distinctness from the patients, an offer which he thankfully did not come back to, sparing me the embarrassment of declining a well-meaning gesture which however illustrated well the medical team's pronounced sense of a hierarchical separation between them and the patients. Enhancing

my authority vis-à-vis the families was seen by them as a means to facilitate my research rather than as an ethically problematic pretension to scientific authority on my part.

Unsurprisingly, the sense of being a misplaced outsider, juggling the conflicting feelings of desiring to do my best as a researcher and staying alert to opportunities of gathering data while fearing to be a meddlesome burden adding to the geneticists' manifold responsibilities and packed schedule, was most intense during the initial days of my stay in the clinic. As my intimacy with the proceedings grew and my personal closeness to the team members increased, the initial sharp sense of being an outsider waned and with growing familiarity with the space and its rules came greater confidence at being in the clinic due to a sense of having learned how to manoeuvre through it. At the same time, however, my profound unease at finding myself an intruder into the dynamics and proceedings at the clinic remained a constant presence. This sense of unease emanated not only from the lingering concern that I might hinder or interfere with the team's work duties by blocking rooms with ongoing interviews or distracting them with my incessant and hopelessly naïve questions, but also from my conscious choice to not "blend in" as much as I was offered the opportunity.

Negotiating Data Collection and the Recruitment of Families for Interviews within Clinical Space

As indicated by the anecdote with the white coat, the medical professionals at the clinic, seeing how I had gained approval for the research from the directory of the university which the hospital was associated with, chose to treat me like one of the medical students they frequently hosted and trained at the clinic. They explicitly encouraged me to sit in on counselling sessions and consultations with the patients, generously discussed interesting aspects of their work and intriguing patient cases with me whenever they had the time, invited me to internal meetings and regularly asked me to join in on lunch outings. While I was glad and grateful to be "adopted" as part of the team in terms of socializing and while I happily discussed their work with the medical and administrative members of the team, I made a conscious choice to decline the offer of observing consultation sessions because it was established practice at this teaching hospital to not ask patients for consent regarding the presence of medical students or other staff

members not directly involved with the consultation. My initial attempts at tweaking this situation by imploring with the geneticists to get consent from the incoming families concerning my presence as a non-medical student proved unfruitful. I was welcome to participate as an observer as long as established routine within the confined time-space of the clinic could go on; my ethical considerations and principles, in contrast, emerged as an impractical and burdensome nuisance which the geneticists were unable or unprepared to accommodate into their packed schedules. As a consequence, I withdrew from consultation sessions, restricting fieldwork to observations not including the presence of patients as well as consent-based interviews.

This refusal on part of the geneticists to ask their patients for consent constituted a demonstration of power which on the one hand was directed at incoming patients whose compliance with the presence of third persons during the consultations was taken for granted and thus imposed. However, the refusal to ask for consent was also an exercise of power vis-à-vis me as the researcher, rendered all the more pervasive because of how it operated through an apparently laissez-faire rather than constraining attitude. It demonstrated the geneticists' ability to define the terms as to how I could (not) engage with incoming families as part of my research, not by inhibiting my contact with these families but by performing a certain kind of permissiveness which reinforced the power imbalances between clinical in-house staff and patients. The geneticists' motive to have me blend in with the team as far as possible and play by the rules of clinical space stemmed not only from their understandable desire to have my research create as little fuss and disturbance within the tightly packed schedules of the clinic. It also testified to their wish to prevent destabilizing effects which my research practices might have on the power relations within the clinic. At the time of my fieldwork, I experienced my subsequent decision to opt out of observing consultations as a move which allowed me to re-establish a sense of clear boundaries and control in a space within which I felt ambiguously and thus precariously placed. I understood it as a conscious choice which helped me delineate my own positionality and movements within the clinic during the initial days of my stay. However, looked at from another angle, what I perceived to be a regaining of control in fact simultaneously acted as a powerful demonstration of the clinical professionals' ability to steer

me and my movements within what was essentially their space, not by imposing rigid boundaries but by often effacing them and keeping them in a blurred and fluid state.

Retrospectively, the question arises as to whether I might have found better approaches to dealing with the ethical challenges and dilemmas of the place. By drawing boundaries in a way which placed me outside of ongoing consultation sessions, I opted out of possibilities to conduct critical research, letting myself be steered away from potentially insightful and meaningful encounters with geneticists and incoming families. With hindsight, different arrangements might have been negotiated which could have been respectful of patients' rights without completely shutting the door on observations which I had been offered access to. However, at the time of my fieldwork I felt overwhelmed and sandwiched by the often conflicting guidelines of the LSE Ethics Committee and the realities on the ground at the genetics clinic which reflected starkly different understandings of ethnical clinical practices. My lack of previous comparable fieldwork experiences in a closed health care setting added to these difficulties and my insecurities in dealing with them. In the end, I opted for an approach which I felt safest with in terms of preventing harm and which, although it did include letting go of some unique chances for observation, nevertheless offered manifold opportunities to collect data through interviews and observations drawing on situations beyond the face-to-face patient work.

Although I had decided to stay out of consultations during the initial days at the clinic, I quickly realized how tricky it would prove to consistently adhere to this strategy and maintain in practice the boundaries which I had intended to delineate. The confined character of the space, with patients constantly coming and going, some staying for longer consultations while others appeared to drop in only for a short time; the common practice of doors to examination rooms being kept open with ongoing consultations inside; and the fluctuating presence of staff, entering and leaving rooms where patient consultations were going on, initially created an impression of confusing chaos for me. These dynamics rendered it difficult in the beginning to gauge whether or not I was crossing a self-imposed line, whether I was unwillingly sitting in on a consultation or merely witnessing a short bureaucratic exchange between one of the geneticists and an incoming person or family. However, I soon established that usually all

encounters between geneticists and patients – no matter whether they happened behind closed or open doors, whether they appeared to be rushed and informal exchanges or intense, prolonged consultations – constituted part of a newly beginning or long established process of consultation and treatment. Consequently, I started vacating the room, moving either to an unoccupied examination room or the corridor of the clinic once patients entered into conversation with the professionals, although I often feared to appear uninterested in the geneticists' work or unappreciative of the generous opportunities for data collection which they offered me. In light of these constant efforts to self-consciously maintain the principles of what I hoped was an ethical solution to the dilemmas arising from my double role as insider and outsider, I sometimes took "refuge" with the foetal examinations. To my own surprise, these examinations quickly started to emerge as a calm anchor for me within the unpredictable space of the clinic. Due to their rather disturbing nature, these examinations imposed clear boundaries in the form of closed doors and strict spatial exclusion of patients. These clear boundaries presented me with a space within which I had the chance to learn about and observe a routine aspect of clinical geneticists' work and question them about their professional activities without infringing upon the rights of incoming patients by suddenly finding myself intruding upon the privacy of their consultations.

While I decided against the observation of consultations, I approached patients for interviews with the help and mediation of the geneticists. Such interview recruitment required sensitivity to the intrinsic power dynamics within the relatively closed site of the clinic. Having gone through the process of gaining official approval for my research from the university directory, I had the gatekeepers guarding clinical space, namely the medico-genetic professionals who could facilitate or restrict my access to opportunities of data collection within the clinic, unequivocally "on my side". While I absolutely valued their support, I felt a profound unease regarding the gap of authority and power between the incoming families and the geneticists. As medical professionals, they were in charge of managing and controlling the proceedings in the clinic, had access to highly confidential patient information and constituted

crucial players in assisting couples in emotionally and socially charged matters of reproduction and family making.

In light of these difficulties and in consultation with the geneticists, recruitment advanced in two stages, both involving a clearly stated opportunity for refusal. During their consultations, geneticists initially identified a couple or individual person as a potential participant based on (1) whether kin marriage was given, and (2) whether the consultation process went "smooth/easy" (*rahat*) enough for them to bring up the question of my research and potential participation. In other words, geneticists only proceeded to mentioning the research project if they had a strong sense that the consultation had not left a couple or person in emotional turmoil, had not yielded new and potentially destabilizing information and had unfolded with good rapport. If these conditions were met, they informed the couple in a few sentences about my research project, asking them if they would like to speak to me for more information while reassuring them that this was voluntary and they could refuse. I then informed those who were interested in learning more about the research, about my identity and affiliation, stressing my guest status in the clinic and my non-clinical background, the nature of the research project and the conditions of interview participation. Once again, I emphasized the voluntary nature of this participation and the possibility to not participate. Only after all of these steps did I then conduct an interview with those couples or individuals who in light of the information given verbally consented to being interviewed.

During my stay, I conducted in total 13 qualitative interviews in the clinic, 6 of these with individual women and 7 with couples. Participants were mostly in their 20s to 40s. The majority of them were living in Istanbul but had migrated to the city at one point of their lives from provinces in Inner, Eastern or South Eastern Anatolia. Their application reasons mirrored the general profile of cases in the clinic. Most of them had infants or young children with genetic conditions that were either already diagnosed, meaning the family came to the clinic for regular control check-ups, or were still in the often tricky process of being diagnosed. Some of the participants were pregnant or planning a future pregnancy and sought genetic health services because previous children had been born affected and they wished for a healthy baby. Others

had been sent to the clinic following stillbirths suggesting a genetic condition. Interview questions explored participants' marriage stories, their reasons and motivations in applying to the clinic, their experiences with and expectations of genetic health services, their ideas and concepts concerning "genetic disease", and their experiences with caring for affected children. The interviews took place within the clinic as that proved most convenient and also reassuring for the participants. They lasted on average 15 to 20 minutes; longer interviews would have put an unnecessary strain on the participants who often came to the clinic with their children and waiting relatives. All interviews were in Turkish and I recorded 5 interviews out of 13 with the permission of participants while taking detailed notes during the other interviews.

As a consequence of careful contemplation I did not ask for written but instead verbal consent. In doing so, I did not seek to compromise my participants' rights for informed choice making or to circumvent the norms of ethical research. Rather, this decision was motivated by the political implications of requesting signed consent within the context of my field site. Many people in Turkey, especially those who occupy socio-economically marginalized positions and those who have not had access to secondary or higher education, associate the signing of documents not with the protection of their rights but with an unwelcome visibility heightening their exposure to state policies and bureaucracies. They are acutely aware of and sensitive towards power inequalities between themselves and representatives of established institutions. Therefore, I preferred to opt for verbal consent to protect my participants' anonymity and identity and reduce their fear of exposure to any form of external intervention policies.

While I made sure never to interview anybody without their explicit verbal consent based on detailed information about the project, myself and the technicalities and conditions involved in interview participation, the two-step recruitment process as outlined above rested on the existence of ideal conditions. The real-life scenario often ended up being messier due to the unpredictability of the clinical space and the challenges it imposed on the practitioners as well as on me as the visiting researcher. During their packed schedules, geneticists did not always remember or find the time to ask incoming families about my research and sometimes there simply was no available space to conduct interviews because all consultation rooms were

occupied. Couples or individuals who did not want to get involved in the research usually clearly declined either speaking to me in the first place or participating in an interview once they had been given more information on my part, often referring to waiting family members or the lack of time after an already time consuming trip to the clinic. Such a response constituted not only a polite way of refusal; it also acted as a completely legitimate way of saying "no" in the face of medical authority which reassured me that couples did indeed make use of the possibility to opt out when they desired to do so. However, three instances arose when referred participants voiced their consent although it became quickly obvious during the interview that they did not desire participation and had probably agreed out of fear to refuse. In all three cases, I ended the interview very early on, making sure the participating couple had the necessary information to contact me in case of any lingering questions. I did not use any information conveyed during these interviews in the context of this thesis.

The sensitivity of the research project did not only extend to the nature of interview recruitment and the negotiation of the inherent power inequalities shaping the recruiting process. The very topic of my research proved highly sensitive in character as it singled out couples practicing kin marriage in a setting of genetic health care. It thus concentrated on a form of contested family making whose stigmatization is increasingly driven by the very discourses and technologies upon which the practices in the genetics clinic rest. Only by deliberately bracketing the question of kin marriage as a genetic risk factor, waiting for participants to formulate this question on their own terms and accepting their otherwise choice of silence, did I find it possible to enter into conversation with the couples or women interviewed. By thus opting for silence on my part and embracing participants' own agency in either continuing or breaking this silence, I sought to counter the reproduction of medicalized stigmatization and blaming which might otherwise easily be propelled by a research project targeting exclusively couples with kin marriage within a clinical space dedicated to the management of genetic risk and its manifestations.

Interviewing couples within medico-genetic space, while offering a plethora of valuable insights, remained constrained due to the temporal and spatial limitations in the clinic as well as

the sensitive nature of couples' experiences. Therefore, I decided to move beyond the clinical realm in order to interview women/couples practising kin marriage referred to me by acquaintances from my own social circle. These interviews offered the chance for longer and more in-depth exploration of interviewees' experiences and reflections concerning their marriages, reproductive decisions and family health matters. They also provided a perspective on kin marriage that was not necessarily medicalized. The participants interviewed outside of the clinic had either not experienced reproductive health issues or they had married and founded their families at a period when biomedical discourses about kin marriage as risky had not yet become salient in the public imagination. Specifically, I conducted five interviews with 4 women and 1 man who were all married to either their paternal or maternal first cousins. I recruited all of these participants within my own circle of acquaintances. Three of the women came originally from the Eastern Black Sea region in Turkey and were in their 50s and 60s. They went through their early reproductive lives and their pregnancies before the biomedicalization of kin marriage had gained its current scope and they had largely experienced kin marriage as a "non-medicalized" practice. In contrast, the remaining two participants who, although I interviewed them separately, were a married couple in their early 30s coming originally from a South Eastern Anatolian city found themselves in a completely different situation. They were aware of biomedical discourses defining kin marriage as a medical problem and consequently had to engage actively with notions of "genetic risk" while making decisions regarding the management of their own reproductive risks. While my own gender identity restricted my ability to interview men outside of the clinical setting, this gender bias is somewhat corrected for in the interviews I conducted at the clinic which often involved couples rather than individual participants.

Interview questions explored participants' marriage stories, their ideas about and experiences with kin marriage as a form of family making, their conceptualizations of relatedness in connection with medical risk and their experiences with reproductive health, particularly premarital health screening and prenatal care. Significantly, none of these participants recruited outside of the clinic had experienced reproductive health problems and all

of their children had been born unaffected which in turn sets them further apart from couples recruited and interviewed in the clinical context. The non-existence of affected children also rendered the issue of genetic risk far less sensitive than it was in the clinical setting where couples had to cope with blaming and feelings of guilt as a result of the close association of kin marriage with genetic disease. It effectively meant that I could discuss responses to and renegotiations of biomedical risk relatively freely and at ease with these participants. All interviews were conducted in Turkish and all but one were recorded with the participants' permission. Interviews usually took 40 to 60 minutes.

While the decision to interview medico-genetic professionals was motivated by the idea of "studying up" and interrogating some of the stakeholders of the biomedicalization of kin marriage, the methodological move to also include families' narratives and experiences was driven by the desire to trouble rather than perpetuate silences and invisibilities. The proliferation of risk management practices allocates genetic and biomedical professionals the authority to largely determine the terms of how kin marriage becomes framed as a health risk in the public imaginary. Often, families' experiences are primarily fitted into these discursive framings in ways which further enhance biomedical authority and the moralizing quality of risk discourse. In representing families as suffering victims or selfish, ignorant perpetrators, both common themes proliferated by the public media, established and hegemonic notions regarding disability, good parenthood and normative reproduction are reproduced. Experiences beyond these clichéd imaginaries are largely omitted from view by representations which bracket the complexities of the link between kin marriage and genetic risk as well as the complexity of the processes through which families are (not) made. Interviewing couples practicing kin marriage about their reproductive experiences and including their narratives was thus a methodological move to bring these experiences back into the picture, to complicate the reductionist public imaginary of how kin marriage, risk and disability link up, and to challenge the processes through which blame and moral censorship become distributed.

Data Analysis and Translation of Turkish Language Data Material

As detailed both in the introduction and this chapter, I understand the biomedicalization of kin marriage as a complex process unfolding within and across different sites, spanning the overlapping realms of medicine, the state and the family. To trace this biomedicalization process across these various sites, I analysed three data sets: qualitative interviews, field site observations during my stay at a genetics clinic and 20th-century as well as contemporary Turkish health policy documents relating to kin marriage, family making, and reproduction. These distinct data sets tell different stories; they offer different narratives, told from a variety of sometimes divergent, sometimes convergent perspectives. A central analytical concern of mine in moving through these data sets was to put them not only alongside but also in juxtaposition with each other. I thereby searched not only for recurring motives, patterns and narratives but also for contradictions, tensions and moments during which the different narratives contained within and across these data sets revealed complexity and ambiguity exactly because they didn't neatly align with each other. I will discuss my analytical approaches in making sense of these different data sets in the following.

Semi-structured, qualitative interviews

(a.) With medico-genetic professionals:

The stakes of the biomedicalization of kin marriage are largely determined by medico-genetic professionals who due to their scientific know-how and resources as experts occupy a key position with regard to the biomedical reconceptualization of kin marriage as a reproductive genetic risk factor. Consequently, as detailed above, I devoted a significant share of data collection to the conduction of qualitative interviews with medico-genetic professionals to develop an understanding of their routine work practices, their professional encounters with couples practising kin marriage as well as their professional and personal stances regarding kin marriage, its riskiness and common prevalence in Turkey as a family making strategy. The semi-structured qualitative interviews which I had conducted with medico-genetic professionals left me with 15 interview recordings (all in Turkish with the exception of one interview conducted partly in Turkish and partly in English), ranging from 25 to 90 minutes, and 4

interview protocols (all in Turkish) which I had written directly after the interviews with the help of my interview notes. I produced complete interview transcriptions of all recordings which left me with a considerable amount of interview-text data.

While I used NVivo coding as a means to systematically code, group and store the interview data in a database, coding did not evolve as my main analytical tool to make sense of my interview data. What helped me get "into" the data was rather an immersive reading and re-reading of these transcripts and protocols as whole texts. Using the rather mundane tools of pen and paper, I worked with the printed-out transcripts, setting them next to each other, cross-reading and annotating them. Based on these close readings, I created memos containing my thoughts and reflections emerging from the reading process. This allowed me to identify key themes, elements and narrative strands which I then mapped out, again with the simple help of pen and paper, using the three core mapping techniques of situational analysis (Clarke, Friese, and Washburn 2018). Significantly, I did not employ the mapping techniques of situational analysis as my key methodology, turning the maps thus produced into integral parts of the thesis' core arguments as envisaged by situational analysis (ibid.). I rather approached the process of mapping as a starting point to initiate new ways of seeing and understanding my data whenever I felt stuck in my analysis, thus generating new ideas and angles for the core analytical work which I undertook through memo writing.

Similar to my reading of governmental documents, I read the interview transcripts with an analytical interest in tracing not only distinctive themes and patterns but also contradictions and tensions emerging within individual interviews and across different interview scripts. I treated such emergent contradictions and tensions as being expressive of discursive shifts which revealed different moments of alignment on part of the narrator that were worthy of exploration. During the interviews, the medico-genetic professionals often spoke as scientists using a particular scientific language which enabled them to align themselves with the discursive practices and truths of medicine and science, often in an emphasised opposition to what were perceived to be unscientific, irrational or non-progressive practices on part of the government as well as patient families. At other times, however, their narratives switched towards an alignment

with the state reproducing governmental framings of the family and reproduction which underpin nationalist ideology and state governance in Turkey. Then again, they performed yet another shift in their discursive positioning, situating themselves "alongside" (Latimer 2019, 2013a) the families they were working with, genuinely partaking in these families' diagnostic troubles and emotional journeys, in their fears, aspirations and hopes in ways which deeply moved me.

All of these narrative shifts took place in a conversational context which was furthermore significantly shaped by the narrators' relation to me as the listener being present, a relationship which, as detailed earlier in this chapter, was fraught with its own ambiguities and tensions. Approaching this body of interview data analytically, I sought not to deny or simplify its multi-layeredness revealing the complex entanglements of clinic, state and family, all brought to the fore within a charged and hierarchically ambiguous interviewer-interviewee-relationship. Instead, I sought to work with and through this complexity, unpacking it without privileging one narrative tonality or account over another as being more or less "true" or "authentic" but treating them all as partial accounts which cannot be rid their contradictory moments.

(b.) With couples / individual lay participants practising kin marriage:

Stemming from my desire to restrict this thesis not only to governmental and professional perspectives but to also include the voices and experiences of couples practising kin marriage, I conducted additional interviews with lay participants both inside and outside of the clinical realm. These interviews left me with another body of textual interview data in the form of 18 Turkish language interview protocols and transcripts. In terms of analysing this data set, I proceeded as I had done with the professional interviews. I used NVivo coding in addition to writing memos based on my in-depth readings and markings of printed-out transcript and protocol texts and mapping the data with situational analysis maps whenever deemed helpful to generate new analytical insights. However, this lay interview data set presented me with significant challenges due to its highly heterogeneous nature.

The majority of these interviews (13 out of 18) had been conducted within the clinic where I conducted fieldwork in contrast to the smaller number of interviews that had taken place within non-clinical settings, either in the participants' familiar private homes or in the case of one interview a public café. While fewer in numbers, the non-clinical interviews had, however, proceeded from easy rapport resulting in significantly longer interviews (30 to 70 minutes), most of which I could record (4 out of 5). In contrast, the clinical interviews were less often recorded (4 out of 13) and had remained noticeably shorter (10 to 20 minutes) as a result of the spatial-temporal constraints within the clinic and a more challenging process of establishing rapport. Adding to this data heterogeneity was a significant generational gap between those 3 participants (all interviewed outside of the clinic) who had been married in the 1970s and 1980s before the widespread unfolding of the (bio)medicalization of kin marriage, pregnancy and child birth in Turkey and the participants of the other 15 interviews who were in their reproductive ages and fully experiencing the implications of this biomedicalization process.

This heterogeneity of the interview contexts as well as participants' backgrounds unsurprisingly translated into a great variety of narrative themes emerging during the interview conversations which required me to make strategic choices about what to follow up on in terms of my data. I could impossibly do justice within the context of the thesis to the sheer scope of emergent narratives centring on marriage and marital life, family making, reproduction and pregnancy in the face of genetic risk as well as diagnostic odysseys and experiences of having (lost) a child with a genetic condition in the family. What is more, while some narrative themes were present during multiple or most interviews, others were voiced only in the context of a single interview. At the end, every family's experience with genetic risk was highly unique and the limited number of interviews conducted made me wary of simplifying generalizations.

I sought to meet these challenges by focusing on a few select key narrative moments which surfaced during conversations with couples and individual participants both inside and outside of the clinic and integrating these into the argumentation of one thesis chapter only (chapter 4). These moments coalesced around the question of kin marriage as a potential

reproductive genetic risk factor as well as experiences of kin marriage as a stigmatized form of family making in the wake of the rise of discursive practices of genetic risk management. I decided to particularly foreground these moments because (a.) the relevant data was considerably rich, allowing for exploration across the clinical/non-clinical divide characterizing my interviews with lay participants, (b.) they linked up closely with key questions of the thesis, and (c.) they lend themselves to a fruitful juxtaposition and cross-reading with professional discourses which dwelt in detail on issues of genetic risk, reproduction and relatedness.

Significantly, I approached lay participants' narratives regarding the relation between genetic risk and kin marriage by analysing them not as "true" or "false" statements, i.e. "accurate" or "inaccurate" renditions of biomedical concepts and discourses demonstrating lay participants' "understanding" of the facts of genetic risk and appropriate genetic risk management. Instead, I read them as processes of negotiation and sense making of the biomedicalization of kin marriage that were crucially shaped by the unequal terms upon which professional and lay couples met within the spatial and discursive context of biomedical expertise. As critical counter-narratives, they helped reveal what was often rendered invisible or remained unsaid by medico-genetic professionals' scientific discourses. They made apparent the inherently political nature of risk (Douglas 1996, Douglas and Wildavsky 1982, Kaufert and O'Neil 1993) and brought to the fore the marginalizing and stigmatizing potential of the biomedicalization of kin marriage. Lay participants' narratives thus added another layer of complexity by introducing an additional perspective which allowed me to read not only governmental but also professional discourses "against the grain". In that sense, they opened up a space for critical inquiry concerning the non-neutrality of reproductive genetic risk management practices in Turkey and their biopolitical implications.

Clinical observations

Although my fieldwork stay in a genetics clinic primarily served the purpose of contacting and recruiting potential interview participants from among the families, couples and individual patients frequenting the clinic, it also offered me various opportunities to closely observe different aspects of medical geneticists' clinical work. Being physically present in the

clinic, I developed a sense of the daily routines unfolding within this space, becoming familiar with the ways in which medical professionals, support staff and patients moved through the clinic while entering into various encounters with each other. Although I largely stayed out of patient consultations, I was nevertheless presented with an overwhelming array of possible starting points for observations. I regularly witnessed conversations among clinical staff, sometimes having the chance to actively join in whenever one of the geneticists started to involve me by explaining what was being discussed and by encouraging me to ask questions. I also observed parts of the diagnostic research work which often proceeded while the patients themselves were absent, regularly sitting in on the foetal examinations and attending one joint discussion panel where clinical and lab professionals exchanged knowledge about ongoing and diagnostically tricky patient cases. Every day, I joined the assistant doctors for lunch which, apart from the much welcome opportunity to socialize, offered additional possibilities to listen to their clinical chats and gossip. Finally, due to the often fluid spatial boundaries between patient consultations, teaching and admin work described earlier in this chapter, I also did occasionally end up observing parts of patient consultations which, though not pursued in a systematic but rather accidental fashion as a consequence of the ethically motivated choices I made, nevertheless added to my understanding of the clinical space and its dynamics.

While being in the clinic, I took to scribbling down quick, sketchy observational notes on my phone which I then typed out and transferred in more detail to my fieldwork journal once back at home. Much as I would have liked to document observations and informal conversations in a detailed style in this journal, the long commute home after an exhausting day at the clinic meant that even those typed-out notes remained somewhat clipped and brisk in tone. These fieldnotes have for the most part found only indirect entry into this thesis; I used them very rarely as a direct data source, relying instead more heavily on interview data and textual/archival material. However, the stay in the clinic – besides bringing me into contact with families – helped me immensely in making sense of my interview data and in contextualizing medico-genetic professionals' narratives and experiences; as such, the observations, experiences and informal conversations, which arose from my several weeks-long presence in the clinic,

have found particular entrance into chapters 2, 4 and 5, while being implicitly present throughout the thesis. They have shaped my understanding of the daily proceedings at the clinic, of the encounter between families and medical geneticists, of the surprising assemblages of technoscience and only seemingly mundane clinical practices which undergirded the diagnostic journeys in which professionals and families jointly partook in. Most significantly, they have rendered more palpable and comprehensible the daily ethical challenges, micro-tensions and moral as well as emotional conflicts characterizing geneticists' clinical work on the ground which were voiced time and again during my interviews with medico-genetic professionals and which especially chapters 4 and 5 explore in more detail.

Textual Analysis of State Documents

Particularly chapter 3 relies on a close reading of Turkish language legal documents and government texts concerning reproductive health, marriage and the family (listed as "primary sources" in the bibliography section of this thesis) which span the time period from 1930 to 2018 and which are publicly accessible on the internet. I focused on these governmental documents which consist of legislative texts, circular notes, regulatory frameworks, and public health related counselling guidebooks because they help illuminate the incorporation of kin marriage and genetic risk into governmental and medical infrastructures in Turkey. In reading these texts, I paid particular attention to discourses and practices highlighting the role of the family within state and society as well as those emphasising "healthy" family making and the management of "healthy" reproduction in order to trace how kin marriage and its associated reproductive risks emerge as a concern within governmental discursive contexts. Thus, I approached the textual documents in question as a "major source of evidence for grounding claims about social structures, relations, and processes" (Fairclough 1992, 211). I understood them to be of political significance not only because of how they testify to the historical emergence of new discursive elements and discursive shifts but also because of the crucial and constitutive role which they play with regard to the exercise, negotiation and circumvention of power in the form of social control and social domination (ibid., 212).

This understanding of language and text as being not simply a reflection of the world but rather constitutive of it (Rorty 1979), shaping how people see, make sense of and ultimately act on their surroundings, is indebted to Foucault's notion of "discourse" as something that goes beyond the individual by being ultimately generative of social order. Directing his attention not so much to the meaning but rather practical uses and effects of language, Foucault has traced how discursive regimes, founded upon certain "truths", emerge and shape social order as a result of how language becomes (not) employed in different practical contexts such as for instance the realm of medicine and the clinic (Foucault 1978, 1994, 1995). In reading and analysing textual documents issued and produced by changing government regimes in Turkey, I was thus interested in their immanent discourses as expressions of "language in use" (Jaworski and Coupland 2008) which shed light on the practices and procedures through which the state exercises, secures and reproduces power and social control.

I treated these documents as testimonies in a two-fold sense. They give insights into how the state chooses to present and position itself in relation to its own subject population, and they offer glimpses of state technologies in the making and in action. I am well aware that the documents I worked with do not and cannot represent any entity conceived of as "The State" in its entirety. Such an entity does not exist except as a reified image and concept. What I broadly conceive of when speaking of "the state" consists of a heterogeneous set of institutions, human and non-human elements, practices, discourses and spaces, all hold together through complex networks which often expand well beyond the state's recognizable bodies into the very intimacy of everyday life processes.

Thus, by drawing on a specific array of governmental documents, I sought to unpack a set of practices and technologies employed by the current government, some of which are of recent making, others dating back to the founding years of the Turkish Republic, which have explicitly or implicitly been driving the biomedicalization of kin marriage. I read these documents to trace discursive shifts and continuations underpinning the making and employment of state technologies which have been shaping the ways through which genetically healthy families are being made in Turkey, thereby inquiring into the both intentional and

unintentional, the visible and less visible implications of these shifting discursive practices. In doing such a reading of these state documents "against the grain", I asked not only what was being said, but also what was *not* being said, what was being implied, silenced or rendered present through its absence.

A Note on Translation

With the exception of one interview conducted partially in English and partially in Turkish, all interview and archival data which found entry into this thesis were originally in Turkish and translated to English by me for quotation purposes. Every translation process presents its own particular challenges due to ambiguities in signification or multiple significations of a given term in one language which can only partially be rendered in the language translated into. Throughout this thesis, I have thus provided the original Turkish version of key words and phrases in addition to the English translation. A couple of keywords which are conceptually concerned with kinship, disability, and disease require a more detailed discussion in the following because of their non-straightforward translations into English which overlap only partially with the original Turkish terms.

(a.) Kin marriage:

Throughout the thesis, I use the term "kin marriage" as the best possible approximation to the original Turkish term *akraba evliliği* which literally means "marriage between relatives". I have chosen this term over the otherwise common term "consanguineous marriage" which is predominantly used by the medical literature but differs in its meaning from the Turkish *akraba evliliği*. Derived from the Latin word for "blood-relationship" (cōnsanguinitās), the term "consanguineous marriage" foregrounds a Euro-American understanding of kinship as shared substance, specifically shared blood ties (Schneider 1980, Schneider 1984). This understanding of kinship is not straightforwardly transferrable to the Turkish context, as especially the fourth thesis chapter explores. In contrast, the Turkish term *akraba* ("relative", "kin") does not contain such a reference to shared substance or blood ties. It is derived from the Arabic *qarīb* meaning "close" and related to the Arabic term *qarābah* ("closeness") which forms one of the nearest equivalent terms in Arabic for "kinship" in English (Clarke 2007a, 380). "Kin marriage" thus

constitutes a more accurate rendering for *akraba evliliği* than "consanguineous marriage" although both terms refer to marital unions among those considered to be "related".

(b.) Health, Disease and Genetic Variation:

Part of the recurring key vocabulary employed by governmental texts and interviewed medico-genetic professionals revolved around the condition of "health" and genetic conditions as an expression of its absence. Speaking about "health", governmental discourse and professionals unanimously made use of the Turkish noun *sağlık* or its adjective form *sağlıklı* ("healthy"). Alternatively, the term *sağlam* ("sound", "healthy", "robust") was used, often in the context of phrases stressing the soundness of body and mind, the robustness of family and society, or the biopolitical link between the health of the individual body and the body politic. In contrast, the absence of health was overwhelmingly described in terms of a state of "disease" (*hastalık*) which was usually understood to also contain genetic conditions.

Genetic conditions were predominantly framed in Turkish governmental and professional medical discourses as "genetic diseases" (*genetik hastalıklar*). This conceptualization gives weight to medical authority by emphasizing the need for medical expertise and intervention while suggesting the possibility of treatment. A pathologizing language surrounding genetic variation undergirded these notions of "genetic disease". Formulations such as "damaged genes" (*bozuk genler*) or "diseased genes" (*hastalıklı genler*) as opposed to "healthy" or "sound genes" (*sağlıklı / sağlam genler*) were regularly employed by governmental texts and some of the medico-genetic professionals interviewed. This dominant perception of genetic conditions as an expression of a state of disease contrasts with the language used within the clinical context observed by Joanna Latimer during her fieldwork in a dysmorphology clinic. As she has pointed out, the dysmorphologists she engaged with did not describe themselves as being involved in the classification and diagnosis of "diseases" but rather "syndromes". Such genetic syndromes were clearly differentiated from diseases; they constituted "combinations and associations between diseases, and other signs and symptoms, including unusual features, which may or may not represent pathologies and deformities" (Latimer 2013b, 12).

Translating from the original Turkish-language data material, I have sought to maintain this prevalent conceptual emphasis on genetic conditions as a form of "disease" which I encountered within the medico-genetic realms that this thesis explores. The translations of quotes and texts reflect the vocabulary employed in the original language to describe health, disease and genetic variation as perceived and framed by the speakers. Wherever appropriate, I also provided both the English and Turkish terms to make apparent the process of translation and render visible the original connotations of the Turkish terms used. The emergent conceptualizations of genetic variation as a form of disease testify to the powerfully suggestive significations of the pathological which medico-genetic professionals relied upon in rendering genetic processes understandable to lay audiences. These conceptualizations are also indicative of medical geneticists' desire to stress the authority and legitimacy of their still relatively recent and emerging sub-field of clinical medicine in Turkey when it comes to managing the development and diagnostic processes of patients with genetic conditions.

(c.) Disability:

In Turkish, many different terms exist which are used in relation to "disability". The prominent ones recurring in my collected data material were *engelli* ("disabled"), *özürlü* ("handicapped", "defective", also "impaired"), and *sakat* ("impaired", "crippled", also "disabled"). While all three terms are often used in the public and also medical realms in Turkey to refer to those living with disabilities, significant variations exist regarding these terms' connotations. With its rights-based conceptualization of disability as a form of social discrimination and exclusion, *engelli* (or *engellilik* in the substantive form) comes closest to the English term "disabled". The 2005 "Law on People with Disabilities" (Official Gazette no. 25868) describes as *engelli* a person who because of losses to varying degrees in their physical, intellectual or sensory capacities is impacted on by environmental conditions and a societal attitude which restrict their active participation on equal grounds with other persons in society.

In contrast, the still commonly used term *özürlü* (or *özürlülük* in the substantive form) aligns more closely with the English terms "handicapped" or "defective" and similar to its English counterpart, it has started to become seen as politically offensive and obsolete over

recent years. In 2013, a change of language and underlying disability conceptualizations was introduced to the 2005 "Law on People with Disabilities" which saw the systematic replacement of *özürlü/özürlülük* with *engelli/engellilik* (Official Gazette no. 28636). Prior to 2013, the law contained a definition of *özürlü* (now replaced with the above referred to definition of *engelli*) as a person who because of congenital or later-life loss of physical, intellectual, sensory or social abilities experiences problems in adapting to social life and is in need of protection, support and rehabilitation services. This discursive shift is illustrative of the differences in meaning between the two terms. *Engelli* locates the problem of disability in society, namely social exclusion and environmental discrimination in response to what are described as losses in physical and/or intellectual capacities. Contrastingly, the conceptualization of *özürlü*, which draws on a paternalistic language of charity-provision, corresponds more closely to the medical model of disability (Oliver 1990, Shakespeare 1995) in its understanding of disability as an individual problem resulting from physical or intellectual abnormalities which require intervention and normalization strategies.

Besides *engelli* and *özürlü*, the term *sakat* (or *sakatlık* in the substantive form) was also occasionally used by interview participants when referring to people with disabilities. With its connotations of "crippled" and "impaired", it was usually employed by interview participants to indicate a visible or physically apparent form of impairment. However, *sakat* has also been self-consciously reclaimed by disability activists as an identity category in Turkey (Açıksöz 2020, 199). In light of the near complete invisibility of disability activism within the social worlds that my interview participants moved through, it was, however, the former meaning of *sakat* which was suggested by the speakers. In addition to the three above discussed terms, which recurred regularly in all data streams, the Arabic-derived term *maluliyet* ("invalidity", "disability") needs short mentioning. This term emerged exclusively in a few cited governmental documents concerning abortion. As an outdated term in the realm of spoken modern-day Turkish, it is now mainly employed within the context of state discourse and legislations (ibid., 199).

Throughout this thesis, I give both the Turkish and the English terms used when quoting participants or texts in their discussions of disability-related issues. These translations can only

ever be an approximation. Turkish and English terms only partially overlap in their connotations and the boundaries between the Turkish terms indicating disability cannot always be drawn as strictly as suggested by the discussion above. For instance, the growing salience of *engelli* in the public realm in Turkey has not necessarily displaced individualized and medicalized understandings of "disability" and in some instances an exchange of the terms has not gone hand in hand with a changing rights-based conceptualization of disability as illustrated by the case of the "Social Services Law".[10] As this thesis makes apparent, the usage of the terms *özürlü* and *sakat* continue to occupy a prominent position in discussions of disability both within lay and medico-genetic realms in Turkey. Undoubtedly, both terms could also simply be translated as "disabled", a practice regularly observed by Turkish scholars writing in the tradition of critical disability studies (Açıksöz 2012, Bezmez and Yardımcı 2010, Yilmaz 2010). However, by giving both the Turkish original and the most approximate translation of the terms used, I aimed at providing a clear sense of the connotations suggested by the speaker or text in question. By doing so, I do not seek to reproduce the often pathologizing and medicalizing understandings of disability transported by some of these terms. I rather seek to make apparent and problematize these discursive framings of disability which are employed by some of the very professionals who, due to their expertise in genetic medicine, are directly involved in processes through which medical framings of disability are gaining a stronger than ever hold in the wake of expanding genetic health services.

****

Researching kin marriage in medico-genetic space required awareness and negotiation of multiple boundaries. Being highly stratified in character, the boundary between private and public health care infrastructures significantly shapes the genetic health services sector, determining the distribution of technologies, know-how as well as services. This stratification also informs couples' pathways to accessing these technologies and services. Legal regulations furthermore delineate the technoscientific, temporal as well as spatial boundaries within which

[10] While the law's vocabulary changed in 2013, introducing a replacement of *özürlü* with *engelli*, the law still defines as *engelli* somebody who is unable to adapt to the "requirements of a normal life" due to the loss of physical, intellectual, sensory or social capacities and thus in need of rehabilitation and support services (Official Gazette no. 18059b).

genetic health services may be employed in Turkey in relation to reproduction and family making. The particular conditions under which the encounters between medico-genetic professionals and couples or families took place thus arose out of the historical circumstances which have shaped the emergence and institutionalization of genetic health care in Turkey in accordance with existing regulations governing family life and reproduction. Entering the medico-genetic realm as a social scientist coming in from "outside" of Turkey required not only an engagement with these infrastructural and legal boundaries; it also necessitated the navigation of ethical boundaries in light of existing power inequalities unfolding within the closed space of the clinic as well as within relational encounters between me as the researcher and those whom I interviewed or whose work I observed. On the one hand, as a Western researcher who ventured into the clinical realm coming from a social science background, I occupied the role of a "double stranger" within medico-genetic space. However, my familiarity with Istanbul as a site and Turkish as a language and the overarching boundary between patients and clinical staff which turned me into an "insider" within the clinic partially erased my "strangeness" in the field.

While my close association with the clinical team eased rapport with the team members during my stay at the clinic, greatly facilitating my ability to observe the team's working routine and understand the clinic's daily proceedings, it entailed challenges regarding the maintenance of ethical research principles. I myself had to constantly draw, assert and re-assert the boundaries of acceptable situations within which I found myself prepared to collect data, while differentiating these situations from contexts of unacceptable and unethical research activities. I was constantly conscious of how my identity and the topic of my research brought legacies of colonial and Orientalist appropriations of Turkey as a site for the extraction of research data into the various encounters with my participants. While I could not prevent the haunting presence of these legacies due to the seeming proximity of my research with colonially inflected research endeavours of the past, I sought to negotiate this troublesome presence through various methodological choices. Devoting a significant part of data collection to interviews with highly educated professionals, I consciously put myself in situations which complicated the binary of

researcher and researched as those being interviewed were themselves far more senior and professionally experienced academics than me. Drawing clear ethical boundaries to regulate my own movement through clinical space, delineating the terms of my encounters with incoming patients, I eschewed what I considered to be exploitative research relations. Finally, instead of negating the close entanglement of the biomedicalization of kin marriage with legacies of Orientalism and constructions of "otherness" vis-à-vis the West, I chose to turn it into a target of sociological enquiry in itself as the following chapters unpacking this entanglement will illustrate.

Chapter Three: Premarital Health Screening and the Emergence of Genetic Risk as a Public Health Concern in Turkey

When doing fieldwork and interviewing medico-genetic professionals offering genetic health services to families and couples with kin marriage, I was struck by how often they criticized what they perceived to be a politically motivated negligence and indifference on part of the government regarding the medical risks of kin marriage. They initially impressed on me the idea that kin marriage had largely evaded government implemented medical supervision and control, thus limiting risk management to the initiative of individual couples. When asking these medical professionals about government policies and health campaigns regarding kin marriage, I was surprised how quite a few of them proved rather outspoken in their criticism of the government, notwithstanding the fact that the interview was recorded. One geneticist working at a prestigious private hospital's genetics clinic, voiced her disdain openly.[11] As she put it, she "wasn't expecting anything" from the government as far as kin marriage related health issues were concerned. She presented me with a narrative which I was to encounter more than once during my conversations with health care professionals: those in charge at the government level had no interest in tackling kin marriage as a health problem because they themselves practiced it frequently, as did the "common people" (*halk*) who voted for the party. The ruling party would never risk losing votes by pushing for stricter health policies regarding kin marriage. "The policies of the Ministry of Health are not so much about health as they are about politics, and it's all very political", she said.

This conveyed impression of the government turning a blind eye was further enhanced by the reproductive health infrastructure I encountered in Turkey. The proliferation of reproductive genetic health services, while spanning the divide between public and private health care, advances particularly rapidly in the commercialized private health sector which offers services such as PGD or package carrier testing for multiple genetic conditions still

[11] Female clinical geneticist in her 50s, working at a private university hospital's clinical genetics centre. Interview conducted in Turkish by author, 15 February 2017, Istanbul.

unavailable within public health care. The privatized and commercialized nature of significant technologies of reproductive risk management easily renders invisible the interest which the government has come to employ with regard to genetic risk and kin marriage related reproductive health issues over the last three decades. This chapter, which constitutes the first empirical chapter of this thesis, sets out to explore this process of emerging interest by focussing on the institution of premarital health screening as a key procedure through which kin marriage has become addressed as a public health problem. Neither the state's desire to craft healthy families as the cornerstone of a healthy society and strong nation, nor the socio-legal significance of the family as the primary social unit are new phenomena when discussing the state's intervention into family life, reproduction and marriage in Turkey (Acar and Altunok 2012, Delaney 1994, Gürsoy 1996, Öztan 2014a, Sirman 2007, Kılıç 2010, Yazıcı 2012, Yilmaz 2015). However, the emergence of genetic risk as a target of legal regulation and state intervention is a comparatively recent and still ongoing process which deserves closer attention. Tracing the incorporation of kin marriage and genetic risk within premarital screening offers a unique and fruitful opportunity to explore how healthy family making as a form of population management unfolds in Turkey in the age of genomics when reproduction becomes a potential threat to future generations, when healthy families are no longer only defined by the existence of a legal marriage contract, the internalization of nationalist values and the upbringing of future citizens in line with these values, but by their very genetic material and the processes of how future citizens are to be conceived, born or prevented from being born.

Reports on the medical disadvantages of kin marriage have been popularized via public media since the 1980s, turning the idea that marrying one's kin may result in children with congenital health issues gradually into common sense knowledge in Turkey. Over the same period, the reproductive health sector in the country has undergone a major transformation as a result of the introduction and increasing routinization of new reproductive and genetic health technologies allowing for different forms of prenatal diagnosis and, gaining intensity from the 2000s onwards, also assisted reproduction, PGD, and genetic carrier testing. Notwithstanding these developments, kin marriage has remained widely practiced, with the national rate of 23%

of marriages being between close kin (TUIK 2016). Couples with kin marriage have not become the target of health policies singling them out for specifically consanguinity related screening programmes. Rather, the emergence of kin marriage as a genetic health issue has entailed a proliferation of discursive practices which are marked by an emphasis on voluntary risk management and individualized responsibilization. It is this lack of consanguinity-specific health policies and regulations which has likely motivated medico-genetic professionals' perceptions of government inactivity and lenience regarding kin marriage and their call for a more extensive prevention infrastructure.

This chapter seeks to problematize this narrative by exploring the incorporation of kin marriage and genetic risk into premarital health screening, arguing that it reveals the government to be anything but indifferent towards kin marriage and associated reproductive risks. Tracing the changing regulations for the institutionalization of premarital health screening in Turkey, the first part of this chapter discusses the recent reconceptualization process of the examination procedure during the 1990s and 2000s which has placed genetic risk, carrier screening and kin marriage at the heart of the examination. The second part of the chapter has a closer look at how the government envisages premarital genetic risk management to happen in practice. While the reproduction of healthy families and thus a healthy nation body has remained a central concern of the premarital screening procedure, the recent shift to genetic risk management marks a decided concern with the genetic quality of the marital couple and their future offspring which reveals the government's propagated pronatalism to be "selective" (Thompson 2005, Mutlu 2017) as to what kind of children are desired in the name of the nation.

Highlighting the government's concern with genetic risk and its tacit endorsement of selective reproductive risk management to prevent the birth of children with genetic conditions, this chapter contributes to the rich scholarly discussion of reproductive policies and the turn to pronatalism in Turkey. AKP policies regarding the family and reproduction have received wide interest, being the recurring topic of scholarly and public debate. The scholarly literature has focused on family making and reproduction as key areas through which the party seeks to realise its political agenda, consolidate political hegemony and secure social order. Familialist

terminology is central to the framings of citizenship, welfare provision and nationalist imaginations of state and family (Öztan 2014a, b, Yazıcı 2012, Yilmaz 2015) which place biopolitically "healthy" families at the heart of a "strong" nation. Not accidentally, the ruling party's 2012 programme presents the married heterosexual couple as the primary social unit for raising "the mentally and physically healthy citizens with strong moral and ethical values that the new Turkey needs" and promises to implement a social policy that "strengthens the institution of marriage, protects the unit of the family and maintains family values" (quoted after Öztan 2014a, 32-33). Notably, the transformation of the welfare regime under AKP rule has strongly promoted the family as the primary social institution and a key provider of social support complementing the privatization of care services (Buğra and Keyder 2006, Coşar and Yeğenoğlu 2011, Yazıcı 2012).

Significantly, scholars repeatedly speak of a "new politics of the intimate" (Acar and Altunok 2012) or a "new reproductive governmentality" (Altıok 2013) when describing the AKP's approach to reproduction and reproductive health care. They emphasize that the government's management of reproduction and family making marks a distinct shift, a departure from government-endorsed antinatalism which has shaped and dominated developmentalist policy approaches to reproduction in Turkey during the second half of the 20th century (Erten 2015, Gürtin 2016, Toksöz 2011, Unal and Cindoglu 2013, Cindoglu and Unal 2017). These scholars demonstrate how the prevalent religious conservatism and the distinct "neoliberal" quality of the recent turn to pronatalism distinguish the AKP's politicization of family and reproduction from early 20th century Republican pronatalism as propagated by the Kemalist regime.

The ideological endorsement of pronatalism blends well with the conceptualization of the family as a guarantor of social stability and welfare. The iterations of former prime minister and current president Recep Tayyip Erdoğan which demonize birth control and abortion, glorify motherhood as the most sacred responsibility of women, and propagate at least "three-children-per-woman" as a new reproductive ideal are highly visible signifiers of this shift towards pronatalism. As scholars focusing on the new reproductive technology landscape in Turkey (and

Northern Cyprus) remind us, the government's pronatalist turn occurs at a time period of technoscientifically intensified and increasingly commercialized reproductive management (Gürtin 2016, Gürtin, Inhorn, and Tremayne 2015, Gürtin-Broadbent 2013, Mutlu 2011). They have illustrated how the government has legally regulated assisted reproductive technologies in such a way that they do not threaten visions of "healthy" family making nor destabilize the notion of the heterosexual conjugal couple as biological and social father and mother of the child. As Zeynep Gürtin argues, "patriarchal pronatalism" is perpetuated rather than undermined by how accessibility to assisted reproductive technologies has been institutionally inscribed in Turkey (Gürtin 2016, 2011). This placement of reproductive technologies within "conjugal confines" (Gürtin 2016) which seeks to guarantee the maintenance and reproduction of the heteronormative family makes apparent the inherently conditional character of pronatalist policies in Turkey. By sanctioning only certain kinds of reproductive outcomes and family making while banning others, this turn to pronatalism remains deeply "selective" in character (Mutlu 2017).

This chapter builds on and contributes to this rich body of literature detailing the politicization of reproduction in contemporary Turkey and the selectivity of pronatalist policies with regard to family making. It foregrounds notions of "genetic risk" and "genetic quality" as further significant axes of stratification shaping the government's pronatalist discursive practices which do not welcome the births of all future children in an equal manner. I do not intend to make an argument of simple parallelism, describing the recent turn to pronatalism as a mere return to early Republican reproductive policies. Such an argument would easily lose sight of the particularities of the current reproductive policies landscape as well as the major regime transformations introduced under AKP rule. However, this chapter cautions against an unequivocal emphasis on the "new-ness" of the current government's "politics of the intimate" by highlighting how these politics perpetuate a long-standing systematic devaluation of bodies deemed a threat to the "quality" of the population and "health" of the nation.

The Emergence of Genetic Risk as a Target of State Regulation

Before discussing in depth how the examination approaches genetic risk as a threat to healthy family making and how the government departs from its endorsement of pronatalism in light of genetic disease while individualizing the responsibility and, often also, financial burden for active genetic risk management, it will be necessary to historicize the emergence of genetic risk as a target of state regulation. Particularly, I will trace two crucial trajectories which mark this rise of genetic risk as a political concern. The first trajectory is what I describe as the reconceptualization of premarital health screening as a tool of genetic risk management which shifts the focus away from contagious disease containment and early 20th century concerns with public hygiene and seeks to reinvent the examination as a contemporary 21st century counselling opportunity regarding matters of marital health, among them most predominantly genetic risks. The second trajectory concerns the government's gradual endorsement of haemoglobinopathies as a primary public health issue, leading to the launching of the Haemoglobinopathies Control Programme in 2002. Both trajectories have significantly shaped the contemporary regulation of genetic risk and kin marriage within premarital health screening.

The Institutionalization of Premarital Health Screening in Turkey and Its Recent Shift towards Genetic Risk Management

Premarital health screening has been a legal requirement for marriage in Turkey since the early years of the Republic. Articles 123 and 124 of the 1930 Public Health Law (Official Gazette no. 1489) as well as the 1931 Bylaw on the Marital Examination (Official Gazette no. 1904) constitute the legal basis for these examinations. According to these laws, future marriage partners need to undergo a health examination by a medical doctor prior to getting married. Those afflicted by syphilis, gonorrhoea, chancroid, leprosy, and mental illness (*marazı akliye*) are prohibited to marry while those with active tuberculosis first need to seek treatment before entering into marriage. These laws were passed in the aftermath of the Turkish War of Independence during the forming years of the Republic when deprivation, poverty and non-existent health facilities in large parts of the country furthered the spread of still largely incurable infectious and sexually transmitted diseases among a heavily decimated population

newly emerged from war. With the possibility of future wars looming on the horizon, the government greatly feared further loss of the population, decimating the resources for developing the nation and, if necessary, defending its newly drawn borders (Günal 2008, Öztamur 2004).

Although eugenics was never systematically implemented by the Turkish state as a political programme, the introduction of premarital health examinations occurred during a time period when eugenic thinking was popular and well received among Turkish intellectuals and political figures (Alemdaroglu 2005, Ergin 2008, Salgirli 2010). Notwithstanding the particular circumstances of its implementation, the requirement for premarital health screening spoke to the desire to bar those deemed physically and mentally "unfit" and socially dangerous from marriage (and thus socially endorsed reproduction) for the "common good" of the nation. As the very first article of the Public Health Law declares, the state considers it among its public responsibilities "to improve the country's health conditions, to fight against all diseases and other factors which are deleterious to the health of the nation, and to safeguard the healthy upbringing of the future generation (*müstakbel neslin sıhatli yetişmesi*)" (Official Gazette no. 1489).

As this article illustrates, the government's move to subject future spouses to the scrutiny of a state accredited medical professional marked family making and reproduction as primary areas of state intervention for the realization of nationalist goals. Shaping and controlling the transition of subjects into "familial" citizens as "wives" and "husbands" (Sirman 2005), the examinations served as a performative display of the state's capacity to enter the very intimacy of family life. As a biopolitical tool, it was rooted in the government's desire to craft a healthy citizenry out of healthy families. As such, the examination formed part of a whole array of government policies and campaigns which combined the spread of medical services with the inculcation of a nationalist consciousness and nationalist values to raise biopolitically "healthy" generations who were to be both physically strong and ideologically committed to the cause of the Republic. Following the passing of the Public Health Law in 1930, various hygiene and medical education campaigns were launched for villagers under the tutelage of the Etimesgut

clinic and articles proliferated in scientific and popular magazines which sought to cultivate a healthy, rational, clean and scientific-minded citizenry (Dole 2012). These campaigns reveal a new concern for a scientific management of family life and reproduction. Mandatory premarital examinations were introduced, childcare institutions founded and education programmes for mothers launched to teach them the requirements of "modern" motherhood in line with medico-scientific principles (Öztamur 2004, Alemdaroglu 2005). These efforts to educate and train the population in terms of modern, scientific citizenship reveal how medicine acted as a "political technology of social reform" during the early years of the Republic which helped craft new relations between the population and the state, turning people into citizens of the new nation state (Dole 2004, 2012).

Although Turkey experienced several political coups and regime changes during the 20th and early 21st centuries, entailing the passing of new constitutions (1961, 1982) and a new Civil Code (2001), the requirement for premarital health screening remains in place until today. Following the end of military rule in 1982 and predating the passing of major amendments to the Civil Code in 1985 by a couple of months, a new law called the Bylaw on Marriage was passed in 1985 (Official Gazette no. 18921) which specifies the legal aspects of the marriage procedure and ceremony. While the actual conduction of a physical health examination may not have always been strictly enforced, especially in rural areas,[12] Article 15 of the current version of the 1985 Bylaw on Marriage, amended as of 28 July 2003, maintains the obligation to obtain a health report in line with the 1930 Public Health Law and the 1931 Bylaw on the Marital Examination (Official Gazette no. 18921). Similarly, the new Civil Code from 2001 reaffirms the requirement for a premarital health report (Article 136, Turkish Civil Code, Official Gazette no. 24607).

[12] The original version of the 1985 Bylaw on Marriage, whose articles dealing with the premarital examination were significantly amended in 2003 and 2006, included templates for health report forms ("Health Report for Marriage Procedures", *Evlenme İşlemlerine Mahsus Sağlık Raporu*) which contained a particular wording allowing couples living in rural areas to obtain a health report based on their medical records without appearing for an examination in person (Official Gazette No. 18921). These health report templates were abolished when the Bylaw on Marriage was amended in 2003, indicating a possible desire on part of the government to close this loophole. Interviews I conducted with women from rural areas who got married in the 1970s and 1980s also indicated such a non-systematic enforcement of the examination as none of them could remember seeing a physician prior to marriage.

However, the early 2000s mark an emerging desire on part of the government to reform the premarital examination procedure. A circular note issued by the Ministry of Health in March 2002 argues that the legal framework and regulations for premarital health screening, specifically paragraphs 123 and 124 of the Public Health Law "require revision in light of current knowledge and new necessities." These changing necessities and circumstances are further specified in the following and refer to the increasing knowledge and available treatments concerning many infectious and chronic diseases and the changing nature of contemporary diseases (Directory for General Health Services 2002). The circular note suggests that premarital health examinations should be conceived of as an "opportunity for offering a counselling service (*danışmanlık hizmeti*) concerning infectious and genetically transmitted diseases (*genetik geçişli hastalıklar*) which are of increasing significance in our contemporary times" in order to "raise awareness among the people with regard to potential risks (*olası riskler*), consequences and prevention methods" (ibid.). Furthermore, this circular note emphasizes the need for a standardized guidebook which should inform physicians about the examination procedures, laboratory tests, and counselling services they are expected to perform until a reformed legal framework is passed.

It took the government more than 10 years to finally produce such a new regulation concerning the premarital health examinations. In 2014, a circular note on "Premarital Counselling" (Turkey Council of Public Health 2014) was issued by the Ministry of Health which marked the culmination of a process during which premarital health screening was conceptually reworked and implementation-wise reoriented towards a primary focus on genetic risk, without existing laws enforcing the obligatory obtainment of a premarital health report becoming abolished. Putting emphasis on the significance of "robust and healthy" (*sağlam ve sağlıklı*) families for the maintenance of "a robust and healthy" society, this recent circular note echoes the 2002 one in describing the premarital health examination as an opportunity for offering a "counselling service" (*danışmanlık hizmeti*) concerning reproductive health and pregnancy, infectious and genetically transmitted diseases, and family planning. Such a counselling opportunity is said to develop people's "health literacy" (*sağlık okuryazarlığı*) and

render possible "early prevention of health related risks" (*sağlığa yönelik risklerin erken tespiti*). However, whereas the 2002 note envisaged a revision of the legal basis of the premarital health examination, the 2014 one refers to existing legislation, namely the 1930 Public Health Law and article 136 of the Civil Code, prescribing the health report requirement, thus reaffirming these regulations' continuing validity. Significantly, a "Premarital Examination and Counselling Guide" (Ministry of Health 2013b), issued by the Ministry of Health, is attached to the 2014 circular note. This 92-pages strong guidebook consists of two parts, the first one offering guidelines for medical professionals regarding the implementation of the examination and the second one containing information on various reproductive health issues for which counselling should be offered. Attached to the note is also an abbreviated and simplified version of the second part of this guidebook, published as "A Healthy Start into Marriage: Reproductive Health" (Ministry of Health 2014) which is to be given out as a take-away brochure for couples attending the premarital examination and counselling session.

The examination guidelines as envisaged by the Ministry of Health are specified in the 2013 guidebook (Ministry of Health 2013b, 6-24). Examination and counselling are to be conducted at community health centres, public or private hospitals and the prospective spouses should attend the appointment together, unless this is impossible to arrange due to residence in different provinces. They are required to fill in a "Risk Assessment Form" (*Risk Değerlendirme Formu*) which aims at identifying persons facing increased reproductive risks (risk categories include for instance "drug use", "prostitution", or "previous cases of infectious diseases", but also "kin marriage"). The actual examination procedure is to be kept at a minimum level to avoid unnecessary laboratory tests. Medical lab tests for infectious diseases (such as TB, HIV, or hepatitis) should only be conducted if the examining physician strongly suspects the presence of one of these diseases based on the anamnesis or the risk assessment form or in case the couple explicitly requests a specific test (in which case the couple has to pay the expenses). All couples applying for the examination within a province where the government's Haemoglobinopathy Control Programme is being enacted must furthermore undergo carrier screening for thalassemia and sickle cell anaemia, which thus constitute the only tests to be

strictly and systematically performed at premarital level. Significantly, while screening is obligatory in provinces forming part of the Haemoglobinopathy Control Programme, the detection of joint carrier status does not impose an impediment to the couple getting married. Neither does a HIV or hepatitis diagnosis bar a person from marriage. Only the above mentioned diseases specified as impediments to marriage by the 1930 Public Health Law (syphilis, gonorrhoea, chancroid, leprosy, active TB and the vaguely formulated "mental illness") continue to constitute a legal impediment (Ministry of Health 2013b, 11).

The Reconceptualization of the Premarital Examination as an Expression of a Changing Landscape of Public Health Threats and Governance

The reform process of the premarital examination speaks to three different but interconnected efforts. First, there is the desire to account for the changing nature of diseases considered a public health issue. The primary threat no longer stems from those infectious and sexually transmitted diseases which haunted public health authorities back in the 1930s. The availability of treatment options, vaccines and demographic change have long since rendered these diseases largely controllable and manageable in Turkey and the 2002 circular note explicitly refers to this changed landscape of disease treatments. Instead, genetic diseases and contemporary infectious diseases such as AIDS rise to the fore as new public health concerns while the language of the circular notes and the 2013 guidebook mark a corresponding shift in language which emphasizes risk assessment, awareness, and prevention.

During the interim period between the passing of the 2002 and 2014 circular notes, the government sought the advice of medical professionals in its efforts to rework the examination regulations and publish a guidebook. Discussion roundtables took place and the report of one of these roundtables, held in 2002 by members of the Istanbul Medical Chamber, exists in published format (Demirel and Özgen 2002). This report offers valuable insights into the actual reconceptualization process of the examination. Mirroring the government documents' shift away from contagious disease containment towards risk management, the report shows participating medical professionals' conviction that the premarital health examination regulations specified by the Public Health Law are outdated as the diseases it lists as

impediments to marriage have become successfully manageable by modern medicine. In contrast, genetic diseases are discussed as being still largely incompletely understood and diagnosable and premarital counselling and testing for common genetic diseases is recommended. This shift is also expressive of the changing landscape of reproductive health services which, starting in the late 1980s and rapidly increasing in intensity and scope over the early 2000s, have been marked by an expansion and routinization of genetic health facilities and services. The Haemoglobinopathies Control Programme is one highly visible example which I will return to in detail later.

Second, the reform efforts speak to a desire to standardize the examination procedure by introducing official guidelines for implementation, closing loopholes for subversion and minimizing local variations in implementation. As the meeting report of the Istanbul Medical Chamber roundtable reveals, medical professionals back in 2002 were well aware of the existence of such variations as a result of which some couples were subjected to extensive laboratory tests for a whole series of infectious disease such as TB, hepatitis A, B and C, and AIDS, while others obtained health reports without any real examination and medical anamnesis having taken place. The 2013 guidebook states unmistakeably that health reports must only be issued following an examination and that couples must attend the examination in person to get a report. However, seeing how the practical examination regulations specified by the guidebook give great discretionary powers to individual physicians in what to test for based on their personal judgements regarding the likely absence or presence of infectious diseases, it remains doubtful whether standardization will ensue.

Third, the conceptual reworking of the examination procedure as a "counselling opportunity" reveals unease about the coercive character of the examination and a desire to give it a contemporary outline fitting the desired image of a modern, progressive nation in the 21st century. The foreword to the second part of the 2013 guidebook presents the premarital examination as a beneficial citizen service which testifies to the state's relentless commitment to improve reproductive health care (Ministry of Health 2013b, 5). The examination procedure is framed as part of the Ministry of Health's reproductive health programmes which in line with

the guidelines of the WHO seek to provide reproductive health care throughout the life cycle. This reference to the WHO conveys the impression that premarital screening is actually endorsed by the WHO and in line with international health care standards, downplaying the coercive and ethically problematic character of obligatory premarital screening. Thinking along similar lines, the foreword refers to the effective distribution and presentation of this newly published guidebook as an important means to raise the standard and quality of reproductive health services, thus highlighting "service" provision rather than state intervention. The AKP government has reaffirmed the validity of the 1930s laws as the legal basis of the examination. The 2014 circular note explicitly refers to the Public Health Law and in 2003 and 2006 amendments of the 1985 Bylaw on Marriage were passed which reintroduced previously absent references to the 1930s laws as the main guidelines for the issuing of premarital health reports. Seeing this continuing commitment to these early laws, the euphemism of the "premarital counselling" rebranding becomes all the more apparent.

The Ministry of Health's 2002 circular note which marks the emergent desire of the government to rework the examination procedure predates the AKP's rise to power in November 2002. However, the main reform procedure and efforts fall squarely within AKP rule. Both the 2014 note and the preface of the guidebook (Ministry of Health 2013b, 5) bear the hallmark of the AKP's ideological politicization of the family. Both contain an identical paragraph praising the significance of "healthy families" as the fundament upon which a "robust and healthy" society rests. Stressing the social importance of marriage, this paragraph also argues that healthy future generations are to be born and raised within the heterosexual, married family. The paradoxical presentation of the examination as a counselling *opportunity* and health *service* while in fact it constitutes a form of enforced state intervention into the intimacy of family life and reproduction fits well with the AKP's approach to family and reproduction as significant sites for the realization of socio-political change and the anchoring of party hegemony. Maintaining the examination as a crucial moment offering the government the opportunity to shape, control and ideologically invest in healthy family making speaks to the party's political line. Rebranding the examination as a counselling opportunity, however, masks

this politicization of the family while signalling the much celebrated spirit of progressive departure and political opening which characterized the early 2000s. Those years had been marked by the government's endeavours to perform a visible departure from the troubling past of the 1980s and 1990s, softening the Kemalist ideology, reducing the legacy of military rule and moving towards the West and the EU (Insel 2003). Presenting the reformed examination as proof for the high quality of reproductive health care in Turkey thus furthered the cause of having Turkey internationally acknowledged as a prime model of a modern, democratic country.

Premarital Haemoglobinopathy Carrier Screening and the Haemoglobinopathy Control Programme

The premarital health examination's shift towards genetic risk management intersects with a second trajectory of public health policies in Turkey, namely the prevention campaign regarding thalassemia and sickle cell anaemia, two genetically inherited blood diseases. Both diseases are characterized by structural changes of the haemoglobin molecule, as a consequence of which they are classified as haemoglobinopathies. Different forms of thalassemia exist, beta-thalassemia being the most common form of thalassemia in Turkey with incidence rates ranging from 2.1% to 13.1% depending on the region (Canatan et al. 2006, Erdem and Tekşen 2013). There are different levels of severity in beta-thalassemia but people affected by it usually suffer from a lack of beta-globin, leading to reduced oxygen in the blood and a shortage of red blood cells. The second most common haemoglobinopathy in Turkey is sickle cell anaemia the incidence rate of which is about 10% in the Çukurova region of Southern Turkey (Çürük et al. 2008). It is caused by atypical haemoglobin molecules leading to the formation of sickle shaped red blood cells which hinder the provision of oxygen-rich blood to the body's tissues and organs. As a consequence, people affected by sickle cell anaemia suffer from swelling, pain in the limbs, anaemia, an increased risk for stroke and heart attack and other severe consequences.

The guidebook for the premarital examination describes haemoglobinopathies as "a significant public health problem" (*önemli bir halk sağlığı sorunu*) in Turkey and lists 33

provinces[13] (out of Turkey's total 81 provinces) where premarital carrier screening for these two diseases is systematically conducted for all incoming couples (Ministry of Health 2013b, 58). These provinces are concentrated mainly in Turkey's major cities as well as the Aegean and Mediterranean coastal strips. The implementation of such a massive genetic screening infrastructure, officially known as the Haemoglobinopathy Control Programme (*Hemoglobinopati Kontrol Programı*), as part of premarital health evaluations did not emerge overnight. Rather, it was the result of decades of biomedical research, medical professionals' campaigning efforts and governmental legislation during the second half of the 20th century.

The early beginnings of Turkey's haemoglobinopathy screening programme date back to the mid-1950s when Muzaffer Aksoy, an Antalya-born haematologist who received his medical education and training in Istanbul and Boston from well-known internists and haematologists like Erich Frank and William Dameshek, published his pioneering work on sickle cell anaemia in Turkey. His early publications (Aksoy 1955, 1956, Aksoy et al. 1958) present his findings regarding previously unknown high incidence rates of sickle cell anaemia and sickling trait among Alawi families living in Turkey's Eastern Mediterranean provinces. Throughout the 1960s and 1970s, he conducted much follow-up research on haemoglobin variations, mostly sickle cell trait and different forms of thalassemia traits, among Turkish and Alawi communities in Southern Turkey (Aksoy 1961, 1970, Aksoy, Dinçol, and Erdem 1978, Erdem, Aksoy, and Çetingil 1966).

While significantly influencing haemoglobinopathy research in and on Turkey, Aksoy's work has been of particular influence in shaping research activities and campaigning efforts by medical professionals in Turkey's Çukurova region where Aksoy had conducted most of his studies. During the 1980s and 1990s, local haematologists such as those at Çukurova University in Adana engaged in extensive campaigns to raise the local population's awareness, extend treatment infrastructure and lobby the government for recognizing thalassemia and sickle cell anaemia as national health problems requiring control through targeted health policies (Yürür 2005, 17). Campaigning proved to be fruitful. The government officially recognized thalassemia

[13] As of 2018, the number of provinces in which mandatory premarital haemoglobinopathy carrier screening is conducted has been increased to 41 (Ministry of Health 2018).

and sickle cell anaemia as public health concerns by passing the Law for the Fight against Inherited Diseases in 1993 (Official Gazette no. 21804) which defines the prevention of haemoglobinopathies and "other inherited diseases which cause impairment/handicap" (*özürlülüğe yol açan diğer kalıtsal hastalıklar*) as a matter of state responsibility.

Following the issuing of the law, a pilot project was launched. It envisaged the establishment of diagnostic and treatment centres for haemoglobinopathies in the southern provinces of Antakya, Antalya, Mersin and Muğla and the institutionalization of voluntary premarital carrier screening (Canatan 2011, 2014) which was gradually expanded to other areas in the region and became compulsory in Mersin, Hatay and Adana in 1999 (Tosun et al. 2006). Between 1995 and 2000, the Ministry of Health conducted a screening survey in the Aegean, Marmara and Mediterranean regions of the country to establish prevalence rates. In 2001, together with the Turkish National Haemoglobinopathy Council founded back in 2000, the Ministry of Health produced a national inventory of registered patients with haemoglobinopathies (Canatan 2011, 2014). All of these policies and data collection initiatives culminated in the launching of the Haemoglobinopathy Control Programme in May 2003. This programme became active in first 33 and by now 41 "high-risk" provinces in the Thrace, Marmara, Aegean, Mediterranean and South Eastern regions of the country, selected by the Ministry of Health and the National Haemoglobinopathy Council due to their high prevalence of severe haemoglobinopathies. As part of a multi-level diagnosis and treatment infrastructure, compulsory premarital carrier screening was implemented and gradually expanded in these provinces. Following the start of the Haemoglobinopathy Control Programme, the Ministry of Health and the Thalassemia Federation (the successor organization of the National Haemoglobinopathy Council) also started large-scale awareness, education and training campaigns in areas covered by the Programme.

According to official data produced by the Ministry of Health, the Haemoglobinopathy Programme has been very effective, reducing the number of affected births by 90% between 2002 and 2008 (Canatan 2011). As very few couples opt against marriage after learning about joint carrier status (Gali 2001, Savas et al. 2010), these data suggest that couples actively

engage in active risk management. However, the statistical data issued by the Ministry of Health needs to be approached with caution. Non-governmental data concerning the impact of the Haemoglobinopathy Control Programme is noticeably rare. A recently published evaluation of the screening programme issued by the Turkish Society of Paediatric Haematology questions the accuracy of the government-produced data (Aydınok et al. 2018). Based on a compiled registry of 2000 patients from 27 different haemoglobinopathy screening centres across the country, their study indicated no significant changes in the rate of affected births between 2003 and 2009, with a noticeable, gradual decrease in the rate only emerging from 2009 onwards which is much slower, however, than the one suggested by government graphs (ibid., 16). The authors of the study explained the discrepancies between their findings and the data issued by the Ministry of Health with reference to insufficient reporting of new cases to the official registry of the government. Instead of relying on the government's registry, the authors of the study had set out to produce a new one drawing on multiple haemoglobinopathy centres in the country.

Any evaluation of the screening programme which, like the study cited, conceptualizes "efficacy" primarily in terms of "prevented births" remains highly problematic, propagating a eugenic approach to reproduction and falling short of taking into account the complexities involved in the decisions that couples at risk have to make regarding their reproductive futures. However, the study refers to the programme as a "failure" (ibid., 12) not only because it fell short of desired prevention outcomes. It also reveals that couples after undergoing screening were regularly either misinformed or not informed at all about their actual risks. Roughly 40% of the couples with at least one affected child who had been premaritally screened had either received no feedback about their joint carrier status or were wrongly informed to be not at risk of having a child affected by a haemoglobinopathy (ibid., 15). Furthermore, the study highlights discrepancies regarding the density of the screening infrastructure, suggesting that especially in the Eastern and South Eastern provinces of the country participating in the Control Programme a significant rate of couples slipped through, getting married without premarital haemoglobinopathy screening (ibid., 15). Similar geopolitical discrepancies also appear to exist

regarding access to prenatal and preconceptional risk management services, a point I will come back to later.

This disjunction between the conceptualization of the screening procedure as a systematic tool of reproductive risk management and the inconsistencies of its practical implementation do not necessarily point to indifference on part of the government regarding the prevalence of haemoglobinopathies in the country. As Michelle Murphy has argued, even if governments or implementing bodies do not follow up on the change or results affected by population level "experiments" (as is often the case), what remains crucial is the establishment and reproduction of an epistemic infrastructure of experiment (Murphy 2017, 91). In the case of Turkey's premarital screening programme, this infrastructure reproduces the presence of the state within the intimacies of citizens' everyday lives. As their genes become exposed to the probing gaze of the state apparatus, information about genetic risk is collected which is then regularly fed back to the government (but not necessarily to the couples as the above cited study suggests). However, the screening infrastructure involves a variety of actors, some of whom, such as the implementing physicians, may not necessarily identify with the government and its priorities. Those on the ground, who are charged with conducting the examination and screening, may not all bring their full care and attentiveness to the realization of state bureaucratic procedures which they have to deal with in addition to other responsibilities. It is the very banality and bureaucratic nature of the screening procedure which furthers its normalization but also turns it into a site of easy neglect.

Although premarital haemoglobinopathy screening was quickly expanded during the early 2000s, the initial focus of the haemoglobinopathy prevention campaign concentrated on the Eastern Mediterranean region of Turkey, specifically the Çukurova region, where many Alawi families are living who share close cultural, linguistic and religious links with the Alawites of Syria. The above mentioned pioneering work conducted by the Turkish haematologist Muzaffer Aksoy in the 1950s to 1980s has brought the Alawi in Turkey to international biomedical attention by tracing the high prevalence rate of the sickle cell trait among them (Aksoy 1962, 1955, Aluoch et al. 1986). However, his research findings have not

been explicitly translated into the Haemoglobinopathy Control Programme's implementation structure. As a population screening procedure, the premarital examination targets all couples intending to get married, irrespective of the couple's age, kinship relation, or ethnicity. The only axes of differentiation are the place of registered residence (which is decisive in whether or not haemoglobinopathy screening is implemented) and obviously a couple's actual intention to get married. The Ministry of Health describes sickle cell anaemia and thalassemia in general terms as a significant national public health concern and as "the two most commonly observed inherited blood diseases in our country" (Ministry of Health 2013b, 58). Notwithstanding the absence of ethnicity-specific targeting, the examination procedure is caught up in processes through which internal otherness is managed and hegemonic Turkishness reproduced. Both the examination guidebook and the Bylaw on the Haemoglobinopathy Control Programme (Official Gazette no. 24916) explicitly refrain from mentioning the fact that sickle cell anaemia is predominantly prevalent among Alawi families.

Keeping in mind the racializing and stigmatizing effects of sickle cell anaemia screening in the US which exposed black communities to discriminatory targeting and exclusion while perpetuating the notion of sickle cell anaemia as a disease of the "black body" (Duster 2003, Tapper 1995, 1999, Wailoo 1999, 2001), the reluctance on part of the Turkish Ministry of Health to introduce ethnicity-based screening constitutes a striking contrast. While it may reveal a possible sensitivity to the racializing and stigmatizing potential of ethnic targeting practices, Kızılca Yürür has argued that this reluctance constitutes a political silence on part of the government which harks back to nationalist anxieties (Yürür 2005). The Alawi have historically lived in a geopolitically contested region, namely the Eastern Mediterranean province of Hatay which borders on Syria. This province became part of the Turkish Republic comparatively late, in 1939, following a highly politicized and contested referendum. The Alawi's linguistic and religious ties to the Alawites in Syria were deemed a politically destabilizing element, exposing the shakiness of Turkish hegemony in the area, and thus officially denied by the government (ibid., 50ii). Government discourse systematically referred to the Alawi as "Eti-Turks", literally

meaning "Hittite Turks"[14]. This term, which has found entry into biomedical discourse because it was adopted by Aksoy in his much cited research articles, sought to emphasize the community's genuine Turkishness and downplay any links to Alawites living in Arab countries.

Writing his articles, Aksoy was well aware of the sensitive nature and potential political implications of his findings which might destabilize the political hegemony of Turkishness as the encompassing national identity for all Turkish citizens. Although published in the early days of population genetics, his articles are marked by a consistent interest as to how the high incidence of the sickle cell trait among Alawi families, which proved to be unparalleled in the rest of Turkey's population (Aksoy et al. 1958, Tadmouri et al. 1998, Aksoy 1962), could be interpreted in terms of ancestry and population admixture. His subsequent publications, both co-authored and single-authored, are marked by a careful interpretation of genetic data gained from the comparative analyses of haemoglobin variation and blood group patterns of Alawi and Turkish sample groups. Downplaying aspects of the data which suggest potential ancestral links with Middle Eastern and African population groups while highlighting similarities between "Turkish" and "Eti-Turk" genetic data as well as general genetic overlap with European populations (Aksoy et al. 1958, Aksoy 1961, Aluoch et al. 1986), his publications embed the genetic findings within origin narratives that do not destabilize notions of hegemonic Turkishness while carefully positioning Turkey in a desired position within the highly stratified "family of nations" (McClintock 1995).

The government's decision to avoid any references to ethnicity-specific discrepancies in risk must be contextualized with regard to the complex positionality of the Alawi within Turkey. It constitutes a strategic silence which is informed by long-standing nationalist fears that genetic data might be read as offering "biological proof" for identity claims challenging hegemonic Turkishness. However, as Yürür's ethnographic fieldwork concerning sickle cell anaemia among Alawi communities has shown, these communities themselves, including Alawi medical professionals, are opposed to ethnicity-based targeting approaches (Yürür 2005, 46-47).

[14] This terminology draws on early Republican historiography which had sought to consolidate the break with the Ottoman past by presenting the Hittite civilizations of ancient Anatolia as civilizational predecessors of modern Turkey (White 2002, 34).

They fear not only stigmatization but also neglect on part of the government should sickle cell anaemia be primarily coded as a "minority issue" (ibid., 61). Thus, they are highly aware that visibility does not necessarily amount to the acknowledgement of rights and the granting of legitimacy, but may also enhance surveillance and vulnerability (Star and Strauss 1999). Rejecting ethnicity-based framings of the disease, many lay people and professionals of Alawi identity prefer geographic explanations of susceptibility which link the sickle trait to the commonness of malaria in the Mediterranean region against which it offers certain protection. Thus, they turn the trait into a proof for belonging to the land, making it assume the quality of a socio-political legitimacy in claiming the land one naturally belongs to through ones ancestors (Yürür 2005, 67-68). As Yürür argues, these explanatory framings also serve as a means to detach genetic risk from cherished socio-cultural practices such as endogamy and kin marriage (ibid. 8) which are often cited by the biomedical literature as a significant factor contributing to the high prevalence of haemoglobinopathies among Alawi families (Aksoy 1955, Tosun et al. 2006).

Turkey is not unique in implementing a premarital haemoglobinopathy carrier screening programme. Similar mandatory or voluntary screening programmes have been launched since the 1970s in several Mediterranean, Middle Eastern and Asian countries (Alswaidi and O'Brien 2009, Hadjiminas 1994, Hoedemaekers and Ten Have 1998). While Turkey could even be considered a relative late-comer in institutionalizing such health policies compared to other Mediterranean countries such as Cyprus or Italy, its haemoglobinopathy screening programme constitutes a continuation of a much longer established practice of state controlled medical intervention into family making and reproduction. While transporting the existing desire to bar those deemed mentally and physically unfit from marriage and reproduction into the 21st century, the premarital examination's reconceptualization process with its recent shift towards genetic risk management and haemoglobinopathy carrier screening also marks the emergence of novel dynamics. It appears to indicate a growing concern with genetic relatedness which expands "healthy" family making beyond the legally sanctified institution of the married (heterosexual) couple by introducing notions of "healthy" relatedness, kinship and ancestry.

Producing "Averted Birth": Selective Pronatalism and Genetic Risk Management within the Context of Premarital Health Screening

In the following, I will have a closer look at how kin marriage, genetic risk and haemoglobinopathy management have become incorporated into the premarital examination procedure based on a close reading of the "Premarital Health Examination and Counselling Guide" attached to the Ministry of Health's 2014 circular note. Published originally in 2013 by the Ministry of Health, this guidebook was compiled by a committee of representatives from universities, research hospitals, medical institutions and ministry representatives. As I argue, genetic risk management as envisaged by the examination and counselling guidelines is marked by an individualized responsibilization of at-risk couples in the name of the nation's overall well-being and economic advancement. The guidebook reveals a departure from the AKP's generally propagated pronatalism and politicized demonization of abortion as a sin against the nation. It encourages couples facing increased reproductive genetic risk, due to kin marriage and/or detected joint carrier status, to opt for prenatal selective technologies. The guidebook thus signals a prioritization of "quality" rather than sheer "quantity" of offspring and an emphasis on healthy family making which rests on a close articulation of genetic disease and disability which are presented as a burden and threat to the health of the nation.

Governmental Framings of Kin Marriage as a Genetic Risk Factor

Although individual physicians may well have counselled incoming couples on the risks of kin marriage beforehand, the publication of the guidebook and its attachment to a government issued regulatory note signal the official integration of kin marriage into premarital health screening, turning the practice into a target of a nationwide implemented and government supervised reproductive health policy which allows the state to monitor relatedness as a public health concern. This incorporation of kin marriage into premarital health screening occurs at different levels of the procedure, namely in the form of data collection as part of the examination bureaucracy and within the context of premarital counselling.

According to the guidebook, couples wishing to obtain a premarital health report first have to fill in a "Premarital Health Report Application Form" (*Evlilik Öncesi Sağlık Raporu*

Başvuru Formu) (Ministry of Health 2013b, 16). This form asks for their personal data, their consent for laboratory tests for infectious diseases if those are deemed necessary by the examining physician and their consent regarding the sharing of test results with their future spouse. The personal data section explicitly asks for kin marriage status and, if existent, the degree of relatedness between the spouses. Based on couples' personal information, statistical data is collected about the number of applying couples, their age group, educational background and kin marriage status which in line with the regulations of the 2014 circular note is regularly reported back to the Ministry of Health's Department of Women's and Reproductive Health (attachment no. 3, Turkey Council for Public Health 2014). Furthermore, prior to the actual examination, couples are requested to tick relevant boxes in a "Risk Assessment Form" (*Risk Değerlendirme Formu*) (Ministry of Health 2013b, 17) which lists "kin marriage" among several categories of risky behaviour such as drug use, engagement in sexual activity in exchange for payment, a family history of tuberculosis, Hepatitis B or "severe psychiatric disease", or previous suicide attempts, many of which indicate stigmatized risk groups. In short, a couple's kinship relation is treated as important and valuable statistical data which already has to be disclosed at the level of initial application before the actual examination takes place. Second, kin marriage is classified and treated as a form of risky lifestyle behaviour, revealing a medicalized and potentially pathologizing conceptualization of kin marriage which dissociates it from the complex socio-cultural environment within which it is practiced as a form of family making.

The introduction of comprehensive premarital health counselling constitutes one of the major ambitions of the examination's reconceptualization. The second part of the guidebook is devoted exclusively to the issue of counselling, discussing in detail the various topics for which counselling should be offered which encompass issues of reproductive health, family planning, kin marriage and genetic conditions, infectious and sexually transmitted diseases, and mental health. The introductory section of the guidebook's second part stresses the importance of premarital counselling for the creation of a protective, harmonious and affectionate "home" (*yuva*) within which "healthy generations" (*sağlıklı nesiller*) will be able to thrive and grow up

properly (Ministry of Health 2013b, 26). It idealises the nuclear family, defined as the married, heterosexual couple and their children, as a private haven of love, peacefulness, mutual trust and affection. This depiction masks the gendered power inequalities which have sustained this image of the family (Sirman 2005) and which have been aggravated rather than alleviated by the AKP's conservative family policies (Coşar and Yeğenoğlu 2011, Güneş-Ayata and Doğangün 2017). As the recurring emphasis on the significance of marriage and "healthy" family making throughout the guidebook illustrates, premarital counselling and screening are not only about enhancing and consolidating the physical or mental health of the couple; they are also about affirming the "healthiness" of marriage as a gendered institution upon which the government's vision of an ideal society rests. In other words, the premarital examination procedure is just as much about protecting marriage from the threat of reproductive health risks as it is about protecting the institution of marriage as such. As a ritual of the state, it affirms marriage as the only legitimate space within which "healthy" sexuality, reproduction and family making are to take place while highlighting the central role of biomedicine in safeguarding the making of healthy families.

"Risk" (*risk*) emerges as a crucial concept of the new counselling approach endorsed by the government, as is for instance emphasized by the above mentioned "Risk Assessment Form" (*Risk Değerlendirme Formu*) to be used during the examination (Ministry of Health 2013b, 17) or by the 2014 circular note's statement that the "premarital counselling services" will ensure the uptake of necessary health measures by providing "early identification and treatment of risks" (*risklerin erken tespiti, tedavisi*) (Turkey Council of Public Health 2014). As a prominent keyword, "risk" appears a staggering 41 times and an additional 21 times in the adjective form "risky" (*riskli*) in the guidebook. A section of the guidebook's counselling part is devoted to "Kin Marriage" and its associated genetic risks (Ministry of Health 2013b, 61-62), another one to the reproductive risk management measures implemented by "The Control Programme for Inherited Blood Diseases" (ibid., 58-60).

The section on kin marriage frames the practice exclusively in medical terms, bracketing its embeddedness within socio-cultural dynamics of family making as well as

processes of socio-economic change. In other words, the Ministry of Health is concerned with kin marriage exclusively as a genetic risk factor. The section emphasizes the link between consanguinity, genetic disease and disability, adopting a medicalized conceptualization of "disability" framed as "handicap" or "impairment" (*özürlülük*) which treats it as interchangeable with "disease". It states that kin marriage is "a condition which significantly impacts on the epidemiology of genetic diseases" (*genetik hastalıkların epidemiyolojisini oldukça etkileyen bir durumdur*) (ibid., 61). While the section does not present kin marriage as generally causing "disability", a grossly simplifying trope which is much reproduced by the public media in Turkey, it argues that consanguinity between spouses is associated with a couple's roughly doubled risk (8 to 9%) of having a "handicapped" (*özürlü*) child (ibid., 61). Obviously, these population-level risk statistics say little about the actual risk of individual couples who may face a much higher or lower probability depending on their medical family histories, degree of relatedness and previous reproductive health issues. However, the guidebook does not elaborate on this discrepancy between individual and macro-level risk.

It does, however, specify the impact of consanguinity in terms of reproductive risk by explaining the inheritance pattern and risk probabilities of autosomal recessive genetic diseases. The guidebook thus introduces genetic language by referring to "genes" (*genler*) and "chromosomes" (*kromozomlar*) through which the "mother's and father's characteristics" (*anne babanın özellikleri*) become transmitted to the child and by stating that couples who come from "the same lineage" (*aynı soydan*) have similar "genetic characteristics" (*gen özellikleri*). It explains the recessive inheritance model relevant to kin marriage by pointing out that both parents need to be "carrying" (*taşımak*) the same "damaged gene" (*bozuk gen*) in order for a child to be born with a genetic condition (ibid., 61). However, as the guidebook emphasizes in the following, the children of a couple being joint carriers may also be healthy (*sağlıklı*) if they get "the undamaged gene" (*sağlam gen*) from both mother and father, or they may end up being carriers (*taşıyıcı*) like their parents if they inherit "one undamaged and one diseased gene" (*bir sağlam bir hastalıklı gen*) (ibid., 61). Significantly, carriers are distinguished from healthy children because "they may transmit the disease to the next generation", and "once they get

married they may themselves have a sick (*hastalıklı*) child". Once again highlighting the importance of marriage as a precondition for reproduction, such a framing turns risky relatedness into a threat to the health of whole generations of the future population. The trope of population level threat resulting from kin marriage is most pronounced in the section discussing blood diseases. It describes thalassemia and sickle cell anaemia as a "serious public health concern" and as "the most common blood disorders" in the country (ibid., 58). High kin marriage rates are cited as one of the major factors contributing to high prevalence rates of these diseases in Turkey.

Seeing the great emphasis which the guidebook and the reconceptualization of the examination place on counselling as a strategy of risk prevention through consciousness raising, the high technicality of the language used is striking. The explanation of the link between genetic risk and kin marriage does not offer an explanatory communication of basic genetic concepts, thus presupposing a considerable level of genetic literacy to adequately make sense of and understand the condensed references to genetic inheritance, risk and consanguinity. Keeping in mind how counterintuitive and possibly even alien genetic notions of relatedness and inheritance may feel for some incoming couples (as explored in more detail in chapter 4), the effectiveness of genetic risk counselling as envisaged by the guidebook remains more than doubtful.

Selective Pronatalism: the Government's Tacit Endorsement of Selective Reproductive Technologies

While premarital health screening has enabled the Turkish state's intervention into reproduction and family making since the early years of the Republic, the recent shift to genetic carrier screening and risk management has introduced a new genetic quality to this intervention. Genetic screening confronts individuals with a newly "revealed genetic identity" (Armstrong, Michie, and Marteau 1998), thus introducing a new form of genetic responsibility in the face of risk probabilities (Novas and Rose 2000). The process of learning about one's reproductive health risks is not a neutral one as it creates changes in a person's sense of selfhood and a moral obligation to act responsibly by minimizing the risk (Douglas and Wildavsky 1982, Petersen

and Lupton 1996). Such reproductive genetic risk management is rendered possible by a whole array of prenatal technologies and services which turn conception and pregnancy into fields of moral negotiation, selective evaluation and technological assistance, thus fundamentally altering the processes through which desired and undesired forms of life are differentiated, kinship is conceived and the family (un-, re)made (Rothman 1988, Franklin 1997, Rapp 1999, Thompson 2005). Significantly, although these reproductive technologies and their implications may be experienced as highly individualized, they are often shaped by the socio-economic realities and political agendas of the nation state as well as inequalities of the global world order (Anagnost 1995, Browner and Press 1995, Ginsburg and Rapp 1991).

The Turkish government does not seek to deprive couples facing genetic risk of their right to get married. The presence of genetic carrier status indicating a reproductive risk for genetic disease does not pose an impediment to marriage. As the examination guidebook clearly states in line with the existing legal framework, only the diseases listed by the 1930 Public Health Law will prevent the issuing of a marital health report (Ministry of Health 2013b, 11). Genetic diseases do not figure on that list. Furthermore, as highlighted by the guidebook, the guidelines of the Haemoglobinopathy Control Programme explicitly protect the right of a couple with joint haemoglobinopathy carrier status to get married and have children (ibid., 15, 20). However, while the examination procedure may not explicitly enforce eugenic regulations barring the genetically "unfit" from marriage and reproduction, it performatively acknowledges and enforces the state's right to know about and citizens' duty to disclose their respective genetic risks for haemoglobinopathies as part of their transition to marriage. According to the Turkish Civil Code, a person may sue for the annulment of marriage if the marital spouse has concealed the existence of a disease which poses a serious health threat to the partner or offspring (Article 150, Turkish Civil Code, Official Gazette no. 24607). This legal regulation as well as the examination procedure highlight future spouses' obligation to mutually inform the other about the presence of potential health threats as far as they are known or can be made known.

While thus not prohibiting couples with genetic risk to get married, the government seeks to encourage at-risk couples to make use of strategies for active risk management in order to prevent the birth of children with genetic conditions. Selective prenatal technologies and medical termination of pregnancies in case of genetic disease are explicitly endorsed by the Ministry of Health, revealing the government's approval of reproductive genetic health services which are implicitly eugenic in character in how they aim at improving the population's gene pool through means of selective reproduction. The examination guidebook classifies couples with kin marriage and/or a family history of genetic conditions as "high risk pregnancy" (*yüksek riskli gebelikler*) groups (Ministry of Health 2013b, 36-37) and recommends that these couples should be referred to genetic and preconceptional counselling (ibid., 62). Furthermore, such at-risk couples should be advised to seek close medical supervision during pregnancy and opt for prenatal services so that "cases of impairment/handicap" (*özürlülük durumları*) may be detected early on and if possible avoided (ibid., 62).

The guidebook also specifies a list of "the most common diseases encountered in kin marriages" which includes specific conditions such as blood diseases or the metabolic disorder phenylketonuria but also vague umbrella terms like "mental retardation" (*zekâ geriliği*) or "physical defects" (*vücut yapısındaki bozukluklar*) (ibid., 62). It frames the birth of a child affected by these conditions in exclusively negative terms. Such children are described as a "burden to society and family" and their reduced life quality as well as their dependence on medication and care are listed as generating significant financial and emotional strain on their parents (ibid., 62). The template of the consent form for premarital haemoglobinopathy screening which is included in the guidebook argues along nearly identical lines. It justifies the institutionalization of premarital carrier screening with reference to the financial costs of lifelong treatment and the difficulties these diseases inflict on families. It says, "to prevent the birth of a sick (*hasta*) child, it is necessary that couples undergo carrier testing prior to marriage and that couples who are identified as being joint carriers make use of genetic counselling before they have a child. When keeping in mind how difficult and expensive the treatment of these diseases is and how problematic they are for the family and the child, the need for

prevention becomes more easily understandable" (ibid., 20). The counselling chapter on haemoglobinopathies further specifies how prevention is conceptualized. A combination of consciousness-raising, population level screening for the identification of carriers, genetic counselling and the use of prenatal diagnostic technologies to detect affected foeti during pregnancy is referred to as the "most effective method" to control these diseases (ibid., 58). The recommended prenatal diagnostic technologies are furthermore specified as amniocentesis, cordocentesis or chorionic villus sampling (ibid., 59).

Significantly, the guidebook's discourse is marked by a slippery language which moves seamlessly between "disease" (*hastalık*) and "impairment/handicap" (*özürlülük*). Kin marriage is introduced as an important factor impacting on "genetic disease epidemiology" (*genetik hastalıkların epidemiyolojisi*) but also presented as facilitating the birth of and "impaired child" (*özürlü çocuk*) (ibid. 61). Tellingly, when speaking of disability, the guidebook systematically employs the term *özürlülük*, carrying meanings of "defectiveness", "impairment" or "handicap", instead of the term *engellilik* which corresponds to the rights-based, non-medicalized concept of "disability". As stated above, the list of "diseases" most commonly associated with kin marriage (*akraba evliliklerinde en sık rastlanan hastalıklar*) includes ableist formulations like "mental retardation" (*zekâ geriliği*) or "physical defects" (*vücut yapısındaki bozukluklar*), evoking intellectual and physical disabilities which are simultaneously medicalized as a form of "disease". Similarly, the framing of the legal text of the Law for the Fight against Inherited Diseases closely articulates "inherited disease" (*kalıtsal hastalık*) and "impairment/handicap" (*özürlülük*) by describing the former as a direct cause for the latter (Official Gazette no. 21804). Such slippery language is not confined to governmental discursive practices; it was also much reproduced by the professionals interviewed during fieldwork for this thesis as the fifth chapter will explore in more detail. Its pervasiveness indicates the dominance of medicalized framings of disability throughout medico-genetic space in Turkey. By discussing genetic risk and disease in relation to constructions of disability, this thesis does not seek to reproduce the medicalization of disability which has been criticized by disability scholars as contributing to the oppression of people with disabilities (Shakespeare 2005, 1998). Rather, it treats the very

slipperiness of the concepts as encountered in medico-genetic space as central to the processes through which ableism is reproduced within medical and state infrastructures in Turkey.

Evoking the efficacy of disease prevention vis-à-vis the financial burden of genetic disease, the guidebook speaks to the established biomedical discourse on haemoglobinopathies in Turkey. Biomedical articles regarding haemoglobinopathy control in Turkey reproduce this calculative logic which presents the implementation of a screening infrastructure for the prevention of affected births as more sustainable for the country's economy and the family than lifelong treatment for affected individuals (Beksac et al. 2011, Tosun et al. 2006). These calculations frame the affected newborn as "better-not-born" or "better-to-have-never-lived", replacing it with the figure of "averted birth" (Murphy 2017). This figure acts as a hallmark of what Michelle Murphy describes as the "economization of life"; it is a produce of abstract quantification which differentially values and governs life depending on its ability to contribute to the fostering of the nation's economy (ibid.). Such quantification which conceptualizes life and disease at the aggregate level of the population cannot but conceive of "aggregate solutions" in the form of biopolitical population-directed measures (Casper and Moore 2009, 67). Aiming at "averting" births, the screening infrastructure of the premarital examination, however, does not only define certain lives as disposable because of their harmful impact on family and society; it also "casts a shadow over living people who were also better-not-born"(Murphy 2017) .

Disability scholars have criticized how selective reproductive technologies perpetuate the "long and unsettling history of discrimination against people with disabilities" (Gammeltoft and Wahlberg 2014, 5), contributing to the medicalization and marginalization of disability in society (Asch 2001, Ettorre 2000, Lippman 1991, Shakespeare 1995, 1998). The government's endorsement of selective reproductive technologies as a means to achieve healthy reproduction and prevent the birth of children affected by genetic disease forms part of this history. So does the framing of kin marriage as a facilitator of variously framed inherited diseases or disabilities which burden state and family and drain the nation's resources. What is striking is the explicit departure from the AKP's marked propagation of pronatalism which the government's

suggested risk management approach amounts to. President and former prime-minister Erdoğan has repeatedly triggered heated discussions in the country by publicly emphasizing his pronatalist stance, demonizing pregnancy termination and birth control as sinful acts against the nation, glorifying motherhood and stressing the national goal of at least three-children-per-woman (Acar and Altunok 2012, Kılıç 2010, Öztan 2014a, Yilmaz 2015). Geneticists I interviewed repeatedly referred to the mounting difficulties women face when trying to have an abortion at a public hospital in the absence of explicit medical causes. They also repeatedly blamed the government's religious conservatism and pronatalist ideology for what they considered to be a growing rate of couples opting out of routine prenatal diagnostic screening tests like the nuchal scan. One family doctor I interviewed explicitly criticized the government of caring more about quantity than quality of offspring. As he put it, "the sole policy is about increasing reproduction, increasing the number of the children. But this is wrong; everybody should only have as many children as they can look after, the child should be brought up in good quality (*herkes bakabileceği kadar çocuk sahibi olmalı, kaliteli yetişsin çocuk*)."[15]

These narratives may omit from view how the AKP's propagated pronatalism rests on a tacit endorsement of healthy children as the desired norm. The politicized idealization of motherhood and the multi-child family does not extend to the birth of children with genetic conditions who are perceived as a potential threat to the well-being of society and family. In other words, the government's pronatalism is in itself highly selective as to what births are desired. This selective nature of the AKP's pronatalism, however, is easily pushed towards invisibility by the government's otherwise manifest anti-abortion stance. The examination guidelines offer a glimpse of the government's endorsement of selective reproductive policies in the face of genetic risk and disease, but mostly this endorsement of selective pronatalism remains a haunting presence of the government's politicization of reproduction. It surfaces only as the abject that is negated, marginalized and silenced by the government's emphasis on "healthy" family making and reproduction. Throughout the guidebook, the significance attributed to "healthy" families and "healthy" reproduction is highlighted. Already the preface

[15] Male family doctor in his 40s, working within the public health sector in Adana. Interview conducted in Turkish by author, 27 January 2017, Adana.

of the guidebook argues that "a society will be robust and healthy to the extent that the family from which it arises rests upon a robust and healthy foundation" (Ministry of Health 2013b, 5). "Healthy" families are thus celebrated as the corner stone of an imagined "robust" nation body within which the "non-healthy" body, variously cast as being marked by a "genetic disease" or "disability", is hard to accommodate and becomes marginalized as alien to the true character of the nation. The institutionalization of premarital screening is both a consequence of and a vehicle perpetuating this nationalist myth of "fictive ability" (Galusca 2009), which "contains human bodies within a public health system, confining individuals to a coherent narrative of able-bodiedness that undergirds national communities" and which seeks to "differentiate, marginalize, and control individuals under the aegis of the nation's well-being" (ibid., 138).

The emphasis on healthy family making produces the category of the "non-healthy". Those contained within this category are framed as burdensome or inhibiting to the nation, draining its resources without contributing to them and unable to engage themselves in healthy family making and reproduction. They are excluded from full citizenship but this exclusion is silenced and rendered invisible on multiple levels. This erasure is not accidental; it marginalizes the bodies, voices and experiences of those who are hard to accommodate within nationalist ideology. Silencing and erasure, the creation of absences act as powerful political tools and means of social control (Star 1991, 281; Jones, Robinson, and Turner 2012). The government's endorsement of ableist sensibilities and health policies geared towards "flexible eugenics" (Taussig, Rapp, and Heath 2005) is easily rendered invisible as a result of the AKP's explicitly displayed anti-abortion stance. As pointed out above, the AKP's approach to reproduction is primarily associated with the party leader's marked pro-life stance which seeks to delegitimize abortion as "murder" and birth control as "treason". Repeated, unsuccessful attempts on part of the AKP to push for a general prohibition of abortion in 2005 and 2012, which were met with forceful criticism by the political opposition and women's rights organizations, stressed the sanctity of life and the unborn child's right to life (Acar and Altunok 2012, 16, Unal and Cindoglu 2013). Some representatives of the party explicitly claimed this right-to-life to be absolutely non-conditional, such as the former minister for health, Recep Akdağ, who back in

2012 publicly declared his conviction that pregnancy following rape or diagnosed disability of the future child constitute illegitimate reasons for seeking abortion (2012, 1 June). Such iterations and political measures as advanced by AKP members and their party leader effectively obscure how the government's health policies are informed by ableist and eugenic sensibilities, marginalizing the conditioned nature of the government's pronatalism in public consciousness.

The invisibility of the government's endorsement of selective reproductive technologies hinges upon and is normalized through the general invisibility of disability within conceptualizations of the nation body. Primarily framed in medicalized terms, people with disabilities are not perceived and treated as political subjects with full citizenship rights in Turkey (Açıksöz 2016). Notwithstanding the recent emergence of rights-based language in certain discursive contexts (especially those scrutinized by the probing gaze of international bodies such as the EU or the UN)[16], charity and patronage-based approaches continue to primarily define the relation between the state and citizens with disabilities at the level of practical policy implementation. The disabled community has remained largely excluded from decision-making processes affecting them and their lived realities, being cast in the role of "needy" receivers of whatever services the "benevolent" state decides to offer or withhold (Bezmez and Yardımcı 2010, Bezmez 2013).

It is against this background of political exclusion that the government's pro-life arguments which claim to protect the lives of the disabled must be placed. These discourses are not driven by a rights-based, inclusionary citizenship approach; they employ disability as a strategic figure to enhance the legitimacy of ideologically motivated, restrictive reproduction policies which undermine women's rights and reinforce gender inequality by defining women primarily as "mothers". The side-by-side existence of the government's anti-abortion stance with its endorsement of selective reproductive technologies is far from contradictory. It

[16] This change of language is particularly noticeable in highly visible, symbolic areas, such as the government's ratification of the UN Disability Convention, the announcement of 2005 as the "Year of Disability", or the change of language from *özürlü* (carrying notions of 'defective' or 'handicapped') to *engelli* (indicating 'disabled' in the sense of disability rights activism) in public signposting, (Bezmez and Yardımcı 2010).

illustrates the selectivity of the AKP's pronatalist policies which are directed at rendering possible and privileging not only certain kinds of family making but also certain reproductive outcomes over others.

Stratified Access and the Burden of Individualized Risk Management

The prevention of the birth of children with genetic conditions as envisaged by the examination guidelines is to be achieved through individualized responsibilization rather than directive state coercion. The government refrains from embarking upon openly eugenic policies enforcing the abortion of future children diagnosed with genetic conditions. Such a policy would not only sit uncomfortably with the reformed counselling outline of the exam; it would also seriously endanger the party's legitimacy with its religious base as well as entail a whole set of ethical complications and international sanctions. Instead, genetic risk management strategies envisioned by the examination guidelines are built upon the presumption that couples themselves will desire to minimize their risks once these are known to them and voluntarily seek out recommended risk management services such as professional genetic counselling and preconceptional or prenatal health services. As discussed above, the examination and counselling guidelines of the guidebook make it obvious that examining physicians can only "recommend" or "advise" at-risk couples to opt for further genetic health services once the wish for children materializes. That way, not only the responsibility regarding reproductive genetic risk is individualized but also the bearing of the financial burden for many relevant health services promising risk management.

Reproductive health services which are covered by national health insurance schemes in Turkey have undoubtedly greatly expanded over the last decades. Prenatal diagnostic services such as ultrasound, amniocentesis or CVS are offered at public hospitals and largely covered if the patient does have a national health insurance which, however, is not the case for everyone in Turkey (Günal 2008). Preimplantation Genetic Diagnosis (PGD), in contrast, which is a popular technology for couples with a diagnosed genetic condition who oppose medical termination following amniocentesis or CVS on moral grounds, was only available through private clinics and hospitals in Turkey at the time of fieldwork. With costs for a cycle amounting to several

thousands of Turkish Lira and with no government funding available for PGD except for the purpose of facilitating the birth of a "saviour sibling" who can donate matching stem cells for the treatment of an affected sibling (Official Gazette no. 28597), this option is far from accessible to most people. One geneticist I interviewed who owned a private genetics clinic and lab in Istanbul which saw much demand for PGD services, criticized the inconsistencies in the government's approach to genetic disease. As she argued, investing in extensive premarital screening for thalassemia and sickle cell anaemia was not enough if a simultaneous expansion of government-covered genetic health services did not ensue. She especially considered it the government's duty to invest in a more accessible PGD infrastructure after having created what she considered to be an environment of moral disdain regarding abortion which estranged parts of the population from prenatal diagnostic services like amniocentesis or CVS.[17]

While the guidebook reveals the government to endorse selective reproduction for the management of genetic risk in general, it highlights the special place which blood diseases occupy within governmental consciousness. Thalassemia and sickle cell anaemia form the only genetic diseases for which a premarital screening infrastructure exists so far and they are the only genetic diseases to which a whole separate chapter of the guidebook is devoted. Blood is a non-neutral substance. In Turkey, as in other national contexts, it is symbolically overdetermined, serving, among other bodily fluids such as milk or semen, as a "cultural idiom of relatedness"(Franklin 2013) and kinship (Delaney 1991), while also naturalizing the "imagined community" (Anderson 2006a) of the nation as an extended kin group (Delaney 1994). Furthermore, in Turkish nationalist discourse blood features prominently as a symbol of heroic masculinity and martyrdom in the name of the nation (Bryant 2002). Blood diseases "causing disability" as framed by the Law for the Fight against Inherited Diseases (Official Gazette no. 21804) threaten to reverse this symbolism. They create bodies which expose the fictivity of the myth of the able-bodied nation as one healthy family and constitute an uncanny reminder of the fragility of able-bodied, heroic masculinity which may all too easily give way to loss of ability in exchange for services in the name of the nation (Açıksöz 2016, 2012).

[17] Female clinical geneticist in her 40s, working in a private genetics clinic. Interview conducted in Turkish by author, 27 February 2017, Istanbul.

Haemoglobinopathies, thus, emerge not only as a physical danger but also a symbolic threat to the virility and power of the nation.

Investing in a screening infrastructure for these diseases and presenting the implemented screening policy as effective therefore assumes political relevance for the state as a touchstone of governmental performance. While non-governmental statistics reveal the relation between the screening programme and reproductive outcomes to be complex and far from straightforward (Aydınok et al. 2018), statistics produced by the Ministry of Health claim a 90% reduction of affected births since 2003, suggesting that active risk management is both highly desirable and easily accessible for couples at risk (Canatan 2011, 10). However, the above quoted recent non-governmental study produced by the Turkish Society of Paediatric Haematology criticizes this reduction rate as over-optimistic. It argues that prenatal or preconceptional risk management is far from being desired by or being available for all couples finding themselves at risk of having a child affected by haemoglobinopathies (Aydınok et al. 2018). Based on their extensive registry of haemoglobinopathy affected patients of 27 thalassemia centres in the country, the study has found that a significant part of couples undergoing premarital haemoglobinopathy screening were incorrectly informed about their carrier status. Only 60% of couples with affected children who had married after the implementation of the Haemoglobinopathy Screening Programme in 2003 were correctly informed about their joint carrier status and resulting risk condition, whereas the remaining 40% either received no feedback about carrier status and risk or were misinformed. Out of these 60%, a significant majority of 82% did not have prenatal diagnosis (the study does not specify whether this was due to conscious opting-out, lack of access, or unawareness of risk and preventive measures), while the remaining 18% underwent prenatal diagnosis but willingly decided to have an affected child (ibid., 15).

The study furthermore revealed that significant geopolitical discrepancies exist regarding the systematic implementation of premarital screening and couples' subsequent uptake of prenatal diagnosis. Examples were given for Izmir and the South Eastern Anatolian city of Urfa. In Izmir, 79% of the couples who had married after 2003 and had at least one

affected child had undergone premarital screening, with half of those identified as being at risk opting for prenatal diagnosis but still giving birth to an affected child. In contrast, only 27% of couples in Urfa had undergone premarital screening, with 8% of those identified as being at risk opting for premarital diagnosis but still giving birth to an affected child (ibid., 15). These discrepancies suggest that unequal access to prenatal and preconceptional health services does play a role in shaping couples' responses to genetic risk, turning risk management into a site of "stratified reproduction" (Colen 1995, Ginsburg and Rapp 1995b).

Arguably, the study in question is exclusively based on a sample group of affected patients and their parents; it only includes data relating to couples who have had one or more affected children. Thus, a significant group of married couples who is most likely to have actively sought risk management strategies is not represented in the study. Notwithstanding this exclusion, the study offers valuable insights by highlighting how the implementation of a screening infrastructure does not straightforwardly translate into the uptake of risk minimization and management strategies on part of designated risk groups. It shows the Haemoglobinopathy Control Programme to be a heterogeneous, both stratified and stratifying, institution which incorporates and affects multiple actors between whom incidences of misinformation, miscommunication or even lack of communication resulting in outright neglect occur. Most significantly, it reveals how couples' family making strategies, motivations and decision making processes often diverge from those intended by the designers of the screening programme. Furthermore, it emphasizes how those couples who may wish to act along the lines of healthy reproduction and minimize their reproductive risks, whether through private or public health care providers, or whether with the help of prenatal diagnostic technologies or PGD, may be faced with access issues determined by their respective socio-economic backgrounds.

As the above discussion has detailed, the premarital examination procedure is not only marked by an unequal distribution of rights and duties as expressed by the contrast between the state's right to know and the subjects' duty to disclose and make known. It also introduces an imbalance by placing a significant share of the moral and economic burden of risk management on the couple. This is well in line with the government's preferred approach to welfare which

has been characterized as a neoliberal strategy of outsourcing welfare services and social support to the family which not only reinforces gendered inequalities in the provision of care but also leaves those without family networks in lack of social support (Buğra and Keyder 2006, Coşar and Yeğenoğlu 2011, Yazıcı 2012). Notwithstanding the coercive nature of the premarital examination, couples do have the choice to decide whether and how to act regarding reproductive risk. However, this choice has to be made in an environment of obligatory carrier screening, a systematic devaluation of disability as a burden to the nation, and limited support facilities for families who do have to care for a child affected by genetic disease. In the absence of state-enforced eugenics, couples are confronted with what Taussig, Rapp and Heath refer to as "flexible eugenics" (Taussig, Rapp, and Heath 2005). They are presented with a proliferating array of new and old technologies allowing for the modification of biological assets perceived as harmful to future children. However, these technologies are employed in a context of long-standing bias against atypical bodies, thus exerting a strong push towards genetic normalization and turning choice into the constraint to choose.

****

Contradicting medico-genetic professionals' impression that the government is indifferent towards the medical risks of kin marriage, the established institution of premarital health screening has undergone a recent reconceptualization process which places great emphasis on genetic risk and its links with consanguinity. Since its institutionalization in the 1930s, the premarital examination has been a significant site for the making of biopolitically "healthy" families and the reproduction of a "healthy" and "strong" nation body. As a state ritual, it has performatively testified to the normativity of heterosexual marriage by treating reproductive health as synonymous with marital health. However, the recent shift to genetic risk has introduced a new genetic quality to the procedure. The newly present salience of genetic disease as a "disabling" condition which constitutes a material burden on resources and a symbolic threat to the ideological propagation of the healthy nation is rendered apparent by the incorporation of increasingly routinized and available genetic risk management technologies into the examination process. This emergent focus on genetic risk and consanguinity has turned

relatedness into a site of state scrutinizing and targeting which reveals a marked government concern regarding the genetic quality of offspring.

Prior to its gradual reconceptualization during the early 2000s, premarital health screening focused on the manifest physical or mental health of the couple, sources of infectious disease and the various dangers these might pose to a healthy sexual life, reproduction and the creation of a nurturing environment for children. With the shift to genetic risk, the health status of future, still unmade and unborn children comes under scrutiny as couples' genetic make-up is envisaged as the inherited legacy of the future nation's population. Haemoglobinopathies constitute the main target of genetic risk related government interest. The introduction of premarital haemoglobinopathy screening in so-called high-risk areas, which encompass all major cities and thus the majority of the population, has entailed a more rigorous and systematic enforcement of the premarital health examination and enabled the state to gather vast amount of data regarding the population's genetic risks for inherited blood diseases. Significantly, the examination's redirection towards genetic risk management does not take the form of eugenic coercion. It rather corresponds with late modern or "neoliberal" modes of intervention which seek to create incentives for individualized responsibilization and active risk management on part of those identified as being at-risk. Such an approach leaves room for couples to not comply with the examination's recommendations for healthy reproduction but it also places the financial burden for risk management unequally upon families while contributing to the masking of mandatory carrier screening as a reproductive counselling service benevolently offered by the state for the sake of the health of its citizens.

The desire to encourage families to practice selective reproduction and opt for the prevention of affected births does not contradict the government's pronounced pronatalist stance, but is rather complementary to it. The examination guidelines reveal how the government's propagation of pronatalism rests on the tacit endorsement of healthy reproduction as normative reproduction which not only marginalizes and devalues the birth of children with disabilities or genetic conditions but also renders this marginalization completely invisible from public discourse. This invisibilization of ableist and eugenic sensibilities shaping reproductive

health policies finds a parallel in the invisibilization of ethnic heterogeneity within the context of premarital genetic screening procedures. The concern with genetic risk introduces anxieties regarding Turkishness and national identity, turning premarital screening into a site where hegemonic Turkishness is reproduced. With regard to the implementation of screening policies, a marked silence reigns regarding ethnicity-related discrepancies in risk for sickle cell anaemia. This silence suggests unease about the potential of genetic data to destabilize the nationalist vision of Turkey and the "Turkish population" as an indivisible whole. However, this political silence also translates into an avoidance of ethnicity-based targeting, thus forestalling increased ethnicized stigmatization of those carrying the sickle cell trait in Turkey.

As this chapter has shown, silences surrounding bodies which are constituted as internal "others" are intrinsic to the workings of the premarital examination procedure which addresses genetic risk through an intersection of coercive screening and individualized, seemingly choice-based responsibilization. Significantly, these silences do not point to indifference, neglect or inattentiveness on part of the government; rather, they act as articulations of power. The ideological praising of healthy family making devalues the reality of lived disability, erasing it from conceptualizations of nation and society, while allowing the ruling party to endorse selective reproductive policies without risking a delegitimization of their displayed pronatalist and religious pro-life attitudes. Working along somewhat different lines, the invisibilization of ethnic heterogeneity from discursive practices of reproductive health and risk management allows the government to deflect genetic threats to hegemonic claims of Turkishness while simultaneously addressing haemoglobinopathies as a national health concern. The crafting of healthy families at the heart of a strong nation hinges upon the conjoined perpetuation of nationalist and eugenic as well as ableist sensibilities which cast the nation body as both "Turkish" and genetically "healthy" while creating silences around those bodies which are seen as prone to destabilize this imaginary of the nation.

Chapter Four: Kin Marriage and Genetic Risk: Negotiating "Risky Closeness" in Medico-Genetic Space

> "When the patients come to us, and we also point this out to the doctors, then we ask them 'is there kin marriage (*akraba evliliği var mı*)'? [speaker switches from Turkish to English] They immediately say 'no'. And then I ask them, 'your parents, are they cousins?', for example. They say 'yes'. So they do not know actually what does consanguinity mean. [switching back to Turkish] So, the families don't understand, upon asking the patient, the family who comes to you, 'are your mother and father kin relatives (*akraba mı annen baban*)?', they say 'no'. But if you say, 'are your mother and father cousins (*annen baban kuzen mi*)?', they say 'yes'."[18]

> "Some, or sometimes even all, of the family elders kept saying to us 'you are kin relatives (*akrabasınız*), if you marry you will have problems with your child (*çocukta sorun yaşarsınız*)'. Then, when our child turned out like this [their girl died in infancy because of a genetic condition], there was so much talk like 'we told you before!' It would be lie to say there wasn't any talk like 'didn't we tell you before?!'. We finally started feeling like we were murderers, that's what I felt like. How does somebody feel who has killed somebody? Guilty (*suçlu*)! Well, the doctors say so as well, it didn't happen a hundred percent because we are related, they say, you could be two strangers (*yabancı da olabilirsiniz*) but if you are carriers (*taşıyıcı olursanız*) you could still have a child with that disease (*bu hastalığı olan çocuğunuz olabilir*), they said, but being related of course triggered it (*akraba olmanız da tabii tetikledi*). When they spoke like this and when the family elders and friends said so as well, then one feels guilty (*insan kendini suçlu hissediyor*)."[19]

Both quotations above coalesce around the question of what kin marriage is and how it links up with genetic risk and blame. What sets them apart from each other is not only the relative position of the speaker, one being a genetic professional commenting from a safe distance from the moral implications of reproductive risk upon lay people's inability to grasp the meaning of "consanguinity", while the other is a woman who has lost her first and so far only child in infancy to a severe and undiagnosed genetic condition after a long and traumatizing battle and who is reflecting on the possible role that her marriage choice may or may not have played in her loss. It is also the discrepancy regarding the speakers' respective awareness of the power dynamics and moral censure involved in the designation of risk groups which differentiates both statements. Both quotations hint at the contestations and negotiations surrounding definitions of "closeness" and its riskiness in the medico-genetic realm; but

[18] Female molecular geneticist in her 50s, working in a public university's molecular biology and genetics department. Interview conducted in Turkish and English by author, 12 January 2017, Istanbul.

[19] Canan (name has been changed), woman in her 30s from Adana, Southern Turkey, who is married to her maternal aunt's son. I interviewed her and her husband at the genetics clinic which they attended for ongoing genetic tests to identify the genetic condition that had led to their daughter's premature death in infancy. They required such a diagnosis to render possible risk management during future desired pregnancies. Interview conducted in Turkish by author, 24 July 2017, Istanbul.

whereas the geneticist appears to trace these contestations back to discrepancies between scientific facts and erroneous beliefs regarding kin relatedness, the second quote brings to the surface how blaming and guilt, moral consciousness and stigmatization play into the mapping out of "risky closeness".

This chapter explores how genetic risk and kin relatedness become differently "attached" and "detached" (Latimer 2013b, 2007b, a, 2004) by those involved in and affected by the biomedicalization of kin marriage, namely medico-genetic professionals and couples practicing kin marriage. It is thus theoretically indebted to Joanna Latimer's approach of pursuing (dis)connections in a dysmorphology clinic by tracing shifting "detachments" and "attachments" between actors and materials which unfold in clinical space, generating relations which are crucial to the operations of power in the medical realm (Latimer 2013b, 2007a, b). This chapter argues that kin marriage cannot be approached as a given and self-evident concept but is invested with changing meaning depending on who defines it in what particular circumstances. Such heterogeneity of meaning is not surprising seeing how "kin marriage" is situated at the intersection of the biological and the social. Conceptualizations of kin marriage inevitably rely on notions of "kinship" and "relatedness" which are neither contained within a social nor a biological realm but are part social and part biological, resting on close bio-social entanglements (Strathern 1995, 1992). Furthermore, the clinical settings within which kin marriage becomes managed as a health issue are not only concerned with the transmission of genetic substance but also the implications of such transmission for the making of families (Latimer 2013b, 2007b). Genetic health services thus constitute a primary site where "kinship" as a biosocial hybrid is done and undone, rendering explicit how the biological and the social co-constitute each other in the (un)making of kin relationships (Thompson 2005).

As this chapter traces, medico-genetic professionals and families in their conceptualizations of the relation between kin marriage and genetic risk variously foregrounded or downplayed what they considered to be the biogenetic or social aspects of kin marriage. While geneticists' pushed for a "geneticization" (Finkler 2005, 2000, Lippman 1991) of kin marriage, presenting it as a primarily biogenetic problem requiring technical intervention

through genetic health services, this geneticization of kin marriage remained partial and incomplete. Moments of "non-geneticization" repeatedly emerged in the clinical realm, brought about by geneticists' own discursive practices, families' pushbacks against biomedical attachments of risk and biogenetic relatedness, as well as infrastructural constraints regulating what kind of families did (not) have access to genetic health services. Exploring these moments of "non-geneticization", this chapter joins in with scholarship that has cautioned against rash fears of a "geneticization of kinship" (Finkler 2000, 2005), arguing that kinship reckoning often remains underdetermined by scientific genetic understandings (Featherstone et al. 2006, Franklin 2013, Shaw 2009, Konrad 2003).

Families' pushbacks against biogenetically based delineations of their marriage choices as "risky" are particularly pertinent. They reveal how biomedicalization processes may constitute a site of contestations and resistances, underlining how biomedicalization unfolds "unevenly" (Clarke et al. 2003, 166). Significantly, these contestations need to be contextualized with regard to the inherently political nature of risk discourse and the practices of risk management (Douglas 1996, Rose 2001). They are expressive of families' conscious attempts to deflect moral censure and blaming for having married "close" despite the reproductive risks commonly associated with kin marriage. Families are thus well aware of the non-neutrality of risk discourse which politicizes an already contested practice of family making as a threat to future children's health and wellbeing. Their experiences indicate a perpetuation of the stigmatization of kin marriage backed by the authority of science which is, however, easily obscured by the scientific technicality of the language of Mendelian genetics.

This chapter seeks to disentangle this coming together of genetic risk, kin relatedness, family making, moral blaming and the significations of kin marriage as a socio-politically contested practice in Turkey by exploring first geneticists' and second couples' engagements with the question of "closeness" becoming a "risk" in terms of reproduction.

What Is "Kin Marriage"? The Tricky Issue of Identifying "Risky Closeness" in Medico-Genetic Space

From Causality to Probability: Biomedical Framings of Kin Marriage as a Genetic Risk Factor

Asked to specify their understanding of the medical dimensions of kin marriage, most medical professionals I interviewed, especially those with a background in genetics, carefully complicated the links between relatedness, consanguinity and genetic risk, thus distancing themselves from the reductionist portrayals of kin marriage as a direct cause for disability which are so frequently reproduced in the public media realm. Drawing on a Mendelian framework of inheritance, they argued that consanguinity between two partners does not automatically result in genetically affected children but rather increases the risk for recessive genetic conditions. As one geneticist working in a private genetics centre in Istanbul put it:

> "For whole generations, [the mutations] may remain hidden, they are only passed on in the form of carrier status and we can't know when they will emerge (*hep taşıyıcı taşıyıcı giderler, ne zaman çıkacağını bilemeyiz*). If there are no mutated genes (*mutasyona uğramış gen*) in the family, you may keep practicing kin marriage for over seven generations, there will be no problem because the genes are undamaged (*genler sağlamdır*). What I mean is that kin marriage does not damage the gene (*geni bozmaz*), it only makes the mutated gene become apparent (*mustasyonu olan genin ortaya çıkışını sağlar sadece*). But if there is no mutated gene, then there is no problem with practicing kin marriage."[20]

Contrary to popular discourse which often conflates causality and probability, this quotation deconstructs notions of kin marriage as a cause of genetic disease. Differentiating between "undamaged" and "mutated" genes, the geneticist argued that the emergence of genetic disease is primarily a question of a couple's genetic make-up than kin marriage as such. While she thus detached the alteration or "mutation" of genetic material from consanguinity, she nevertheless highlighted how kin marriage may act as a risk factor facilitating the expression of especially rare, recessive genetic conditions:

> "If we come to think of it, we have ca. 30,000 genes, there are two copies for every gene, one from the mother's and one from the father's side. In case of recessive diseases (*çekinik karakterli hastalıklarda*), there needs to be a mutation (*mutasyon*) in both genes, both mother and father need to be carriers (*taşıyıcı*) for such a disease. And the odds are considerably low (*oldukça düşük bir*

[20] Female clinical geneticist in her 40s, working at a private university genetics clinic in Istanbul. Interview conducted in Turkish by author, 20 December 2016, Istanbul.

ihtimal) that two people, each of them having a mutation in the same gene out of 30,000 genes, will come together, marry and have children. That is a situation like hitting the jackpot in the lottery (*büyük ikramın çıkması gibi bir durum*), that's what the calculation of probabilities (*olasılık hesapları*) indicates. But in case of kin marriage we are talking of shared genes (*ortak gen*) and of several individuals carrying the same mutation. And therefore, when they marry among themselves, the recessive diseases start bursting out (*patır patır ortaya çekinik karakterli hastalıklar ortaya çıkar*)." [21]

According to this argumentation, kin marriage does not cause genetic disease but may nevertheless impact on a couple's reproductive futures. As the geneticist emphasized, the likelihood of two unrelated people having a child with a rare recessive condition is significantly lower, "a situation like hitting the jackpot", than in case of a consanguineous couple who have a significant share of genes in common. The above two quotes are quite representative of how the geneticists I interviewed framed the relation between genetic risk and consanguinity. They treated a couple's shared genetic heritage as the crucial factor regarding potential reproductive risks and argued that the identification of such shared genetic ties during genetic consultation sessions constituted a tricky issue in Turkey. According to the geneticists interviewed, the common biomedical definition of "consanguineous unions" consisting primarily of first and second cousin marriages (Bittles 2003, 1994) falls short of the complexity on the ground in Turkey. Consequently, these geneticists regularly had to go beyond that definition in their work with families in identifying genetically risky unions. As the molecular geneticist quoted at the beginning of this chapter argued,

Sometimes it happens that they say 'we are not kin (*akraba değiliz*)', (...) but when I ask 'are your mother and father from the same village (*aynı köyden mi)*, [switching to English], are they from the same village', they say mostly 'yes'. [Switching back to Turkish] But this is also kin relatedness (*bu da akrabalık*), you have to be very careful in Turkey when you speak of kin relatedness because in case of the same village, the same town or small towns, they are anyway all kin to each other there (*hepsi birbirleriyle akraba zaten*).[22]

The geneticist quoted above was voicing a theme I repeatedly encountered during interviews with the professionals. She pointed out how geneticists' professional conceptualizations of "kin marriage" resting upon shared genetic substance might well run counter to couples' own notions of who constituted "kin". Especially in small settlement areas

[21] Ibid.
[22] Female molecular geneticist in her 50s, working in a public university's molecular biology and genetics department. Interview conducted in Turkish and English by author, 12 January 2017, Istanbul.

with frequent practices of intra-community marriage, small gene pools had formed which according to the geneticists turned marriages within the community into de facto "kin marriages" even if the families themselves thought differently. The geneticists thus employed a careful strategy of questioning during consultations which did not rely solely on families' own concepts of kin relatedness but included inquiries about a family's place of origin and settlement in order to trace potential genetic ties. As another clinical geneticist working in a private university's paediatrics department added, the situation was further complicated by the existence of what she termed "ancestral relations" among members of certain endogamous communities in Turkey:

> "We have something called gene pools (*gen havuzları*) and if you go for example to certain regions in Antakya [a city/county in Southern Turkey], there are only Arabs and Alawi living there who are often ancestral carriers (*çok 'ancestral' taşıycılıkları var*). Even if they do not practice kin marriage, they have a higher chance of being carriers because they come from the same village or origin (English term *origin* used by speaker), such ancestral relations ('*ancestral' ilişkiler*). This is really important here in Turkey. When you ask them, they say 'no, we are not related (*akrabalığımız yok*)' whereas in fact they are from the same village or neighbourhood. So, the actual terms are a bit different here in Turkey. (…) It's not only about cousin marriage (*kuzen evliliği*). When thinking about kin marriage, then I definitely consider regional factors, unless a couple is from really different cities I am always inclined to consider a recessive disease (*resesif bir hastalık*) in their children."[23]

As the quotes above illustrate, geneticists interviewed conceived of "kin marriage" in terms broader than mere "cousin marriage", arguing that one had to be "very careful" when considering kin relatedness in Turkey where "terms [were] a bit different" due to the existence of small gene pools, tight-knit rural communities and "ancestral relations" among endogamous communities such as the Alawi in Southern Turkey. In light of these complexities, geneticists were usually not inclined to take couples' statements regarding their non-relatedness at face value, probing deeper to rule out a potential genetic relatedness which might indicate a risk for recessive conditions. Trained in the language and concepts of biomedicine, the geneticists thus maintained a biogenetic understanding of kin relatedness which treats shared, genetic substance as prior to and independent of social relations and conceives of the genetic tie as constitutive of the "natural facts" of kinship (Strathern 1999). Thus, for the geneticists "kin marriage" was

[23] Female clinical geneticist in her 40s, working in a private university's paediatrics department. Interview conducted in Turkish by author, 21 March 2017, Istanbul.

"whatever the biogenetic relation is" (Schneider 1980, 23), but they were well aware that their scientific conceptualization was often at odds with families' lived experiences and everyday understandings of kinship. Some geneticists, similar to the one quoted at the beginning of this chapter, complained of these expert-lay discrepancies, arguing that the people in Turkey simply did not understood what "kin marriage" or "consanguinity" means:

> "The term 'kin marriage' is not understood in Turkey, unfortunately. Everybody thinks that only first cousins (*birinci derece kuzen*) constitute a kin marriage whereas in genetics we even consider it a kin marriage when it's the same lineage (*aynı soydan*), when it's second, third cousins (*ikinci üçüncü derece kuzen*), because for us it's the shared genetic heritage (*ortak genetik miras*) that is important."[24]

Arguing that lay and genetic understandings of "kin marriage" were often not identical in Turkey, the above quoted geneticist emphasized that the classification of a marital relationship as "kin marriage" in medico-genetic space hinged upon the identification of a "shared genetic heritage" which might be traced by the geneticists well beyond what the families' themselves thought of as "kin". For this geneticist, it was obvious that lay people in Turkey were largely unable to grasp the scientific facts of genetic kinship. Geneticists' observation of a disjuncture between biogenetic and lay notions of kin relatedness does not come as a surprise seeing the close affinity between Western or "Euro-American" kinship concepts and biomedical concepts of inheritance and relatedness (Featherstone et al. 2006, Franklin 1995, Strathern 1995, 1992) which do not necessarily correspond with non-Euro-American forms of kinship reckoning (Clarke 2007a, b, Raz 2005, Shaw 2009). What I rather want to focus on in the following is how professionals' genetic framings of kin marriage, which could be read as a "geneticization" (Lippman 1991) of kin marriage, remained always only partial in character. Although geneticists stressed the "genetic origins" of kin marriage as a phenomenon and emphasized the need for genetic technologies as a means for intervening into kin marriage related health problems, they themselves repeatedly made sense of kin marriage in other than genetic terms. Geneticists effected such a "non-geneticization" of kin marriage in a twofold way, namely by re-evoking the significance of the family as a social institution which

[24] Female clinical geneticist in her 40s, working in a private genetics clinic. Interview conducated in Turkish by author, 27 February 2017, Istanbul.

shapes both the management of genetic risk as well as access to genetic health services, and by framing kin marriage as not only a genetic health concern but also a socially problematic form of family making.

Moving Beyond the Genetic Tie: the Emergence of Moments of "Non-Geneticization" of Kin Marriage in Medico-Genetic Space

One way in which this "non-geneticization" of kin marriage was brought about is illustrated by a case story which I will discuss in the following. This case story, which revealed a conceptualization of kin marriage as being something more than mere genetics, was shared by a geneticist who was working at a private university's genetics clinic in Istanbul at the time of the interview.[25] The geneticist had spent her years as an assistant doctor at a public university's genetics clinic and the case story dated from that time. This case story of a family seeking genetic health services during pregnancy makes apparent how genetic framings of kin marriage do never fully displace other-than-genetic ways of doing and conceptualizing kinship and family within the clinical realm. It highlights how in the encounter between the family and genetic professionals processes of geneticization remain interspersed with moments during which misalignments between the social and the biogenetic dimensions of the "family" arise, rendering visible the partialness of geneticization.

The geneticist told of a couple who had applied to the public genetics clinic where she used to work earlier during her career as an assistant doctor in genetics. The woman was pregnant and as the couple had one child living with a genetic condition, they wished to know whether the future child was likely to be affected as well. The born child's condition had been clinically diagnosed but a genetic diagnosis did not exist. A genetic sample of the child was thus analysed at the clinic which revealed the child to be homozygous for the genetic condition it had. This result initiated the first moment of confusion because the couple had stated to be not related but the child being homozygous for a rare recessive condition raised the geneticists' suspicion that the couple might have misinformed them about their actual kin relationship. The

[25] Female clinical geneticist in her 40s, working at a private university genetics clinic in Istanbul. Interview conducted in Turkish by author, 20 December 2016, Istanbul.

geneticists had also taken blood samples from the parents to examine their respective carrier status. Confusion grew even more when only the woman turned out to be a carrier for the genetic condition of her born child whereas the man was shown to be a non-carrier. Assuming that they had made a mistake, the tests were redone in the lab but the results remained unchanged. At this point, the genetic team was quite sure that there was something unusual about the couple, something the couple wished to withhold.

The couple had attended most of their sessions at the clinic accompanied by another man who had not taken any active part in the sessions. Upon questioning the couple, the geneticists learned that it was this man accompanying the couple who was the biological father, both of the born and the unborn child. He was also the first paternal cousin and husband of the woman but they had never married in a legal ceremony, having performed only a religious marriage ceremony.[26] The man who had entered the clinic claiming to be the children's father was instead a distant relative of the family. However, he was indeed officially married to the woman but they had performed the marriage act only pro forma because neither the woman nor her actual husband (that is the father of her children) had access to any health insurance. Seeing the plight of the family struggling with genetic disease, the relative had offered to marry the woman officially so that she and the children could be covered by his own insurance scheme, a move rendered possible by the strong familialism of Turkey's social insurance system (Kılıç 2010). Once the geneticists had been put in the picture, they redid the carrier test and the result showed the companion whom they had learned to be the biological father and husband to be indeed a carrier for the child's condition. In light of this complicated situation and desiring clarity, the lead geneticist secretly conducted also a paternity test which confirmed the man's claim to be the biological father. As my interview participant emphasized, this last test result had only been meant as internal information for the clinical team who had wanted to be really sure that they had got the "facts" right this time. With all the kin relationships, genetic diagnosis

[26] The law in Turkey requires every couple to be married in a legal ceremony for the marriage to be officially recognized. Couples may opt for an additional religious ceremony but the state does not accept it as a replacement for the legal ceremony. In 2017, changes in the marriage regulations have accredited religious officials with the right to conduct a legal marriage ceremony but these changes have not abolished the legal requirement for an official legal marriage ceremony (Article 7, Bylaw on Marriage, Official Gazette no. 18921). Notwithstanding the legal situation, the official marriage ceremony in Turkey is not performed by all families, with some conducting only a religious one.

and carrier status sorted out, the team finally proceeded to test the foetus via prenatal diagnosis which indicated that the future child was only a carrier like the parents but not affected. With this information, they sent the family on their way. The geneticist interviewed referred to this incidence as the most "striking one" of her whole career. She clearly remembered the whole story as one which threatened to undo the very categories of what constitutes a "family":

> "It's like the frame of the family becomes all weird (*ailelerde çerçeve de bir değişik oluyor*), or rather it's like it gets erased, the boundaries get erased (*sınırlar siliniyor*). On the one hand, there is kin marriage, on the other hand there is this absence of a legal marriage, then there is this taking shelter with another relative (*başka bir akrabasına sığınıp da bir şey yapmak*). Now, it's such a story, everything is mixed up (*öyle bir hikaye ki karman çorman*), it's unclear who has done what with whom, whose are the children, it's not even clear if they are aware of it. We said, the baby is healthy (*bebek sağlıklı*), just go, just go and don't come back, [she laughs] we can't put up with things like that (*biz böyle şeyleri kaldıramayız*). That was the weirdest (*acayip*) thing I ever experienced, just like in the 'reality shows'."

The case story narrated by the geneticist is a striking example of how the encounter between families and geneticists in the clinic may give rise to contradictory but co-existing dynamics of non-geneticization and re-geneticization. The family in the case story presented itself at the clinic with a family arrangement that was not easily accommodated by the clinic's conceptualization of social family arrangements being based on and mirroring the "natural facts" (Strathern 1992) of procreation. Limitations and inequalities in access to health care, the desire to withhold details revealing the marriage to be "kin marriage", and the parallel marriage systems of legal and religious marriage had all together resulted in a "choreography" (Thompson 2005) of family making which challenged the attachment of genetic health services to the reproduction of the heteronormative, conjugal family in Turkey. The kinship truths presented by the incoming family proved to be at odds with the kinship truths emerging from the family's genes; consequently, the geneticists felt compelled to further probe into the family's history. In the end, the medical team elucidated answers that allowed them to bring biological reproduction, family arrangement and genetic information in line.

What the case story illustrates is how families are made in ways which do not always easily map onto biogenetic notions of relatedness. Confronted with the messiness of family making in practice, the genetic professionals in the case story experienced problems in aligning the family's social arrangement with its genetic substance. As the final quote above makes

apparent, there is a profound sense of unease when suddenly "the frame of the family becomes all weird" and "the boundaries get erased." What becomes in fact "erased" here, I would argue, is an alignment between the two meanings of the "family" as a "social institution hosting the lived relations people have with one another and as the carrier of biological matter of which a family is made up" (Latimer 2013b, 161). By questioning the couple and elucidating answers, the geneticists achieved a re-alignment between social relations and biological matter, thus pushing effectively for a re-geneticization the family's "frame".

This (re-)geneticization, however, is never complete. As the family's strategies aimed at gaining access to genetic health services illustrate, other-than-genetic ways of doing family and conceiving of kinship and relatedness do not become fully displaced by genetic ones. It was exactly by enacting a form of family making which defies geneticization that the family in question could enrol in genetic risk management and obtain the desired information from the clinical professionals. The very structure of the health care system consolidates this incompleteness of geneticization as it is the socio-political significance attributed to the family as a primary unit of social organization which regulates families' access to health services. The couple in question made creative use of the family-centred character of the social security system in Turkey by adopting a family arrangement which allowed them to negotiate the constraints and opportunities of this system in order to manage the health of their children and get a desired diagnosis.

These moments, during which geneticization was revealed in its partialness and other-than-genetic ways of conceptualizing and doing kinship and family were rendered visible, stand in stark contrast to the exclusively biogenetic language employed by medico-genetic professionals in their framings of kin marriage as a genetic risk factor. Such moments of "non-geneticization", however, were not only brought about through processes which re-evoked the significance of the family as a social institution shaping both the management of genetic risk as well as access to genetic health services. Medico-genetic professionals also repeatedly referred to kin marriage as not only a genetic health concern but also a *socially* problematic form of

family making, revealing their familiarity with those discursive legacies framing kin marriage as a signifier of non-modernity and internal otherness in Turkey.

Shifting easily between narratives defining kin marriage as variously genetically or socially problematic, medico-genetic professionals made apparent how processes of a "geneticization" of kin marriage had not wholly displaced those earlier discursive legacies. They repeatedly conceived of kin marriage as a lingering contradiction to the ideals of modernity, its presence indicating Turkey's inability to fully overcome "traditionalism" and leave behind its "Eastern" or "Oriental" otherness vis-à-vis the West. As the same geneticist narrating the above case story remarked,

> "Of course, when we look at Turkey in regional terms we can see how one regional group shuns another. For example, I often see on social media how especially the group from the area of Thrace [a region in Western Turkey] emphasizes 'we don't do kin marriage'. Kin marriage is seen as a kind of symbol for Easternness and lacking civilization (*doğululuk ve medeniyetsizlik simgesi*) that's where it is pushed. And actually not unjustly so because it really isn't a civilized condition (*medeni bir durum değil*), kin marriage, like I said it's not really something that conscious and thinking societies could do (*bilinçli ve düşünebilen toplumların yapabileceği birşey değil*). But our country [she laughs], you know… That's what it is, it is seen as equivalent with Easternness (*doğululukla eş değer görülüyor*), a sign of Easternness (*doğululugun bir simgesi*), kin marriage is a sign of the Orientals (*Oryantallerin bir simgesi*). But when we look to Europe, we only see kin marriage in upper society, always emperors, kings, over there we observe kin marriage in the very high levels of society. Probably there were also cousin marriages (*kuzen evlilikleri*) there among aristocrats in certain periods of time. Over there it is a sign of nobility (*asalet simgesi*), something that noble families do, here among us it is rather something that the group of low socio-economic standing does."[27]

The geneticist framed kin marriage as a practice which signifies all that is not modern, Western, or civilized in Turkey and which is particularly common among people of "low socio-economic" standing. These negative connotations, she pointed out, turn kin marriage into a symbolically powerful category for the construction of distinctions between "self" and "other" as well as "Oriental Easternness" and "civilized Westernness". Kin marriage becomes thus employed as a category for creating distinctions on part of certain parts of the population in Turkey who seek to distinguish themselves as more progressive and "Western" vis-à-vis others. While the geneticist initially presented her reflections as mere observations, she quickly moved on to approve of these negative portrayals of kin marriage as "justified", thus reproducing the

[27] Female clinical geneticist in her 40s, working at a private university genetics clinic in Istanbul. Interview conducted in Turkish by author, 20 December 2016, Istanbul.

notion of kin marriage as a marker of lingering internal "otherness" threatening to betray Turkey's claim to modernity. Her half mocking, half deprecating reference to Turkey as "our country, you know" transported a sense of slightly amused embarrassment opposite me as an outsider which made apparent her notion that this claim to modernity and civilization had never fully materialized in her eyes.

As a trained medical professional, she belonged like the other medico-genetic professionals whom I interviewed to a social elite in Turkey who strongly identified with the principles of "modernism" and "scientific rationality" and who had had access to leading education institutions both in Turkey and abroad which were shaped by the traditions of Western thought and positivistic science. "Kin marriage", framed as a signifier of Turkey's unfulfilled modernity and Westernization, thus clearly represented for her an expression of those aspects of Turkey's society she could least identify with. This particular geneticist's reflections were not of a stand-alone character but were complemented by other geneticists' framings of kin marriage as a practice which could be expected to decrease with growing "modernization" and "urbanization" but which nevertheless persisted in regions, especially in the East, where "feudal organization" (*feodal düzen*) and "tribal structures" (*aşiret*) continued to exist. Such discursive framings positioned kin marriage within a chain of associated practices considered to be a persistent remnant of the past, contradicting the principles of a modern, democratic society.

As discussed in the introduction, these discursive articulations of kin marriage predate its biomedicalization. The genetic discourse presenting kin marriage primarily as an issue of shared genetic ties, carrier status and recessive inheritance related risk largely steers clear of the political terrain within which kin marriage is embedded in Turkey. With its scientific technicality, it suggests a shift towards neutralization of these socio-political implications of kin marriage and appears to effect a de-stigmatization by detaching genetic disease from the practice of kin marriage as such and attaching it instead to the absence or presence of a couple's joint carrier status. However, the seeming neutrality of the genetic language masks how kin marriage is always also social in character, how its targeting as a genetic risk factor inevitably

touches upon and imbricates larger socio-political questions about family making, responsible reproduction as well as conceptualizations of kinship which may prove far messier than the clarity of the genetic discourse suggests. The challenges encountered by medico-genetic professionals in working with couples practicing kin marriage make apparent how more than genes is at stake in the biomedical re-conceptualization of kin marriage as a genetic risk factor.

Concealing Kin Marriage in Medico-Genetic Space: the Moral Imperatives of Risk and the Threat of Blaming

The neutrality of the scientific language of consanguinity and genetic inheritance masks how risk discourse exerts the moral imperative to act upon risk in order to minimize it, exposing those unwilling or unable to do so to moral censure and blaming (Douglas 1996, Novas and Rose 2000, Petersen and Lupton 1996). The discursive practices of risk management are embedded within power inequalities and structures of stratification in how they render especially marginalized groups' practices visible as "risky behaviour" in need of intervention (Kaufert and O'Neil 1993). Both medico-genetic professionals and couples were aware of the moral and thus political implications of the singling out of kin marriage as a "risky" practice. Turkish media and popular entertainment productions are replete with stereotyping and simplifying portrayals of kin marriage which tend to present it as a form of forced marriage, imposed upon the unhappy couple by their usually traditional, conservative families, and ending in severely disabled and suffering children. Sitting in her living room in a house on the European side of Istanbul, Dilba, a woman in her early 30s who was sharing her experiences concerning her relationship and marriage with me, emphatically criticized this reductionist view of kin marriage when we were half-way through our interview:

> "I don't know how much you know about this but in Turkey it is so often talked about in the media and films and soap operas, how some young people have done kin marriage and how they didn't want each other but were forced to marry by the relatives and then when they have children these promptly turn out disabled (*engelli*) and so on. Because of that people in Turkey often say that when marrying one's kin relatives (*akrabalar evlenince*), the children will become impaired (*sakat*). You encounter this very often in everyday life. When you say that you are related, people immediately ask 'is your child is healthy (*sağlam*)?'"[28]

[28] Dilba, interview conducted in Turkish by author, 30 May 2017, Istanbul.

Her own story fairly contradicted common stereotypes about kin marriage in Turkey. Not only had she married her paternal aunt's son following a long relationship of mutual love and affection; also, like many other children born to couples with kin marriage in her immediate social circle, her little daughter had been born healthy. Nevertheless, she was acutely aware of a growing tendency to perceive couples practicing kin marriage as morally suspect and irresponsible regarding the health of their (future) children. As mentioned earlier in the introduction chapter, Turkish media headlines reading "The Great Danger in Kin Marriage" (2012, 9 Nov), "33% of Infant Deaths Occur due to Kin Marriage" (2017, 14 June), or "Kin Marriage: A Genetic Threat to Health of the Çukurova Region" (2016, 31 Aug) are no exception. This increasingly hostile atmosphere surrounding kin marriage in the public realm, which feeds on a simplistic portrayal of kin marriage as a direct cause of genetic disease, significantly shaped the encounter between professionals and couples practicing kin marriage in medico-genetic space.

During interviews, medico-genetic professionals repeatedly described couples' deliberate attempts at concealing the "kin" part of their marriages. They presented accounts of couples who had chosen to withhold certain "truths" about their marriage choices which were later "given away" by their genes suggesting a close kin relation between the partners. When I asked the geneticists why they thought that families wanted to keep their kin marriages secret, they usually explained this with reference to families' feelings of guilt and their fear of being blamed for their children's genetic conditions. As one clinical geneticist who had worked with many different families throughout her career remarked, "some people shy away from telling us if they have sick (*hasta*) children. They say that they will be blamed (*suçlanacaklarmış diyor*). They blame themselves (*kendilerini suçluyorlar*) and then they think that we are going to blame them as well."[29] While this geneticist suggested that it was primarily the families themselves from whom this sense of guilt and blame emanated, some of the professionals I interviewed adopted a more self-critical tone. They argued that some families chose to keep their marriages secret after having had negative experiences with doctors reproaching them for their marriage

[29] Female clinical geneticist in her 50s, working at a private university hospital's clinical genetics centre. Interview conducted in Turkish by author, 15 February 2017, Istanbul.

choices. One female clinical geneticist working in a private university's paediatrics department voiced such self-criticism, saying: "Some of them hide that they are kin relatives. Why? Because they are so afraid that the doctor will get angry with them and will tell them 'all of this happened because of your kin marriage'. This is what we as physicians have to change."[30] Such comments make apparent how at least some couples practicing kin marriage, irrespective of whether or not they had indeed made such negative experiences, entered medico-genetic space anticipating moral censure for their marriage choices.

During my stay at the genetics clinic, I never observed any of the clinical geneticists engaging in such direct practices of blaming vis-à-vis their patients. Prior to starting fieldwork at the clinic, I had interviewed two members of the clinic's professional team, a molecular and a clinical geneticist, who both explicitly voiced their sensitivity of the matter. They pointed out how it was important to make families grasp the complexity of the link between kin marriage and genetic risk without inculcating notions of guilt and revealed their concern about the harm inflicted through direct or indirect acts of blaming or reductionist framings of kin marriage as a cause of genetic disease. However, one particular encounter during the interviewing phase of my fieldwork, which occurred at a private university hospital, revealed how such sensitivity on part of the professionals was not necessarily representative. In that particular situation, my research became the trigger for a geneticist's engagement with a present family which brought to the fore a tangible communication of blame.

The clinical geneticist whom I interviewed, a woman in her late 40s, was working in the private university hospital's paediatric genetics clinic. We had just finished our interview in her consultation room when there was a knock on the door. In came a young woman carrying an infant in her arms who was accompanied by an elderly woman wearing *çarşaf* (a long, black robe worn by some religious women in Turkey), presumably the younger woman's mother or mother-in-law. They asked for a specific doctor working in the clinic, desiring to speak to her. After answering the woman's question, the geneticist suddenly turned to her asking, "Are the parents of the child kin marriage (*çocuğun anne babası akraba evliliği mi*)?", using an often

[30] Female clinical geneticist in her 40s, working in a private university's paediatrics department. Interview conducted in Turkish by author, 21 March 2017, Istanbul.

heard phrasing which framed "kin marriage" as something one *was* rather than *did*. The elderly woman was clearly taken by surprise by this question and responded hesitatingly, saying "yes, they are". Without giving further explanation to the family, the geneticist turned towards me, remarking in front of the women, "see, here we have such a family. They keep intermarrying within the family and then they end up having children with genetic conditions." I felt helpless and guilty at that moment, having been the trigger for the geneticist's behaviour with my request for an interview regarding her professional experiences with kin marriage. The women had said nothing in reply but they lingered in the room and as I could sense that they wanted to speak to the geneticist, I thanked her for the interview and left the room.

Such a situation had never happened before during my interviewing encounters with professionals but I had always dreaded such a scenario. The last thing I wanted to do was inflicting harm and distress as a researcher on those already struggling with the implications of genetic risk but as the situation discussed above clearly showed I had not managed to prevent such a turn in this particular instance. When I saw the older woman leave the room, I approached her wishing all the best for the child while she in return wished me a quick recovery, suggesting that she had thought me to be a patient as well. I wanted to say something about the scene that had just happened without knowing how to do so but the woman's mind was differently occupied. With an anxious voice she asked me if I knew how quickly test results were to be expected, adding that she hoped "they would arrive today". Telling her that I did not know, I once more wished a recovery for the child and left the clinic. On my way home, I was thinking that the geneticist's remark had probably targeted a family who was still at the very beginning of their odyssey in learning about and dealing with a reproductive genetic condition, feeling responsible and guilty about the additional anxiety that the geneticist's remark, triggered by my presence, may well have created.

The encounter narrated above illustrates how moral accusations and blaming, even if they did not materialize, constituted an omnipresent potential threat for couples practicing kin marriage once they entered medico-genetic space. This potentiality shaped their encounter with the professionals, negatively impacting on the building of trust relationships as revealed by

cases of families who preferred to keep their kin marriages to themselves, withholding respective information from the professionals. Complications regarding the identification and management of kin marriage and kin marriage related genetic risks within the clinic thus emerged not only as a result of divergent lay notions of kin relatedness or couples' strategies and performances of family making which ran counter to the clinically expected alignment of natural facts and social family arrangements. Complications also arose due to the sensitivity which kin marriage assumed in medico-genetic space as a consequence of the moral responsibilization effected by risk discourse. Families' renegotiations of biomedical risk discourse unfolded in response to their awareness and partial rejection of this responsibilization, as explored by the next part of this chapter.

"I'm anyway against Kin Marriage": Negotiating Genetic Risk while Marrying "Close"

Anticipating Moral Blaming, Choosing Silence

The couples and individual women whom I interviewed during my stay at the clinic had all experienced genetic reproductive concerns. Their heterogeneous experiences encompassed miscarriages or the premature death of a child in infancy due to genetic disease, the constant responsibility of caring for one or more children being affected by milder or more severe forms of a genetic condition, or the distressing process of being in diagnostic limbo waiting for the diagnosis of an elusive and hard to classify condition their child was probably suffering from. While all of these couples and women had informed the geneticists about their kin marriages, as was clearly indicated by their patient folders, they had most likely entered the clinic with an awareness of the potential threat of moral accusations and blaming. In contextualizing these families' often emotionally traumatizing experiences with regard to the pervasiveness of moral judgements of kin marriage in the public realm, it does not come as a surprise that they did not endorse biomedical risk discourse in a straightforward way. Patricia Kaufert and John O'Neil have pointed out how the language of risk can be used to affirm or challenge power relations (Kaufert and O'Neil 1993). They argue that the tensions between biomedical risk discourse and lay responses to risk must be contextualized with regard to the power inequalities between

professionals and often marginalized risk groups. Drawing on their insights, I argue that the renegotiations of biomedical risk discourse on part of couples and women practicing kin marriage constituted heterogeneous, albeit conscious strategies to reclaim their marriage choices as a legitimate form of family making in the face of potential blaming and stigmatization.

Seeing the sensitivity of questions surrounding kin marriage and genetic risk, I completely refrained from asking in a directive manner whether or how couples practicing kin marriage conceived of genetic risk in relation to their relatedness during interviews with them, instead waiting for them to bring the issue up if they chose to do so. Perhaps unsurprisingly, an overwhelming majority of those interviewed at the clinic opted for a decided silence on the matter. While they talked about their marriages, their reasons for applying to a genetics clinic, their experiences and fears in dealing with reproductive risk as well as their hopes for their children and future reproductive plans, they more often than not remained silent on how they causally conceived of their reproductive problems and whether or not they considered kin relatedness to have played a decisive role. These silences acted as a means to push back against an attachment of genetic risk and kin marriage. The families I spoke to did reflect on their marriage choices, portraying their marriages sometimes as happy and fulfilling, at other times as difficult and tension-laden; they also shared their feelings and experiences regarding genetic health issues. During most interviews, however, these strands of narrative remained separate. Couples thus effectively detached what medico-genetic framings of kin marriage so closely attached by keeping genetic risk and relatedness discursively apart.

In contrast to the domineering silences I encountered, a small minority of lay participants interviewed ventured into the realm of relatedness, risk and inheritance, sharing their reflections on how they considered kinship and risk to link up. I want to focus in detail on three couples who, in very different ways, responded to the biomedical risks associated with kin marriage by renegotiating conceptualizations of "risky closeness". Their renegotiations constituted yet another moment revealing the "geneticization" of kin marriage to be always only partial in character. Countering genetic framings of "kin marriage" with their own socially grounded understandings of what kin marriage is (not), these couples effectively differentiated

their marriage choices from the idea of practicing "kin marriage", while marrying nevertheless "close" in genetic terms. Significantly, none of the three couples had children with a severe, recessive genetic condition, a situation which likely impacted on their ease in discussing the question of risk and kin marriage with me.

"Growing up like relatives, that's what I find weird, what I'm against!": the Case of Nedim and Emine

I first encountered and then interviewed Nedim and his wife Emine in a section of the genetics clinic which dealt with the practical conduction of prenatal diagnostic tests such as CVS or amniocentesis and related counselling. The female counsellor responsible for these prenatal counselling services had been very supportive of my research by telling me in detail about her work and background and by repeatedly encouraging me to talk to women and couples coming in for her services.

Nedim was a young man in his late 20s who attended the hospital with his 18-year-old pregnant wife, Emine. They had been sent to the clinic by the young woman's gynaecologist due to unusual bleeding during the first months of pregnancy, a case of undiagnosed disability in her family, and the fact that the couple were first cousins, his mother and her father being siblings. In light of these risk factors, the gynaecologist had recommended them to have a detailed ultrasound at the clinic which, however, had been deemed "normal". After their final consultation with the prenatal counsellor, the counsellor introduced me to the couple and I had the chance to talk to them. The 20-minute interview took place in the counsellor's considerably small room which proved to be quite packed with the three of us and the counsellor sitting around the counsellor's desk facing each other. In this particular context, the counsellor stayed in the room with the couple's explicit consent. Whereas she appeared to be interested in hearing the couple's story and witnessing the interview, the couple signalled that they found her presence reassuring. The following conversation took more the form of a long monologue by Nedim regarding his marriage and feelings for his wife as well as his ideas on kin marriage, occasionally interrupted by the counsellor's remarks and comments, than the form of an interview steered by my questions. Emine, who had initially glanced doubtfully at me when I

introduced myself, remained nearly completely silent during the conversation but her gestures and mimics showed her active interest and engagement in her husband's narration. It was in particular her reticence which made me decide against asking for a recording to avoid any increased anxiety. In contrast to his wife, Nedim reacted animatedly to my request for an interview, agreeing immediately. As soon became apparent, he greatly enjoyed the opportunity to talk at length about his experiences, and his wife's initial scepticism gave way to an attitude of engaged and intense listening, interspersed by occasional comments on her part, as his narrative progressed. As I only took notes during the interview, the following shared details will mostly take the form of re-narration rather than direct quoting.

According to Nedim, his and his wife's family came originally from Mardin, a province in South Eastern Turkey in close proximity to Syria. However, neither he nor his wife had ever lived there, as his family moved to Istanbul shortly after his birth while she had grown up in Adana, a city in the Eastern Mediterranean region of Turkey. Due to their spatial separation, they hardly spent time with each other while growing up. But when he went on a family visit to Adana in 2015 he saw her again at his uncle's place for the first time after a long period of absence and he was forcefully struck by her beauty, appearance, and natural grace, as he put it:

> "We got married in June 2016, we had both a legal and a religious marriage ceremony. My wife is my maternal uncle's daughter. My mother was anyway on the look-out for a suitable match for me when we went for a visit to my uncle's place in Adana. On that visit to my uncle, we were sitting together when suddenly my wife entered the room. The moment I saw her something emotional happened to me and I was immediately struck by her natural grace and beauty. My mother saw how I was looking at her and I got so embarrassed because normally I would never have looked (*böyle gözle bakmazdım*) at any of my uncle's daughters that way."[31]

While he was sharing these memories, Emine was noticeably moved and started holding her husband's hand. His emphasis that he normally "would never have looked at any of [his] uncle's daughters that way" suggests that up until the above narrated encounter the idea of kin marriage had not been a preferred or privileged option on Nedim's part. However, as he continued to explain, upon his return to Istanbul, he could not forget his cousin and no longer showed interest in any of his mother's suggestions for a future wife. Instead, Nedim began to

[31] Emine and Nedim D. (names have been changed), couple aged 18 and 28 whose family comes originally from Mardin. I interviewed the couple at the genetics clinic which they had attended for a detailed ultrasound scan. Interview conducted in Turkish by author, 16 June 2017, Istanbul.

engage his mother's and father's support in inquiring into the possibility of a marriage match with his cousin. Initially, neither his maternal uncle (Emine's father) nor Emine herself were in favour of such a match. His uncle pointed out his daughter's young age and her need to focus on her education and Emine, as Nedim confessed, "reacted very badly when her father asked her. She said, 'I'm still too young, I want to study, why should I get married, with a relative of mine on top of that?!'" Nedim explained in detail how he did not relent in his efforts to win her heart and convince her parents and how she finally started returning his feelings. Their mutual attachment as well as his promise to support her in her plans for higher education gained her parents' consent in the end and paved the way for their marriage in 2016. During the interview, an intriguing exchange between the counsellor and Nedim took place. Having completed his account of their marriage story, Nedim emphasized that kin marriage had never been on his mind and that he was generally opposed to it. The crucial point here for him was not risk but the question of whether or not one had been co-socialized and grown up with one's future spouse. As he argued:

> "We didn't grow up like relatives (*akraba gibi büyümedik*). I was actually strictly opposed to kin marriage, not because, you know, the children may be impaired (*sakat*) or something like that. I am quite fatalistic (*kaderci*) in that regard. For example, even in America white people (*beyazlar*) and black people (*siyahiler*), anybody, might have an impaired (*sakat*) child. Even though there is no kin marriage, we can see that impaired children are born there as well. So what does kin marriage do? It increases the risk a bit (*riskini biraz arttırıyor*) but people of any religion (*din*) or race (*ırk*) may have such a child."

The geneticist intervened, explaining the particularities of recessive inheritance and how this renders kin marriage a significant risk factor. But Nedim did not pick up on her arguments and refused to engage with her on the basis of a notion of increased risk through shared genetic substance. Instead, he responded by shifting the focus away from genetic relatedness as risky and problematized kin marriage in terms of how it is made and what kind of sociality it emerges from:

> "The risk increases (*risk artıyor*) but that can happen to anyone, as I said, I see this as a question of fate (*kader*). In my family there are other people who have married their first cousins but they grew up together in the same place, they grew up as relatives (*akraba olarak da büyüdüler*) and that is what I am against, what I find weird (*tuhaf*)."

Once the couple had left, the counsellor came back to this argument about risk and relatedness. She remarked to me that it was "all very odd; as if he were opposed to kin marriage for the wrong reason." However, before the interview finished, Nedim emphasized that he and his wife had applied for a detailed ultrasound at the hospital because they were taking the concerns raised by Emine's gynaecologist seriously, namely the bleeding in combination with Emine's young age, the case of disability in her family and them being related. As Nedim stated, "he told us that it was a risky pregnancy (*riskli gebelik*) and that we had better have it checked. It's important to take these things seriously and not be fatalistic (*kaderci*)."

Nedim's narrative and his interchange with the counsellor reveal an engagement with risk, relatedness and kin marriage which is at odds with biomedical conceptualizations of kin marriage as a genetic risk factor and which pushes back against notions of individualized responsibility and accountability vis-à-vis reproductive risk. Challenging the counsellor's scientific language of Mendelian genetics and recessive inheritance describing consanguinity as a factor enhancing genetic risk, he rejects the notion that kin marriage may have a significant impact on a future child's potential "disability". Instead, he declares that "anybody can have disabled children; even though there is no kin marriage, we can see that disabled children are born". Thus, while the counsellor introduces a differentiation between risk groups who are unequally exposed to the risk of having a child with a disability as a consequence of their particular risk factors (here kin marriage), Nedim presents the birth of such a child as a general possibility that is largely unrelated to kin marriage and that all people, irrespective of "religion or race", may face in equal measure. His remark that due to kin marriage "the risk may increase" mirrors the genetic counsellor's language but not her conceptualization of risk and probability as he immediately adds that it "can happen to anyone". Whereas the counsellor speaks of differential more or less enhanced probability regarding future events, Nedim refers to the absolute character of a manifest outcome. Such outcomes he sees as ultimately unrelated to kin marriage, framing them as a "question of fate". However, such confessions of "fatalism" do not prevent him from applying to the hospital with his wife for expert advice and medical

control. When it comes to potential pregnancy risks and complications, there is no allowance to fatalism, as he puts it.

Clearly, Nedim does not consider medical surveillance and intervention futile, nor does he oppose the idea that one pregnancy might entail more complications than another, turning additional medical controls into a matter of responsible decision-making. In that sense, his concession to "fatalism" does not translate into passivity and determinist acceptance. What he rejects by declaring himself "fatalist" is the notion of his own behaviour, specifically his marriage choice, being a contributing factor regarding disability. He achieves this rejection by reframing the question of the link between risk and relatedness in terms of causality rather than probability, correctly dismissing the notion of kin marriage being a *causal* factor regarding the birth of a child with a disability. Presenting the birth of such a child as an absolute event that either manifests or not, he points out that this event is ultimately beyond his control and that by not marrying a relative he may not prevent this event as both couples with and without kin marriage are known to have children with disabilities. What Nedim thus challenges is the notion of individual responsibility which risk discourse and the designation of differential risk groups introduce. His recourse to "fate" in light of the counsellor's delineation of genetic risk constitutes a strategic refusal to be rendered accountable for his reproductive outcomes which allows him to deflect moral blame and individualized guilt. Carlos Novas and Nikolas Rose have argued that being "genetically at risk" does not give rise to passive "fatalism" but active enrolment in risk minimization strategies through responsible choice-making and life style adjustments (Novas and Rose 2000). As Nedim's case illustrates, recourse to "fatalism" may be far from an expression of passivity but an active response of refusal to become enrolled. Such recourse to "fatalism" does not hinge upon a deterministic conceptualization of genetics but rather upon a rejection of genetics as a meaningful way of conceptualizing heredity and reproductive outcomes.

In contrast to medico-genetic professionals' genetic framings of kin marriage, Nedim proposes a non-genetic conceptualization of kin marriage which enables him to simultaneously voice his opposition to the idea of "kin marriage" while endorsing his marriage to his uncle's

daughter. Grounding his disapproval of kin marriage in the social rather than genetic aspects of what it means to be *akraba* or "related", Nedim causes the counsellor to remark that he appears to be opposing kin marriage "for the wrong reason". As becomes apparent during the conversation, both Nedim and Emine are dismissive of "kin marriage" as an abstract idea while actively practicing it. What resolves this seeming paradox is the absence of previous intimacy that might have given rise to an emotional and psychological sense of "being related". Not having grown up together is the key factor which renders his marriage acceptable in Nedim's eyes and differentiates it from the "kin marriages" in his family. Nedim perceives these marriages as "weird" because of the social rather than genetic "closeness" of the spouses. It is the social and spatial distance between him and his future wife which had rendered possible his stark emotional response and ensuing romantic attachment upon seeing her in his uncle's house, an attachment which he cannot imagine developing vis-à-vis somebody he had grown up with in close contact. Although constituting an unequivocal case of "kin marriage" in the eyes of the genetic counsellor, Nedim rejects this labelling of his marriage with Emine, not because he seeks to contest the biological link but because he dismisses it as far less meaningful than the social upbringing between the partners when it comes to conceptualizing "relatedness" and thus kin marriage.

In summary, Nedim's narrative and communication exchange with the counsellor reveal a twofold push-back against the counsellor's framing of his marriage as "genetically risky" because it represents a case of close "kin marriage". First, he refuses to engage with a probabilistic conceptualization of genetic risk upon which the conceptualization of kin marriage as a risk factor rather than causal factor for genetic conditions hinges. This refusal translates into a rejection of individualized responsibilization in light of the genetic risk entailed by his marriage choice. Second, he dismisses the concept of "kin marriage" as an adequate label for his marriage by strategically downplaying the closeness of the biogenetic link while emphasizing the absence of a socially meaningful sense of "relatedness" between his wife and himself.

"I'm considering our marriage in a positive light because it is more distanced, not like maternal or paternal first cousin ones": the Case of Yasemin and Tolga

Yasemin and Tolga were a couple in their mid- to late 30s whom I interviewed together at the genetics clinic. Since 2011, they had been coming to the clinic regularly with their nine-year old son who had been diagnosed with Ehlers-Danlos-Sydrome (EDS) type III, an autosomal dominant condition which affects collagen synthesis as a consequence of which the boy was experiencing joint hypermobility and difficulties in walking. In comparison to many other cases in the clinic, the geneticists considered the boy's condition to be "mild" as it was associated with a normal life expectancy and no forms of intellectual disability. The diagnosis had been based on a clinical evaluation of the boy's symptoms pointing to EDS type III, as one of the geneticists informed me after the interview. A genetic test to confirm the particular type of EDS in question had not been done because it was too expensive for the family, requiring a larger genetic region to be analysed, and not recommended as necessary for future risk management by the geneticists.

The couple's family came originally from the Black Sea region in Turkey and Yasemin had grown up in a major city of the area while her husband Tolga had lived all his live in Istanbul. Following their marriage in 2007, Yasemin had moved to Istanbul. They were second degree cousins, her paternal and his maternal grandfather being brothers. Neither Yasemin's nor Tolga's parents, however, had married a kin relative. Both Yasemin's and Tolga's specification of their relatedness and the pedigree in their patient folder were identical in technical terms, although interpretations of the "closeness" in question varied with regard to the descriptive terms used as will become clear. Tolga and Yasemin both emphasized that they had married "by choice" (*kendi isteğimizle oldu*) because they loved (*sevmek*) each other and highlighted that their marriage had not been "arranged" (*görücü usulü değil*). Although they had grown up in different cities, they had known and seen each other regularly since childhood, occasionally engaging together in social activities like going to the cinema or a cafe. It was a after a prolonged period of not seeing each other, that their feelings towards the other started to change. Both narrated how they were each struck with how "grown up" and "attractive" the other one

had become. They started dating secretly, finally telling their families once they had decided to get married. Yasemin's parents were initially concerned about the relatedness between them and the impact it might have on future children. She said,

> "in the beginning, my parents were against it. My father said 'that is my paternal uncle's daughter's son (*amcamın kızının oğlu*).' But I said, come on *baba*, so many generations have passed (*kaç kuşak geçiyor üstünden*)! I said, I love him and he loves me (*ben seviyorum o da beni seviyor*). And in the end, my father did no longer object."[32]

Like the marriage story of Nedim and Emine, Yasemin's narrative contradicts the stereotype of the forced cousin marriage which privileges family interests over the couple's own desires and happiness which has already been criticized by Alison Shaw with regard to marriage practices among British Pakistani families in the UK (Shaw 2009, 2006). The parents of Yasemin and Tolga only became involved in their children's relationship after the couple had decided to get married. Significantly, Yasemin's father raised the couple's relatedness as a potential problem, an objection which implicitly indicates his familiarity with the idea of kin marriage being medically problematic. Upon facing her father's initial reservations and concerns, Yasemin did not relent, however, emphasizing how Tolga and she were in love and stressing the distance in their degree of relatedness which lay "generations" back.

The following fascinating dialogue reveals how both Yasemin and Tolga emphatically voiced their opposition to what they considered to be a "close" kin marriage while clearly differentiating their own marriage as not falling within that category:

> "Y: Well, you know, when it's first cousins, fully related first paternal cousins (*öz amca çocukları*) who get married, then I am against it. Eighty, ninety percent of the incidences (*olaylar*) that happen are among them, and I am against that of course…
>
> T: Same here…
>
> Y: …but as we said, when it comes to our marriage, we are related through our grandparents, right [turning to Tolga]?
>
> T: Third generation (*üçüncü kuşak*).
>
> Y: We are the grandchildren of siblings, so I am looking positively (*olumlu bakıyorum*) at our marriage because it is more distanced (*daha uzak*), not like maternal or paternal first cousin ones...

[32] Interview with Yasemin and Tolga (names have been changed), a couple in their mid- to late 30s whose family came originally from the Black Sea region in Turkey. I interviewed them at the genetics clinic which they regularly attended for check-up visits with their son who had been diagnosed with EDS. Interview conducted in Turkish by author, 12 June 2017, Istanbul.

T: [interrupting Yasemin and speaking somewhat simultaneously with her] Especially paternal cousins related on their fathers' side, you should add that!

Y: …I'm against those.

T: From the father, paternal cousins carry more genes from the father (*babadan daha çok gen taşır*), see. From the father.

Y: Exactly, and then there is more impairment (*sakatlık*) and afterwards there are more problems (*sorunlar*).

T: There are problems and then when it comes to the birth… Ha, ok, we come here with our son, that's right. He has an ailment (*rahatsızlığı var*) but do I connect this with kin marriage? No, I don't! Ours is fate/chance (*kısmet*). Yes, there is something, there is apparently an issue with our genes, it has been passed on and on and on and it has hit him, it can't be helped. It's fate/chance (*kısmet*)."

The above dialogue reveals how Yasemin and Tolga opposed the idea of first cousin marriage which according to them was very likely to lead to all kinds of "problems" (*sorun*) and "impairment" (*sakatlık*). In contrast, they stressed that their marriage was a "third generation" marriage, they were the "grandchildren of siblings", and consequently they had no objection to it. Tolga furthermore differentiated between maternal and paternal relatedness, arguing that relatedness traced through the father was closer and that children had more genes in common with their fathers, as a consequence of which problems were more likely to come through the father's side. He, however, considered himself to be related to Yasemin through his mother's side. At the very beginning of our interview, Tolga had described his wife as his "mother's paternal uncle's granddaughter" (*annemin amcasının torunu eşim*), adding that this connection made her "not a very close kin relative" (*çok yakın akraba değil*) but "a third degree relative". Having made his remark about paternal relatedness, Tolga immediately went on to reflect on his son's condition, leading to a marked change of language. Instead of referring to his son's condition as a "problem" (*sorun*) or "disability/impairment" (*sakatlık*), the terms used by Yasemin and Tolga as well as other lay participants most often to describe the effects of kin marriage, he spoke of *rahatsızlık*, a Turkish term bearing the multiple meanings of "ailment", "sickness", but also "distress", "discomfort", or "disturbance". *Rahatsızlık* thus does not necessarily indicate a chronic condition or disability and it is also often employed for less serious and more temporary conditions. He explicitely detached his son's diagnosis with EDS

from kin marriage arguing that there was "an issue with the genes" but that it was ultimately a matter of "fate" or "chance" (*kısmet*) that this genetic issue had surfaced in their son.

The case story above reveals how the discrepancies in biogenetic and lay conceptualizations of relatedness, kin marriage, and risk form part of strategies to renegotiate risk discourse and deflect individualized responsibilization. The family's pedigree drawn by the genetic counsellor in the patient folder defines their relatedness as "second degree cousin marriage" (due to the couple being the grandchildren of siblings) and thus as a form of kin marriage commonly characterized by the genetic literature as still falling within the category of "consanguineous unions" which are differentiated from non-consanguineous ones in terms of their associated genetic implications (Bittles 2003, 1994). In contrast, Yasemin and Tolga employed phrases such as "third generation" or "my mother's uncle's granddaughter" (a phrase used by Tolga earlier during the interview before engaging in the above quoted dialogue) to highlight how distant they perceived their relatedness to be.

While they problematized first cousin kin marriage, they clearly differentiated its associated risks from their own marriage situation, with Yasemin claiming that "80 to 90 percent of incidences happen in marriages between first cousins". Her husband further distanced their marriage choice from "problematic" kin marriages by introducing a differentiation between maternal and paternal closeness. Downplaying the patrilineal connection between himself and his wife through the siblingship of their grand*fathers*, he foregrounded the maternal connection through his mother being the latest link between his and her branch of the family to further enhance his notion of being genetically distantly related to his wife. His non-bilateral conceptualization of heredity fits with geneticists' often voiced complaints during our interviews about their patients' privileging of patrilineal connections as the more significant, or even exclusive, ties of biological relatedness as well as with anthropological research concerning the symbolic and socio-political significance attached to patrilineal descent in many Middle Eastern societies (Holy 1989, Joseph 1999, Raz 2005).

It is misleading to treat such discrepancies between biomedical and lay notions of heredity and kinship as an exotic peculiarity of "non-Western" societies. Based on their

ethnographic research in Wales among families with genetic conditions, Katie Featherstone et al. have pointed out how genetic information is always socially mediated as it becomes incorporated into lay people's own established conceptualizations of inheritance and substance transmission (Featherstone et al. 2006). They criticize how the contrasting of lay/popular beliefs with professional/scientific narratives often constructs the former in an "orientalizing" way as expressive of a *völkisch*, premodern and traditional repertoire of cultural beliefs (Featherstone et al. 2006, 58). Cautioning against a simplistic dualism of science versus culture, they argue that the "so-called 'lay beliefs' are dialectically produced as a consequence of a sustained engagement with the clinical domain where biomedical ideas of relatedness and inheritance penetrate other (non-biomedical) models of relatedness" (ibid., 58).

Keeping the ideological pitfalls of the science-culture dualism in mind, I approach Tolga's conceptualization of relatedness and disease inheritance as the result of such a dialectic intersection of biomedical genetic concepts and established non-medical notions of relatedness which emerges from the family's necessary "sustained engagement" with the domain and parlance of the clinic. While adopting genetic terminology, Tolga integrates it into concepts of relatedness and heredity in a way which releases himself and his wife from being held personally "responsible" for their son's condition. His engagement and negotiation with biomedical concepts cannot be made sense of in isolation of the threat of blame and responsibilization which couples who practice kin marriage and have a genetically affected child face. This deflecting of blame is achieved not only through the repeated emphasis on the distant nature of their kinship tie but also through the explicit statement that he understands his son's condition to be unconnected with kin marriage, followed by his reference to "fate".

Although mentioning an "issue in the genes" being passed on through the generations, Tolga makes it clear that he considers the manifestation of a genetic condition in his son's case a matter of "chance" or "fate". His confident uptake of the question of a possible link between kin marriage and his child's condition, which was so markedly different from the silences I often encountered in this regard, may well have been shaped by what genetic counsellors told him about the dominant inheritance pattern of EDS III. Seeing how neither Tolga nor Yasemin

had been diagnosed with the syndrome, the genetic counsellors at the clinic may well have informed the couple that their son's condition was probably the outcome of a spontaneous de novo mutation which could indeed be framed as an incidence of mere chance or *kısmet*. In that sense, Tolga's conceptualization of causality would not have been that far removed from the biomedical one.

Similar to Nedim, Yasemin and Tolga thus distance themselves discursively from the notion of "kin marriage" while having actively chosen to marry "close" according to biomedical definitions of "consanguinity". Without generally rejecting the notion that "kin marriage" entails significant genetic risks, Tolga and Yasemin acknowledge the idea of "close" kin marriage having potential medical implications but engage in a redefinition of "closeness" which detaches their own marriage choice from genetic risk. Like Nedim, they evoke a sense of "distance" interfering with the idea of being "related", allowing them to re-classify their marriage as different from close kin marriages. Stressing this sense of "distantness" while integrating genetic and non-genetic notions of causality regarding their son's condition, Tolga and Yasemin doubly detach their marriage from "kin marriage" as well as from genetic risk.

"I don't know if I could forgive myself if there was any problem with the child": the Case of Dilba

The experiences of Dilba, a woman in her early 30s who had married her maternal uncle's son after a long relationship of mutual love, makes apparent how the biomedicalization of kin marriage does not necessarily displace otherizing discourses concerning kin marriage but easily intersects with its significations of internal otherness, thus perpetuating these. Dilba had been a friend of mine for several years and although I knew her to be married and had occasionally met her husband, I had never been aware of their marriage being kin marriage. I had just started fieldwork at the clinic in late spring in 2017 when we met one afternoon at a café, catching up and having a coffee while her one-and-a-half year old daughter was sleeping in her pram. We were casually talking about relationships when I asked her for the first time how she and her husband had met. A short silence ensued before Dilba, laughing nervously, said that her story might be of much interest for my research because she and her husband were

actually related. Seeing my surprise, she added that she would not lie about her marriage but that she usually preferred to keep the kin marriage part of it to herself when possible because of previous negative experiences, which is why she had never explicitly told me before. However, knowing about my research, she offered to talk in more detail about her experiences. A week later I visited her at home for an interview.

Dilba and her husband, Serhat, had been married for a couple of years at the time of the interview. Coming from a Kurdish family, they were born in a city in South Eastern Anatolia but as a consequence of the intensifying armed conflict in the area Dilba's immediate family migrated to Western Anatolia in the early 1990s when she was still a child. Consequently, she and her husband did not grow up in close proximity, rarely seeing each other during their childhood and teenage years. It was during their university times when both of them happened to spend considerable time together in Istanbul that they gradually developed feelings for each other, eventually starting to date. They decided to get married after five years of having a relationship. While they were dating, they kept their relationship initially secret from their families; not because they feared opposition but rather because they wanted to prevent intervention or pressure to get married before they themselves felt sure about it. Their families turned out in favour of the match and Dilba and Serhat got married in 2012. Although kin marriage was an accepted and common practice among her extended family network, Dilba spoke in length of the difficulties she experienced in coming to terms with her feelings for Serhat at the beginning of her relationship:

> "Actually, kin marriage was something I had never wanted but at the same time it is not something alien to us, culturally speaking. It's a bit of a cultural thing, there are cultural codes (*kültürel kodlar var*) which exert a prohibition up to a certain degree and beyond that it's no longer prohibited. In our culture, kin marriage isn't a big thing, it's even considered to be something positive (*olumlu görülen bir şey*). Like, you don't marry a girl off to a stranger (*yabancıya kız verilmez*), it's the people you know in your social circle who are a source of trust (*güven*) and so on. We don't find [kin marriage] weird (*tuhaf*) because this is how we have grown up. But at one point there is also the wider society which you become a part of, for instance, my friends and social circle at university, I always thought, will they find me odd (*beni yadırgarlar mı*), will they look down on me (*beni küçümserler mi*)? Somehow, because kin marriage is associated with the east, with backwardness (*gericilik*) etc., I didn't want it, although it is very common in my environment, it's not prohibited or even seen as something bad, but I was probably scared of being

> looked at that way and I wanted to see myself as a more progressive (*ilerici*) and educated (*aydın*) woman, I suppose. That's why I didn't want it, but then [laughing] I fell in love (*aşık oldum*)."[33]

Dilba's narrative is informed by a profound tension between kin marriage experienced as a normalized aspect of everyday life and a stigmatized practice signifying the internal others of Turkey's modernity, namely "backwardness" and "Easternness". She described kin marriage as a common form of marriage within her own familial environment and socio-cultural context which explicitly endorsed the idea of love, attachment, and mutual affinity between the children of siblings. Dilba referred to "cultural codes" rendering it permissive to love and marry one's cousin but not for instance one's sibling. This cultural notion of the cousin being considered a particularly suitable partner in marriage was a theme she repeatedly came back to during the interview, emphasizing how for instance many Kurdish love songs lingered on cousins, particularly the children of brothers (*amca oğlu – amca kızı*) being "destined" for each other. Thus, she underlined how she grew up in an environment which attached positive value to the notion of cousin marriage and regarded it as a pragmatic means to facilitate a union between people considered familiar and trusted.

However, on the other hand, Dilba felt deeply ambivalent about commencing a relationship with Serhat. Noticeably, her ambivalence was not rooted in biomedical concern but rather in her awareness of kin marriage being regarded in Turkey's "wider society" as a "backward" or "Eastern" practice which she felt she had left behind as a highly educated and "progressive" young woman. She confessed having herself internalized these stereotypical notions of kin marriage which she kept encountering beyond the circle of her family, particularly once she started going to university in Istanbul. Consequently, she had a sense that her upward social mobility had rendered kin marriage a somewhat non-appropriate practice for her, being at odds with her self-identity. However, as she laughingly concludes, in the end she could not help her own feelings but "fell in love".

Indeed, once moving beyond her family circle Dilba did come to experience reproachful and judgemental reactions regarding her choice of partner. Throughout the years of her

[33] Dilba (name has been changed), interview conducted in Turkish by author, 30 May 2017, Istanbul.interview conducted in Turkish by author, 30 May 2017, Istanbul.

relationship and marriage, she encountered essentializing and stigmatizing remarks, especially from Turkish acquaintances, university friends, or neighbours, as she pointed out. Often, she heard voiced surprise or even disdain that she as a highly educated woman should have ended up in a kin marriage. Such comments were undergirded by the implicit or explicit assumption that such allegedly anachronistic marriage arrangements were ultimately to be expected from a Kurdish family coming from the East of the country. Dilba was particularly upset about these comments' underlying essentialism associating Kurdishness with backwardness, ignorance and female oppression, turning Kurdishness into a signifier of everything the "Turkish" were assumedly not:

> "I didn't even want to tell my close friends that we [she and her partner] are related, I usually didn't mention it until they asked. (...) I was expecting responses like she is anyway Kurdish and that's what the Kurdish do as if I also had accepted the thought that the Turkish don't do it. I was eschewing these kinds of things because we really encounter them and that's why I didn't really talk about it. For example, your neighbour asks 'what part of the country are you from, what work does your husband do, where does he come from', you say 'he is also from our region', [and the neighbour asks] 'ah are you relatives', [you say] 'yes we are', [and the neighbour says] 'hm that's anyway a very common thing where you both come from, they don't give a girl to a stranger there (*sizin orada zaten yabancıya kız vermiyorlar*)', that's how for example some woman might talk to you. When people talk like this it sounds like this is only typical for that area and of course I don't like that. Just think about it, it's the same thing with honour crimes for example. Usually when you mention 'honour crimes (*töre cinayeti*)', everybody immediately thinks of Kurdistan, the Kurdish region, Eastern and South Eastern Anatolian regions (...). They think there are tribal systems (*aşiret*), honor crimes (*töre cinayetleri*), family councils (*aile meclisi*) and so on in these areas. I have not experienced these things, I am from that area, I am the child of a family who comes from that area, I am the child of a Kurdish family but I don't know about these things but when you say that you are Kurdish they immediately burden you with all that baggage (*o bagajların hepsini yüklüyorlar size*). And of course, because it is just the same with kin marriage I avoided telling my friends, especially my Turkish friends, in the beginning."

The above quote communicates a profound sense of kin marriage being set in an associative chain with other practices signifying the internal otherness of Kurdish people in Turkey. Dilba lists kin marriage among other signifiers of "Eastern" or "Kurdish" identity such as "honour crimes" or "tribal" clan structures which are closely associated with Kurdishness in the public imaginary in Turkey (Koğacıoğlu 2011). While self-consciously embracing her Kurdish identity, Dilba clearly felt alienated by these stereotypical ascriptions which she considered to be misrepresenting her own and her family's experiences and self-understanding. In Goffman's words, she experienced how her choice of partner "discredited" her in the eyes of

others, creating a "discrepancy" between her own sense of self and external ascriptions of an identity that had become "tainted" (Goffman 1968, 3-5). She narrated her strong reluctance to share the nature of her relationship and later marriage even with her close friends and acquaintances, especially if they were Turkish, anticipating their stigmatizing reactions and judgements. Dilba's experiences speak to social science studies which have argued that Kurdish people in Turkey have become subjected to an increasingly ethnicized otherization since the 1990s which has replaced former official and societal denial of the existence of Kurdish people in Turkey (Ergin 2014, Koğacıoğlu 2011, Zeydanlıoğlu 2008). These studies emphasize how this otherization process works through the close associative linking of certain practices such as honour crimes, tribalism and arranged marriage or kin marriage with essentialized depictions of "Kurdishness" within public media and policy discourse. These discourses have had the effect of detaching the same practices from constructions of "Turkishness". Consequently, as Dilba very discerningly argues, these practices, including kin marriage, are rendered particularly visible when they occur among Kurdish families.

In reminiscence of the previous case stories, Dilba's narratives communicate a sense of unease with the idea of her marriage being a "kin marriage". She seeks to differentiate her own experience and marriage story from the negative and stigmatizing stereotypes which she considers to be associated with kin marriage but clearly at odds with her own self-identity and personal experiences. It is these significations of internal otherness and non-modernity attached to kin marriage which she initially considers as the main source of ambivalence regarding a possible relationship with her cousin. In contrast, issues of genetic risk and reproductive health only gradually emerge as a concern as her relationship moves into marriage and finally prospective parenthood. As she argued,

> "In our social circle, there were people getting married in a kin marriage. It's been something I regularly encountered in our close environment. But come to think of it, I never came across anyone with a disabled (*engelli*) child. (…) So, of course I didn't think that kin marriage necessarily amounts to having a disabled (*engelli*) child. When we started something like this, my first thought wasn't 'I'll get married and have children'. It was rather the things we've been talking about that came to my mind, the issue of being stigmatized (*damgalanma konusu*), the fact that it's not something that's approved of in society (*toplum içinde hoş görülmeyen bir şey olması*), that it is equated with backwardness (*gericilikle eşit görülmesi*). It was rather these social issues than health that occupied my mind."

The above quote reveals how the experience of seeing kin marriage practiced in her family network without any reproductive problems taking shape had rendered Dilba somewhat sceptical of discourses presenting disability as an inevitable outcome of kin marriage. In contrast, she felt the threat of stigmatization weigh far more heavily than biomedical risk concerns when it came to making up her mind about whether or not to start a relationship with Serhat. However, acquaintances' reactions to her choice of partner make apparent how biomedical risk discourse lends itself easily to advancing moral judgements which may contribute to further stigmatization.

> "For instance, once I told a friend, they said 'ah Dilba, have you really thought this through; when you get married in the future your children will have a high risk of being impaired (*çocuklarının sakat olma riski çok yüksek olacak*)'. There were quite a lot of people saying things like that. I was staying in the student hall at university and my friends from the student hall, they knew about the relationship and when they said such things, I got really sad and upset and regretted having told them. Some people went so far as to bluntly say 'well, you may not be thinking about yourself right now but what about your future child, do you not think about your child at all?' (…) Like, 'you over there in the East anyway get married without thinking and then the children are born impaired (*sakat*)' and so on."

Apparently, biomedical risk came up as one of the first arguments Dilba's friends and acquaintances hold up against her to dissuade her from having a relationship with her cousin. They accused her of behaving in an ignorant and selfish way towards her future children by consciously inflicting harm upon them. At the same time, they treated this lack of reproductive responsibility and risk awareness as yet another proof for the incorrigible backwardness of the "East", seeing Dilba's marriage choice as an expression of her inability to leave behind her own essential "Easternness". Dilba might have feared primarily the social stigma of a relationship regarded as "non-modern" while considering biomedical risk a somewhat distant and secondary concern. However, she quickly came to experience how one's unwillingness or inability to conform to the moral imperatives exerted by biomedical risk discourse may easily become framed as "ignorance" of the medical facts and thus another marker of one's failure to be "modern". As her wording above illustrates, Dilba was deeply hurt by these responses, perceiving them as patronizing and offensive. They have left a lasting impact by motivating her to speak as little as possible to others about her relatedness with Serhat until this day.

As the second last quote illustrates, the frequency of kin marriage in her wider family had had a rather reassuring effect on Dilba because none of her relatives who had married "close" had experienced any reproductive concerns. However, during her pregnancy anxieties regarding reproductive risk started to emerge:

> "I felt a more profound concern (*endişe*) once I became pregnant, like what if something happens, what if my child will be disabled (*engelli*), what if there is a possibility (*ihtimal*) that this might happen etc. In the end, I do not really know what the doctors are medically saying in this regard, how much of an effect (*etki*) kin marriage may have. I don't really know much about these things, I haven't read much about it. But for instance when we had the double and the triple test during the first months of pregnancy, they made us fill in a form which asked for kin marriage. So when they ask for that, you realise that they treat it as a risk factor (*risk faktörü*). We even talked about it with the doctor, telling her – I mean we had already indicated it on the form – but telling her explicitly that ours was a kin marriage. She said there was nothing to worry about (*bir şey olmaz falan dedi*) but we said we really wanted to make sure (*gerçekten emin olmak istiyoruz*), so she sent us to the Florence Nightingale hospital for a detailed ultrasound."

Dilba described her pregnancy as a turning point when she started to feel worried about potential reproductive complications as a result of her marriage choice. Notwithstanding her reassuring family experiences, she admitted not knowing enough about the actual risks involved in kin marriage to confidently dismiss them. Thus, during a prenatal check-up, she and her husband explicitly asked their doctor about potential implications of their kin marriage. Although the pre-examination forms, which Dilba had to fill in, listed "kin marriage" as a "risk factor", the examining physician adopted a reassuring attitude, trying to convince Dilba and Serhat that "there was nothing to worry about". The relaxed approach of the professional stands in stark contrast to the couple's anxiety and desire for further medical control which induces the examining physician to transfer the couple to a private hospital for an expensive detailed ultrasound scan. Dilba explained her emerging anxiety about the potential risks of kin marriage with an acute sense of responsibility regarding her future child's health:

> "Once a child becomes part of the picture, I sometimes become anxious (*tedirgin oluyorum*). For instance, I can handle and face the other issues, like if somebody stigmatizes me (*biri işte beni damgalarsa*), if I come across all these social issues I can handle that, but once it comes to the health of a child (*iş çocuğun sağlığına falan gelince*), this can really become a great worry to me (*beni çok endişlendirebilir*). It would grieve me so much if a decision I myself made – after all I knowingly (*bilerek*) had a kin marriage – if my own decision had only the slightest impact on my child's health, my child's life. (…) This is such a serious responsibility (*ciddi bir sorumluluk*). I haven't experienced this with my own daughter but I don't know if I could forgive myself if there was any problem with the child because of us (*yüzümüzden çocukta bir sorun olursa kendimi*

affedebilir miyim bilmem). Thankfully, nothing like this has happened but you don't know what it will be like with future children."

With the above quote, Dilba's reflections concerning kin marriage have shifted from the societal to the individual level. Whereas previously her narratives had perceptively deconstructed the socio-political dimensions of her ambivalence regarding kin marriage through reference to Turkey's legacies of internal otherization, her language now assumes an acute sense of individual responsibility and moral guilt. Fear of stigmatization has moved to the background while reproductive health concerns start to weigh more heavily, now that a future child is no longer an abstract possibility but an emergent, embodied reality. Dilba now takes up the matter of social stigmatization as something she feels she can confidently face and defy exactly because she is aware of its socio-political determinants. In contrast, she communicates an individualized sense of responsibility for the reproductive implications of her marriage choice. Her conscious decision to opt for kin marriage despite its probable riskiness, thus acting against the moral imperative to minimize a risk once it is known, generates a feeling of irresponsibility and moral guilt. Reminiscent of Canan, the woman quoted at the beginning of this chapter who felt her profound grief upon losing her daughter aggravated by a strong sense of guilt, Dilba wonders if she "could ever have forgiven" herself if her daughter had been born with a serious health issue. What might otherwise be seen as an incidence of chance beyond one's control becomes a consciously inflicted harm once kin marriage, discursively framed as a known and deliberately accepted risk factor, enters into the process of family making.

Dilba's experiences and reflections may go some way in contextualizing the silences I encountered at the clinic. They highlight the sensitivity which the evocation of kin marriage in clinical space inevitably entailed and give a hint of the emotional traumata and difficulties which some of the families were probably experiencing but reluctant to voice in front of a stranger in an environment of medico-genetic expertise. The sense of individualized responsibility transported by discourses framing kin marriage as a source of consciously inflicted suffering, genetic disease and premature death create an environment of moral censure and blame which delegitimizes these couples' personal losses and traumata, rendering their grief and suffering invisible and unspeakable.

As Dilba's narratives furthermore reveal, the moral responsibilization generated by the discursive practices of genetic risk management intersects with existing legacies of kin marriage as a stigmatized marker of non-modernity and internal otherness. Upon practicing kin marriage, couples risk not only being cast as a failure in terms of their parental responsibility but also their achievement of modernity. Problematizing the reproductive outcomes of an already socio-politically contested and stigmatized form of marriage arrangement, biomedicalization processes have turned kin marriage into a double moral failure regarding healthy family making, adding a new layer of scientific authority to existing legacies of stigmatization and otherization of kin marriage. Although it is hard to extrapolate from Dilba's narratives alone, her experiences indicate the possibility that the stigmatizing effects of the biomedicalization of kin marriage might be felt unequally across the population along ethnic lines. They suggest that the biomedicalization of kin marriage may intensify the marginalization of those parts of the population whose family making practises have historically seen greater public scrutiny and visibilization as an expression of their essential otherness vis-à-vis the imaginary of Turkish modernity.

****

Tracing how genetic risk and kin relatedness become variously "detached and attached" (Latimer 2013b, 2007a, b) in medico-genetic space, this chapter has argued that the question of how much "closeness" is risky in terms of reproduction is far from answerable in a straightforward manner. Employing the scientific language of Mendelian genetics and recessive inheritance, geneticists framed kin marriage primarily as a risk factor for rather than direct cause of genetic disease. Based on their biogenetic conceptualizations of kin relatedness, they argued that kin marriage is what the biogenetic tie is, emphasizing that shared genetic substance, including unremembered ancestral relations, rather than families' everyday notions of "kin" were crucial to the identification of a couple's relation as "kin marriage". Such exclusively genetic framings of kin marriage provided a safe discourse for the professionals to talk about kin marriage which suggested technical neutrality, bracketing the socio-politically sensitive terrain within which kin marriage is embedded in Turkey.

However, as this chapter has argued, this "geneticization" of kin marriage stood in contrast to discursive practices and moments which revealed a simultaneous move towards a "non-geneticization" of kin marriage in the clinical realm. These moments of non-geneticization revealed how the management of genetic risk as well as access to genetic health services brought in the "family" as an institution which encompasses but also transcends the biogenetic. The encounter between geneticists and incoming families ran smoothly only as long as biogenetic procreation and social family arrangements realigned in accordance with the model of the heteronormative family but ran into obstacles once the kinship truths spelt out by the genes could no longer be reintegrated into a seemingly divergent family arrangement. What was seen as arising misalignments between the social and the biogenetic dimensions of the "family" on part of the geneticists highlighted the significance of the genetics clinic as a site where not only reproductive genetic risks become managed but where also the social norms defining what the "family" is are validated and reproduced. Kin marriage, which has historically sat uncomfortably with the principles of "modern" family making, may have entered the clinical realm as a genetic health concern. However, medico-genetic professionals' framing of kin marriage as a social problem exposing the ever postponed modernity of Turkey reveal how the biomedical reconceptualization of kin marriage has been targeting a highly contested form of family making in Turkey. While talking "genes", geneticists were able to adopt a scientific discourse suggesting a neutralization of the socio-politically contested status of kin marriage; however, families' experiences with and responses to the biomedicalization of kin marriage make apparent how the implications of risk are far from neutral and how older legacies of kin marriage as an otherized and stigmatized practice are not displaced but rather perpetuated as a consequence of biomedicalization.

As the second part of this chapter has traced, couples practicing kin marriage did not endorse biomedical risk discourse in a straightforward manner but were engaged in pushbacks and resistances which aimed at detaching reproductive risk from their marriage choices. It is easy to dismiss such renegotiations as ignorance of the scientific facts, as some geneticists did, or to reframe them as an expression of the encounter between global science and local

"traditional" belief systems. Without negating the existence of heterogeneous approaches to questions of relatedness, inheritance and disease challenging the hegemonic claims of biomedicine regarding conceptualizations of the body and reproduction in Turkey (Delaney 1991, Yürür 2005, Prager 2015), I seek to adopt a different approach to make sense of these lay-expert discrepancies. I find Janet Shim's approach which contextualises such discrepancies with regard to questions of power inequality particularly helpful here. Based on her work regarding cardiovascular heart disease and stratified biomedicalization, she asks what is reified as scientific facts and what gets excluded or marginalized by the designation of some knowledges as "expertise" and the depiction of others as "subjective" beliefs or interpretations and she continues to trace how such exclusions contribute to the maintenance and reproduction of social inequalities (Shim 2010). Presenting families' renegotiations of genetic risk as an expression of lacking modernity, cultural backwardness and the inability or unwillingness to grasp the scientific facts, I thus argue, is a way of depoliticizing the potentially oppressive and stigmatizing effects of the biomedicalization of kin marriage.

Families' rejections of biomedical framings of their marriage choices as "risky" constituted an active strategy to deflect the threat of culpabilization and blaming in light of their reproductive outcomes. These families were aware that their marriage choices exposed them to intensified public scrutiny and moral judgements regarding their (in)ability to perform the principles of both (Turkish) modernity and responsible parenthood. They did not conceive of genetic discourse as heralding a shift towards neutralization and de-stigmatization of kin marriage but perceived it as a threat to further delegitimize their chosen forms of family making. Carefully detaching their marriages from what they conceived to be "actual" kin marriages, they pushed back against genetically based reattachments defining their relationships as "close" and thus "risky" in reproductive terms.

Lay renegotiations of biomedical discourse take place against the background of a multiplicity of concerns and ethical challenges which couples are facing. They have to come to terms with their emotional desires and familial expectations while making decisions about future partners which were likely to have a significant impact on their personal and familial

happiness. They have to negotiate increasingly authoritative biomedical depictions of kin marriage as genetically risky while navigating societal hostilities and the threat of stigmatization. This threat of stigmatization appears to have gained a new subtlety backed by hard-to-defy scientific authority rather than being on the decline as a consequence of the proliferation of the discursive practices of risk management. Finally, if they happen to experience reproductive complications or the birth of a child with a genetic condition – which no matter how much suggested otherwise by discourses of willingly inflicted harm and irresponsible choice making may come as a completely unanticipated shock – these couples have to face accusations of having acted in a negligent, egoistic or ignorant way, causing feelings of moral guilt and parental failure. Furthermore, once learning about their "burdens of genealogy" (Konrad 2003) after the birth of an affected child, these couples have to make conflicted decisions about future children, risk management enrolment and the possibility of pregnancy terminations, as the next chapter will explore in more detail.

These complexities easily get lost, however, by discursive presentations of couples with kin marriage as irresponsible perpetrators violating the health of their children. What is more, such discourses delegitimize couples' emotional challenges and difficulties, implying that those practicing kin marriage ultimately reap what they have sowed. It is against the background of these overlapping oppressions that couples sought to challenge biomedical attachments of risk and kin relatedness while nevertheless enrolling in biomedical surveillance by making active use of the possibilities of genetic health services. Their uneven engagement with the discursive practices of genetic risk management, particularly their pushbacks against reconceptualizations of kin marriage as a genetic risk factor, highlight what Shim has described as "the partiality and instability of biomedicalization" (Shim 2010, 220).

Finally, as indicated by this chapter, the biomedicalization of kin marriage intersects with older legacies of stigmatization and otherization of kin marriage, investing them with a new scientific credibility. The stratifying effects of biomedicalization processes have been observed to sustain and intensify existing social inequalities while also creating new ones (Clarke et al. 2003, Shim 2010). Targeting a social practice which has historically coded

internal “otherness” in Turkey, the biomedicalization of kin marriage may have unequally stigmatizing effects across the population as suggested by Dilba’s narratives. It may offer a seemingly neutral discourse to justify intensified public scrutiny and biomedical surveillance of the family making practices of those parts of the population who have experienced particular marginalization and exclusion as a result of their contested positionality within the nation state.

Chapter Five: Normative Healthy Reproduction and the Management of Reproductive Risk, Kin Marriage and Genetic Disease within Medico-Genetic Space

Turkey's urban landscape constitutes a space within which technoscientific infrastructures of reproductive (genetic) health services are rapidly expanding, opening up reproduction for biomedical intervention, management and consumption (Aciksoz 2012, Gürtin 2016, Gürtin, Inhorn, and Tremayne 2015, Mutlu 2011, Özbay, Terzioğlu, and Yasin 2011). Carrying further the question of how healthy family making is shaped and achieved at the genomic level, this chapter asks how reproductive risk, kin marriage and genetic disease are managed within medico-genetic space in relation to the crafting of families considered to be "healthy". While the expansion of technoscientific health infrastructures in Turkey as well as in other geopolitical contexts is strongly driven by an emphasis on individualization, self-optimization and commercialized health care (Clarke et al. 2003, Clarke et al. 2010), those infrastructures also take shape within particular national contexts characterized by their specific trajectories of nationhood, state making and governance (Browner and Sargent 2011, Ginsburg and Rapp 1995a).

Drawing like the previous chapter on Joanna Latimer's notion of "detachment" and "attachment" (Latimer 2013b, 2007a, b, 2004) as a means to trace the (un)making of relations in medico-genetic space, this chapter seeks to unpack these intersections between technoscience, the state and the family in Turkey by exploring how the management of reproductive risk and genetic disease unfolds within the contexts of clinical genetic health care. The first part of the chapter foregrounds how medico-genetic professionals working in reproductive genetic health care experience the ongoing politicization of reproduction for nationalist agendas as a threat to their professional practices and autonomy. It discusses how medico-genetic professionals discursively position themselves in antagonism to the current government which they perceive to be curtailing reproductive rights in an environment of increasing political oppression.

The second part of this chapter explores how the discursive practices of clinical geneticists are informed by their expectations that families facing genetic risk engage in risk minimization and reproductive decision-making in ways which facilitate as far as possible the birth of a child considered to be "healthy", that is, a child not affected by a genetic condition or "disability" in the eyes of the medico-genetic professionals. It is this emergence of "healthy" reproduction as an expected trajectory against which families' decision-making processes are judged and evaluated as (ir)responsible that I refer to as "normative healthy reproduction". Tracing how clinical geneticists' professional practices are strongly guided by this paradigm of normative healthy reproduction, the second part of the chapter argues that a profound convergence between the state and medico-genetic space exists, notwithstanding apparent lines of conflict and tension between the government and professionals working in reproductive health care. This convergence hinges upon shared eugenic and ableist sensibilities and a joint push towards healthy reproduction which not only informs government policies regarding genetic disease but also clinical practices of reproductive risk management.

The final part of this chapter concentrates in detail on the management of kin marriage in medico-genetic space, tracing how kin marriage is intrinsically caught up with questions of managing genetic disease through genetic health services and how it is in itself crucial to rendering Turkey a cherished site for the search for valuable genes in the stratified realm of global science. It argues that kin marriage occupies a paradoxical position within medico-genetic space, exposing the limits of the known and the lingering presence of uncertainty characterizing the provision of genetic health services while simultaneously playing a key role in further expanding the frontiers of genomic knowledge by virtue of being a valuable resource for rare genetic material and its mapping.

Seeking to further follow up on this thesis' overarching interest in the coming together of medico-genetic space, state and family within the context of the biomedicalization of kin marriage, this chapter does not foreground families' everyday negotiations of reproductive risk, genetic disease and disability but draws instead heavily on interviews and conversations with medico-genetic professionals working in private and public genetics clinics, including the one I

stayed at for several months during fieldwork. It thus makes a conscious choice of directing the gaze towards those who in their discursive practices set the stakes for how reproductive risk and kin marriage are defined and approached as sites of biomedical intervention and surveillance in Turkey. With its choice of focus, this chapter contributes to discussions of how genetic health services may be employed for "selective reproductive" outcomes (Gammeltoft and Wahlberg 2014), thus perpetuating eugenic aspirations to improve the population's gene pool while rendering these aspirations more "flexible" (Taussig, Rapp, and Heath 2005) through recourse to individualized decision-making and responsibility. Drawing on scholarship regarding eugenics and body politics in Turkey (Alemdaroglu 2005, Ergin 2008, Kadıoğlu and Ayşe 2010, Salgirli 2010), this chapter furthermore seeks to expand the still rare literature on the governance of disability (Açıksöz 2016, 2012, Bezmez and Yardımcı 2010, Yilmaz 2010) and the management of genetic risk in Turkey (Aciksoz 2012, Prager 2015, Yürür 2005).

The Politicization of Reproductive Health Care: Antagonistic Framings of "Reactionary Conservatism" and "Progressive Science"

Being positioned at the heart of reproductive management, the geneticists I interviewed and talked to found themselves entangled within one of the most politicized areas of contemporary Turkish politics within which reproduction and family making constitute a pronounced battleground between the ruling party and oppositional forces. Geneticists working in the clinical realm, being in direct contact with families experiencing reproductive health issues, consciously reflected on the highly politicized nature of reproduction in contemporary Turkey. Already prior to starting proper fieldwork, I was to encounter an often repeated theme during one of my initial access negotiations with a genetics clinic. It was the immediate aftermath of the 2016 coup attempt and a tangible sense of anxiety emanated from the members of the clinical team I spoke to about my research. My affiliation with a university abroad was seen as a potential obstacle to gaining permission for a research project at a time period when collaboration with Anglo-American institutions had suddenly become a target of potential government suspicion. But it was also the very topic of my research, genetic risk and reproductive health services, which caused concern. They feared that the research might cause

trouble for the team in case my findings would "not please everybody". They argued that the rise of the AKP had had a dramatic impact on the provision of reproductive health services, leading to a decline in families opting for prenatal health services, premarital genetic counselling and abortion. In contemporary times when, as one of the geneticists put it, "politics enter into the very intimate space of the bedroom", my topic had assumed a sensitivity which they were acutely aware of and understandably anxious about.

While engaging with medico-genetic professionals during fieldwork, I realized how strongly many of them felt alienated from the current government and professionally threatened by the social changes enacted by the ruling party. Their criticism of the government's ongoing curtailing of reproductive freedom and its interventions into reproductive health care emerged as a recurring theme during interviews as well as less formal conversations such as the one narrated above. As one clinical geneticist working at a public university's genetics clinic argued,

> "Turkey's colour has changed over the last ten to fifteen years (*Türkiye'nin rengi değişti son on senede son on beş senede*). Nowadays, it's no longer possible to have a normal abortion which is not necessary for health reasons in a public hospital or it's theoretically possible but the public hospital doesn't want to do it. We have a prime minister who can say, well he was prime minister back then, now he is the president, who can say 'you should have three children'."[34]

His argumentation illustrates how he perceives the time period coinciding with the AKP's rise to power as a turning point, marking a shift towards more oppressive state intervention into family making. His indignation is strong enough to overrule cautious discretion as he openly criticizes the government's endorsement of pronatalism as well as its strategy of leaving abortion legislation untouched while rendering it both morally unacceptable and institutionally inaccessible. Medico-genetic professionals considered the government responsible for exploiting religious sentiments in estranging the population from reproductive health services, especially prenatal selective screening technologies, thus undermining the people's ability to act in an informed, responsible way with regard to healthy reproduction. One

[34] Male clinical geneticist in his 30s, working in a public university hospital's genetics clinic. Interview conducted in Turkish by author, 20 February 2017, Istanbul.

medical geneticist working in a private university hospital's genetic clinic made the following argument neatly summarizing this line of criticism:

> "Usually, the majority [of incoming patients] does not accept amniocentesis because they don't want to kill a living being once it has entered the womb (*rahime düşen bir canlıyı öldürmek istemedikleri için*). This has changed a lot in recent times, over the last fifteen years it has incredibly changed. I don't know but this may be related to the government because they have promoted so many programmes on TV about how this is a sin (*günah*) and of course, because the patients, especially the housewives, watch these daytime programmes a lot, it has changed dramatically. The number of those who want this [amniocentesis] has decreased, I mean the number of those who actually opt for it. Definitely. They say, I am anyway not going to have an abortion, so I won't do amniocentesis. This has happened many, many times."[35]

Dating the period of change once again to the last fifteen years, this geneticist argues that moral and religious sentiments, specifically the unwillingness to conduct the "sin" of "killing a living being" in the womb, account for couples' dramatically increased refusal of selective screening technologies such as amniocentesis. Cautiously venturing for an explanation of this perceived shift, she considers the government's propagation of religious morality via media outlets mainly responsible for the increase in patients who deliberately opt out of prenatal screening. Such causal explanatory frameworks are, of course, hard to prove. While there may indeed have been a noticeable increase in patients rejecting the option of prenatal screening and termination over the last couple of years, coinciding with the period of AKP rule, as was repeatedly argued by medico-genetic professionals, the underlying pattern of causal changes is hard to trace.

The question of how easily or reluctantly government policies become endorsed and enacted on part of the population is a tricky and contentious one. After all, what has changed since the early 2000s is not only the ideological outline of the government in Turkey but also the scope of access to prenatal selective health services which have evolved from being an exclusive asset of upper and upper middle class culture and become a more widely accessible ritual of pregnancy surveillance in the urban centres of the country (Erdem and Tekşen 2013). As a consequence of this increased routinization, the population becoming exposed to selective reproductive services can be expected to have become more heterogeneous in socio-cultural

[35] Female clinical geneticist in her 30s, working in a private university hospital's genetics clinic. Interview conducted in Turkish by author, 24 March 2017, Istanbul.

terms. However, I do not want to focus on the question of whether or not women's and couples' (non-)endorsement of amniocentesis and related technologies has indeed changed and what underlying causal factors could or could not be identified. What interests me in the context of this chapter is professionals' conviction that the government's paradigm shift regarding reproductive policies has a direct and decisive impact on their work practices. While not all geneticists and family doctors I talked to problematized the ongoing politicization of reproduction, it is noteworthy that a significant number of them did explicitly raise the issue while giving a recorded interview, notwithstanding the ongoing oppressive persecution of dissent on part of the government. Their narratives proved remarkably similar and consistent in character. They all framed the 2000s following the AKP's rise to power as the decisive period of change and referred to both couples' declining uptake of selective reproductive services and the shrinking of institutional infrastructures protecting reproductive freedom as the essence of what had changed. Religion and religious sentiments played a key role in these narratives as the primary explanatory themes offered for couples' withdrawal from prenatal screening and risk management.

Explaining couples' rejection of enrolment in selective reproductive measures with reference to their religious sentiments and moral concerns was a common trope which I repeatedly encountered during fieldwork. According to these narratives, families opting against prenatal screening considered a child with a genetic condition or disability as "granted by God" (*Allah verdi*) and accepted it as their "fate" (*kader*). Only rarely did I come across a more differentiating argumentation such as the following one made by a geneticist working in a public genetics clinic which receives many patients who place emphasis on their religious principles. Asking him whether pregnancy termination was a popular choice among his patients upon identification of a genetic condition, he replied:

> "You never know, the families' experiences can be so different, but religion is an important factor. Those with religious sensibilities (*dini hassasiyetleri olan*) are of course more determined about a continuation of the pregnancy. But their main concern here is, most of the patients here are Muslim of course, that's why they ask whether there is any risk for the mother (*anneye riski var mı*), because according to Islamic principles the question of harm (*zarar*) to the mother is of primary concern. If there is harm to the mother, then the pregnancy can be terminated, otherwise it is continued. This is very decisive. But for instance, if the family has three or two impaired

(*özürlü*) children or troublesome (*sıkıntılı*) children – I keep saying 'impaired' (*özürlü*), if there are disabled (*engelli*) children or if you talk to the family in more detail, then they can change their mind."[36]

This geneticist cautions against a reductionist opposition of science versus religion. While arguing that religion is an important factor regarding families' opposition to a pregnancy termination, he points to a complex interplay of a families' religious beliefs, previous reproductive experiences and the clinically detected condition shaping couples' actual decision-making processes. Pointing out that in case of potential harm to the mother Islamic principles permit abortion, he acknowledges that couples' "religious sensibilities" do not categorically exclude the option of a termination. Most significantly, however, he emphasizes that the existence of other "disabled" children (a term he self-consciously employs to correct his initial use of the term *özürlü*) may prove decisive in bringing about a couple's acceptance of abortion notwithstanding their religious beliefs.

As indicated, narratives highlighting how a couple's particular family situation and experiences with disability or genetic risk rather than "religion" per se shaped reproductive decision-making were comparatively rare which is why the above quotation stands out. Much more pervasive during my encounters with medico-genetic professionals was a generalizing equation of religiosity with "fatalism" and a categorical opposition to risk management. The following quote taken from an interview with a clinical geneticist working at private university hospital offers a rather representative impression:

"Those rural families who practice kin marriage and who don't want to abort the child, even if they learn after amniocentesis that it will be impaired (*özürlü*), are anyway the families considering amniocentesis unnecessary because they say I won't have an abortion even if my child is going to be impaired (*özürlü*). That's why they don't much apply for these diagnostic services, to be honest. They come and listen but say 'we won't have an abortion'. But at least the pregnancy will proceed more comfortably (*gebelik rahat geçer*), at least you won't have to wait for nine months until you find out about the result! But then they bring up the issue that there is a small miscarriage risk (*düşük riski*) and so on, and so on. There is anyway a high risk of the child being impaired, but they still think about the small risk of miscarriage! That's why they don't do it, if they are not prepared to have an abortion, they don't do amniocentesis. I haven't seen many do it. In the end, they just wait and see, saying 'we have faith in God (*Allah'a güveniyoruz*), whatever

[36] Male clinical geneticist in his 30s, working in a public university hospital's genetics clinic. Interview conducted in Turkish by author, 20 February 2017, Istanbul.

> the outcome will be, it comes from God (*ne gelirse Allah'tan*)', that's how they accept it (*kabul ediyorlar*)."[37]

The above quote is informed by a pronounced notion that religious couples, who are portrayed in a rather stereotypical way as "rural" and "practicing kin marriage", principally reject prenatal screening due to their moral opposition to abortion. It reproduces the familiar discourse which puts rational decision-making in opposition to religious fatalism. Downplaying the selective nature of prenatal screening procedures like amniocentesis, the geneticist presents them as a means of reassurance ("at least you will be at ease") and frames families' opting-out as an irrational rejection of health services the ambiguous and ethically problematic aspects of which she deliberately brackets from her narrative. Her frustration with couples' refusal of prenatal screening is furthermore informed by an explicit devaluation of disability which presents a miscarriage in case of a foetus with a detected disability as somewhat less of a tragedy which should not worry couples too much. This intersection of medico-genetic professional's push for normative healthy reproduction and the perpetuation of ableist and eugenic sensibilities is a point I will come back to in more detail later during the chapter. What I want to concentrate on here is the discursive opposition of science versus religion and modernist rationality versus traditionalist fatalism which the above quotation so strongly evokes. It is an opposition which I also often heard repeated from the geneticists whose work I could observe at the fieldwork clinic. When informal conversations moved to the issue of prenatal screening and pregnancy termination, these geneticists emphasized how they, as "physicians" or "scientists" – although of course respecting families' ultimate reproductive decisions, as they always highlighted – found it very hard to "feel empathy with" or "understand" couples who for religious reasons decided to carry to term a pregnancy with a child diagnosed with severe congenital conditions.

Such standpoints reveal a particular reading of Islam as "reactionary" and "anti-science" on part of the medico-professionals I interacted with. This reading contrasts with the existing heterogeneity of Islamic religious responses to reproductive technologies (Gürtin,

[37] Female clinical geneticist in her 40s, working in a private university hospital's genetics clinic. Interview conducted in Turkish by author, 24 March 2017, Istanbul.

Inhorn, and Tremayne 2015, Inhorn et al. 2017) and pregnancy termination (Gürsoy 1996, Shaw 2009). Disproving Orientalist stereotypes of Islamic "fatalism" rendering Muslims categorically inimical to scientific intervention (Hamdy 2009), technoscientific procedures with selective reproductive outcomes are far from principally prohibited or shunned in Turkey and Middle Eastern countries with a majority Muslim population. Practices such as PGD for couples experiencing reproductive genetic risk or IVF-related multifetal pregnancy reduction have been explicitly endorsed by Sunni Islamic religious authorities and are practiced in countries with a majority Muslim population (Inhorn and Tremayne 2016), notwithstanding the selective character of these technologies.

This permissive stance is partly facilitated by a far more flexible position on abortion than suggested by medico-genetic professionals' portrayals of religious couples as being rigidly opposed to medical termination. Significantly, there is no single, clear-cut position regarding pregnancy termination within Islamic religious teachings. The complexity of Islamic philosophy, jurisprudence, history and social life has given rise to a range of standpoints and interpretative traditions (Gürsoy 1996, 534-35). Most of these interpretations prohibit termination after 120 days (the date "ensoulment" is said to take place) unless there is a threat to the life of the mother or the foetus is expected to have a severe disability. However, the permissibility of termination during the first 120 days is subject to debate and varying interpretations exist which are informed by different stances concerning the moral status of the foetus and the process of foetal development (Shaw 2009, 180).

This heterogeneity of Islamic religious responses to abortion is easily rendered invisible by narratives which present couples' religiosity as an indicator for their supposedly anti-science attitudes. Such narratives must be seen as saying less about Islamic religious practices or Islam "as such" than about the speakers' specific self-identification with a particular tradition of secularism and its reading of Islam in Turkey which reaches back to the societal transformations initiated as part of the nation building process. The creation of the Turkish Republic had hinged upon a deliberate detachment of the nation from its Ottoman past and what were perceived to be "the corrupt, religion-bound traditions and institutions of the old regime" (White 2002, 34). In

the context of nation building, the religious institutions and networks upon which society and governance in the Ottoman Empire had rested were dismantled and *laiklik*, a form of state secularism which placed religious affairs under state control, was introduced as one of the core principles of Kemalism upon which the new nation was to be founded. However, with the rise of a new self-consciously Muslim elite since the 1980s which has gained increasing economic and political power over the last decades, the traditional secular elite in Turkey and their vision of state and nation have been severely challenged (Tuğal 2009, White 2014). Turkey's society today is marked by a significant polarization concerning the position of religion within the state. Pervading public and private spaces in Turkey alike, this polarization feeds on ideological battles pitting Islamism and Secularism against each other in a reductionist binary logic which easily masks overlapping practices and attitudes of these ideological camps (Gürtin 2012a, 296, White 2014, 181).

Claims to modernity and being "modern" occupy a key position in these contestations over Turkey's identity. Those situating themselves on either side of the polarized debates concerning Islam and secularism in Turkey employ rhetorical references to modernity in their crafting of group-identity and self-identification (Gürtin 2012a, 296). Science and medicine constitute crucial sites where these contesting claims over modernity are being played out. Leading religious authorities in Turkey have emphasized the compatibility of Islam with scientific progress, pointing out Turkey's burgeoning IVF sector and its wide range of routinely available, highly innovative reproductive health services, some of which are not equally accessible in European countries, as proof of this compatibility (ibid., 297). In contrast, narratives by medico-genetic professionals presenting couples' religiosity as interfering with the innovations of modern science evoked long-standing discursive framings of religious piousness as a marker of lingering internal backwardness and resistance to the Republic's promise of modernity. Such framings allowed medico-genetic professionals to position themselves in line with the tradition of secularism and the Kemalist project of modernization while casting religious couples' behaviour within the clinical realm as not only a challenge to their professional ethos but also a threat to the founding principles of the Republic.

Couples rejecting or avoiding risk management despite the presence of genetic risk thus came to signify in medico-genetic professionals' narratives Turkey's uncompleted modernity. Couples' reproductive attitudes and behaviours in eschewing medical supervision and management were orientalized as an expression of their inability to ultimately achieve Western rationality and modernity. While geneticists repeatedly voiced their conviction that Turkey's population was still lagging behind regarding awareness of genetic risk and enrolment in risk management, one geneticist's respective thoughts neatly summarize this articulation of risk consciousness with Western scientific modernity:

> "What do our citizens usually not understand? Unlike Europe's population they don't understand risk calculation (*risk hesabı*) in the least. For instance, you tell them that there is a 25 percent likelihood that their child will be ill (*hasta*) and they say 'that's very low, there's a 75 percentage that it will be normal (*normal*)'. While a European will grasp this as a high risk (*yüksek risk*), they say 25 percent is very low, I'll still have my normal (*normal*) child. Or let's say one child has not turned out sound (*sağlam olmadı*) but is of poor health (*sağlıksız oldu*); then they say that the second child will fall within the 75 percent. When such a family has more than sick (*hasta*) child, then it's usually because they haven't understood the numeric figures and couldn't grasp the concept, so persistently they keep having sick children." [38]

While social science studies regarding reproductive and genetic risk in Western geopolitical contexts emphasize how lay people's interpretations of risk and probability are far from straightforward and indicate a translational gap between genetic risk experience and the calculative language of risk probabilities (Edwards 1999, Featherstone et al. 2006), the above quoted statement assumes a fundamental difference between the "West" and "Turkey" in how probability is understood. Her framing presents probability as a concept that is easily mastered by "Western" minds but misunderstood by the people in Turkey. Thus, the "gap between genetic information, which is often highly technical but incomplete, and meaningful knowledge which, by definition, is socially, not medically defined, evaluated and acted upon" (Franklin 2013, 298) becomes orientalized as a signifier of Turkey's essential non-Westernness.

Such narratives illustrate how these medico-genetic professionals position themselves as part of a legacy of scientific Western modernity, a legacy which they see threatened to be undermined by government policies enhancing religious sentiments and eroding the principles

[38] Female clinical geneticist in her 40s, working in a private genetics clinic. Interview conducted in Turkish by author, 27 February 2017, Istanbul.

and infrastructures of scientific reproductive management. Throughout this thesis, I have repeatedly referred to the central role which Western biomedicine has played in the formation and expansion of the modern Turkish nation state (Dole 2012, Evered and Evered 2011). Biomedical discursive practices and institutional infrastructures served not only as a display of the state's dedication to achieving modernity; they also constituted important means for inculcating the population with the values of scientific modernity and rationality. It was this commitment to the principles of science, secular rationality and modernity which were defined as core characteristics differentiating the new Republic from the Ottoman past while legitimizing the transition as a move from the obscurity of Ottoman religious backwardness and traditionality to the clarity and progressiveness of Republic modernism. Medico-genetic professionals acted as leading public figures of the state during the founding years and as pioneers of the Republic committed to the creation of a healthy nation and population.

Medical practice thus came to constitute a site where debates over citizenship, religion and modernity were and continue to be played out until this day, as the professionals' narratives so powerfully demonstrate. Speaking the language of "civilization", medicine had emerged "as one of many strategies for embracing a 'modern' status—in terms of both national development and the negotiation of personal identities" (Dole 2012, 273). Consequently, approaches to the body, health and disease which are seen as not conforming to Western biomedical practices continue to "enact a series of debates over threats to and of modernity; national, personal, and moral development; secularism and the gaining political influence of Islam; state authoritarianism and the meaning of democracy; and rationality" (ibid., 271). Medico-genetic professionals' naturalization of an oppositional "science-versus-religion" rhetoric must be understood in relation to the close interrelations between scientific modernity and secularism. This oppositional rhetoric is deeply rooted in the founding narratives of the Republic, as a consequence of which conversations about the "good patient" invariably continue to evoke questions about what it means to be a "good citizen" (Dole 2004, 12).

It is necessary to recapitulate this symbolic and material relevance of medicine as a central pillar of the modern, secular nation state in Turkey to fully grasp the sense of threat

which medico-genetic professionals working in the area of genetic reproductive health care felt to increasingly emanate from the endorsement of religious values on part of the population and government. The geneticists' critical comments regarding the government's reproductive policies as well as couples' reproductive decision-making processes speak to each other. Taken together, they convey geneticists' impression that they are working in a precarious environment which they perceive to become more and more religiously conservative and inimical to the principles of their professional ethos which stresses scientific risk management and rational choice-making for the achievement of healthy reproduction. Their narratives reveal how they experience Turkey's society to be undergoing profound socio-political change which is driven both from below in the form of couples' dynamics of family making and from above in the form of the government's discursive practices delegitimizing selective and antinatalist reproductive health services.

The Normativity of Healthy Reproduction and the Perpetuation of Ableist and Eugenic Sensibilities in Medico-Genetic Space

This section of the chapter explores how medico-genetic professionals endorse healthy reproduction as normative. It traces how clinical geneticists' discursive practices are shaped by their expectations that families facing genetic risk should direct their reproductive decision-making processes towards risk minimization and the achievement of "healthy" reproduction. As I argue, their emphasis on the facilitation of healthy reproduction as a means to reduce suffering and help families achieve reproductive fulfilment renders invisible how their discursive practices perpetuate long established eugenic and ableist sensibilities which tie the well-being of state and society to a citizenry with "healthy" bodies and minds. Thus, notwithstanding medico-genetic professionals' felt antagonism vis-a-vis the government's ideological politicization of reproduction, their discursive practices partially mirrored the government's idealization of "healthy" families and the eugenic and ableist sensibilities it transports.

In this subsection of the chapter, I ask why this convergence is so hard to trace. I argue that the outwardly recognizable opposition and antagonism between the ruling party and the medical practitioners on the ground in terms of their reproductive agendas and values plays a

crucial role here. However, it is also through endorsing the idea of "healthy" reproduction and family making as an unconditional good that medico-genetic professionals managed to detach their professional practices and ethos from the legacy of eugenics and state concerted intervention into the arenas of family life and reproduction. I will explore in the following how the medico-genetic space emerges as a site where eugenic legacies which hark back to conceptualizations of the nation body and particular practices of population governance are reproduced while being rendered legitimate by a powerful narrative of alleviating suffering and facilitating family well-being and happiness.

Making the Next Generation Healthy in the Absence of Treatment

Clinical geneticists working in the areas of reproductive health care represented a branch of medicine dealing with the diagnosis and management of genetic conditions, many of which were congenital and severe in character, eschewing effective treatment and cure. As medico-genetic professionals, they not only witnessed on a regular basis parents' helplessness in watching their children gradually deteriorate and die as a consequence of their genetic conditions; often it was them who in the first place had to break the unhappy news to the parents that their children were affected by a genetic condition offering only limited options for medical intervention. The emotional difficulties of the profession, in addition to spatial and temporal constraints experienced in their various clinics, were among the most commonly cited professional challenges and drawbacks brought up by the geneticists during conversations and interviews. In the absence of treatment for most genetic conditions, the best case scenario of medical help which clinical geneticists could hope to offer the families was a diagnosis followed by long-term clinical observation and management of the genetic condition as well as assistance in managing future reproductive risks. "It's a not a branch offering treatment", said one geneticist working at a private university hospital during an interview.

> "Sometimes I wonder to what degree I am actually doing a service (*hizmet*) to the people. This has become something like a question mark on my mind, because treating somebody with medication

is not our concern. As clinical geneticists, it's our job to offer help (*yardım etmek*) in making the next generation healthy (*sağlıklı*)."[39]

Notwithstanding certain advances in the field of genetic therapies, this quote underlines how clinical genetics is still not primarily concerned with treating but with identifying, diagnosing and managing genetic conditions. With gene therapies being far from a widely accessible and effectively implementable option for most genetic conditions, the one moment which opens up space for medical intervention in the name of facilitating health concerns reproduction and the "next generation" of children in the making. It is the promise of future healthy pregnancies, achieved with the assistance of genetic health care, which emerges as the most effective form of "treatment" that the geneticist has to offer for the families. Only, this form of "treatment" does not hinge upon healing or improving the condition of the genetically affected child but upon medical surveillance of the parents facing genetic risk as well as medical intervention with regard to the yet unborn. It is this process of assisting families in achieving healthy reproduction which figures prominently as a moment of professional fulfilment and achievement in the narratives of the same geneticist:

"But of course, we also have good news to tell the families. During prenatal diagnosis, we share joyous moments. The families are waiting full of anticipation (*dört gözle bekliyorlar*) and we tell them that the baby is healthy (*bebek sağlıklı*), I mean as far as the disease (*hastalık*) we are checking for is concerned, of course. We can't know if there are other diseases, but this joy is really something profound, taking away their fears (*korkularından sıyırmak*), making them happy (*mutlu etmek*), them learning that they will have a healthy baby. All of this is really beautiful. It's the most joyous part of the job, when you can give good news."[40]

The profound sense of personal joy and professional satisfaction, which the above lines convey, illustrates the strong emotional power which the idea of healthy reproduction exerts. The amount of uncertainty and difficulties involved in the diagnosis and classification of genetic conditions, however, render these moments of professional control and effective reproductive risk management comparatively rare. This trajectory sounds deceptively straightforward but as the above quoted geneticist herself points out during our conversation this scenario materializes "in case of probably one among fifty patients". It presupposes a clearly defined risk based on

[39] Female clinical geneticist in her 40s, working at a private university genetics clinic in Istanbul. Interview conducted in Turkish by author, 20 December 2016, Istanbul.
[40] Ibid.

the clinical diagnosis of the genetic condition in question as well as an identification of the genetic variation involved, the families' ability and willingness to use prenatal or preconceptional health services, correct test results and furthermore the non-interference of other, non-tested-for conditions as hinted at by the above quote.

However, notwithstanding the difficulties and elusiveness involved, the experience of successfully facilitating healthy reproduction and fulfilling a couple's emotional demand and need for a healthy child constituted a powerful theme of professional motivation in geneticists' reflections on their profession and professional mission during interviews. These moments of shared happiness between the professionals and families stood out among what the geneticists perceived to be the far more common experience of suffering and misery brought about by genetic reproductive problems. When asking the medico-genetic professionals about particularly memorable or striking incidences during their work with families, many lingered upon the emotional traumata, financial difficulties and marital problems which they saw as being inflicted upon families through the birth of children suffering from severe metabolic diseases, genetic conditions impacting on the functioning of vital inner organs or through undiagnosed conditions resulting in multiple miscarriages or stillbirths. They described the conditions of these families in terms like "helplessness" (*çaresizlik*), "financially and morally broken" (*hem madden hem manevi olarak çökmüş*), "sad" (*üzücü*), or "difficult" (*zor*), emphasizing that especially the lack of healthy children and repeated unsuccessful attempts at having a healthy child greatly enhanced the family's suffering. In their framings, severe genetic diseases emerged as a profound threat and greatly destabilizing factor regarding a family's overall emotional, social and financial well-being and happiness which often only the birth of a healthy child could promise to somewhat alleviate.

There can be no doubt that medico-genetic professionals in facilitating the management of reproductive risk and assisting families in having a child unaffected by genetic conditions fulfilled profound emotional and social needs on part of the couples seeking their help. Neither do I want to question the intense feelings of happiness and joy which both the families and professionals took jointly part in once a pregnancy actually resulted in a healthy birth. However,

this emphasis on selective reproductive management as a means to reduce suffering and create happy families also acts as a master narrative which lends legitimating power to medico-genetic professionals' endorsement of healthy reproduction as normative while obscuring the unsettling legacies of eugenics and ableism which deeply inform their push towards genetically healthy reproduction. Working from within different socio-political contexts, a similar argument has been made by many other scholars working at the intersection of disability and reproductive technologies who have pointed out how the so-called new reproductive technologies are far from "new" in their devaluation of disability as unworthy of life (Browner and Press 1995, Ettorre 2000, Shakespeare 1998, 2005). In what follows, I seek to unpack how this endorsement of selective reproduction within Turkey's medico-genetic space, and the perpetuation of eugenic sensibilities which undergird it, hinges upon particular conceptualizations of the nation body and its citizenry as they have historically emerged in Turkey.

Significantly, the geneticists I talked to always carefully stressed couples' right to give birth to a child with a detected genetic condition and those whose work I could observe were professionally involved with the clinical management of babies and children born with genetic conditions just as much as or even more than they were with the minimization of reproductive risk. As such, their discursive practices were not simply or exclusively directed at producing "averted birth" (Murphy 2017). However, both during interviews and my stay at the genetics clinic, I nevertheless encountered a pronounced sense of disability and genetic disease, which were often treated as synonymous or interchangeable states of being by the medico-genetic professionals, as being major socio-medical ills that were best prevented both for the sake of the families, the wider society and the state. Medico-genetic professionals' endorsement of healthy reproduction as a normative ideal manifested itself in how they commented on families' reproductive decision-making as either responsible and rational (when risk management was observed and geared towards healthy reproduction) or irrational and irresponsible (when risk management was refused and thus unnecessary suffering inflicted on the children and the couple). It also surfaced in their conceptualizations of genetic disease as a threat to the stability

and well-being both of the state and the family. In the following, I will discuss in detail both these levels on which their push towards healthy reproduction manifested itself.

Individualized Reproductive Responsibilization and the Push towards Healthy Reproduction

Already prior to the actual period of fieldwork when I began contacting geneticists in Turkey and meeting them for initial informational talks, they shared fundamental principles of their clinical work with me to help me get a sense of what they were professionally doing. Among those principles, the rule of non-directive counselling as a central pillar of their professional ethos figured prominently. Echoing the global language of bioethics and reproductive health care, they informed me that they counselled families and couples regarding their reproductive risks, communicating risk scenarios, reproductive options and risk management strategies without interfering into couple's reproductive decision-making processes. However, once I started conducting in-depth interviews and spending time with the geneticists on a daily basis during my stay at the clinic, a more complex and less idealized picture started to emerge.

The emphasis on free reproductive decision-making on the basis of non-directiveness as a guiding principle of genetic counselling plays a crucial role in distancing contemporary clinical genetics from past coercive eugenic practices (Raz 2010, 3). However, tensions between the ideal of non-directive genetic counselling and practical realities on the ground putting significant constraints on this ideal have been widely discussed (Arribas-Ayllon and Sarangi 2014, Clarke 1991, Michie et al. 1997, Petersen 1999). Significantly, the often noted discrepancies between the theory and practical realization of non-directiveness do not simply stem from inadequacies of implementation. Rather, this ideal is based on the model of a socially free-floating, rationally thinking and acting, liberal subject which omits from view how genetic technologies and services as well as reproductive experiences are shaped by socio-political conditions, among them the normativity of healthy reproduction and legacies of systematic devaluation of bodily difference (Lippman 1991, Lippman 1994, Shakespeare 2005, Rapp 1999, Rothman 1988). In that sense, the following discussion does not aim at making an argument

about reproductive health services in Turkey "failing" to live up to this ideal of non-directive counselling. Instead, it seeks to offer a discussion of how reproductive risk management in Turkey is situated within a "social moral terrain" (Rapp 1999) that is shaped by ableist sensibilities and eugenic anxieties which predate the emergence of genetic reproductive technologies in Turkey.

As geneticists shared their professional experiences, views and practices with me, I increasingly sensed that, notwithstanding their ultimate acceptance of couples' own reproductive decisions, they perceived the prevention of congenital genetic conditions and their associated impairments as a strong professional mission. Significantly, geneticists were not alone in their normative expectations of healthy reproduction but shared this attitude with many incoming families who prior to experiencing reproductive genetic issues had been expecting and aspiring to have a healthy child. Both medico-genetic professionals' and couples' interview narratives related families' traumatic memories and moments of shock brought about by the totally unexpected news of a child being affected by a genetic condition. Often couples themselves sought out genetic health services because they desired to achieve a healthy pregnancy, a desire usually becoming more pronounced and desperate with each attempt ending in a miscarriage or the premature death of a child. The above related geneticist's reflections on the most joyous part of her work being the successful facilitation of a healthy pregnancy draw exactly on such shared aspirations and efforts between lay couples and medico-genetic professionals which render possible these joint moments of joy. Thus, although the following discussion mainly explores how the push for normative healthy reproduction was facilitated and reinforced by particular alignments between the clinical realm and the state, it is important to keep in mind that couples themselves actively participated in maintaining this normativity.

Whereas geneticists experienced their work with incoming families to be running smoothly and satisfactorily when all parties involved joined forces in bringing about the birth of healthy children, tensions arose once couples acted in ways which in the eyes of the geneticists led them astray from achieving healthy reproduction. During interviews, medico-genetic professionals often voiced feelings of frustration with families whom they considered to be

making wrong decisions in rejecting healthy reproduction. One geneticist who worked at a public university hospital's genetic clinic was quite explicit about his perceptions of right and wrong reproductive decision making regarding the possibility of giving birth to a child with a genetic condition:

> "Let's say [the family] already has two sick (*hasta*) children and although they know that the third child will be ill as well, they nevertheless decide to give birth and we can't say anything because at the end, it's their own decision. But it makes me sad, I mean, it makes me sad on behalf of the child but it's about them not me, so I can't say anything, we can't say anything. (…) Sometimes when I see a family I feel happy, there is a child who will be born with Down syndrome, the mother and father are perfect people (*anne de baba da pırıl pırıl insanlar*), you can feel that they are very positive (*pozitifler*), they have money. It's not for certain that everything will turn out well but you say 'ok, they can do a lot for their children'. Actually, it's not always about money, sometimes there are families who have seven or eight children, you can feel how they look after every single one of them, teaching them things and so on. This family is the right kind of family (*o aile doğru aile*). But then think of a mother who has two 18-year-old children, completely blind, overweight weighing more than 100 kilos, aggressive and with a mental retardation (*agresif ve zekâ geriliği olan*) and she wants to give birth to a third one like the others, now, how is this family going to look after them?! See, again I'm getting angry [laughs]! This makes me sad, but of course I can't say anything. What are you going to say, you can't say 'go and have an abortion!'"[41]

The above quotation conveys a strong sense of helpless frustration resulting from the ethical impossibility of interfering into processes of reproductive decision-making perceived to be wrong due to the anticipated suffering and burden expected to result from them. Significantly, the geneticist quoted does not categorically reject the thought of giving birth to a child with a genetic condition. He refers to the familial context and social upbringing as crucial factors shaping the experience and the development of children with genetic conditions like for instance Down syndrome. However, his conditional endorsement of the birth of a child with Down syndrome rests upon a distinction which he makes between "good" and "bad" families. He describes as "the right kind of family" the family who can devote sufficient time, energy, financial resources and commitment to provide their children with a good upbringing and caring environment. In short, he frames them as families capable of accommodating disability without jeopardizing their own and their children's well-being.

Similar to other geneticists interviewed, his narrative shows this geneticist to be particularly upset about the idea of a family knowingly giving birth to multiple children with

[41] Male clinical geneticist in his 30s, working in a public university hospital's genetics clinic. Interview conducted in Turkish by author, 20 February 2017, Istanbul.

genetic conditions who thus in his eyes clearly strain the limits of what he considers them capable of coping with as a family. While many genetic conditions may escape prenatal screening prior to the birth of a child with the condition, it is the existence of a previously born child with a genetic diagnosis which then directs the medico-genetic gaze towards screening for this condition in further pregnancies. With all the technologies available and risk management rendered feasible, the idea of healthy reproduction being repeatedly thwarted through families' refusal of enrolling in risk management apparently proved particularly upsetting for medico-genetic professionals as many similar narratives to the one quoted above which emerged during interviews reveal. While the quoted geneticist acknowledged that a child with Down syndrome may be a source of family happiness – and he was singular among those geneticists I interviewed in explicitly making this argument – he framed this experience of family making in terms of an alternative and rather exceptional pathway from the principally preferable scenario of selective reproduction and pregnancy termination in case of a prenatally detected genetic condition.

Distinguishing between what he considered to be "rightly" and "wrongly" acting families, he employed an individualizing discourse which locates the question of the (non-)accommodation of a genetic condition to be resting primarily with the family and its ability to raise children well, against all odds. What remains largely missing from his narrative, being only implicitly hinted at by his reference to money concerns, are the structural disadvantages which families caring for children with genetic conditions or disabilities have to face. The distinction between "good" and "bad" parenting renders these structural constraints largely invisible, suggesting that the relative "success" in raising a child with a genetic condition is primarily contingent on the family's individual commitment or lack thereof in addition to the severity of the condition in question. What this distinction effects is a detachment of the family from the state. In framing the accommodation of a genetic condition or a disability in terms of families' financial and emotional resources, the question of what kind of a state might be envisaged which is able to provide a "good" environment for families caring for children with genetic conditions or disabilities remains unasked. It is the bracketing of this question which

gives weight to conceptualizations of genetic conditions as a financial drain and burden on state and society as I will discuss later on in more detail.

Here, I want to focus on how the clinical geneticist's above given quote is also significant in how it introduces the issue of genetic conditions presenting in a spectrum of severity. While the absence or presence of a genetic condition may be prenatally detectable, the severity of the condition in question, as for instance in case of Down syndrome, often is not (Rapp 1999, Rothman 1988). However, it is the question of the severity of a detected condition which constitutes a crucial factor regarding the permissibility of termination after the 10th week of pregnancy in Turkey. As specified by the 1983 Law on Population Planning (Official Gazette no. 18059a), such a termination is legal in case of a child diagnosed with "severe disability/invalidity" (*ağır maluliyet*). The Ministry of Health has passed an accompanying bylaw on abortion and sterilization listing specific conditions, among them blood diseases, metabolic diseases or congenital conditions like Down Syndrome or Marfan Syndrome, which render a pregnancy termination legally permissible (Official Gazette no. 18255).

However, this bylaw also lists the vague formulation "other inherited conditions which entail a high likelihood for the birth of an impaired (*sakat*) child" as an acceptable reason for medical termination (ibid.). This formulation introduces "impairment" as an umbrella term without further differentiation, turning it into a generally acceptable reason for termination. Both the 1983 Law on Population Planning and its accompanying bylaw thus accredit medico-genetic professionals with the authority to evaluate the acceptability of pregnancy termination based on the expected severity of a future child's condition. Significantly, according to the bylaw's wording, the permissibility of termination hinges upon a genetic condition being considered as causing "impairment". As Can Açıksöz has rightly argued, this legal framing leaves medico-genetic professionals with great discretionary power in judging which inherited conditions should be categorized as having disabling consequences for the child and which forms of life should be classified as (not) worth living (Aciksoz 2012, 42). The above quoted geneticist himself pointed out during the interview how much depended on the physician's "initiative", as he put it, in deciding upon a permissible abortion in the absence of clear-cut

guidelines. While he praised the opportunities for late trimester intervention and abortion in case of late manifesting, severe congenital conditions offered by the existing regulation, he also indicated the moral responsibility and burden which it entailed for medico-genetic professionals.

At the clinic where I conducted fieldwork, professionals confided negotiating this existent room for manoeuvre in ways which allowed them to carefully channel families towards healthy reproduction. In situations when non-directive counselling appeared inadequate to them, they sought to facilitate what they regarded as the right decision and best interest for the family. Walking back towards the clinic after a lunch break during my first week of fieldwork at the clinic, I happened to be talking with one of the assistant doctors. From the very beginning of my stay at the clinic, this assistant doctor had much supported me and made me feel welcome within the clinic's team. As I had realized, she was also very sensitive as to whether or not it was appropriate in a given situation to inform incoming families about my research project. She knew about my ethical concerns and principles when it came to recruiting families and on our way back to the clinic, she started talking about patient rights and ethics. She told me how she had attended and greatly enjoyed an international seminar on ethics and genetics the previous year, "but", she continued, "many ethical issues are hard to realize in Turkey. In theory, we are expected to be non-directive in our counselling but often that is impossible. Many families have only a low level of education. They ask us for advice and want to be guided." As she clarified, she did not shy from directly recommending an abortion if there were medical issues with the future child and if the family wanted to have her reproductive advice.

Significantly, by thus straying from "non-directive" counselling, geneticists like this assistant doctor did not seek to compromise patients' reproductive choice making. They rather participated in the creation of a shared moral ground with their patients by shouldering part of the responsibility with regard to these difficult decision making processes. Another anecdotal story narrated by a geneticist after the end of the interview recording further illustrates this willingness towards shared moral responsibility. The geneticist referred to the case of a couple facing the difficult decision of terminating a pregnancy following prenatal diagnosis. Ongoing

examinations had been indicating increasingly severe malformations of the foetus' internal organs, including the heart and the brain, which were expected to significantly impact on the baby's intellectual and physical development after birth. While the woman was in favour of a medical termination, her husband remained opposed on moral grounds. During one clinical consultation the couple started arguing. In the end, the husband furiously consented to having an abortion, stating, however, that he would not consider himself accountable for the sin (*günah*) of committing this act. His wife alone would be morally accountable, he maintained. She refused such an agreement, arguing that he as her husband should take equal responsibility and accept his "share" (*pay*) of the sin. Seeing the woman's willingness to have the abortion and seeking to back her up, the geneticist intervened making an impromptu argumentation. He sought to reassure the couple and assuage their dispute, saying the sin would be shared by all involved, namely the couple and the medical professionals signing the termination decision protocol. This, he reasoned, would greatly reduce the couple's share of the sin (*günahın payı*). The geneticist voiced his doubts during the interview as to whether or not the couple had truly found this convincing in the end; but, as he conceded, his argumentative intervention had at least proved effective in putting an end to the discussion and settled the couple's decision to go ahead with the termination.

Ilpo Helén has argued that foetal diagnosis in antenatal care has brought about an ethical split between technical and ethical responsibility. As she claims, the field of action and responsibility of the medical profession remains restricted to the technical management of the diagnostic processes whereas the ethical responsibility in the form of choice concerning the medical operations to be performed is left to the pregnant woman and sometimes her family (Helén 2004). However, both the geneticist's and the assistant doctor's above discussed bending of non-directive counselling principles complicate and blur this strict division suggested by Helén. Rather than affecting a split between professionals' technical responsibility and couples' or women's moral responsibility regarding the prenatal management of foetal development, interventions like those narrated by the geneticist and the assistant doctor illustrate a willingness on part of medico-genetic professionals to assist couples in navigating the moral ambiguity

surrounding reproductive decision making. By acting in ways which do not strictly conform to the practices of non-directive counselling, these professionals helped legitimize couples' termination decisions by accepting to shoulder part of the burden of responsibility.

As became clear from the interviews I conducted with families at the clinic where I conducted fieldwork, this approach of straying from non-directive counselling seemed to be observed by several of the geneticists at the clinic and not the only by the assistant doctor who started the above conveyed conversation with me about ethics and patient rights. Particularly, those women or families who had given birth to a child with a genetic condition but who had also at least one other unaffected child were directly advised by the geneticists at the clinic to avoid future pregnancies because of the risk involved. Having achieved healthy reproduction, any further pregnancies were described to them as unnecessary risk taking by the geneticists. Referring to this notion of avoidable and unnecessary risk, one of the medico-genetic professionals working in the clinic's genetics lab who earlier during her career had worked in closer contact with the patients made the following comment during an interview with me. Rather than criticizing or blaming families practicing kin marriage for their marriage choices, she had always preferred the approach of her former mentor who used to tell those families to not further strain their "luck" and "stop on time" before unknown risks might manifest themselves.[42]

As the above narratives and conversations highlight, medico-genetic professionals counselling couples and families on genetic risk did respect couples' reproductive plans and choices. They did not engage in coercive practices of pressuring families into certain reproductive decisions. However, their professional ethos as well as the technologies and services they administered were situated within a "social moral terrain" (Rapp 1999) which re-inscribed the normativity of healthy reproduction by presenting the birth of a child with a genetic condition as only ever an alternative to what was essentially considered to be the preferential option of termination. Channelling families towards risk minimization and the prevention of especially multiple births of children with genetic conditions emerged as a strong

[42] Female molecular geneticist in her 50s, working at a public university hospital's genetics laboratory. Interview conducted in Turkish by author, 30 January 2017, Istanbul.

professional drive within medico-genetic space which at times was hard to reconcile with the requirements of non-directiveness. As some of the geneticists and women interviewed revealed, this principle was not always strictly employed at the level of discussing future reproductive plans. Geneticists not only sought to actively discourage couples who had already achieved healthy reproduction from engaging in any future risky reproductive practices; they also occasionally became involved in couples' decision making processes in a more directive way by explicitly encouraging couples to opt for medical termination. However, while such practices reinforced the normativity of health reproduction, they also created a shared moral ground between medico-genetic professionals and couples which allowed geneticists to assist families in managing the burden of responsibility involved in reproductive decision making.

Couples' choices to opt for termination cannot be separated from the socio-economic and political environments within which they have to consider giving birth to a child with a disability. Disability scholars working beyond the mainly Western-centric focus of the discipline have repeatedly warned against a de-contextualized criticism of the medical model of disability, which prioritises medicalized, tech-centred approaches to disability, when speaking about contexts where access to health care and support infrastructures are far from given or evenly distributed (Barker and Murray 2010, 69). The socio-political marginalization of people with disabilities as well as severe inequalities in health care provision undeniably impact greatly on those families who have to care for members with a genetic condition in Turkey. These families invariably have to make not only a decision about the birth or abortion of a future child but about "kinds of living" (Wahlberg 2009) shaped by the consequences of that choice. However, the socio-economic constraints families faced were largely rendered invisible by the individualized language of reproductive decision-making and responsibility which traces families' refusal to engage in healthy family making back to an inability to perform rational, responsible choice-making due to religiosity or lack of education. Detaching the state from the responsibility to enable and support families' active decision for a child with a genetic condition, this language lends itself easily to ableist and eugenic sensibilities as discussed in the

next sub-section. Further marginalizing the experience of disability, these sensibilities contribute to the emotional difficulty of reproductive choice-making in the face of genetic risk.

The Long Shadow of Eugenic Thinking and Nationalist Body Politics: Framings of Genetic Disease as a Burden on State and Society

One day towards the end of my stay at the clinic, the assistant doctors working at the clinic and I went for lunch together as usual but this time we were accompanied by some of the senior geneticists as well as well as by an assistant doctor specializing in paediatric neurology who had recently joined the medical team at the clinic for a one-month rotation stay. As we were eating, a conversation between the medical team members unfolded who were discussing the policies of state support for medication. The general tone of the conversation was critical of the government's support schemes which, as the senior geneticist present argued, were too generous for the country to be economically affordable. At one moment during the conversation the visiting assistant doctor suggested that those couples who refused prenatal diagnosis as well as those who willingly and knowingly gave birth to a "sick" (*hasta*) child should be held responsible for paying out of their own pocket all the financial expenses required for their children's care. The senior geneticist responded by arguing that the government should at least offer substantial support for PGD in case of common genetic conditions. This senior geneticist's two seemingly contradictory statements – a critique of the government spending unaffordable amounts of money on medical treatments for those with chronic conditions and a call for more government support regarding PGD – were left suspended in the air as the conversation quickly moved in a different direction, but both of them clearly expressed concern for the economic costs of life-long treatment for people with genetic conditions. While the senior geneticist mitigated the assistant doctor's suggestion to effectively punish families for their reproductive decision-making, both their statements converged in a pronounced sense of congenital genetic disease being a burden on the state. Supporting PGD, so the argument went, and thus making reproductive risk management more accessible to couples morally rejecting prenatal diagnosis, is economically more advantageous than subsidizing lifelong medical support.

The sense that more was at stake than individual families' happiness informed medico-genetic professionals' discursive practices regarding reproductive risk on various occasions. In framings reminiscent of state discourses which cast families as the cornerstone of society, they presented genetic disease as a threat to the population and the state. One geneticist working at a private genetics clinic shared the case of a couple, the woman pregnant with her third child and her two other children affected by a severe metabolic disorder, who had applied to her clinic wishing for assistance in achieving the birth of a healthy child. The team at the clinic was able to make a genetic diagnosis for the children's condition and level the path for risk management through prenatal diagnosis. When the woman was pregnant in her 16th week she underwent prenatal screening, revealing the third child to be also affected by the same disease. "In such a case", the geneticist said, "with prenatal diagnosis, there is only one recommendation we can give the family, namely not to give birth to the child if this is desired. But the family decided to have the child and so there was now also a third child."[43]

Sharing the story of the family, the geneticist became clearly agitated as she considered the family to have made the wrong decision. In an exasperated voice, she described the whole affair as a waste of money and energy. "Why opt for prenatal diagnosis in the first place; why pay all the money?!" she asked rhetorically, implying that opting for reproductive risk management technologies makes only sense if prevention of an affected child was to be the ultimate goal. Questioning the family's reproductive decision-making, the geneticist not only voiced her concern that the couple was taking more on board than they could cope with, overstretching their emotional and financial capacities by adding a third affected child to their responsibility of care. She also made it clear that she considered the birth of the child an additional economic burden for society:

> "So, the third child will be born, it will need treatment and this and that. This means your lives will be dedicated to this. But will you be able to deal with a third child? They say they will be, but of course this also causes the national economy difficulties because all the treatment will only help to keep the child alive, it will not cure the child, it will not make it reach a productive stage (*üretken hale getirmecek*)."

[43] Female clinical geneticist in her 40s, working at a private university genetics clinic in Istanbul. Interview conducted in Turkish by author, 20 December 2016, Istanbul.

The case story shared by the geneticist referred to a family enrolling in risk management without ultimately opting for healthy reproduction. From what is being said, it is impossible to tell whether abortion had been out of the question for the family all along or whether their decision to carry the pregnancy to term emerged as both risk management and the pregnancy itself progressed. What becomes apparent, however, is the geneticist's expectation that risk management should have resulted in the prevention of a child diagnosed with a genetic condition. Clearly, she considered the couple's reproductive decision to have a negative impact not only on their well-being as a family but also the economic condition of the state. Her narrative thus turns society and state into victims of the couple's irresponsible reproductive behaviour, implicitly framing risk management as a citizenship duty. Rather than describing care for those having a genetic condition as a duty of the state towards its citizenry, she considered responsibility to lie with the couple who should make use of the possibilities for healthy reproduction offered to them.

Another clinical geneticist working in public health care at a university hospital's genetics department brought up the question of genetic risk as a matter of population and state concern from a different perspective. The interview with her stands out in the sense that she was the only medico-genetic professional who made an explicit reference to eugenics, voicing uneasiness about the closeness of her argumentation to legacies of eugenic thinking and seeking to differentiate her line of thought from coercive practices of the past. Talking about the medical problems associated with kin marriage and its impact on genetic disease prevalence at the population level, she made the following argumentation which I will quote in full length:

> Geneticist: "So why is kin marriage problematic in terms of disease (*hastalık*)? Ultimately, what we call natural selection (*doğal seleksiyon*), the existence of gene diversity (*genlerin çeşitliliği*) or allelic diversity (*alellerin çeşitliliği*), is a necessary process for the survival of living beings. Therefore, if we we limit the same gene pool (*gen havuzu*) and keep practicing kin marriage, then we will start observing recessively inherited diseases like cystic fibrosis or SMA, these kinds of diseases, more frequently in the population. (…) That is why when we look at kin marriage biologically and from a health point of view, because it hinders genetic diversity, in terms of environmental adaption, even if intellectual and developmental developments become fully realized - but please let's not practice 'eugenism' (uses English term *eugenism* in original) - I think that with kin marriage we render a community that could live intelligently or more healthily in its adaptation to the environment more 'vulnerable' (uses English term *vulnerable* in original) and 'fragile' (uses English term *fragile* in original).

> MK: So, on the one hand, there are the individual families and on the other hand, there is society (*toplum*).
>
> Geneticist: It affects society's (*toplum*) general health in the long run, of course. (...) If we can't prevent it, then prenatal screening and – of course, I am again putting 'eugenism' (uses again English term *eugenism* in original) to one side here, there shouldn't be any directive intervention into the genome, it is a system which should proceed with its own normal diversity and processes without us intervening into it, but at least certain measures could be taken for the prevention of disease while protecting this diversity. As you know, there are already premarital screening tests for thalassaemia, Mediterranean anaemia, and they are applied to couples with relatively low costs. If there is something like that, then they receive counselling and at least they can be assisted in having an unaffected (*hasta olmayan*) child. All of these are processes, of course."[44]

The above discussion makes apparent how the geneticist considered genetic conditions both a medical and, by extension of its impact on population health, also a social problem. Arguing that frequent practices of kin marriage limit the gene pool of a population, thus decreasing its genetic diversity while rendering the same population more "vulnerable" to recessively inherited diseases, she describes kin marriage as having a negative evolutionary effect regarding population health. However, she also framed genetic risk as a social threat by associating an increased genetic disease prevalence rate with the loss of a community's ability to live together in an "intelligent" and "healthy" way. Following my remark that her argument was now spanning families and society as a whole, she continued her line of thought, further clarifying her understanding of "eugenics" as directive interference into a population's "normal genetic diversity". However, facilitating healthy reproduction by "assisting families in having an unaffected child" with the help of selective reproductive technologies and preventing disease through screening while "protecting" the genetic diversity are clearly detached from any eugenic implications in how she framed her narrative.

I would argue that, notwithstanding the geneticist's discursive distancing, her line of argumentation reproduces eugenic concerns in how she presents recessively inherited conditions as an evolutionary and degenerative threat, advocates selective reproductive technologies and screening policies for the sake of improving the overall health of the population by reducing the prevalence of disease and in how she conceptualizes genetic risk as simultaneously a medical and social problem. However, by describing "eugenics" as interference into "normal" genetic

[44] Female clinical geneticist in her 40s, working in a public hospital's clinical genetics department in Istanbul. Interview conducted in Turkish by author, 20 March 2017, Istanbul.

diversity, she achieves a detachment of her advocacy of healthy reproduction from eugenic legacies, delineating genetic variation giving rise to genetic conditions as a legitimate ground for medico-genetic intervention – if necessary with the help of government supervised screening policies.

The conversation with this geneticist took one more interesting twist. Reflecting on the societal significance of healthy reproduction and reproductive health care, she chose to conclude the interview by quoting Mustafa Kemal Atatürk:

> "A healthy mind rests in a healthy body (*sağlıklı akıl sağlıklı bedende bulunur*). That is a saying by Atatürk, isn't it? These words are a very nice finish [to the interview]. A healthy mind (*sağlıklı zihin*) rests in a healthy body, in that sense first the body will be healthy and then there will be a good society (*güzel bir toplum olucak*), the children will grow up in a better way. They will achieve better things than we have in our times." [45]

Referring to Atatürk's saying, which privileges physical and intellectual ability and defines both healthy body and healthy mind as mutually constitutive, the geneticist evokes Kemalist body politics which had declared physical and mental fitness to be a primary citizenship duty for the sake of the nation's future. Articulating social and bodily health while emphasizing the significance of healthy reproduction for a healthy society, her narrative is strongly reminiscent of contemporary government discourse. But her deliberate reference to Atatürk, an increasingly political statement which in these days affects an ideological positioning of the speaker in opposition to the ruling party and its political agenda, masks this very closeness.

All three conversations discussed in this sub-section reveal how medico-genetic professionals at times framed genetic disease as a socio-medical threat endangering the well-being of state and society at large. These framings thus perpetuated long-standing eugenic anxieties and ableist sensibilities which have historically informed nationalist discursive practices and body politics in Turkey. Although eugenics was never systematically implemented by the Turkish government, eugenic thinking was highly influential among Turkish intellectuals during the 1930s, informing the passing of the 1930s Law for Public Hygiene and the regulation of premarital health screening as envisaged by this law. As a movement of thought, eugenics

[45] Ibid.

was particularly promoted by a group of publicly highly visible and influential doctors and political figures who, themselves educated in Europe at the heyday of European eugenics, sought to encourage eugenic discursive practices back in Turkey (Ergin 2008, Salgirli 2010). They stressed the significance of bodies as the most valuable capital of the nation state and problematized inherited disease in terms of population degeneration while emphasizing the economic burden produced by the unfit and disabled (Alemdaroglu 2005, 69-70). While there is ongoing debate as to how significantly eugenic thought has shaped nationalist imaginations of state and society in Turkey, no doubt ableist idealizations of a healthy body and mind played a central role in Kemalist ideological practices. Working on the socio-political rejection and stigmatization of disability in Israeli society, Meira Weiss has coined the term of the "chosen body" to describe the privileged position of the healthy, physically strong and able male Ashkenazi body in nationalist ideology (Weiss 2007). As she argues, the emergence of this idealized body image is inseparably connected with the Zionist movement and the process of the formation of the state Israel which required young, male and able bodies for the realization of the state building project as well as its military defence. A similar body image informed the Kemalist project and the role of body politics within it. Physical education and sports were seen as central to the creation of a healthy strong youth as part of forming the modernized, civilized and healthy "New Turk" (Kadioğlu 1996) on whom the nation would rest. The Body Discipline Law of 1938 sought to "'regulate games, gymnastics and sports that improve the physical and moral capabilities of the citizens in accordance with the national and reformist principles" (Alemdaroglu 2005, 65). Furthermore, nationalist discourse has idealized notions of heroic militaristic masculinity which are pivotal to constructions of masculinity in Turkey to this day and the institutionalization of military service as a rite de passage for the transition to male adulthood (Açıksöz 2016, 2012)

Thus, notwithstanding ideological discrepancies between the Kemalist and the current AKP state projects, there is a marked continuum in how hegemonic ableism and healthy reproduction are framed as central to the overall well-being of the nation. Medico-genetic professionals' endorsement of normative heathy reproduction is deeply informed by the legacies

of these body politics locating those not conforming to the ideal of healthy body and mind as outside of the nation body. However, their tendency to present their work practices in individualizing and de-politicizing terms as voluntarily sought out health care services tailored towards alleviating families' reproductive plights and assisting them in achieving their reproductive desires largely brackets these legacies. As a consequence, the continuing presence of these legacies is easily rendered invisible within the context of an ever expanding landscape of consumer oriented reproductive genetic technologies.

Kin Marriage as a Reproductive Threat and Research Resource in Medico-Genetic Space: Exposing the Limits of Certainty, Pushing the Frontiers of Science

The biomedicalization of kin marriage and the growing medicalized stigmatization of this form of family making hinge upon medicalized framings of "disability" as a genetic aberration requiring management and prevention as discussed in the previous sections of this chapter. This section will have a closer look at how kin marriage itself emerges as a site of biomedical intervention in relation to the management of reproductive risk and genetic disease. I argue that kin marriage occupies a somewhat paradoxical position within medico-genetic space. I will trace how within the context of the clinic it emerges as a serious reproductive threat and challenge to risk management, thus exposing the limits of the known and the lingering presence of uncertainty within discursive practices surrounding reproductive risk. On the other hand, however, kin marriage constitutes a highly cherished opportunity and resource for genetic research which allows for an expansion of the limits of science and the known. This paradox position of kin marriage corresponds to the positionality of Turkey within the global landscape of genetic health care and research, constituting both a site for expanding and increasingly commercialized health services and a site providing valuable "raw" material for driving genetic research.

Kin Marriage as a Reproductive Threat and Challenge to Risk Management and "At-Risk" Subjectivity

Kin marriage occupies a key strategic role in Turkey regarding the expansion of genomic knowledge and technology infrastructures. Public and private genetics clinics throughout the country work with a significant rate of patients practicing kin marriage and a simple web search, browsing through these clinics' websites, quickly reveals how couples with kin marriage are consistently listed as one of the major genetic risk groups who are expected to benefit from the services these clinics have to offer. Furthermore, promising fruitful possibilities for rare gene collection, kin marriage also drives the development and expansion of the very technoscientific knowledge infrastructures of which couples practicing kin marriage are expected to be major users. While I will focus on the issue of gene collection and genetic knowledge production in the final sub-section of this chapter, the following discussion will concentrate on the question of kin marriage as a site of biomedical intervention aiming at genetic risk management. Notwithstanding its prominent position within genetic health care infrastructures in Turkey, I argue that kin marriage is not easily accommodated by the workings and logics of genetic risk management. It often does not allow for the translation of uncertainty into risk probabilities unless genetic risk has become manifest in the form of a specific medical family history which offers further clues for intervention. Thus, it occupies a space which largely eschews control, defying "genetic responsibility" (Novas and Rose 2000) and exposing the lingering power of the accidental.

Genetic counselling and genetic health services thrive on the desire to control the unpredictable, manage the probable and reduce the accidental. If there is risk, it needs to be known and acted upon. The proliferation of genetic health services and technologies promises ever more refined tools of generating data which render manageable reproductive risk. However, often "new knowledge" is accompanied by the creation of "new ignorance" (Douglas and Wildavsky 1982). "Knowledge always lacks. Ambiguity always lurks" (Douglas 1996), and with lingering uncertainty comes the need for yet more techno-science and expert knowledge (Latimer 2007b, Latimer et al. 2006). The generation of new data thus does not translate in a

straightforward way into knowledgeable facts giving clear-cut directions for how reproductive decisions should be made. Rather, with increasing knowledge come new ambivalences and a growing sense of knowing less rather than more. This dynamic of co-emerging knowledge and uncertainty surfaced in medico-genetic professionals' narratives which presented genetic reproductive technologies variously as a powerful tool for effective risk management and reproductive control or as failing to live up to past hopes in the face of the complexities of the genetic.

As the geneticists I interviewed repeatedly emphasized, reproductive risk management for couples genetically at risk relied heavily on "clues" offered by the family's past medical history and pedigree. Kin marriage, by the very particularities of the nature of its associated risks, often does not present such clues. The recessive conditions for which it is known to increase the risk probabilities may well remain hidden over generations, being transmitted through non-symptomatic carriers. Consequently, these conditions are largely unfathomable by existing routine testing technologies. In light of these uncertainties, geneticists' narratives regarding kin marriage often coalesced around the limits of effective risk management and healthy family making. The following comment by a geneticist working in a public university hospital gives a good impression of these narratives:

> "When they ask us, 'we are going to get married, what precautions (*önlem*) should we take?', we cannot offer them many precautions because in genetics, unfortunately, there is still obscurity concerning the genes (*genler hala bilinmezlikler içinde*). We cannot tell them, 'yes, you are planning to have a kin marriage, there are five hundred diseases for which you are at risk (*riskli olduğunuz beş yüz tane hastalık var*) and we should be screening both of you for all these five hundred diseases'. We can recommend [tests] for very well-known diseases, for instance thalassaemia in Turkey, or for some well-known muscle diseases. We ask for the family history, we draw a pedigree for each of them and we check if the pedigrees indicate any risky (*riskli*) conditions. If there is something risky, then we can expand our inquiries in that direction but in the end we cannot tell them that they will have a healthy (*sağlıklı*) child for hundred percent sure, that they won't be facing anything because there are a lot of rare diseases we don't know about and for which they could be carriers (*taşıyıcı*). We can only tell them that we have checked for thalassaemia, some muscle diseases and that they don't show any carrier status for these. (...) But we nevertheless tell them 'you are still at risk for numerous diseases because you are kin relatives (*birçok hastalık için siz hala risklisiniz çünkü akrabasınız*)."[46]

[46] Female physician in her 40s with a specialization in genetics and biochemistry, working at a public university's biochemistry and genetics laboratory. Interview conducted in Turkish by author, 02 March 2017, Istanbul.

The above quoted narrative highlights how lingering uncertainty regarding many genetic conditions together with the absence of a medical genetic history in the family constitute significant obstacles to effective risk management for couples with kin marriage. While existing accessible tests may be applied, these cannot eliminate persisting risk which often remains elusive until after manifestation when intervention becomes at best possible for future reproductive plans. Thus, the only "guarantee" which the medico-genetic professionals can give is that there is no guarantee for healthy reproduction. Like many other professionals I interviewed, the above quoted geneticist pointed out that couples practicing or intending to practice kin marriage rarely applied for genetic counselling prior to experiencing reproductive issues due to genetic risk. The medico-genetic professionals described these couples as a highly educated and "conscious" minority, praising them for their "awareness" and "responsibility" while criticizing those who only came to a genetics clinic once it was "too late" and a child with a severe genetic condition had been born. Paradoxically, it is exactly those couples who seek to act consciously with regard to their genetic identity who have to face disappointment when the medico-genetic professionals inform them of the limited possibilities of preventive intervention as the following account, given by another geneticist working at a public university hospital, reveals:

> "The greatest disappointment (*hayal kırıklığı*) experience couples with kin marriage who come to us and tell us that they want a carrier screening test (*taşıycılık açısından tarama testi*). But once we talk, they get confused - for what do they want to be tested? (…) So what do we do? The family relaxes (*rahatlıyor*) somewhat once they understand that there isn't a test as such that they can do. There are some newly emerging specific tests [screening for multiple genetic conditions at once] but these are not really customized (*özel yapılmış değil*) or 'tailored' (*tailored edilmiş değil*) for the Turkish population (*Türk toplumu*) or for Turkey's population (*Türkiye toplumu*). They could do these tests, they are very new and as I said not very meaningful for our population. So, once they understand that they can't just do a test, they relax (*rahatlıyorlar*) somewhat." [He then cites a couple of routinely available prenatal diagnostic procedures such as ultrasound which up to a certain degree offer insights into the presence or absence of genetic conditions, and which they routinely offer to couples presenting with genetic risk, and concludes by saying,] "'Let's do as much as we can (*elimizden geleni yaptıralim*) and after that let's leave it to fate (*sonra yine kadere bırakalım*)', when we say that they become somewhat more at ease (*bir şekilde rahatlıyorlar*)."[47]

Referring to the absence of general genetic risk testing and the limited validity of newly emerging package tests which are often not sufficiently tailored to the genetic profile of the

[47] Male clinical geneticist in his 30s, working in a public university hospital's genetics clinic. Interview conducted in Turkish by author, 20 February 2017, Istanbul.

population in Turkey, this geneticist points out how couples appear to find reassurance not only in the idea of having a pregnancy as closely monitored as possible under the current conditions of genetic health care. They also seem to draw a sense of relief from learning that there is little that can be done. It is the medico-genetic professional's concession to "fate", his acknowledgement of the need to ultimately trust to one's fate that emerges as a source of reassurance. This acknowledgment of the impossibility of control and the need for acceptance in the face of processes which ultimately transcend human as well as technoscientific agency is surprising; it stands in stark contrast to the kind of subjectivity which professionals otherwise seek to inculcate and delight in encountering among the families they work with.

Kin marriage thus emerges as a condition which is hard to reconcile with the particular subjectivity upon which risk management technologies and practices hinge. The management of reproductive genetic risk presupposes a certain form of subjectivity which takes a pro-active and responsibly conscious stance with regard to the reproductive future and its potential risks while engaging in rational choice-making to effectively minimize existing risks. Carlos Novas and Nikolas Rose have argued that the rise of molecular genetics producing the person "genetically at risk" has entailed the generation of "genetic responsibility". Rather than giving in to fatalism, their argument continues, individuals finding themselves "genetically at risk" engage in new "life strategies", involving practices of choice, self-actualization and prudence in relation to one's genetic identity (Novas and Rose 2000). As geneticists' narratives reveal, kin marriage does not lend itself easily to such practices of prudent genetic identity management. Although medico-genetic professionals did encourage couples with kin marriage to make use of whatever accessible technologies were available to minimize their risks as far as possible, there remained nevertheless a certain mismatch between the proliferation of risk discourse surrounding kin marriage and the actual opportunities of practical risk management.

It is the very elusiveness and omnipresence of risk in case of kin marriage which renders established forms of risk management of little help while turning the absence, rather than presence, of a manifest medical history into a source of undefined threat because it precludes a pro-active stance and thus a sense of control. Ironically, the medico-genetic

professionals had to disappoint exactly those couples who had internalized a sense of reproductive responsibility in the face of genetic risk resulting from consanguinity and who showed a preventive consciousness, desiring genetic counselling prior to any pregnancy. As a consequence of limited opportunity for intervention, reassurance may paradoxically arise from the acceptance of these limitations and recourse to trusting one's "fate". Kin marriage, once framed as a risk factor, becomes a threat to healthy reproduction and family making, albeit one which is hard to manage and control via the established discursive practices of reproductive risk management. It challenges these practices by exposing and foregrounding lingering uncertainty which, unlike specific diagnosable and manageable conditions, does not translate into the calculable probabilities of risk management discourse.

Kin Marriage as a "Golden Mine": Pushing the Frontiers of Genetic Knowledge Production

The previous subsection traced how kin marriage poses a challenge to risk management, bringing to the fore the limitations of the tools and technologies employed for the minimization of risk and the achievement of healthy pregnancy. Within a clinical context that seeks to diagnose, manage and prevent genetic conditions, kin marriage is framed as a potential threat to healthy reproduction which is hard to supervise and manage until uncertainty has become manifest, turning into calculable risk. However, there is a second, rather, contradictory framing of kin marriage sitting at the heart of medico-genetic discursive practices. Once moving to the context of genetic research, kin marriage no longer figures predominantly as a health problem and risk concern but as a valuable resource and opportunity for expanding the limits of genetic knowledge production. It becomes, as one molecular geneticist framed it during an interview, a "golden mine" for the identification of genes associated with rare genetic conditions.

This geneticist worked in a public university's molecular biology and genetics department and during my interview with her, she revealed a profound sense of ambivalence concerning kin marriage. She made it clear that, as a molecular geneticist, she did not work in a clinical setting but within a context of genomic lab research. Although she did not see "patients", she had nevertheless contact with families, many of whom were consanguineous,

who participated in her research projects as "cases", donating genetic material. Initially during the interview she framed kin marriage in terms that by then had started to sound familiar to me. Kin marriage was medically problematic, a genetic health concern, because it significantly enhanced the risk for recessive genetic conditions among children born to consanguineous parents. As such, she said, it was an "awful" thing to do because it inflicted so much suffering among families and their children. However - and here the narrative started to change - from the point of view of genetic research, kin marriage at the same time offered a valuable opportunity:

> "Since they [rare, recessive diseases] affect mostly families in which the parents are consanguineous, they [the geneticists] are trying to identify the genes responsible for these disorders because in human genetics, if you do not have a case, the patients in your hand, you can do nothing. So these patients are actually very valuable in genetic studies, this is very critical. I know that this is very upsetting for the family, very hard to live with, of course the children are always very ill and in very severe conditions but these are what our actually collaborators in Europe say, these are golden mine for genetics, of course they are termed as golden mine. Why golden mine? Because we geneticists, human geneticists want to identify the genes that are responsible for these phenotypes. [original language of the section quoted is English]"[48]

This notion of kin marriage being an important resource for "mining" valuable genetic data enhancing the general understanding of the genotype – phenotype relation in genetic conditions was voiced by all molecular geneticists whom I talked to. As they explained, the identification of genes associated with the phenotypic expression of rare, recessive conditions was greatly facilitated by the phenomenon of consanguinity which allowed for studying extended families with usually multiple individuals affected by the same genetic condition. Not only did kin marriages "produce" very rare and thus understudied recessive conditions, the relatedness between affected individuals also offered the possibility to identify genes via a method called "homozygosity mapping". This method allows for the location of genes involved in rare recessive cases by looking for regions of homozygosity shared by different affected individuals. It thus takes advantage of the small shared gene pool of consanguineous families which makes it very likely that affected individuals are homozygous in the regions containing the genes involved, offering clues as to in what regions of the genome relevant genes might be found.

[48] Female molecular geneticist in her 50s, working in a public university's molecular biology and genetics department. Interview conducted in Turkish and English by author, 12 January 2017, Istanbul.

Families' recruitment for genetic research surfaced in two different ways during my fieldwork. Some of the couples and women whom I had interviewed at the clinic about their experiences with genetic risk and reproductive health services had become enrolled in research projects abroad in Europe or the US. Such enrolment usually involved rare genetic conditions for which the families had not yet received a genetic diagnosis (although a clinical classification of the condition in question might be existent) because the genotype – phenotype relation had so far remained unresolved. Without a genetic diagnosis, carrier screening of unaffected family members or children as well as many prenatal or preconceptional diagnostic technologies were out of reach for these families. In some such cases, the geneticists might offer the couples expensive genetic testing at private laboratories, often abroad, which cooperated with the clinic or, if an opportunity arose, participation in a research project. For families desiring further diagnostic information, who would or could not pay private lab fees, enrolment in research could thus emerge as an alternative option. While families' enrolment in research has something of a win-win situation in which research data in the form of genetic samples is exchanged for the opportunity of free-of-charge genetic testing and analysis, the conditions of this exchange are usually highly unequal in character. Essentially, hope becomes traded for valuable genetic material but while this material propels research, families' desire to receive information levelling the path to future healthy reproduction or even a cure is not necessarily fulfilled. Results can be postponed by years or may never materialize (Latimer 2013b, 179-180, Shaw 2009, 122-123). However, as such incidences of research participation did not figure prominently within couples' narratives as a matter of primary interest and concern, I will explore in more detail a different perspective, namely the phenomenon of rare "gene hunting" as experienced by molecular geneticists.

I want to focus in particular on one molecular geneticist's narratives concerning her research interests and practices which revealed an intriguing intersection of genetic research, consanguinity, disability and the state.[49] These narratives highlighted how certain practices of research and gene hunting facilitated an entwined expansion of the frontier of genetic

[49] Female molecular geneticist in her 60s, working in a public university's molecular biology and genetics department. Interview conducted in Turkish by author, 25 January 2017, Istanbul.

knowledge and the frontier of state governance. Travelling to remote villages in the Eastern and Inner Anatolian regions of the country, this geneticist had cherished the promising opportunity to collect genetic material from village populations with a high rate of kin marriage and rare, undiagnosed genetic conditions. The particular constellation of a rare condition being prevalent in a remote, highly "inbred" community yielded the prospect of pioneering research findings regarding the "identification of new genes" while this process was facilitated through the commonness of consanguinity within the researched communities, allowing for the mapping of genes across families and various family members. These villages acted as "open air laboratories" for her research, a term which she explicitly used during the interview. Working as a senior academic staff member of a university's genetics department, this geneticist had experienced over the course of her career the significant transition which human genetics had undergone as a discipline over the last couple of decades, morphing from a marginal side branch of molecular biology into an increasingly prestigious and highly visible discipline positioning itself at the very frontier of scientific and medical progress. Pursuing her master's and PhD degrees abroad back in the 1970s when human genetics did not yet exist as a distinct discipline at Turkish universities, she had seen an expanding knowledge infrastructure encompassing university disciplines and degrees, private and public laboratories and genetic clinics all relating to the growing field of human genetics evolve from the 1990s onwards in Turkey, as she remarked at the beginning of our interview.

This geneticist, whom I will call Sinem, devoted a significant part of the interview to talk about her participation in a research project which led to the classification of a new genetic syndrome and the identification of the genetic variation associated with it. As she told me, she had been watching TV when she came suddenly upon a programme showing a remote village community in an Eastern province of Turkey afflicted by a mysterious disease impacting on the physical and intellectual abilities of a significant number of the community members. The governor of the province appeared, calling out for somebody willing and able to come and help the families suffering from the disease. The programme immediately caught Sinem's interest and she contacted the governor who voiced his interest in having a research team investigate the

case. Following some precursory research indicating that the disease was likely to be a so far non-researched genetic syndrome, it was arranged that a multi-disciplinary research group consisting of a team of molecular geneticists (including Sinem) and several teams of medical professionals was to embark on a field trip to the village in springtime. Once the snow had cleared from the narrow roads leading up into the mountains, the research team travelled to the remote village which Sinem described to me as consisting basically of "one large family". According to her, the members of the village's roughly 100 households had continuously intermarried and could all trace their ancestry back to the founders of the village, five siblings and their spouses, who had migrated from the Caucasus Mountains towards the end of the Ottoman Empire. Hosted by the supportive head of the village (*muhtar*) and his family, the research delegation spent several days at the village, seeking out families with affected members showing signs of the genetic condition being researched to conduct examinations and collect blood samples. Sinem in particular mentioned the local health director, appointed by the Ministry of Health to serve the province where the village was located. This young representative of the Ministry of Health had proven to be of great assistance in carrying out the fieldwork, as Sinem pointed out with great respect. With a pronounced sense of dedication and responsibility, she said, he had created a register of all the "impaired" (*özürlü*) inhabitants of his appointed province. It was this register which helped the team to easily identify and contact relevant families for data collection.

The research project turned out to be successful in the sense that it generated new scientific findings of interest to the global medical and genetic communities. As indicated above, the collected data allowed for the classification of a new genetic syndrome as well as the identification of the genes involved. Sinem presented her findings at international conferences where she showed video footage of the village to the audience, describing it for them as an "open-air laboratory". Throughout her recollection of the research project, I noticed how much she enjoyed talking about it. She especially cherished the memories of the fieldtrip which she remembered as an exciting and somewhat adventurous excursion. She elaborated on the remoteness of the village and the difficulty of reaching it, the generous hospitality of the

villagers, especially the *muhtar* and his wife, and the deliciousness of the local food they were offered there.

The research project described above is characterized by a set of actors and locations which are marked by distinct power inequalities. The internationally connected scientific community from the metropolis in the West of the country and the rural community of an Eastern Anatolian village, the able-bodied and the disabled, the researchers and those researched, as well as the state representatives and the citizens are brought together within the frame of this project. While the research project's scientific success ultimately depended on an alignment of science, the state and the village community, Sinem's narrative offers little insight into how families' consent to and participation in the project unfolded, lingering instead in much more detail on the interactions with local authorities and state representatives. It is this muting of the local community's actual involvement, which figures mainly as passive research objects, together with the framing of the village as a "laboratory" which renders the narrative reminiscent of the practices of colonial medicine. The notion of diseased "Oriental" bodies requiring colonial intervention has been integral to the functioning of biomedicine and public health as means for the consolidation and legitimization of colonial power and governance in the name of a "civilizing" mission (Anderson 2006b, Arnold 1988, Bashford 2004). The discursive juxtaposition of "Western" bodies impersonating modernity, health and hygiene with dangerously "diseased" and "contaminating" native bodies facilitated the turning of the colonies into laboratories of medical research and experimentation where the "vocabulary and concepts of the life sciences" were shaped and tested (Comaroff 1993, 308). However, Sinem's narrative brings not only colonial "laboratories" to mind but also travel discourses of colonial exploration in how she describes the fieldtrip in terms of an adventurous expedition into the remote parts of Turkey for the sake of scientific knowledge production.

A sense of adventure, the wild, rugged East of Anatolia and the traditionality and seclusion of its villages are discursively evoked as they intersect with narratives of scientific mystery, the hunt for rare genetic material and the examination of "disabled" bodies suffering from yet undiscovered genetic conditions. The emphasis on care and help being offered to the

village community, which is rescued from medical neglect, present the project as inherently benign and in the interest of all. The power inequalities involved are thus smoothed out, rendered invisible. Thus, the legacy of "gene hunting" practices which, being entangled with the histories of colonial power imbalances, have often sought out particularly vulnerable and marginalized people remain unproblematized (Reardon 2009, TallBear 2013). The discursive framing of the project as an act of help to the village furthermore enhances the legitimacy of the research the ensuing benefits of which, however, are far from equally distributed. While the fieldtrip eventually increased the scientific delegation's professional credentials as it yielded material for announcing new discoveries in the realm of human genetics, the research participants' benefits were far less clearly defined. As Sinem herself pointed out, the project's findings do not lead to treatment of those affected by this newly identified genetic condition. They offer the possibility to screen for it prenatally, a service which, as Sinem emphasized, the families who participated could make use of for free by having the tests conducted at their own university laboratory. While this may indeed be an opportunity some families might wish to make use of, presupposing they have the necessary access to hospital facilities, their participation in the research may well have been prompted by the hope for treatment for their living affected family members. After all, as indicated at the beginning of this chapter, prenatal selective services are far from being endorsed by all couples genetically at risk.

Sinem's research project reveals an intriguing alignment of science and the state which deserves further exploration. State representatives, specifically the local mayor and outposts of the Ministry of Health, acted as important facilitators or even initiators of the genetic research project, inviting scientists, collaborating with and hosting them, and aiding in collecting data about members of the local population considered to be having a disability. During the interview, Sinem dwelled in particular on the support which the research team received from the local health director whose register of "disabled" inhabitants proved a valuable asset. She spoke with great respect of this local representative of the Ministry of Health whose lack of training in a specialized sub-field of medicine after his graduation from medical school she contrasted with his outstanding sense of commitment and duty to the local population. Compiling such an

extensive register including remote village populations in the mountains constitutes no easy task and according to Sinem the health director had not shunned the effort required for such a vast voluntary undertaking.

This alignment of state and science reveals how the collection of rare genetic material allows for an expansion of the known in a twofold sense: it not only pushes the boundaries of scientific knowledge but also gets caught up in the expansion of the state's knowledge of its citizens. The frontiers of science and the state are simultaneously shifted. It is this entanglement of governance, medicine and technoscience which brings to mind Turkey's history of internal population governance which has been marked by contentious "centre-periphery" relations since the early years of the Republic. Part of this history has been the violent subordination of communities resisting Turkification and governance through the state and their forced incorporation into the state's territory through coercion, disciplinary and military power (Turkyilmaz 2016, Yeğen 2007, 2004, Zeydanlıoğlu 2008). But part of this history has unfolded through less obviously violent means, namely the extension of state infrastructures by means of an expansion of medical institutions and knowledge infrastructures in areas of the country remote to the central power of the state. The intertwining of medical and state infrastructures was not only prominent during the founding years of the Republic, when medico-genetic professionals occupied highly prestigious public offices and played an important role with regard to the crafting of a nation state (Dole 2012, Evered and Evered 2011, Terzioğlu 1998), but extended far into the mid-20th century. During the 1960s persisting inequalities between urban and rural as well as Western and Eastern provinces of the country became a major source of governmental anxiety in the political climate of the day which approached these discrepancies as a "developmental gap". A major health care reform programme was initiated, the so-called "Socialization of Health Services" which aimed at the extension of health care and the creation of more equal access to health care across the citizenry. Upon insistence of the military ruling the country following the 1960s coup, this socialization project was first implemented in the Eastern provinces of the country as a means for enhancing "national integration" and the "civilization" and "modernization" of Kurdish communities whose growing

nationalist consciousness and politicization was to be quenched that way (Günal 2008, 220-225).

I am not suggesting that the recent practices of gene collection follow the same dynamics as earlier Republican governmental practices which would be extremely simplifying in terms of the contextual particularities of each case. However, undeniably, there is a noticeable continuation in the way how governmental and technoscientific infrastructures mutually depend on and extend each other as newly emerging technoscientific spaces and practices become infused with governmental sensibilities and interests. The collection of genetic material both draws on and produces knowledge which is of interest to the state as the "disabled" members of the village community become first registered and second diagnosed and classified in genetic terms. Using the concept of "co-production", scholars working within science and technology studies have demonstrated how scientific knowledge and social order come into being simultaneously; they are "co-produced" (Jasanoff 2004, Reardon 2009). In that sense, I argue that the infrastructures of genomic health care and research are intrinsically bound up and "co-produced" with governmental infrastructures that place healthy families at the heart of the nation. Both medico-genetic professionals' endorsement of normative healthy reproduction in clinical space as well as research practices mining the population for valuable genetic material reveal a convergence between the state and science. The expansion of the boundaries of scientific knowledge relies upon, affirms and re-consolidates power relations between the state and its subjects which are deeply informed by legacies of the past, just as the push for healthy reproduction within medical space effects the reproduction of eugenic sensibilities and ableist imaginings of the nation body and the role of the family within it.

****

The management of reproductive risk, kin marriage and genetic disease in medico-genetic space is marked by intersecting dynamics of "detachment" and "attachment" (Latimer 2013b, 2007a, b, 2004) which arise from a complex interplay of governmental and medico-genetic discursive practices, historical legacies, technoscientific innovation and actual family making practices.

Eugenic legacies haunted the clinical management of genetic risk as an absent presence. Medico-genetic professionals engaged in a discursive detachment of these legacies from their professional practices through attachments of genetic health services to notions of reproductive empowerment, family happiness and individual choice-making. Drawing attention to the increasingly restrictive stance of the government concerning abortion, they presented the accessibility of selective reproductive technologies as a touchstone for the commitment of the health care system to the principles of progressive science and reproductive freedom. Presenting couples with the opportunity to give birth to a healthy child and facilitating the prevention of genetic disease was framed by these professionals as a morally acceptable means to alleviate suffering and achieve familial happiness. Potentially troubling reminiscences of past eugenic aspirations were further pushed back by emphasis on individual choice and couples' decided right to not opt for prenatal diagnosis or to give birth to a child with a genetic condition. This emphasis on individual choice had the effect of presenting the state as a non-relevant presence in couples' reproductive decision-making. It detached family making and the state, suggesting an absence of state interference or coercion into reproductive choice while simultaneously exempting the state from the responsibility of providing an environment which is socio-politically capable of accommodating the birth of children with life-long genetic conditions. While professionals' foregrounding of individual choice thus underscored the need for non-coercive reproductive decision-making, it also tended to hold primarily the families "accountable" for their reproductive outcomes, individualizing the responsibility for subsequent care for children with genetic conditions.

The dynamics of detachment setting past eugenics apart from the present of genetic health services were, however, interspersed with moments of implicit reattachment emerging during medico-genetic professionals' clinical patient work as well as during their narratives. Clinical geneticists explicitly endorsed the prevention of the birth of children with genetic conditions as a professional mission which expressed itself in their commitment to channel couples towards healthy reproduction as far as permissible within the guidelines of non-directive counselling. Their narratives were marked by healthy reproduction as a normative

expectation. This conceptualization informed professionals' disapproving remarks, voiced during interviews, which presented families deciding against selective reproduction as acting in an ignorant or irresponsible manner. The irresponsibility thus ascribed did not only extend to the family context, which was seen as being negatively impacted on by genetic disease, but also the state. Framing genetic disease as a burden to the financial resources of the state, medico-genetic professionals reattached family making and the state, reproducing long-standing eugenic and ableist anxieties concerning bodies of difference, variously conceptualized in terms of "genetic disease" or "disability".

Evocations of the state on part of medico-genetic professionals have revealed another dynamic of detachments and attachments which coalesced around a convergence of governmental and genetic health care infrastructures. Medico-genetic professionals repeatedly positioned themselves in antagonism to the current government, thus detaching their professional work from governmental practices and policies. They considered these policies as expressive of the religious conservativism of the government and contrasted these with the principles of rational science and progressive modernity which they as positivistically trained professionals identified with. However, this discursive antagonism and the detachment it affected obscured close attachments between the realms of medical genetics and the state. These attachments surfaced in a joint push towards normative healthy reproduction and the prevention of genetic disease as well as in the expansion of the boundaries of genetic knowledge resting on co-produced (Jasanoff 2004, Reardon 2009) governmental and medico-genetic infrastructures.

As the chapter has furthermore revealed, kin marriage constituted a pivotal "resource" for geneticists in their attempts to push back the boundaries of the unknown and expand genetic knowledge. It thus occupied a curiously ambiguous position within medico-genetic space. When attached to well-known and much studied recessive genetic conditions such as thalassemia, its associated risks may be well managed, demonstrating the powerfulness of genetic health services in facilitating healthy reproduction. However, kin marriage is often associated with rare and little researched genetic conditions due to its particular impact on reproductive processes. While this association of kin marriage with extremely rare conditions turned it into a much

valued opportunity for genetic research endeavours, the unpredictability of the genetic conditions which it may facilitate also rendered kin marriage a challenge for clinical risk management. Not only does its impact on the reproductive outcomes of a specific couple remain hard to specify prior to any concrete risk manifestations; the rarity of many recessive, kin marriage associated genetic conditions often entails little understood underlying genotype-phenotype relations, limiting the possibilities for future reproductive risk management. Kin marriage may thus also expose the lingering presence of the uncertain and the limitations of genetic health services in helping couples achieve a healthy pregnancy.

It was this ambiguous positionality of kin marriage within medico-genetic space, as a genetic risk factor both pushing and exposing the boundaries of the known and as a genetic health concern whose reproductive impacts were scientifically well understood but clinically hard to manage, which gave rise to moments of responsibilization and de-responsibilization of couples in clinical space. While the non-engagement with selective reproductive technologies in the face of well understood and preventable conditions was criticized on part of medico-genetic professionals as an expression of families' irresponsibility or ignorant "fatalism", the impossibility of a preventive exclusion of genetic risk in case of kin marriage brought the necessity to trust "fate" back in as a means of ultimately coping with the uncertain.

The above discussed dynamics of detachment and attachment offer contrasting narratives concerning the clinical management of healthy reproduction, genetic risk and kin marriage. Discursive practices of detachment presented the clinical management of reproductive genetic risk as a primarily beneficial, individual-oriented and non-coercive practice propelled by the technoscientific possibilities of genetic health services. In contrast, emerging dynamics of reattachment revealed unsettling moments of perpetuated eugenic sensibilities, intertwinements of biomedicine with governmental biopolitical agendas and the lingering presence of uncertainties with which the clinical management of genetic risk and kin marriage continues to be fraught.

Conclusion

This thesis has explored the conceptualization and management of kin marriage as a genetic risk factor impacting on reproduction in contemporary Turkey. It has traced how the emergence of kin marriage as a relatively recent reproductive health concern is expressive of "biomedicalization" processes (Clarke et al. 2010, Clarke et al. 2003) which have been transforming the relation between biomedicine, health, disease, and the body in an age of increasingly technoscientifically mediated and commercialized health care. At the same time, it has asked how this biomedicalization of kin marriage is informed by existing legacies of how the state and the family have been articulated in modern nation-state Turkey.

While its incorporation into medico-genetic infrastructures may be of a comparatively recent nature, kin marriage has historically constituted both a socially significant but also contested practice in Turkey. Although widely practiced and valued due to its associated socio-economic advantages throughout the Mediterranean area, including Turkey, and the Middle East (Ilcan 1994, Keyser 1974, Tillion 1983), kin marriage became recast as an anachronism by modernizing state elites following the founding of the Turkish Republic. It challenged the Republican recrafting of the family which propagated the nuclear family as a vehicle of modernization and a new basis for the anchoring of nationalist values, thus contradicting the Kemalist vision of Republican modernity and threatening the new bonds of loyalty between the state and its subjects upon which the nation state was to rest (Sirman 2007, 2005).

This thesis has argued that biomedicalization has not displaced earlier significations of kin marriage as a stigmatized marker of internal non-modernity and "otherness". Rather than neutralizing or normalizing kin marriage, discursive practices of reproductive risk management have added a new scientific, biomedical authority to the stigmatization of kin marriage. With kin marriage becoming attached to genetic risk and thus reframed as a threat to the health of future generations, what is at stake is no longer only the modernity of the nation but its very vitality. However, the stigmatizing effects of this biomedical reconceptualization of kin marriage bear a significant potential for stratified targeting as kin marriage constitutes a practice which is strongly associated with socio-economically and politically marginalized and

vulnerable parts of the population whose belonging to the nation state has historically constituted a site of contestation.

The biomedicalization of kin marriage reveals the opening-up of new sites for the (self)surveillance and (self)management of family making and reproduction. It has been shaped and rendered possible by a temporal relocation of reproductive intervention beyond the onset of birth or even conception while extending such intervention to the molecular level. Thus, it points to the emergence of new technoscientifically mediated interfaces between biomedicine, the state and the family. Notwithstanding such unfolding dynamics of transformation, the biomedicalization of kin marriage also indicates the perpetuation of existing legacies of state intervention into the intimacies of family life and reproduction. Although the grounds upon which state, family and biomedicine intersect may have been shifting in the context of the AKP's ongoing ideological and structural remaking of state and society, the management of reproductive risk and genetic disease points to the continued co-production of biomedical and state infrastructures which seek to place healthy families at the heart of a strong and healthy nation.

This double dynamic of transformation and perpetuation informs how couples practicing kin marriage become responsibilized regarding their genetic risks. Their (self)enrolment in genetic risk management strategies has been driven by an emergent emphasis on individual choice as well as voluntary participation in reproductive surveillance and optimization which builds, however, on a longer history of eugenic sensibilities privileging "healthy" body and mind in the name of the nation. The genetic responsibilization of couples practicing kin marriage hinges not only upon the moral imperative to minimize risk once it is known but also the scientific designation of kin marriage as a recognized genetic risk factor. The all too easy slip between probability and causality, which is characteristic of discussions in the public realm where kin marriage is often perceived as the primary reason for genetic disease, further contributes to and intensifies the moral censure of those practicing kin marriage. Healthy reproduction becomes a moral duty which is placed upon the shoulders of couples who are rendered accountable for the reproductive futures resulting from their marriage choices. This

shift towards genetic responsibilization emphasizes risk minimization as an individual duty, largely releasing the state and society from the responsibility to create a socio-political environment which can accommodate disability, bodily difference or chronic disease.

Families facing reproductive genetic risk often make use of genetic health services in order to manage their reproductive futures following previous emotionally difficult or even traumatizing experiences with genetic disease affecting their children. This thesis neither seeks to criticize their recourse to nor medico-genetic professionals' provision of genetic health services. Instead, it has problematized how the individualized responsibilization of couples regarding genetic risk and healthy reproduction not only links up with eugenic sensibilities but also creates a profound moral burden for couples practicing kin marriage by exposing them to blaming and stigmatization and by delegitimizing their experiences of loss, suffering and grief. Biogenetic conceptualizations of risk and kin relatedness may not be universally encompassed or understood among lay people in Turkey. However, framing the continuing practice of kin marriage as well as couples' highly heterogeneous enrolment in risk management strategies as primarily an expression of lacking education, ignorance or religious fatalism depoliticizes the incorporation of kin marriage within reproductive health care infrastructures. Such framings entrench the assumed neutrality of scientific truths while rendering invisible the power inequalities, socio-political constraints and stigmatization threats which families have to navigate in their encounters with the discursive practices of risk management. They obscure how the biomedicalization of kin marriage far from unfolds upon a socially equal terrain but rather one shaped by long-standing socio-political norms and expectations which do not value or enable all forms of reproductive labour and reproductive outcomes equally.

The Incorporation of Kin Marriage into Medico-Genetic Infrastructures as a Case of Partial Biomedicalization

Tracing how biomedicalization processes take shape beyond the U.S. American context, this thesis has been in dialogue with scholarship on biomedicalization. It has contended that the emergence of kin marriage as a genetic risk factor and reproductive health concern is expressive of larger transformative processes of the health care sector in Turkey. Its biomedical

reconceptualization and management as a risk factor is informed and driven by the growing salience of technoscientific innovations such as ever more refined technologies enabling genetic and genomic data analysis, prenatal diagnostic services, or PGD which have been reshaping the relation between health, illness, biomedicine and the body. The incorporation of kin marriage into biomedical infrastructures furthermore heralds the rise of a growing emphasis on surveillance and risk management strategies which seek to optimize reproductive futures by channelling these towards health through risk minimization and the screening out of future bodies deemed "non-healthy". Access to these technologies of risk management is, however, highly stratified and reveals the increasingly commercialized character of the health care system in Turkey. With public health insurance covering only a limited array of genetic diagnostic procedures or risk management technologies, families desiring to identify and actively manage their reproductive risks often have to buy into completely privatized or only partially covered services in order to facilitate healthy reproduction.

The biomedicalization of kin marriage unfolds unevenly and manifests most clearly during the period prior to the birth of a child at the stage of future or imminent life when the push towards responsibilization vis-à-vis risk minimization and healthy reproduction is most explicit. The government-induced implementation of genetic risk management as well as medico-genetic professionals' endorsement of healthy reproduction as a normative ideal both focus on future reproductive outcomes as a site for intervention and health regulation. They seek to contain genetic disease through the identification of risk and the prevention of affected birth. The biomedicalization of kin marriage is therefore most pronounced when it is conceptualized as a risk factor impacting on future or imminent reproductive outcomes rather than born children. Geneticists do emphasize the significance of kin marriage regarding the diagnosis of children who are born with a genetic condition, approaching kin marriage as a clue signposting a probably recessive condition. However, the clinical management of genetic conditions after birth coalesces around classification and differentiation rather than optimization or transformation in the absence of a cure for most of these conditions (Latimer 2013b, 2007b). Such classificatory work reinforces "traditional" forms of medicalization (Zola 1972),

contributing to the extension of biomedical control and authority over the body and reproduction through the identification, naming and diagnosis of the "abnormal".

Revealing the significance of biomedicine as a vehicle of control and transformation, the emergence of kin marriage as a reproductive health concern and its incorporation into the clinical management of genetic conditions hinges upon the simultaneously unfolding of processes of medicalization and biomedicalization which have turned "genetic risk" into a conceptual possibility and a site of biomedical surveillance. Its associated health implications manifest at the genetic level as a consequence of which the biomedical reconceptualization of kin marriage may easily be read as expressive of a shift towards a technoscientifically mediated "geneticization" (Finkler 2000, 2005, Lippman 1991) of kinship and "molecularization" (Rose 2001, 2008) of clinical practices concerning reproduction. However, there remains something about the relation between kin marriage and genetic risk which evades (bio)medicalization and geneticization.

As a valuable resource for genetic research, kin marriage offers cherished opportunities for the expansion of genomic knowledge and the pushing of the frontiers of the unknown. In that sense, kin marriage undoubtedly constitutes a significant starting point for extensions of (bio)medicalization processes. However, it not only facilitates an extension of the boundaries of the known but also repeatedly exposes its limitations. The very elusiveness of the risks involved in kin marriage prior to risk manifestation exposes the lingering presence of uncertainty. Genetic risk management as far as kin marriage is concerned can only ever postpone complete reassurance and certainty as intervention into reproductive outcomes needs to work from what is known or knowable in a couple's genetic make-up but runs into limitations in light of the enduring presence of the unknown. As a result, there is recourse to an acceptance of "fate" as geneticists themselves concede their limited abilities to manage kin marriage related risks in the absence of a starting point for intervention. Couples who have internalized a sense of genetic responsibility and wish to enrol in preventive risk management in light of their kin marriages thus are confronted with the disappointing revelation that the only guarantee geneticists may give consists in an absence of any guarantee regarding a healthy child. New technologies for

more comprehensive genomic data analysis are looming on the horizon of Turkey's health care system, awaiting expanded institutionalization, and the introduction of "package carrier tests" for several hundred known genetic conditions is already unfolding in the private health care realm in Turkey. The constant "deferral" of certainty (Latimer 2007a, Latimer et al. 2006) regarding the elimination of kin marriage related genetic risks may thus entail a chain of enrolment and postponement, with couples opting for ever more refined testing procedures which reduce but never fully eliminate risk, always rendering necessary further enrolment. However, with couples' finite financial resources and the infinite possibilities as to how genetic risk may become manifest following the practice of kin marriage, such trajectories of enrolment remain limited for now, making necessary recourse to an acceptance of "fate".

As Adele Clarke et al. have argued, "the shift from medicalization to biomedicalization manifests the epistemic shift from the clinical gaze (…) to the emergent molecular gaze" (Clarke et al. 2010, 36). If molecularization is central to biomedicalization, then kin marriage – even when it enters the biomedical realm – appears to eschew being completely "biomedicalized". Moments of "non-geneticization" emerge in relation to the clinical management of kin marriage, shaping the encounter between medico-genetic professionals and families. They reveal how other-than-genetic ways of doing and conceptualizing kinship, relatedness and the family are not simply displaced by genetic ones. Not only does the social normativity of the heterosexual, conjugal family ultimately govern access to and application of genetic health services in Turkey; it is exactly by enacting a form of family making that defies geneticization and by contesting geneticized conceptualizations of kin marriage that some of the families can afford to become actively enrolled in risk management.

These families engage in strategies which seek to detach genetic risk from their marriage choices, pushing back against genetic definitions of "closeness" and foregrounding their own socially mediated conceptualizations of what kin marriage implies (not). Although making use of genetic health services in order to manage reproductive risks or supervise the genetic conditions of their children, these families often refuse to become individually responsibilized vis-à-vis their kin marriage choices. Contesting "geneticized" conceptualisations

of kin marriage during their engagement with genetic health services, they seek to deflect blame and accusations of moral failure as parents while seeking to act responsibly towards existing as well as future potential children. This partiality of the biomedicalization of kin marriage does not come as a surprise. It corresponds with observations about notions of kinship or kin relatedness transcending the genetic even among families who are drawn into the medico-genetic realm as a consequence of inherited conditions (Featherstone et al. 2006, Shaw 2009). And it speaks to Joanna Latimer's argumentation that the genetics clinic is never only concerned with aggregate molecular data but reinstitutes the family "as a site of nature-culture" (Latimer 2013b, 160).

While the biomedical reconceptualization of kin marriage as a genetic risk factor in Turkey hinges upon the emergence of biomedicalization processes transforming health care, reproduction and the relation between medicine, disease/illness and the body, this expansion of biomedicalization has not unfolded in a socio-political vacuum. It has been shaped by the context-specific situatedness of biomedicine as a crucial interface between the state and the family and as a vehicle of modernization in Turkey. The biomedical reconceptualization of kin marriage rests upon a complex interplay of unprecedented technological innovations in health care with new and old modes of reproductive governance as well as established infrastructures articulating the state, the family and medicine in Turkey. What emerges is a double dynamic of transformation and continuation, a coming together of new late modern or "neoliberal" modes of self-governance, self-optimization and individualized genetic responsibilization with existing legacies of state intervention into family making and reproduction. This complex interplay indicates how the state evolves as a crucial driver of biomedicalization processes in Turkey which in turn contribute to a molecular extension of the biopolitical governance of "healthy" family making and reproduction in Turkey.

"Healthy" Family Making in Turkey and Its Molecular Extensions

This thesis has also been in dialogue with scholarship discussing the articulation of state, family and biomedicine in Turkey. It has argued that the biomedical reconceptualization of kin marriage hinges upon the symbolic and institutional significance of the family in modern

nation-state Turkey. Changing regimes in Turkey have discursively evoked and institutionally secured the role of the nuclear, heterosexually married couple as the key social institution of state and society (Akkan 2018, Sirman 2007, 2005, Yazıcı 2012), thus identifying reproduction and family making as crucial sites for the anchoring of governmental hegemony and nationalist agendas (Delaney 1994, Yilmaz 2015). Building on existing scholarship which has highlighted the significance of health policies and campaigns in creating the future citizenry of the Turkish Republic (Alemdaroglu 2005, Dole 2012, Evered and Evered 2011, Öztamur 2004), this thesis has traced how "health" enters as a significant axis of differentiation regarding biopolitically (un)desired families which, however, is often rendered implicit due to the seemingly self-evident value attached to the family being a "healthy" one. Drawing on the insight that Turkish citizenship is conceived in gendered "familial" terms (Sirman 2005), it has argued that it is not just the heteronormative, nuclear family as such which becomes institutionally enshrined and protected as the pillar of state, society and nation but the one whose reproductive capacities are imagined as securing a "healthy" future which increasingly encompasses the genetic.

This thesis has concentrated on a particular moment in Turkey's socio-political history, namely the current AKP regime under Erdoğan's political leadership which has invested significant governmental effort in the biopolitical management of the family and reproduction. The AKP regime's "new politics of the intimate" (Acar and Altunok 2012) have been informed by a "political arithmetic" (Foucault 1971, Kanaaneh 2002) which conceives of "healthy families" as the cornerstone of a "strong nation". Departing from previous antinatalist population policies, the AKP regime has propagated pronatalist reproductive policies and health care reforms which have sought to encourage reproduction as a national duty while safeguarding the heteronormative nuclear family and its gendered roles (Cindoglu and Sayan-Cengiz 2010, Gürtin 2016, Öztan 2014a, Yilmaz 2015). However, as this thesis has argued, the government's endorsement of pronatalism is far from unconditional in character. The party leader's ostentatious politicization of the quantity of children each woman should give birth to easily masks how the government is equally concerned about the quality of future offspring in terms of its genetic health. The government's investment in "selective reproductive

technologies" (Gammeltoft and Wahlberg 2014) and infrastructures such as the Haemoglobinopathy Control Programme which are directed at producing "averted birth" (Murphy 2017) reveals how some forms of reproduction and family making are encouraged and facilitated while others are more closely scrutinised, censured or selected for prevention through medico-genetic intervention. These infrastructures testify to the current regime's endorsement of pronatalism being highly selective in character. This selectivity, which is rendered largely invisible by the government's pronatalist stance and its strategic appropriation of religiously grounded right-to-life discourses, marks a perpetuation of long-standing eugenic and ableist sensibilities. Such sensibilities have shaped early Republican body politics and public health measures aimed at enhancing the biological qualities of the population in the name of the nation (Alemdaroglu 2005, Ergin 2008, Kadıoğlu and Ayşe 2010, Salgirli 2010). While the concern with heredity and the quality of offspring is thus not new in itself, the ongoing routinization of new reproductive and genetic health services has far extended the effective means of actually surveying, intervening into and altering the genetic outcomes of reproduction. Far from keeping the question of selective reproduction a concern of state elites and policy makers, this expansion of reproductive genetic health services has rendered this concern an increasingly integral part of people's everyday realities in Turkey.

It is within medico-genetic space, in the realm of the genetics clinic, that families and medico-genetic professionals become involved in the possibilities and moral challenges of reproductive selection and risk management. As this thesis has argued, geneticists working with families and couples experiencing reproductive risk endorse the prevention of the birth of children with genetic conditions as a professional mission while detaching their practices from the troubling legacies of past eugenics. They achieve this detachment through an emphasis on voluntary choice, the alleviation of suffering and the significance of reproductive freedom in a political environment which exerts increasing pressure to render abortion measures morally inacceptable. However, at moments their narratives present genetic conditions as a crucial cause for life-long disabilities and chronic diseases that constitute a financial and social burden for the state. It is these moments which mark a convergence between the state and the biomedical realm

in reproducing the normativity of "healthy" reproduction as a citizenship duty. This convergence has historical depth in Turkey as revealed by the crucial role which biomedicine had played in expanding both the newly formed nation state's infrastructure as well as its legitimacy in claiming governance over the population (Dole 2012, 2004, Evered and Evered 2011).

The historical alignments between state, family and biomedicine thus have cast a long shadow with regard to which the currently unfolding biomedicalization of kin marriage in Turkey needs to be contextualized. Trajectories of state intervention into family making and reproduction keep informing today's landscape of reproductive genetic health services and policies in Turkey and need to be taken into account alongside late 21st century transformations of biomedicine brought about by the introduction of new technologies, the growing salience of the life sciences in medicine and the neoliberal restructuring of the health care market in Turkey. Genetic risk management has become incorporated into existing government infrastructures and state-enforced health policies as most clearly pronounced in case of the reconceptualization of the premarital health examination procedure. This incorporation has introduced a shift towards individualised responsibilization regarding the prevention of genetic disease which ties in with the growing stratification of the health care sector. The result has been a dynamic of mutual invisibilization. The coercive aspects of state intervention are masked by discursive practices of individual choice and responsibility while the inequalities resulting from stratified access to genetic health services and families' unequal resources to deal with genetic risk are masked by the institutionalization of government funded infrastructures of genetic risk screening which are propagated by the government as "health service improvement" and a realization of citizenship rights. This articulation of coercive state surveillance and individualised choice plays out in a highly stratified context of health care infrastructures where not only the implementation of carrier screening appears to be unequally distributed but also access to genetic health services for the management of identified genetic risks. Couples experiencing genetic risk therefore not only have to make reproductive "choices" in a medico-genetic and governmental environment which privileges "healthy" reproduction; they also have

unequal access to those technologies and health services which will delineate their "choice" making in the first place.

As argued throughout this thesis, biomedicine has played a crucial role within the context of the foundation of the Turkish Republic. Embodying scientific rationality and Western technological progress, it has signified modernity "in translation" (Clarke et al. 2010, 387) and provided the state with the infrastructural means as well as with a discourse of legitimization regarding the expansion of its governance over territory and population (Dole 2012, 2004). While biomedicine has historically signified the promises of co-joined Westernization and modernization, kin marriage has long been associated with the "others" of Turkish modernity, constituting a marker of lingering backwardness, rurality, and internal non-modernity. Medico-genetic professionals' narratives reproduce this sense of kin marriage as a signifier of "non-modernity" while often locating this "non-modernity" geopolitically and symbolically as belonging to the "East" of the country. Their narratives thus suggest that kin marriage practices constitute a specifically "non-Western" form of traditionality. With "Eastern-ness" often acting as a placeholder for referencing the "others" of Turkishness, specifically but not exclusively the Kurdish population in Turkey (Ergin 2014, Koğacıoğlu 2011), such framings of kin marriage as an "Eastern" practice are not neutral in character but have significant otherizing effects, easily turning the alleged "non-modernity" of kin marriage into an essentialized cultural trait of those considered to be situated outside of the nation body.

The reconceptualization of kin marriage as a health concern requiring biomedical intervention and surveillance taps into and perpetuates rather than displaces these legacies of otherization. It offers a language marked by scientific authority which may effortlessly be evoked as scientific proof for the practice of kin marriage being a failure of modern, biopolitically "healthy" family making. Couples' non-engagements with or resistances against the discursive practices of genetic risk management thus emerge as yet another site of Turkey's ever "belated" achievement of modernity. Whereas processes of medicalization and biomedicalization have been discussed as contributing in some contexts to the de-stigmatization of socially ostracized forms of behaviour (Boreo 2010, Clarke et al. 2003, Conrad and

Schneider 1992), Dilba's experiences suggest a different trajectory with regard to kin marriage. They reveal how biomedical arguments about reproductive risk may lend authoritative weight to existing otherizing framings of kin marriage as an "ignorant" and "pre-modern" practice which are experienced as stigmatizing by those being thus marked. What is more, the biomedicalization of kin marriage targets a practice which is strongly associated with those parts of the population whose belonging to the nation has historically constituted a site of contestation, and which is also particularly common in areas of the country marked by socio-economic disadvantage and limited access to genetic health services. As a consequence, the stigmatizing effects of kin marriage may prove to be felt unequally across the population, as suggested by Dilba's narratives. They may be experienced particularly by those parts of the population who have already been facing socio-political marginalization and who are least positioned to enrol in active genetic risk management.

****

I am aware that this thesis has opened up questions about the complexities involved in reproductive genetic risk management which it cannot hope to resolve. What my encounters with families and medico-genetic professionals have left me with, however, is the impression that approaches to kin marriage related health concerns which frame the matter simply as one of lacking consciousness and education are at best unhelpful and at worst harmful because they remain insensitive to and render invisible the non-neutrality of the biomedicalization of kin marriage and the power inequalities undergirding it. However, a sensitivity and problematization of these power inequalities must stand at the beginning of any serious attempt to enable couples with kin marriage to access reproductive genetic health services in an environment that does not reproduce stigmatization and social marginalization, thereby disempowering rather than empowering couples in their family making aspirations. Such a move towards de-stigmatization could advance from a critical examination of the impacts of individualized responsibilization on couples with kin marriage as well as from a critical questioning of the assumption advanced by governmental reproductive health policies that a child with a genetic condition or a disability is essentially undesirable. This would render

possible a discussion of what kind of society or state could be imaginable which is willing and able to accommodate and accept responsibility towards those living with or caring for somebody living with a genetic condition. In other words, the move away from stigmatization and individualized blame could progress from a discussion of not only what kinds of life are (un)worthy but also what kinds of society are worth living in.

Bibliography and Sources

Secondary Sources:

Abu-Lughod, L. 1998. "The marriage of feminism and Islamism in Egypt: selective repudiation as a dynamic of postcolonial cultural politics." In *Remaking women: feminism and modernity in the Middle East*, edited by Lila Abu-Lughod, 243-269. Princeton, New Jersey: Princeton University Press.

Acar, F., and G. Altunok. 2012. "The 'politics of intimate' at the intersection of neo-liberalism and neo-conservatism in contemporary Turkey." *Women's Studies International Forum* 41:14-23.

Aciksoz, S. C. 2012. *Navigating in the ocean of risk: discourses and experiences of prenatal diagnosis in Turkey*. Saarbrücken: Lambert Academic Publishing.

Açıksöz, S. C. 2012. "Sacrificial limbs of sovereignty: disabled veterans, masculinity, and nationalist politics in Turkey." *Medical Anthropology Quarterly* 26 (1):4-25.

Açıksöz, S. C. 2016. "In vitro nationalism: masculinity, disability, and assisted reproduction in war-torn Turkey." In *Gender and sexuality in Muslim cultures*, edited by G. Ozyegin, 35-52. London, New York: Routledge.

Açıksöz , S. C. 2020. *Sacrificial limbs: masculinity, disability, and political violence in Turkey*. Berkeley: University of California Press.

Ağartan, T. İ. 2012. "Gender and health sector reform: policies, actions and effects." *Gender and society in Turkey: the impact of neo-liberal policies, political Islam and EU accession*:155-172.

Ahıska, M. 2006. "Occidentalism and registers of truth: the politics of archives in Turkey." *New Perspectives on Turkey* 34:9-29.

Akbaba, M., S. Uludağ Kis, E. Nazlıcan, and E. Gündüz. 2012. "Adana Havutlu beldesinde özürlülük sıklığı ve özürlülerde akraba evliliği sıklığının araştırılması (Research on the prevalence of handicap and of consanguineous marriages among the handicapped in the Havutlu district of Adana)." *TAF Preventive Medicine Bulletin* 11 (6):725-730.

Akkan, B. 2018. "The politics of care in Turkey: sacred familialism in a changing political context." *Social Politics: International Studies in Gender, State and Society* 25 (1):72-91.

"Akraba evliliğindeki büyük tehlike (The great danger in kin marriage)". 2012. *Sun Haber*, November 09. http://www.sunhaber.com/haber/Akraba-evliligindeki-buyuk-tehlike/87734.

Aksoy, M., E. W. Ikin, A. E. Mourant, and H. Lehmann. 1958. "Blood groups, haemoglobins, and thalassaemia in Turks and Eti-Turks." *British Medical Journal* 2 (5102):937.

Aksoy, M. 1955. "Sickle-cell trait in South Turkey." *Lancet*:589-90.

Aksoy, M. 1956. "Sickle-Cell anemia in South Turkey: a study of fifteen cases in twelve white families." *Blood, J. Hematol.* 11 (5):460-72.

Aksoy, M. 1961. "Hemoglobin S in Eti-Turks and the Allewits in Lebanon." *Blood, J. Hematol.* 17 (5):657-9.

Aksoy, M. 1962. "Haemoglobins S and E in Turkish people." *Nature* 193 (4817):786.

Aksoy, M. 1970. "Thalassaemia intermedia: a genetic study in 11 patients." *Journal of Medical Genetics* 7 (1):47.

Aksoy, M., G. Dinçol, and Ş. Erdem. 1978. "Different types of beta-thalassemia intermedia." *Acta Haematologica* 59 (3):178-189.

Alemdaroglu, A. 2005. "Politics of the body and eugenic discourse in early Republican Turkey." *Body and Society* 11 (3):61-76.

Ali, K. A. 2002. *Planning the family in Egypt: new bodies, new selves*. Austin: University of Texas Press.

Alswaidi, F. M., and S. J. O'Brien. 2009. "Premarital screening programmes for haemoglobinopathies, HIV and hepatitis viruses: review and factors affecting their success." *Journal of Medical Screening* 16 (1):22-28.

Altıok, Ö. 2013. "Reproducing the nation." *Contexts* 12 (2):46-51.

Altuntek, S. 2001. "Türkiye üzerine yapılmış evlilik ve akrabalık araştırmalarının bir değerlendirmesi (An evaluation of studies on marriage and kinship in Turkey)." *Hacettepe Üniversitesi Edebiyat Fakültesi Dergisi* 18 (2):17-28.

Aluoch, J. R., Y. Kilinc, M. Aksoy, G. T. Yüregir, I. Bakioglu, A. Kutlar, F. Kutlar, and T. H. J. Huisman. 1986. "Sickle cell anaemia among Eti-Turks: haematological, clinical and genetic observations." *British Journal of Haematology* 64 (1):45-55.

Anagnost, A. 1995. "A surfeit of bodies: population and the rationality of the state in post-Mao China." In *Conceiving the new world order: the global politics of reproduction*, edited by F. D. Ginsburg and R. Rapp. Berkeley: University of California Press.

Anderson, B. 2006a. *Imagined communities: reflections on the origin and spread of nationalism*. London; New York: Verso.

Anderson, W. 2006b. *Colonial pathologies: American tropical medicine, race, and hygiene in the Philippines*. Durham: Duke University Press.

Apak, M., S. Başaran, K. Aydınlı, H. Kayserili, B. Karaman, D. Polat, and Z. Azaklı. 1999. "Genetik hastalıkların prenatal tanısı: İ.Ü. PRETAM'daki üç yıllık uygulama ve araştımalarımızın sonuçları (*Prenatal diagnosis of genetic diseases: the three-year report of our application and research results at PRETAM, Istanbul University*)." *İstanbul Tıp Fakültesi Mecmuası* 62 (2):171-179.

Arat, Z. 1994. "Turkish women and the republican reconstruction of tradition." In *Reconstructing gender in the Middle East: tradition, identity, and power*, edited by F. M. Göçek and S. Balaghi, 57-78. New York: Columbia University Press.

Armstrong, D., S. Michie, and T. Marteau. 1998. "Revealed identity: a study of the process of genetic counselling." *Social Science & Medicine* 47 (11):1653-1658.

Arnold, D. 1988. *Imperial medicine and indigenous societies: disease, medicine, and empire in the nineteenth and twentieth centuries*. Manchester: Manchester University Press.

Arribas-Ayllon, M., and S. Sarangi. 2014. "Counselling uncertainty: genetics professionals' accounts of (non)directiveness and trust/distrust." *Health, Risk & Society* 16 (2):171-184.

Asch, A. 2001. "Disability, human rights, and bioethics." In *Handbook of disability studies*, edited by G. L. Albrecht, K. D. Seelman and M. Bury. London: Sage Publications.

Ayan, D., R. Beder-Şen, S. Yurtkuran, and G. Ünal. 2001. "Ankara'da akraba evliliği (Kin marriage in Ankara)." *Aile ve Toplum* 1 (4):7-26.

Ayan, D., R. Beder-Şen, S. Yurtkuran, and G. Ünal. 2002. "Akraba evliliğinin kültür birikiminde ve toplum hayatındaki bazı görünümleri: dil, din ve tıp (Some aspects of kin marriage relating to cultural culmination and social life: language, religion and medicine)." *Aile ve Toplum* 5 (2):77-90.

Aydınok, Y., Y. Oymak, B. Atabay, G. Aydoğan, A. Yeşilipek, S. Ünal, Y. Kılınç, B. Oflaz, M. Akın, and C. Vergin. 2018. "A national registry of thalassemia in Turkey: demographic and disease characteristics of patients, achievements, and challenges in prevention." *Turkish Journal of Hematology* 35 (1):12-18.

Aydoğan, F. 1995. "Van'da kırsal kesimden kente gelen ailelerin evlenmeye ilişkin tutum ve davranışlarındaki değişmeler (Variations in the marriage attitudes and behaviours among families of rural origin in Van)." In *Aile kurultayı: değişim sürecinde aile; toplumsal katılım ve demokratik değerler. 16 - 18 Kasım 1994*, edited by Aile Araştırma Kurumu Başkanlığı, 166-174. Ankara.

Barker, C., and S. Murray. 2010. "Disabling postcolonialism: global disability cultures and democratic criticism." *Journal of Literary & Cultural Disability Studies* 4 (3):219-236.

Başaran, N., B. S. Şayli, A. Başaran, M. Solak, S. Artan, and J. D. Stevenson. 1988. "Consanguineous marriages in the Turkish population." *Clinical Genetics* 34 (5):339-341.

Başaran, N. 1973. "Anadolu'nun genetik yapısı üzerine çalışmalar, III (Studies on the genetic composition of Anatolia, III)." *Ank. Üni. Diyarbakır Tıp Fakültesi Dergisi* 2:71-86.

Bashford, A. 2004. *Imperial hygiene: a critical history of colonialism, nationalism and public health*. New York: Palgrave Macmillan.

"Bebek ölümlerinin yüzde 33'ü akraba evliliğinden (33% of infant deaths occur due to kin marriage). 2017. *Milliyet*, June 14. https://www.milliyet.com.tr/amp/yerel-haberler/bingol/bebek-olumlerinin-yuzde-33u-akraba-evliliginden-12108056.

Beksac, S. M., F. Gumruk, A. Gurgey, N. Cakar, S. Mumusoglu, O. Ozyuncu, and C. Altay. 2011. "Prenatal diagnosis of hemoglobinopathies in Hacettepe University, Turkey." *Pediatric Hematology and Oncology* 28 (1):51-55.

Bellér-Hann, I., and C. Hann. 2001. *Turkish region: state, market and social identities on the east Black Sea coast*. Oxford: James Currey, School of American Research Press.

Bezmez, D. 2013. "Urban citizenship, the right to the city and politics of disability in Istanbul." *International Journal of Urban and Regional Research* 37 (1):93-114.

Bezmez, D., and S. Yardımcı. 2010. "In search of disability rights: citizenship and Turkish disability organizations." *Disability & Society* 25 (5):603-615.

Bilgel, N., N. Okan, H. Aytekin, and Ö. Gülesen. 1991. "Gemlik yukarı Hamidiye mahallesinde akraba evlilikleri (Kin marriages in the Gemlik neighbourhood of Hamidiye)." *Aile ve Toplum* 1 (1).

Birenbaum-Carmeli, D., and Y. S. Carmeli. 2010. *Kin, gene, community: reproductive technologies among Jewish Israelis*. New York: Berghahn Books.

Bittles, A. H. 1994. "The role and significance of consanguinity as a demographic variable." *Population and Development Review* 20 (3):561-584.

Bittles, A. H. 2003. "Consanguineous marriage and childhood health." *Developmental Medicine and Child Neurology* 45 (8):571-576.

Bittles, A. H. 2015. "The prevalence and outcomes of consanguineous marriage in contemporary societies." In *Cousin marriages: between tradition, genetic risk and cultural change*, edited by A. Shaw and A. Raz, 33-45. New York: Berghahn Books.

Boreo, N. 2010. "Bypassing blame: bariatric surgery and the case of biomedical failure." In *Biomedicalization: technoscience, health, and illness in the U.S.*, edited by A. E. Clarke, J. Shim, L. Mamo, J. Fosket and J. Fishman, 307-330. Durham: Duke University Press.

Bourdieu, P. 1977. *Outline of a theory of practice*. Cambridge: Cambridge University Press.

Browner, C. H., and N. A. Press. 1995. "The normalization of prenatal diagnostic screening." In *Conceiving the new world order. The politics of reproduction*, edited by F. D. Ginsburg and R. Rapp, 307-322. Berkeley: University of California Press.

Browner, C. H., and C. F. Sargent. 2011. *Reproduction, globalization, and the state: new theoretical and ethnographic perspectives*. Durham: Duke University Press.

Bryant, R. 2002. "The purity of spirit and the power of blood: a comparative perspective on nation, gender and kinship in Cyprus." *Journal of the Royal Anthropological Institute* 8 (3):509-530.

Buğra, A, and Ç. Keyder. 2006. "The Turkish welfare regime in transformation." *Journal of European Social Policy* 16 (3):211-228.

Cagaptay, S. 2006. *Islam, secularism and nationalism in modern Turkey: Who is a Turk?* London, New York: Routledge.

Canatan, D. 2011. "Haemoglobinopathy prevention program in Turkey." *Thalassemia Reports* 1 (1):9-11.

Canatan, D. 2014. "Türkiye'de hemoglobinopatilerin epidemiyolojisi." *Hematolog* 4:11-22.

Canatan, D., C. Karadoğan, N. Oğuz, N. Balta, and R. Coşan. 2003. "Frequency of consanguineous marriages in patients with hereditary blood disorders in southern Turkey." *Public Health Genomics* 6 (1):58.

Canatan, D., M. R. Kose, M. Ustundag, D. Haznedaroglu, and S. Ozbas. 2006. "Hemoglobinopathy control program in Turkey." *Public Health Genomics* 9 (2):124-126.

Casper, M. J., and L. J. Moore. 2009. *Missing bodies: the politics of visibility*. New York: New York University Press.

Chatterjee, P. 1993. *The nation and its fragments: colonial and postcolonial histories*. Princeton, New Jersey: Princeton University Press.

Chattopadhyay, S. 2006. "'Rakter dosh'—corrupting blood: The challenges of preventing thalassemia in Bengal, India." *Social Science & Medicine* 63 (10):2661-2673.

Çiçeklioğlu, M., I. Ergin, M. Demirelöz, E. Ceber, and A. Nazlı. 2013. "Sociodemographic aspects of consanguineous marriage in an urban slum of a metropolitan area in İzmir, Turkey." *Annals of Human Biology* 40 (2):139-145.

Cindoglu, D., and F. Sayan-Cengiz. 2010. "Medicalization discourse and modernity: contested meanings over childbirth in contemporary Turkey." *Health Care for Women International* 31 (3):221-243.

Cindoglu, D., and D. Unal. 2017. "Gender and sexuality in the authoritarian discursive strategies of 'New Turkey'." *European Journal of Women's Studies* 24 (1):39-54.

Clarke, A. E., C. Friese, and R. Washburn. 2018. *Situational analysis: grounded theory after the interpretive turn*. London: Sage Publications.

Clarke, A. E., J. Shim, L. Mamo, J. Fosket, and J. Fishman. 2010. *Biomedicalization: technoscience, health, and illness in the U.S.* Durham: Duke University Press.

Clarke, A. E., J. K. Shim, L. Mamo, J. R. Fosket, and J. R. Fishman. 2003. "Biomedicalization: technoscientific transformations of health, illness, and U.S. biomedicine." *American Sociological Review* 68 (2):161-194.

Clarke, A. E., J. K. Shim, S. Shostak, and A. Nelson. 2009. "Biomedicalizing genetic health, diseases and identities." In *Handbook of genetics and society: mapping the new genomic era*, edited by P. Atkinson, P. Glasner and M. Lock, 21-40. London, New York: Routledge.

Clarke, A. 1991. "Is non-directive genetic counselling possible?" *The Lancet* 338 (8773):998-1001.

Clarke, M. 2007a. "Closeness in the age of mechanical reproduction: debating kinship and biomedicine in Lebanon and the Middle East." *Anthropological Quarterly* 80 (2):379-402.

Clarke, M. 2007b. "The modernity of milk kinship." *Social Anthropology* 15 (3):287-304.

Clarke, M. 2008. "New kinship, Islam, and the liberal tradition: sexual morality and new reproductive technology in Lebanon." *Journal of the Royal Anthropological Institute* 14 (1):153-169.

Clarke, M. 2009. *Islam and new kinship: reproductive technology and the shariah in Lebanon*. New York: Berghahn Books.

Colen, S. 1995. "Like a mother to them': stratified reproduction and West Indian childcare workers and employers in New York." In *Conceiving the new world order: the global politics of reproduction*, edited by F. D. Ginsburg and R. Rapp, 78-102. Berkeley: University of California Press.

Collins, P. H. 1998a. "Intersections of race, class, gender, and nation: some implications for Black family studies." *Journal of Comparative Family Studies* 29 (1):27-36.

Collins, P. H. 1998b. "It's all in the family: intersections of gender, race, and nation." *Hypatia* 13 (3):62-82.

Comaroff, J. 1993. "The diseased heart of Africa: medicine, colonialism and the black body." In *Knowledge, power and practice: the anthropology of medicine and everyday life*, edited by S. Lindenbaum and M. Lock, 305-329. Berkeley: University of California Press.

Connelly, M. J. 2008. *Fatal misconception: the struggle to control world population*. Cambridge, Mass.: Belknap Press of Harvard University Press.

Conrad, P. 1992. "Medicalization and social control." *Annual Review of Sociology* 18 (1):209-232.

Conrad, P., and J. W. Schneider. 1992. *Deviance and medicalization: from badness to sickness*. Philadelphia: Temple Univesity Press.

Conseil Santé, SOFRECO, and EDUSER. 2007. Sağlık Arama Davranışı Araştırması (Health Seeking Behaviour Research). Ankara: Turkish Ministry of Health, Directory of Mother-Child Health and Family Planning Turkey Delegation of the European Commission.

Coşar, S., and M. Yeğenoğlu. 2011. "New grounds for patriarchy in Turkey? Gender policy in the age of AKP." *South European Society and Politics* 16 (4):555-573.

"Çukurova'nın sağlığında genetik tehdit: akraba evliliği (Kin marriage: a genetic threat to the health of the Çukurova region)". 2016 *Hürriyet*, 31 August. https://www.hurriyet.com.tr/cukurovanin-sagliginda-genetik-tehdit-akraba-40212847.

Çürük, M. A., F. Zeren, A. Genç, S. Ozavci-Aygün, Y. Kilinç, and K. Aksoy. 2008. "Prenatal diagnosis of sickle cell anemia and β-thalassemia in southern Turkey." *Hemoglobin* 32 (6):525-530.

Das, V. 1995. "National honor and practical kinship: unwanted women and children." In *Conceiving the new world order: the global politics of reproduction*, edited by F. D. Ginsburg and R. Rapp, 212-233. Berkeley: University of California Press.

Dasgupta, S., and S. D. Dasgupta. 2015. "The public fetus and the veiled woman: transnational surrogacy blogs as surveillant assemblage." In *Feminist Surveillance Studies*, edited by R. E. Dubrofsky and S. Magnet, 150-168. Durham: Duke University Press.

Davis, A. Y. 1982. *Women, race and class*. London: Women's Press.

Delaney, C. 1994. "Father state, motherland, and the birth of modern Turkey." In *Naturalizing power: essays in feminist cultural analysis*, edited by S. J. Yanagisako and C. Delaney. London, New York: Routledge.

Delaney, C. 1991. *The seed and the soil: gender and cosmology in Turkish village society*. Berkeley: University of California Press.

Demirci, T., and S. A. Somel. 2008. "Women's bodies, demography, and public health: abortion policy and perspectives in the Ottoman Empire of the nineteenth century." *Journal of the History of Sexuality* 17 (3):377-420.

Demirel, N., and S. Özgen. 2002. "Yuvarlak masa toplantısı: evlilik raporları. İstanbul Tabip Odası pratisyen hekim komisyonu atölye çalışması raporu (Roundtable meeting: marriage reports. Report of the workshop of the Istanbul Medical Chamber committee of practicing physicians)." *STED* 11 (6):210-214.

Dole, C. 2004. "In the shadows of medicine and modernity: medical integration and secular histories of religious healing in Turkey." *Culture, Medicine and Psychiatry* 28 (3):255-280.

Dole, C. 2012. *Healing secular life: loss and devotion in modern Turkey*. Philadelphia: University of Pennsylvania Press.

Donzelot, J. 1980. *The policing of families*. London: Hutchinson.

Douglas, M. 1996. *Risk and blame: essays in cultural theory*. London, New York: Routledge.

Douglas, M., and A. Wildavsky. 1982. *Risk and culture: an essay on the selection of technological and environmental dangers*. Berkeley: University of California Press.

Duben, A., and C. Behar. 1991. *Istanbul households: marriage, family and fertility 1880-1940*. Cambridge: Cambridge University Press.

Duster, T. 2003. *Backdoor to eugenics*. London, New York: Routledge.

Edwards, J. 1999. *Technologies of procreation: kinship in the age of assisted conception*. London, New York: Routledge.

Erdem, S., M. Aksoy, and A. I. Çetingil. 1966. "Distribution of haptoglobin types in Turkish people." *Nature* 210 (5033):315.

Erdem, Y., and F. Tekşen. 2013. "Genetic screening services provided in Turkey." *Journal of Genetic Counseling* 22 (6):858-864.

Ergin, M. 2008. "Biometrics and anthropometrics: the twins of Turkish modernity." *Patterns of Prejudice* 42 (3):281-304.

Ergin, M. 2014. "The racialization of Kurdish identity in Turkey." *Ethnic and Racial Studies* 37 (2):322-341.

Erten, H. 2015. "No more than two with Caesarean': the C-section at the intersection of pronatalism and ethnicity in Turkey." *Anthropology in Action* 22 (1):7-16.

Ettorre, E. 2000. "Reproductive genetics, gender and the body: 'please doctor, may I have a normal baby?'." *Sociology* 34 (3):403-420.

Evered, K. T., and E. Ö. Evered. 2011. "Governing population, public health, and malaria in the early Turkish Republic." *Journal of Historical Geography* 37 (4):470-482.

Fairclough, N. 1992. "Discourse and text: linguistic and intertextual analysis within discourse analysis." *Discourse & Society* 3 (2):193-217.

Featherstone, K., P. Atkinson, A. Bharadwaj, and A. Clarke, eds. 2006. *Risky relations: family, kinship and the new genetics*. Edited by K. Featherstone. Oxford, New York: Berg Publishers.

Finkler, K. 2000. *Experiencing the new genetics: family and kinship on the medical frontier*. Philadelphia: University of Pennsylvania Press.

Finkler, K. 2005. "Family, kinship, memory and temporality in the age of the new genetics." *Social Science & Medicine* 61 (5):1059-1071.

Fosket, J. R. 2010. "Breast cancer risk as disease: biomedicalizing risk." In *Biomedicalization: technoscience, health, and illness in the U.S.*, edited by Adele E. Clarke, J. Shim, L. Mamo, J. Fosket and J. Fishman. Durham: Duke University Press.

Foucault, M. 1971. *Technologies of the self*. New York: Random.

Foucault, M. 1978. *The history of sexuality, vol. 1: an introduction*. New York: Pantheon Books.

Foucault, M. 1984. "The politics of health in the eighteenth century." In *The Foucault reader*, edited by P. Rabinow, 273-289. New York: Pantheon Books.

Foucault, M. 1994. *Birth of the clinic: an archaeology of medical perception*. New York: Vintage Books.

Foucault, M. 1995. *Discipline and punish: the birth of the prison*. New York: Vintage Books.

Foucault, M. 2003. *Society must be defended: lectures at the Collège de France, 1975-1976*. Edited by M. Bertani and A. Fontana. New York: Picador.

Franklin, S. 1995. "Postmodern procreation: a cultural account of assissted reproduction." In *Conceiving the new world order: the politics of reproduction*, edited by F. D. Ginsburg and R. Rapp. Berkeley: University of California Press.

Franklin, S. 1997. *Embodied progress: a cultural account of assisted conception*. London, New York: Routledge.

Franklin, S. 2013. "From blood to genes? Rethinking consanguinity in the context of geneticization." In *Blood and kinship: matter for metaphor from ancient Rome to the present*, edited by C. H. Johnson, B. Jussen, D. W. Sabean and S. Teuscher, 285-306. New York: Berghahn Books.

Franklin, S., and C. Roberts. 2006. *Born and made: an ethnography of preimplantation genetic diagnosis*. Princeton, New Jersey: Princeton University Press.

Gali, E. 2001. "Hatay ilinde evlilik öncesi hemoglobinopati taraması sonuçlarının değerlendirilmesi (Evaluation of premarital haemoglobinopathy screening in the province of Hatay)." *MEU Tip Fak Derg (J Mersin Univ Med Fac)* 3:305-310.

Galton, F. 1909. *Essays in eugenics*. Honolulu, HI: University Press of the Pacific.

Galusca, R. 2009. "From fictive ability to national identity: disability, medical inspection, and public health regulations on Ellis Island." *Cultural Critique*, 72, 137-163.

Gammeltoft, T.S 2014. *Haunting images: a cultural account of selective reproduction in Vietnam*. Berkeley: University of California Press.

Gammeltoft, T. 2007. "Prenatal diagnosis in postwar Vietnam: power, subjectivity, and citizenship." *American Anthropologist* 109 (1):153-163.

Gammeltoft, T., and A. Wahlberg. 2014. "Selective reproductive technologies." *Annual Review of Anthropology* 43:201-216.

Gammeltoft, T., and H. T. T. Nguyen. 2007. "Fetal conditions and fatal decisions: ethical dilemmas in ultrasound screening in Vietnam." *Social Science & Medicine* 64 (11):2248-2259.

Ginsburg, F. D., and R. Rapp. 1995a. *Conceiving the new world order: the global politics of reproduction*. Berkeley: University of California Press.

Ginsburg, F. D., and R. Rapp. 1995b. "Introduction: conceiving the new world order." In *Conceiving the new world order: the politics of reproduction*, edited by F. D. Ginsburg and R. Rapp, 1-17. Berkeley: University of California Press.

Ginsburg, F., and R. Rapp. 1991. "The politics of reproduction." *Annual Review of Anthropology* 20:311-343.

Goffman, E. 1968. *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, N.J.: Prentice-Hall.

Göknar, M. D. 2015. *Achieving procreation: childlessness and IVF in Turkey*. New York: Berghahn.

Greenhalgh, S. 1994. "Controlling births and bodies in village China." *American Ethnologist* 21 (1):3-30.

Göçmen, İ., and A. Kılıç. 2018. "Egg freezing experiences of women in Turkey: from the social context to the narratives of reproductive ageing and empowerment." *European Journal of Women's Studies* 25 (2):168-182.

Gülleroğlu, K. S., N. Sarper, and A. S. Gökalp. 2007. "Public education for the prevention of hemoglobinopathies: a study targeting Kocaeli University students." *Turkish Journal of Hematology* 24:164-70.

Günal, A. 2008. "Health and citizenship in Republican Turkey: an analysis of the socialization of health services in Republican historical context (PhD thesis)." Boğaziçi University, Istanbul, Turkey.

Güneş-Ayata, A., and G. Doğangün. 2017. "Gender politics of the AKP: restoration of a religio-conservative gender climate." *Journal of Balkan and Near Eastern Studies* 19 (6):610-627.

Gürsoy, A. 1996. "Abortion in Turkey: a matter of state, family or individual decision." *Social Science & Medicine* 42 (4):531-542.

Gürtin-Broadbent, Z. B. 2013. "The ART of making babies: Turkish IVF patients' experiences of childlessness, infertility and Tüp Bebek (PhD thesis)." Available from ProQuest Dissertations & Theses Global. (1788100843). Retrieved from https://search.proquest.com/docview/1788100843?accountid=9630.

Gürtin, Z. B. 2011. "Banning reproductive travel: Turkey's ART legislation and third-party assisted reproduction." *Reproductive BioMedicine Online* 23 (5):555-564.

Gürtin, Z. B. 2012a. "Assisted reproduction in secular Turkey: regulation, rhetoric, and the role of religion." In *Islam and assisted reproductive technologies: Sunni and Shia perspectives*, edited by M. C. Inhorn and S. Tremayne, 285-311. New York: Berghahn Books.

Gürtin, Z. B. 2012b. "Practitioners as interface agents between the local and the global: the localization of IVF in Turkey." In *Reproductive technologies as global form*, edited by M. Knecht, S. Beck and M. Klotz, 81-109. Frankfurt, New York: Campus Verlag.

Gürtin, Z. B. 2016. "Patriarchal pronatalism: Islam, secularism and the conjugal confines of Turkey's IVF boom." *Reproductive Biomedicine & Society Online* 2:39-46.

Gürtin, Z. B., M. C. Inhorn, and S. Tremayne. 2015. "Islam and assisted reproduction in the Middle East: comparing the Sunni Arab world, Shia Iran and secular Turkey." In *The changing world religion map: sacred places, identities, practices and politics*, edited by S. D. Brunn, 3137-3153. Dordrecht: Springer.

Güz, K., N. Dedeoğlu, and G. Lüleci. 1989. "The frequency and medical effects of consanguineous marriages in Antalya, Turkey." *Hereditas*, 111, 79-83.

Hadjiminas, M. G. 1994. "The Cyprus experience - screening to combat a serious genetic disease." In *Ethics and human genetics: proceedings. 2nd Symposium of the Council of Europe on Bioethics. Strasbourg, 30 November - 2 December 1993*, edited by Council of Europe, 26-48. Strasbourg: Council of Europe Press.

Hamdy, S. F. 2009. "Islam, fatalism, and medical intervention: lessons from Egypt on the cultivation of forbearance (sabr) and reliance on God (tawakkul)." *Anthropological Quarterly*:173-196.

Hancıoğlu, A., and E. Tunçbilek. 1998. "Akraba evlilikleri, sosyodemografik özellikleri ve çocuk ölümleri üzerindeki etkileri." *Çocuk Sağlığı ve Hastalıkları Dergisi* 41:139-153.

Hashiloni-Dolev, Y., and S. Shkedi. 2007. "On new reproductive technologies and family ethics: pre-implantation genetic diagnosis for sibling donor in Israel and Germany." *Social Science & Medicine* 65 (10):2081-2092.

Hashiloni-Dolev, Y., and N. Weiner. 2008. "New reproductive technologies, genetic counselling and the standing of the fetus: views from Germany and Israel." *Sociology of Health and Illness* 30 (7):1055-1069.

Helén, I. 2004. "Technics over life: risk, ethics and the existential condition in high-tech antenatal care." *Economy & Society* 33 (1):28-51.

Herzfeld, M. 1997. *Cultural intimacy: social poetics in the nation-state*. London, New York: Routledge.

Hilgartner, S. 1992. "The social construction of risk objects: or, how to pry open networks of risk." In *Organizations, uncertainties, and risk*, edited by J. F. Short and L. B. Clarke, 39-53. Boulder: Westview Press.

Hoedemaekers, R., and H. Ten Have. 1998. "Geneticization: the Cyprus paradigm." *The Journal of Medicine and Philosophy* 23 (3):274.

Holy, L. 1989. *Kinship, honour, and solidarity: cousin marriage in the Middle East*. Manchester: Manchester University Press.

Ilcan, S. M. 1994. "Marriage regulation and the rhetoric of alliance in Northwestern Turkey." *Ethnology* 33(4): 273-296.

İlikan, C. G. 2006. "Tuberculosis, medicine and politics: public health in the early Republican Turkey (MA thesis)." Boğaziçi University, Istanbul, Turkey.

Inhorn, M. 2011a. "Globalization and gametes: Islam, assisted reproductive technologies, and the Middle Eastern state." In *Reproduction, globalization and the state: new theoretical and ethnographic perspectives*, edited by C. H. Browner, and C. F. Sargent, 126-137. Durham: Duke University Press.

Inhorn, M. C. 2018. "The Arab world's "quiet" reproductive revolution." *The Brown Journal of World Affairs* 24 (2):147-159.

Inhorn, M. C. 2003a. "Global infertility and the globalization of new reproductive technologies: illustrations from Egypt." *Social Science & Medicine* 56 (9):1837-1851.

Inhorn, M. C. 2003b. *Local babies, global science: gender, religion, and in vitro fertilization in Egypt*. London, New York: Routledge.

Inhorn, M. C. 2011b. "Globalization and gametes: reproductive 'tourism', Islamic bioethics, and Middle Eastern modernity." *Anthropology & Medicine* 18 (1):87-103.

Inhorn, M. C. 2012. *The new Arab man: emergent masculinities, technologies, and Islam in the Middle East*. Princeton, New Jersey: Princeton University Press.

Inhorn, M. C., D. Birenbaum-Carmeli, S. Tremayne, and Z. B. Gürtin. 2017. "Assisted reproduction and Middle East kinship: a regional and religious comparison." *Reproductive Biomedicine & Society Online* 4:41-51.

Inhorn, M. C., and S. Tremayne. 2016. "Islam, assisted reproduction, and the bioethical aftermath." *Journal of Religion and Health* 55 (2):422-430.

Insel, A. 2003. "The AKP and normalizing democracy in Turkey." *The South Atlantic Quarterly* 102 (2):293-308.

Ivry, T. 2006. "At the back stage of prenatal care: Japanese ob-gyns negotiating prenatal diagnosis." *Medical Anthropology Quarterly* 20 (4):441-468.

Ivry, T. 2009. "The ultrasonic picture show and the politics of threatened life." *Medical Anthropology Quarterly* 23 (3):189-211.

Jasanoff, S. 2004. *States of knowledge: the co-production of science and the social order*. London, New York: Routledge.

Jaworski, A., and N. Coupland. 2008. *The discourse reader*. London, New York: Routledge.

Joseph, S. 1999. "Descent of the nation: kinship and citizenship in Lebanon." *Citizenship Studies* 3 (3):295-318.

Kadıoğlu, A. 1996. "The paradox of Turkish nationalism and the construction of official identity." *Middle Eastern Studies* 32 (2):177-193.

Kadıoğlu, A. 2010. "The pathologies of Turkish republican laicism." *Philosophy & Social Criticism* 36 (3-4):489-504.

Kahn, S. M. 2000. *Reproducing Jews: a cultural account of assisted conception in Israel*. Durham: Duke University Press.

Kanaaneh, R. A. 2002. *Birthing the nation: strategies of Palestinian women in Israel*. Berkeley: University of California Press.

Kandiyoti, D. 1991. "End of empire: Islam, nationalism and women in Turkey." In *Women, Islam, and the state*, 22-47. Philadelphia: Temple University Press.

Kaplan, D. 1994. "Prenatal screening and diagnosis: the impact on persons with disabilities." In *Women and prenatal testing: facing the challenges of genetic technology*, edited by K. H. Rothenberg and E. J. Thomson, 49-62. Columbus: Ohio State University Press.

Kaufert, P. A., and J. O'Neil. 1993. "Analysis of a dialogue on risks in childbirth: clinicians, epidemiologists, and Inuit women." In *Knowledge, power and practice: the anthropology of medicine and everyday life*, edited by S. Lindenbaum and M. Lock, 32-54. Berkeley: University of California Press.

Kaya, A. 2014. "Islamisation of Turkey under the AKP rule: empowering family, faith and charity." *South European Society and Politics* 20 (1):1-23.

Kelly, S. E. 2009. "Choosing not to choose: reproductive responses of parents of children with genetic conditions or impairments." *Sociology of Health & Illness* 31 (1):81-97.

Kerr, A. 2004. *Genetics and society: a sociology of disease*. London, New York: Routledge.

Keyser, J. M.B. 1974. "The Middle Eastern case: is there a marriage rule?" *Ethnology* 13(3): 293-309.

Kılıç, A. 2010. "Gender, family and children at the crossroads of social policy reform in Turkey: Alternating between familialism and individualism." In *Children, gender and families in Mediterranean welfare states*, edited by M. Ajzenstadt and J. Gal, 165-179. Dordrecht: Springer.

Kılıç, A., and İ. Göçmen. 2018. "Fate, morals and rational calculations: freezing eggs for non-medical reasons in Turkey." *Social Science & Medicine* 203:19-27.

Kilshaw, S. 2018. "Qatari intersections with global genetics research and discourse." *Anthropology & Medicine* 25 (1):50-67.

Kilshaw, S., T. Al Raisi, and F. Alshaban. 2015. "Arranging marriage negotiating risk: genetics and society in Qatar." *Anthropology & Medicine* 22 (2):98-113.

Kleinman, A. 1997. *Writing at the margin: discourse between anthropology and medicine*. Berkeley: University of California Press.

Kligman, G. 1995. "Political demography: the banning of abortion in Ceausescu's Romania." In *Conceiving the new world order: the global politics of reproduction*, edited by F. D. Ginsburg and R. Rapp, 234-55. Berkeley: University of California Press.

Kogacioglu, D. 2004. "The tradition effect: framing honor crimes in Turkey." *Differences: a journal of feminist cultural studies* 15 (2):119-151.

Koğacıoğlu, D. 2011. "Knowledge, practice, and political community: the making of the "custom" in Turkey." *Differences: a journal of feminist cultural studies* 22 (1):172-228.

Konrad, M. 2003. "From secrets of life to the life of secrets: tracing genetic knowledge as genealogical ethics in biomedical Britain." *Journal of the Royal Anthropological Institute* 9 (2):339-358.

Kressel, G. M. 1992. *Descent through males: an anthropological investigation into the patterns underlying social hierarchy, kinship, and marriage among former Bedouin in the Ramla-Lod area (Israel)*. Wiesbaden: Otto Harrassowitz Verlag.

Latimer, J. 2004. "Commanding materials: (re)legitimating authority in the context of multi-disciplinary work." *Sociology* 38 (4):757-775.

Latimer, J. 2007a. "Becoming in-formed: genetic counselling, ambiguity and choice." *Health Care Analysis* 15 (1):13-23.

Latimer, J. 2007b. "Diagnosis, dysmorphology, and the family: knowledge, motility, choice." *Medical Anthropology* 26 (2):97-138.

Latimer, J. 2013a. "Being alongside: rethinking relations amongst different kinds." *Theory, Culture & Society* 30 (7-8):77-104.

Latimer, J. 2013b. *The gene, the clinic, and the family: diagnosing dysmorphology, reviving medical dominance*. London, New York: Routledge.

Latimer, J. 2019. "Science under siege? Being alongside the life sciences, giving science life." *The Sociological Review* 67 (2):264-286.

Latimer, J., K. Featherstone, P. Atkinson, A. Clarke, D. T. Pilz, and A. Shaw. 2006. "Rebirthing the clinic: the interaction of clinical judgment and genetic technology in the production of medical science." *Science, Technology, & Human Values* 31 (5):599-630.

Lippman, A. 1991. "Prenatal genetic testing and screening: constructing needs and reinforcing inequities." *American Journal of Law & Medicine* 17 (1-2):15.

Lippman, A. 1994. "The genetic construction of prenatal testing: choice, consent or conformity for women?" In *Women and prenatal testing: facing the challenges of genetic technology*, edited by K. H. Rothenberg and E. J. Thomson, 9-34. Columbus: Ohio State University Press.

Lock, M. 1994. "Perfecting society: reproductive technologies, genetic testing, and the planned family in Japan." In *Pragmatic women and body politics*, edited by M. Lock and P. Kaufert, 206-239. Cambridge: Cambridge University Press.

Lock, M., and P. Kaufert, eds. 1997. *Pragmatic women and body politics*. Cambridge: Cambridge University Press.

Mamo, L. 2010. "Fertility, I. N. C.: consumption and subjectification in US lesbian reproductive practices." In *Biomedicalization: technoscience, health, and illness in the U.S.*, edited by A. E. Clarke, J. Shim, L. Mamo, J. Fosket and J. Fishman, 173-196. Durham: Duke University Press.

McClintock, A. 1995. *Imperial leather: race, gender and sexuality in the colonial contest*. London, New York: Routledge.

Michie, S., F. Bron, M. Bobrow, and T. M. Marteau. 1997. "Nondirectiveness in genetic counseling: an empirical study." *American Journal of Human Genetics* 60 (1):40-47.

Morsy, S. A. 1995. "Deadly reproduction among Egyptian women: maternal mortality and the medicalization of population control." In *Conceiving the new world order: the global politics of reproduction*, edited by F. D. Ginsburg and R. Rapp. Berkeley: University of California Press.

Murphy, M. 2010. "Technology, governmentality, and population control." *History and Technology* 26 (1):69-76.

Murphy, M. 2017. *The economization of life*. Durham: Duke University Press.

Murphy, R. F., and L. Kasdan. 1959. "The structure of parallel cousin marriage." *American Anthropologist* 61 (1):17-29.

Mutlu, B. 2011. "Türkiye'de 'üremeye yardımcı' teknolojiler: kadınların tüp bebek anlatıları ('Assisted reproductive' technologies in Turkey: women's test tube baby narratives)." In *Neoliberalizm ve mahremiyet: Türkiye'de beden, sağlık ve cinsellik*, edited by C. Özbay, A. Terzioğlu and Y. Yasin, 73-93. Istanbul: Metis Yayınları.

Mutlu, B. 2015. "The gendered ethics of secrecy and disclosure in transnational sex selection from Turkey to Northern Cyprus." In *Fertile Citizens: anthropological and legal challenges of assisted reproductive technologies*, edited by V. Kantsa, G. Zanini and L. Papadopoulou, 217-229. Athens: Alexandria Publications.

Mutlu, B. 2017. "Morally accounting for sex selection online in Turkey." *BioSocieties* 12 (4):543-567.

Nader, L. 1972. "Up the anthropologist: perspectives gained from studying up." In *Reinventing anthropology*, edited by D. Hymes, 284-311. New York: Vintage Books.

Novas, C., and N. Rose. 2000. "Genetic risk and the birth of the somatic individual." *Economy and Society* 29 (4):485-513.

Oliver, M. 1990. *Politics of disablement*. Basingstoke: Macmillan.

Özbay, C., A. Terzioğlu, and Y. Yasin. 2011. "Türkiye'de neoliberalleşme ve mahremiyetin dönüşümü (Neoliberalization and the transformation of intimacy in Turkey)." In *Neoliberalizm ve mahremiyet: Türkiye'de beden, sağlık ve cinsellik*, edited by C. Özbay, A. Terzioğlu and Y. Yasin, 9-28. Istanbul: Metis Yayınları.

Öztamur, P. 2004. "Defining a population: women and children in early Republican Turkey, 1923-1950 (MA thesis)." Boğaziçi University, Istanbul, Turkey.

Öztan, E. 2014a. "Domesticity of neoliberalism: family, sexuality and gender in Turkey." In *Turkey reframed: constituting neoliberal hegemony*, edited by İ. Akça, A. Bekmen and B. A. Özden, 174-187.

Öztan, E. 2014b. "Türkiye'de ailecilik, biyosiyaset ve toplumsal cinsiyet rejimi (Familism, biopolitics and the social governance of gender in Turkey)." *Toplum ve Bilim* 130:176-188.

Özyürek, E. 2006. *Nostalgia for the modern: state secularism and everyday politics in Turkey*. Durham: Duke University Press.

Panter-Brick, C. 1991. "Parental responses to consanguinity and genetic disease in Saudi Arabia." *Social Science & Medicine* 33 (11):1295-1302.

Parens, E., and A. Asch, eds. 2000. *Prenatal testing and disability rights*. Washington, D.C.: Georgetown University Press.

Parkhurst, A. L. 2014. "Genes and djinn: identity and anxiety in Southeast Arabia (PhD thesis)." Available from ProQuest Dissertations & Theses Global. (1775429789). Retrieved from https://search.proquest.com/docview/1775429789?accountid=9630.

Parla, A. 2001. "The 'honor' of the state: virginity examinations in Turkey." *Feminist Studies* 27 (1):65-88.

Petchesky, R. P. 1987. "Fetal images: The power of visual culture in the politics of reproduction." *Feminist Studies*:263-292.

Petersen, A. 1999. "Counselling the genetically 'at risk': the poetics and politics of 'non-directiveness'." *Health, Risk & Society* 1 (3):253-265.

Petersen, A., and D. Lupton. 1996. *The new public health: health and self in the age of risk*. London: Sage Publications.

Prager, L. 2010. *Die 'Gemeinschaft des Hauses': Religion, Heiratsstrategien und transnationale Identität türkischer Alawi-/Nusairi-Migranten in Deutschland (The 'community of the house': religion, marriage strategies, and transnational identity of Turkish Alawi/Nusairi migrants in Germany)*. Münster: LIT Verlag.

Prager, L. 2015. "'Dangerous liaisons': modern biomedical discourses and changing practices of cousin marriage in southeastern Turkey." In *Cousin marriages: between tradition, genetic risk and cultural change*, edited by A. Shaw and A. Raz, 88-112. New York: Berghahn Books.

Prainsack, B., and S. Gil. 2006. "The rise of genetic couplehood? A comparative view of premarital genetic testing." *BioSocieties* 1 (1):17.

Rabinow, P. 1992. "Artificiality and enlightenment: from sociobiology to biosociality." In *Incorporations*, edited by J. Crary and S. Kwinter, 234-252. New York: Zone.

Rapp, R. 1999. *Testing women, testing the fetus: the social impact of amniocentesis in America*. London, New York: Routledge.

Raz, A. 2004. "'Important to test, important to support': attitudes toward disability rights and prenatal diagnosis among leaders of support groups for genetic disorders in Israel." *Social Science & Medicine* 59 (9):1857-1866.

Raz, A. 2010. *Community genetics and genetic alliances: eugenics, carrier testing and networks of risk*. London, New York: Routledge.

Raz, A. E. 2005. *The gene and the genie: tradition, medicalization, and genetic counseling in a Bedouin community in Israel*. Durham: Carolina Academic Press.

Raz, A. E., and M. Atar. 2004. "Upright generations of the future: tradition and medicalization in community genetics." *Journal of Contemporary Ethnography* 33 (3):296-322.

Raz, A. E., and M. Atar. 2005. "Perceptions of cousin marriage among young Bedouin adults in Israel." *Marriage & Family Review* 37 (3):27-46.

Raz, A. E., and Y. Vizner. 2008. "Carrier matching and collective socialization in community genetics: Dor Yeshorim and the reinforcement of stigma." *Social Science & Medicine* 67 (9):1361-1369.

Reardon, J. 2009. *Race to the finish: identity and governance in an age of genomics*. Princeton, New Jersey: Princeton University Press.

Roberts, D. E. 1998. "Who may give birth to citizens? Reproduction, eugenics and immigration." *Rutgers Race & The Law Review* 1:129-135.

Roberts, D. E. 1999. *Killing the black body: race, reproduction, and the meaning of liberty*. New York: Vintage Books.

Rorty, R. 1979. *Philosophy and the mirror of nature*. Princeton, New Jersey: Princeton University Press.

Rose, N. 2001. "The politics of life itself." *Theory, Culture & Society* 18 (6):1-30.

Rose, N. 2008. *Politics of life itself: biomedicine, power and subjectivity in the twenty-first century*. Princeton, New Jersey: Princeton University Press.

Rothman, B. K. 1988. *The tentative pregnancy: prenatal diagnosis and the future of motherhood*. London: Pandora.

Salgirli, S. G. 2010. "Eugenics for the doctors: medicine and social control in 1930s Turkey." *Journal of the History of Medicine and Allied Sciences* 66 (3):281-312.

Savas, N., E. Turhan, T. Inandi, and H. Kaya. 2010. "Hemoglobinopathy awareness among high school students in Antakya (Antioch), Turkey." *International Journal of Hematology* 91 (3):413-418.

Schneider, D. 1984. *A critique of the study of kinship*. Ann Arbor: University of Michigan Press.

Schneider, D. M. 1980. *American kinship: a cultural account*. Chicago: University of Chicago Press.

Shakespeare, T. 1995. "Back to the future? New genetics and disabled people." *Critical Social Policy* 15: 22-35.

Shakespeare, T. 1998. "Choices and rights: eugenics, genetics and disability equality." *Disability & Society* 13 (5):665-681.

Shakespeare, T. 2005. "The social context of individual choice." In *Quality of life and human difference: genetic testing, health care, and disability*. Cambridge: Cambridge University Press.

Shaw, A. 2006. "The arranged transnational cousin marriages of British Pakistanis: critique, dissent and cultural continuity." *Contemporary South Asia* 15(2): 209–220.

Shaw, A. 2009. *Negotiating risk: British Pakistani experiences of genetics*. New York: Berghahn Books.

Shaw, A. 2011. "Risk and reproductive decisions: British Pakistani couples' responses to genetic counselling." *Social Science & Medicine* 73 (1):111-120.

Shaw, A., and J. Hurst. 2009. "'I don't see any point in telling them': attitudes to sharing genetic information in the family and carrier testing of relatives among British Pakistani adults referred to a genetics clinic." *Ethnicity and Health* 14 (2):205-224.

Shaw, A., and A. Raz. 2015. "Introduction." In *Cousin marriages: between tradition, genetic risk and cultural change*, edited by A. Shaw and A. Raz, 1-32. New York: Berghahn Books.

Shim, J. K. 2010. "The stratified biomedicalization of heart disease: expert and lay perspectives on racial and class inequality." In *Biomedicalization: technoscience, health, and illness in the U.S.*, edited by A. E. Clarke, J. Shim, L. Mamo, J. Fosket and J. Fishman, 218-241. Durham: Duke University Press.

Sirman, N. 1990. "State, village and gender in western Turkey." In *Turkish state, Turkish society*, edited by A. Finkel and N. Sirman, 21-51. London, New York: Routledge.

Sirman, N. 1995. "Friend of foe? Forging alliances with other women in a village of western Turkey." In *Women in modern Turkish society: a reader*, edited by S. Tekeli, 199-218. London, New Jersey: Zed Books.

Sirman, N. 2004. "Kinship, politics, and love: honour in post-colonial contexts – the case of Turkey." In *Violence in the name of honour: theoretical and political challenges*, edited by S. Mojab and N. Abdo, 39-56. Istanbul: Istanbul Bilgi University Press.

Sirman, N. 2005. "The making of familial citizenship in Turkey." In *Citizenship in a global world: European questions and Turkish experiences*, edited by A. İçduygu and E. Fuat Keyman, 147-172. London, New York: Routledge.

Sirman, N. 2007. "Constituting the modern family as the social in the transition from empire to nation-state." In *Ways to modernity in Greece and Turkey: encounters with Europe, 1850-1950*, edited by A. Frangoudaki and C. Keyder, 176-190. London, New York: I.B. Tauris.

Star, S. L., and A. Strauss. 1999. "Layers of silence, arenas of voice: the ecology of visible and invisible work." *Computer Supported Cooperative Work (CSCW)* 8:9-30.

Stern, A. M. 2005. "Sterilized in the name of public health: race, immigration, and reproductive control in modern California." *American Journal of Public Health* 95 (7):1128-1138.

Strathern, M. 1992. *Reproducing the future: essays on anthropology, kinship and the new reproductive technologies*. Manchester: Manchester University Press.

Strathern, M. 1995. "Displacing knowledge: technology and the consequences for kinship." In *Conceiving the new world order: the global politics of reproduction*, edited by F. D. Ginsburg and R. Rapp, 346-364. Berkeley: University of California Press.

Strathern, M. 1999. "Introduction: a question of context." In *Technologies of Procreation. Kiship in the Age of Assisted Conception*, edited by J. Edwards, S. Franklin, E. Hirsch, F. Price and M. Strathern, 9-28. London, New York: Routledge.

Tadmouri, G. O., Ş. Tüzmen, H. Özçelik, A. Özer, S. M. Baig, E. B. Senga, and A. N. Başak. 1998. "Molecular and population genetic analyses of β-Thalassemia in Turkey." *American Journal of Hematology* 57 (3):215-220.

TallBear, K. 2013. *Native American DNA: tribal belonging and the false promise of genetic science*. Minneapolis, MN: University of Minnesota Press.

TallBear, K. 2014a. "Indigenous bioscientists constitute knowledge across cultures of expertise and tradition: an indigenous standpoint research project." In *Re: Mindings: co-constituting indigenous / academic / artistic knowledges*, edited by J. Gärdebo, M. Öhman and H. Maruyama, 173-191. Uppsala: The Hugo Valentin Centre, Uppsala University.

TallBear, K. 2014b. "Standing with and speaking as faith: a Feminist-Indigenous approach to inquiry (research note)." *Journal of Research Practice* 10 (2, article N17):1-8.

Tapper, M. 1995. "Interrogating bodies: medico-racial knowledge, politics, and the study of a disease." *Comparative Studies in Society and History* 37 (01):76-93.

Tapper, M. 1999. *In the blood: sickle cell anemia and the politics of race*. Philadelphia: University of Pennsylvania Press.

Taussig, K., R. Rapp, and D. Heath. 2005. "Flexible eugenics: technologies of the self in the age of genetics." In *Anthropologies of modernity: Foucault, governmentality, and life politics*, edited by J. X. Inda, 194-212. Malden, Oxford: Blackwell Publishing.

Taylor, J. S. 2000. "Of sonograms and baby prams: prenatal diagnosis, pregnancy, and consumption." *Feminist Studies* 26 (2):391-412.

Taylor, J. S. 2008. *The public life of the fetal sonogram: technology, consumption, and the politics of reproduction*. New Brunswick, New Jersey: Rutgers University Press.

"Tecavüze uğrayan da kürtaj yaptırmamalı! (Those who have been raped should not abort!)". 2012. *Radikal*, June 01. http://www.radikal.com.tr/politika/tecavuze-ugrayan-da-kurtaj-yaptirmamali-1089772/.

Tekeli, S. 1992. "Europe, European feminism, and women in Turkey." *Women's Studies International Forum* 15 (1):139-143.

Teman, E. 2003. "The medicalization of "nature" in the "artificial body": surrogate motherhood in Israel." *Medical Anthropology Quarterly* 17 (1):78-98.

ten Kate, L. P., M. E. Teeuw, L. Henneman, and M. C. Cornel. 2015. "Risk calculations in consanguinity." In *Cousin marriages: between tradition, genetic risk and cultural change*, edited by A. Shaw and A. Raz, 46-62. New York: Berghahn.

Terzioğlu, A. 1998. "Turkish medical doctors: historical experience and self-narratives (MA thesis)." Boğaziçi University, Istanbul, Turkey.

Thompson, C. 2001. "Strategic naturalizing: kinship in an infertility clinic." In *Relative values: reconfiguring kinship studies*, edited by S. Franklin and S. McKinnon, 175-202. Durham: Duke University Press.

Thompson, C. 2002. "Fertile ground: feminists theorize infertility." In *Infertility around the globe: new thinking on childlessness, gender, and reproductive technologies*, edited by M. Inhorn and F. van Balen. Berkeley: University of California Press.

Thompson, C. 2005. *Making parents: the ontological choreography of reproductive technologies*. Cambridge, MA: MIT Press.

Tillion, G. 1983. *The republic of cousins: women's oppression in Mediterranean society*. London: Al Saqi.

Toksöz, A. 2011. "The Regulation of abortion in contemporary Turkey: laws, policies, discourses (MA thesis)." Boğaziçi University, Istanbul, Turkey.

Tosun, F., A. Bilgin, A. Kızılok, and A. Arpacı. 2006. "Five-year evaluation of premarital screening program for hemoglobinopathies in the province of Mersin, Turkey." *Turkish Journal of Hematology* 23 (2):84-89.

Tuğal, C. 2009. *Passive revolution: absorbing the Islamic challenge to capitalism*. Stanford, California: Stanford University Press.

TUIK, Turkish Statistical Institute. 2016. Social structure and gender statistics (Toplumsal yapı ve cinsiyet istatistikleri). Accessed September 19, 2019. http://www.tuik.gov.tr/PreTablo.do?alt_id=1068.

Tunçbilek, E., and İ. Koç. 1994. "Consanguineous marriage in Turkey and its impact on fertility and mortality." *Annals of Human Genetics* 58:321-329.

Tunçbilek, E., and M. Özgüç. 2007. "Application of medical genetics in Turkey." *Turkish Journal of Pediatrics* 49 (4):353-359.

Turkyilmaz, Z. 2016. "Maternal colonialism and Turkish woman's burden in Dersim: educating the "Mountain Flowers" of Dersim." *Journal of Women's History* 28 (3):162-186.

Ülker, E. 2008. "Assimilation, security and geographical nationalization in interwar Turkey: the Settlement Law of 1934." *European Journal of Turkish Studies. Social Sciences on Contemporary Turkey* 7.

Unal, D., and D. Cindoglu. 2013. "Reproductive citizenship in Turkey: abortion chronicles." *Women's Studies International Forum* 38:21-31.

Vertommen, S. 2016. "Babies from behind bars: stratified assisted reproduction in Palestine/Israel." In *Assisted Reproduction Across Borders*, 225-236. London, New York: Routledge.

Vora, K. 2009. "Indian transnational surrogacy and the commodification of vital energy." *Subjectivity* 28 (1):266-278.

Vora, K. 2010. "Medicine, markets and the pregnant body: Indian commercial surrogacy and reproductive labor in a transnational frame." *S&F Online* 9 (1-2).

Vora, K. 2012. "Limits of "labor": accounting for affect and the biological in transnational surrogacy and service work." *South Atlantic Quarterly* 111 (4):681-700.

Vora, K. 2013. "Potential, risk, and return in transnational indian gestational surrogacy." *Current Anthropology* 54 (7):S97-S106.

Wahlberg, A. 2009. "Serious disease as kinds of living." In *Contested categories: life sciences in society*, edited by A. Wahlberg and S. Bauer, 89-111. Farnham: Ashgate.

Wahlberg, A. 2016. "The birth and routinization of IVF in China." *Reproductive Biomedicine & Society Online* 2:97-107.

Wahlberg, A. 2018. *Good quality: the routinization of sperm banking in China*. Oakland: University of California Press.

Wailoo, K. 1999. *Drawing blood: technology and disease identity in twentieth-century America*. Baltimore: JHU Press.

Wailoo, K. 2001. *Dying in the city of the blues: sickle cell anemia and the politics of race and health*. Chapel Hill, NC: University of North Carolina Press.

Wailoo, K., and S. Pemberton. 2008. *The troubled dream of genetic medicine: ethnicity and innovation in Tay-Sachs, cystic fibrosis, and sickle cell disease*. Baltimore: JHU Press.

Weindling, P. 2004. *Nazi medicine and the Nuremberg trials: from medical warcrimes to informed consent*. Basingstoke: Palgrave Macmillan.

Weindling, P. 2000. *Epidemics and genocide in Eastern Europe, 1890-1945*. Oxford: Oxford University Press.

Weiss, M. 2007. "The chosen body and the rejection of disability in Israeli society." In *Disability in local and global worlds*, edited by B. Ingstad and S. Reynolds Whyte, 107-127. Berkeley: University of California Press.

White, J. 2014. *Muslim nationalism and the new Turks*. Princeton, New Jersey: Princeton University Press.

White, J. 2002. *Islamist mobilization in Turkey: a study in vernacular politics*. Seattle: University of Washington Press.

Yazıcı, B. 2012. "The return to the family: welfare, state, and politics of the family in Turkey." *Anthropological Quarterly* 85 (1):103-140.

Yeğen, M. 2004. "Citizenship and ethnicity in Turkey." *Middle Eastern Studies* 40 (6):51-66.

Yeğen, M. 2007. "Turkish nationalism and the Kurdish question." *Ethnic and Racial Studies* 30 (1):119-151.

Yegen, M. 2009. ""Prospective-Turks" or "pseudo-citizens:" Kurds in Turkey." *The Middle East Journal* 63 (4):597-615.

Yilmaz, V. 2010. "The political economy of disability in Turkey's welfare regime (MA thesis)." Boğaziçi University, Istanbul, Turkey.

Yilmaz, Z. 2015. "'Strengthening the family' policies in Turkey: managing the social question and armoring conservative–neoliberal populism." *Turkish Studies* 16 (3):371-390.

Yürür, K. 2005. "Sickle Cell Anemia in Hatay (MA thesis)." Boğaziçi University, Istanbul, Turkey.

Yuval-Davis, N. 1996. "Women and the biological reproduction of "the nation"." *Women's Studies International Forum* 19 (1):17-24.

Zeydanlıoğlu, W. 2008. "The white Turkish man's burden: Orientalism, Kemalism and the Kurds in Turkey." In *Neo-colonial mentalities in contemporary Europe? Language and discourse in the construction of identities*, edited by G. Rings and A. Ife, 155-174. Newcastle Upon Tyne: Cambridge Scholars Publishing.

Zola, I. K. 1972. "Medicine as an institution of social control." *Sociological Review*, 20, 487-504.

Turkish Primary Sources:

Directory of General Health Services, Ministry of Health, Republic of Turkey. March 03, 2002. Circular note no. 4134 "The premarital health report" (Evlilik öncesi sağlık raporu).

Ministry of Health, Istanbul Health Directorate, Republic of Turkey. 2013a. Annual report of the Private Diagnostic and Treatment Centres Branch Office (Özel Tanı ve Tedavi Merkezleri Şube Müdürlüğü faaliyet raporu.).

Ministry of Health, Republic of Turkey. 2013b. Premarital examination and counselling guide (Evlilik öncesi muayene ve danışmanlık rehberi).

Ministry of Health, Republic of Turkey. 2014. A healthy start into marriage (Evliliğe sağlıklı başlangıç).

Ministry of Health, Republic of Turkey, Directory of Public Health, Department of Child and Adolescent Health. 2018. Field guide for the premarital haemoglobinopathy screening programme (Evlilik öncesi hemoglobinopati tarama programı saha rehberi).

Official Gazette no. 1489. May 06, 1930. Public Health Law (Umumi Hıfzıssıhha Kanunu).

Official Gazette no. 1904. September 21, 1931. Bylaw on the Marital Examination (Evlenme Muayenesi Hakkında Nizamname).

Official Gazette no. 11976. April 10, 1965. Law on Population Planning (Nüfus Planlaması Hakkında Kanun).

Official Gazette no. 18059a. May 27, 1983. Law on Population Planning (Nüfus Planlaması Hakkında Kanun).

Official Gazette no. 18059b. May 27, 1983. Social Services Law (Sosyal Hizmetler Kanunu).

Official Gazette no. 18255. December 18, 1983. Bylaw on the Conduction and Control of Uterine Evacuation and Sterilization Services (Rahim Tahliyesi ve Sterilizasyon Hizmetlerinin Yürütülmesi ve Denetlenmesine İlişkin Tüzük).

Official Gazette no. 18921. November 07, 1985. Bylaw on Marriage (Evlendirme Yönetmeliği).

Official Gazette no. 21804. December 30, 1993. Law for the Fight against Inherited Diseases (Kalıtsal Hastalıklarla Mücadele Kanunu).

Official Gazette no. 23368. June 10, 1998. Bylaw on Centres for the Diagnosis of Genetic Diseases (Genetik Hastalıklar Tanı Merkezleri Yönetmeliği).

Official Gazette no. 24607. December 08, 2001. Turkish Civil Code (Türk Medeni Kanunu).

Official Gazette no. 24916. October 24, 2002. Bylaw on the Control Programme, Diagnostic and Treatment Centres for the Inherited Diseases Known as Haemoglobinopathies (Kalıtsal Hastalıklarından Hemoglobinopati Kontrol Programı ile Tanı ve Tedavi Merkezleri Yönetmeliği).

Official Gazette no. 25868. July 07, 2005. Law on People with Disabilities (Engelliler Hakkında Kanun).

Official Gazette no. 28597. March 24, 2013. Social Security Council Notice on Health Practice (Sosyal Güvenlik Kurumu Sağlık Uygulama Tebliği).

Official Gazette no. 28636. May 03, 2013. Law on the Alteration of Certain Law and Provision Decrees with the Object of Changing Clauses Relating to Disabled Persons in Law and

Provision Decrees (Kanun ve Kanun Hükmünde Kararnamelerde Yer Alan Engelli Bireylere Yönelik İbarelerin Değiştirilmesi Amacıyla Bazı Kanun ve Kanun Hükmünde Kararnamelerde Değişiklik Yapılmasına Dair Kanun).

Turkey Council for Public Health, Ministry of Health, Republic of Turkey. August 04, 2014. Circular note no. 57536863/233/02 on "Premarital counselling (Evlilik öncesi danışmanlık)".