

The stakes of (not) knowing

Motherhood, disability, and prenatal diagnosis in Jordan

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Abstract

This article draws on the concept of subjunctivity to explore how conditions of uncertainty, experimentation, and refusal shape the lives of women raising children with Down syndrome in Amman, Jordan. The connections that women forge – as mothers of children with Down syndrome – enable them to imagine new possibilities for their families and their futures across boundaries of class and circumstance. Prenatal diagnosis, however, invites possibilities of a different kind, challenging established models for divine creation, human agency, and moral accountability. As women reflect on what they would have done if they had known about their child’s Down syndrome in utero, they reason themselves to different conclusions. Yet their interest in the question itself reveals how, even in its absence, prenatal diagnosis circulates as a technology of subjunctivity, conjuring multiple possible pasts, presents, and futures.

Keywords

kinship, disability, motherhood, diagnosis, knowledge, Jordan

Introduction

On any given day, a steady stream of women and children trickled in and out of the Al-Nur Society, an organization promoting disability rights and awareness in Amman, Jordan.¹

1 All organizations and individuals described in my research have been provided with pseudonyms.

Families find Al-Nur and other organizations like it at different points in their lives. While many mothers (and occasionally fathers) arrived with a newborn in arms, others might enter with a toddler, a teenager, or a grown child beside them, just starting to connect with the disability networks growing across Jordan's capital and, to a lesser extent, beyond it.

Over the course of my research on care and Down syndrome, prenatal diagnostics emerged as a frequent topic of conversation among mothers. In most cases, they focused on a distinctive element of their shared experience: none of these women received a prenatal diagnosis of Down syndrome.² In fact, none of them received any kind of prenatal indicator, let alone confirmation, of fetal difference. This pattern remained consistent within my own purposive sample, despite the widespread availability and accessibility of prenatal healthcare across the country. Whether in the Al-Nur Society's reception room, which functioned as both a waiting area and social hub; during the public lectures and celebrations I attended across the capital; or in the interviews I conducted with women and family members between 2013 and 2015, prenatal diagnostics emerged as a subjunctive presence. Sometimes raised explicitly and other times left implicit, a hypothetical question haunted many of these discussions. 'What would I have done', women wondered to themselves, to each other, and to me, 'if I had known?'

In this article, I use the concept of subjunctivity to highlight how uncertainty, experimentation, and refusal shaped the lives of women raising children with Down syndrome in Amman. The subjunctive 'designat[es] or relat[es] to a verbal mood that refers to an action or state as conceived (rather than as a fact) and is therefore used chiefly to express a *wish, command, exhortation, or a contingent, hypothetical, or prospective event*' (Oxford English Dictionary 2020, my emphasis). Anthropologists have built on this grammatical category to call attention to the subjunctive, as a 'mood of doubt, hope, will, and potential' that becomes especially salient in moments of failing health, illness, or disaster (Whyte 2002, 175; Samuels 2015; Wolf-Meyer and Callahan-Kapoor 2017). Bringing this framework to bear on my ethnographic data, I describe how the birth of a child with Down syndrome introduced profound uncertainties into the lives of the women I met, while also exposing them to new possibilities for community and knowledge. These uncertainties embedded themselves in daily routines and relationships, as Down syndrome in Jordan unsettles taken-for-granted models of human development and adult personhood. Yet despite women's daily struggles to care for their children (or, perhaps,

2 In the context of this article, I use the term 'prenatal diagnosis' to encompass screening and diagnostic procedures.

precisely because of them), the ways that prenatal diagnostics intersect with subjunctivities of fate, choice, faith, and family generated considerable debate and concern.

In the next two sections, I present an overview of local perceptions of Down syndrome in Jordan, outlining the family and social circumstances that shape how mothers assumed care and advocacy labors on behalf of their children. Enduring disability stigma, uneven legislative protections, and a service sector stratified by class and capital informed the dilemmas raised by prenatal diagnostics, while also speaking to broader conditions of subjunctivity that parenting a child with Down syndrome introduced into women's lives. I then connect current interdisciplinary conversations on prenatal diagnostics and selective reproductive technologies to the specific legal, ethical, and ethnographic realities that women in Jordan confront. Turning to my data, I juxtapose my conversations with two mothers of children with Down syndrome who, in reflecting on the lack of prenatal diagnosis in their own lives, reasoned themselves to ostensibly opposite conclusions about the morality of knowing. Both women ultimately shared the same stance on selective abortion, which they considered to be undeniably linked to the pursuit of diagnosis and also deeply objectionable. They differed, however, on the legitimacy of acquiring prenatal diagnostic knowledge itself.

Subjunctivity allows me to highlight how the women in my research constructed themselves as fallible moral agents and considered diagnostic knowledge as deeply embedded in relationships with God and with kin. While the contested status of fetal personhood has dominated North American debates on prenatal diagnostics and selective reproduction (Christoffersen-Deb 2012; Conklin and Morgan 1996; Howes-Mischel 2016; Kaufman and Morgan 2005), relational obligations and forms of accountability emerged as more significant in the conversations I observed. Here, I join other anthropologists interested in exploring how politics and practices of selective reproduction – built through clinical interactions, national biopolitical agendas, transnational reproductive health rights frameworks, and in everyday life – are mediated by memories of colonialism, development, war, and occupation (Gammeltoft 2007, 2013; Ivry 2006; Kanaaneh 2002). The mothers I met located themselves in an expanding technological system that abstractly exemplifies ideals of medical and scientific progress while practically posing serious challenges to established models for divine creation, human agency, and moral accountability. The selective implications of prenatal diagnosis perturbed them, even while they struggled to secure their children's basic rights: access to education, transportation, work, and social futures. Nevertheless, in their divergent reflections on what might have been, should have been, and could come to be, these women relied on the very technologies of subjunctivity that they worked to mitigate and contain in different ways.

From shock to acceptance

In coming to terms with an unexpected postnatal diagnosis of Down syndrome, most women spoke of the initial months or years after the birth of their child as a period of *sadma* (shock).³ The marital and familial discord that can arise during this time certainly contributed to this shock. Many families weathered the tumult of this process while managing to avoid its most destructive or protracted possible conclusions. The fact that I met most of my interlocutors as they pursued services for their child or attended public celebrations and awareness-raising events speaks to the support they received from immediate and extended family, albeit to varying degrees. They did not, then, represent the most vulnerable of cases. Everyone, however, knew women and disabled children facing precarious circumstances, which ranged from spousal conflict and abandonment to child neglect and abuse; particularly egregious cases emerge from time to time in both Arabic and English newspaper and media coverage. The families represented in my research, however, considered themselves fortunately protected from and actively working against this wider and more violent spectrum of experiences that shape Jordan's contemporary disability world (Ginsburg and Rapp 2013).

Whether acquired immediately at birth or after some time, a postnatal diagnosis of Down syndrome occasioned grief and anxiety for many mothers, couples, and families. In addition to not receiving the diagnosis prenatally, several women shared with me that they were not directly informed about their child's Down syndrome. Diagnosis was sometimes withheld from both parents, or the physician might choose to first communicate the situation to a woman's husband or kin. Nevertheless, mothers also spoke of their own intuition that something unexpected had transpired, gathering clues from the long pauses of medical staff, the unexpected arrival of family members at the hospital, or perhaps a fleeting thought that their baby looked slightly different in a vaguely familiar way. The stress and fear that accompany giving birth to a sick baby – health complications among newborns with Down syndrome are common – also created intense emotional and financial struggles that exacerbated *sadma*.

On a deeper level, the diagnosis of Down syndrome compelled parents to confront the normative expectations they nurtured, even if unconsciously, for their anticipated child. Parents of disabled children are by no means alone in confronting gaps between the

3 In this piece, I use a simplified version of the *International Journal for Middle East Studies* Transliteration System. I have omitted diacritics, with the exception of ' for hamza and ' for ayn. Transliterations of direct speech are meant to approximate the majority of my interlocutors' urban, Palestinian/Jordan dialect(s), although I have preserved some Modern Standard Arabic forms, such as Umm (mother), which is often pronounced 'Imm'.

expectations and realities that their children embody, but congenital and early childhood disability seems to hasten and amplify the emotional intensity of these speculative exercises (Landsman 1998; Parens and Asch 1999; Rapp 1999). Ultimately, however, lingering in a state of shock was considered unacceptable. Some women became quite critical of *sadma*, reinterpreting this reaction as both evidence of internalized stigma against disability and momentarily lapsed faith in God. Regardless of its morally ambiguous implications, however, the lived intensity of *sadma* guided interactions between experienced mothers, specialists, and women still grappling with diagnosis, the latter being treated with a mixture of caution and empathy.

Women who no longer felt the burdens of *sadma* offered their own ‘beginning’ stories as they became less emotionally raw with the passing of time. Doing so served as means for cultivating rapport with overwhelmed peers and for establishing their experiential authority in mothering children with Down syndrome (see Landsman 1998 and Thomas 2014 for parallel narrative transitions). This process – one they often described in terms of developing acceptance – was marked in part by the linguistic embrace of Down syndrome. Literally translated as *mutilazamat Down*, and also described simply as ‘Down’ or ‘Down syndrome’, these terms coexist with that of *mongholi*, which remains a popular colloquial description of Down syndrome in Jordan. Most of my interlocutors considered *mongholi* an inappropriate ethno-racial slur and a cruel synonym for stupid, and public awareness campaigns against the use of *mongholi* took place throughout my fieldwork via Facebook, on public television programs, and through community and everyday engagement.⁴ The term also gestures to the entangled global history of Down syndrome and medical scientific racism; John Langdon Down himself introduced the label of ‘mongoloid idiocy’ to describe the individuals he studied at the Royal Earlswood Asylum for

4 In this article, I consider Down syndrome a cognitive or intellectual disability, following arguments made by Eva Feder Kittay and Licia Carlson (2010) and taken up by Patrick McKearney and Tyler Zoanni (2018), as well as language guidelines from the National Down Syndrome Society (2015). Article Three of Jordan’s Law on the Rights of Persons with Disabilities (No. 20 of the year 2017) uses the term *dhibiniyya*, which is translated as ‘intellectual’ in the English document (Higher Council), in its definition of disability (*‘iaqa*). ‘Intellectual’ is followed by the term ‘mental’; the latter does not directly correspond to the five Arabic categories of impairment (*jasadiyya, hassiya, dhibiniyya, nafsiiyya, ‘asabiyya*), which are expanded into six English equivalents (physical, sensory, intellectual, mental, psychological or neurological). A video by the King Hussein Foundation (2018) exclusively uses the term *dhibiniyya*, which is the language used by the Higher Council for the Rights of Persons with Disabilities in its publications and social media. During my research, people often described Down Syndrome with the term *‘aqliyya*, which can also be translated as ‘intellectual’ but may more closely approximate ‘mental’ in English. The rich sociolinguistic and philosophical terrains that involve these and other relevant terms – and issues of translation – are beyond the scope of this piece.

Idiots in Surrey, England, during the late nineteenth century (Chen 2016; Thomas 2017). The term *mongholi* does not appear to have circulated in the region during Ottoman times, when, according to disability historian Sara Scalenghe, people with Down syndrome would likely have fallen under the label of idiocy (*'ataba*) or the broader category of blights (*'abat*) (Scalenghe 2014, 3, 89).

In person, on social media, through group chats, and even in public spaces like restaurants and malls, mothers navigated between the twin poles of normal and exceptional, debating precisely the difference(s) that Down syndrome makes.⁵ With concerns ranging from discipline to toilet training, sibling rivalry to table manners, they alternated between urging each other to treat a child with Down syndrome 'just like any other child' and taking seriously a spectrum of bodily and cognitive differences that could require an alternative approach to reach a goal or meet a milestone. Rayna Rapp (1999, 293) has described these tensions as 'doubled discourses... of sameness and difference', whereby individuals with Down syndrome are coded as exceptional and average, normal and different, a blessing and a burden. Yet, beyond the realm of discourse, these conversations also reflect the shifting and contingent ways that children and adults enact and embody Down syndrome through social, therapeutic, educational, and familial relationships that change over time.

The perils and possibilities of living subjunctively

Mothers' experiences of *sadma*, while dark and difficult, allowed them to connect and communicate experiences across the divides of class and ethnicity that structure everyday life in Amman (Beal 2000; Sukarieh 2016; Tobin 2012). Popular and scholarly descriptions describe a stark division of Jordan's capital city, which houses over 40 percent of the country's nine-and-a-half million residents (Department of Statistics 2015). East Amman, the much larger 'half', covers the densely populated eastern and central districts and is home to several Palestinian refugee camps that are now permanent settlements (Ababsa 2013). West Amman, in turn, houses the country's major political institutions and is marked by its villas, high-end shopping malls catering to international clientele, and luxury hotel brands like the Four Seasons. While residents of East Amman increasingly find themselves working in the booming service sectors that cater to local and foreign elite residents who reside and spend time in the west (Schwedler 2010), these parts of the city remain less familiar and more uncomfortable, as well as prohibitively expensive. As a friend once commented while driving me from her home

5 This phrase draws from and modifies the title of Rod Michalko's (2002) *The Difference That Disability Makes*.

in East Amman to my apartment near the touristic Rainbow Street, ‘You know *this* part of the city much better than I would.’

For many women, the possibility of forging connections through mothering a child with Down syndrome required them to navigate the social and geographical boundaries of east and west, let alone those between capital and the ‘other’ Governorates. This process generated tentativeness, doubt, and subjunctivity. Anthropologists of healing, language, and narrative have explored the significant role that subjunctivity plays in structuring human experience in general and illness in particular, focusing on the ways that narrative subjunctivity enables individuals to sustain open and flexible relations with alternative pasts and futures (Bruner 1986; Good 1994; Good et al. 1994). Beyond narrative, however, Susan Reynolds Whyte (2002, 175) argues that ‘where people are negotiating uncertainty and possibility, subjunctivity is an aspect of subjectivity’. She describes how her interlocutors, living through the AIDS crisis in Uganda, strategically assessed and nurtured relationships with various others while living through conditions of attenuated subjunctivity. I extend her observations here to highlight how Down syndrome perceptibly remade women’s relationships to each other and to the city of Amman itself.

Through their efforts to gather information and seek services, women created relationships with hitherto unimaginable allies and in places they would never have otherwise set out to find. I once spent several hours listening to an utterly lost and very stressed mother repeatedly call the staff at Al-Nur as she attempted to figure out the building’s location. While the city’s large traffic circles, or *dumwars*, provide common reference points for reaching unknown destinations, the nearest *dumwar* unfortunately went by multiple names. She arrived nearly two hours late and more than a little exhausted. The mysteries and mundane drudgery of (un)successfully navigating traffic often became a visible testament of maternal commitment, not to mention bonding material for the foreign anthropologist who was constantly lost or almost lost. In another instance, I accompanied a group of upper-class mothers making home visits to families in one of East Amman’s poorest neighborhoods during the month of Ramadan. At one of our final stops, as we stood in a threadbare apartment with almost no furnishings, our visibly worn-down host hesitantly inquired whether it was really possible that my guide was also the mother of a disabled child. She seemed utterly astonished that they would share this bond, while my guide was equally as amazed by her astonishment.

In the midst of this fellowship, the tangible and concrete impacts of inequality laid bare women’s differential access to money, services, and time. What would their own capacities to care be like, wondered my poorer interlocutors and those displaced by war and regional conflict, if they had the money to hire a foreign domestic worker, as is custom among members of the elite and upper-middle classes? What would have happened, they asked, if they had the money and knowledge to begin early intervention and specialized therapies right away, rather

than two or three years after receiving their child's diagnosis? In other words, in and through each other, women came to envision new possibilities, but also to appreciate the constraints that shaped their individual circumstances and those of their children. The ostensible universality of Down syndrome was always held in visible tension with the impacts of immense social inequalities that expanded to include those between the Global North and South, as made apparent through Facebook, YouTube, and other online social platforms. These engagements with others, and the hypotheticals they inspired, nevertheless unfold within the emergent framework of what Faye Ginsburg and Rayna Rapp (2013) have described as 'disability worlds', which incorporate disability as a central tenet of human experience and mode of culture-building.

Prenatal diagnostics, however, invite hypotheticals of an entirely different kind. Their ability to unmake the disability worlds that, in Jordan and elsewhere, remain deeply grounded in cosmologies of kinship (Gammeltoft 2008) raised the moral stakes of these interventions. Existing work on subjunctivity has focused on the 'tactics' through which chronically ill persons and members of their social networks preserve the possibility of future intervention by cure or miracle (Good et al. 1994, 837). These individually and collectively forged narratives provide the means not only for making sense of the world but also for intersubjectively making social worlds, especially in the presence of sickness or suffering (Bruner 1990; Garro and Mattingly 2000; Ochs and Capps 2001). In her research on HIV, family, and moral conflict in Aceh, Indonesia, for example, Annemarie Samuels (2018, 99) writes that her interlocutor Tabinda 'actively fosters the subjunctive elements of her narrative by leaving future trajectories open rather than clearly thinking through different possibilities'. Tabinda's vague and flexible commitment to sustaining multiple possible futures, Samuels argues, allows her to continuously make and remake her world in the face of challenging circumstances. Ambiguity, deferral, and indeterminacy encompass ways of subjunctively engaging the world while juggling competing moral demands and the ethical dilemmas they engender (Zigon 2014).

Many of the women I spoke with closely associated the ambiguity and indeterminacy of prenatal diagnostics with risk and harm. They felt that nothing good could come from receiving knowledge of a fetus's Down syndrome. Whether an individual privately considered their own lack of prenatal diagnosis a blessing or an injustice, women on both sides of this divide seemed to agree that prenatal diagnosis caused suffering, either by enabling one to know something that they might not be able to change or by enabling one to change something that they perhaps should not be able to know about in the first place. The advent and possible routinization of prenatal diagnostic technologies, however, produce increasingly inescapable conditions of subjunctivity. My interlocutors, in turn, attempted to manage these compromising circumstances by interrogating the value of (not) knowing, demonstrating the contested and suggestive moral ambiguities that attach to certain kinds of knowledge.

Technologies of subjectivity: Negotiating selective reproductive technologies in the Middle East

In the flow of everyday life, women overwhelmingly connected prenatal diagnosis with selective abortion, which they widely described as religiously impermissible (*haram*) regardless of a fetus's condition – unless the mother's life was in danger or fetal death imminent. While prenatal diagnosis does not inevitably lead to termination, the intimate connection between the two reflects what a German obstetrician once described to anthropologist Susan Erikson as the 'strange and very special' nature of the technology; it 'is the only routine scan in all of medicine for which the only treatment is death' (Erikson 2007, 209). In a recent Knowledge, Attitudes, and Practices survey on prenatal genetic testing in Jordan, less than 30 percent of the more than 1,000 women surveyed responded that they would consider seeking an abortion if provided with a prenatal diagnosis of Down syndrome, citing religious and ethical reasons (Abdo et al. 2018, 10-11). Yet this result itself relies primarily on subjunctive reasoning, as the authors themselves acknowledge; just 15 percent of survey respondents had a close relative with a congenital disability and certainly even fewer were personally connected to a child with a congenital disability. The mothers of children with Down syndrome whom I spoke with were highly skeptical that prenatal diagnosis could be extricated from the logic of selective reproduction, although some did in fact hold this separation as key to their moral justification for knowing.

Ethnographers of the Arabic-speaking Middle East have focused on the advent of assisted reproductive technologies (ARTs) in the region, documenting the burdens of infertility and the moral and legal complexities that arise in Muslim communities, where determining legitimacy and protecting norms of relatedness remain paramount concerns (Clarke 2009; Inhorn 2003, 2015). Global scholarship on ARTs follows how racial and ethnic logics, pronatalist state policies, and patriarchal kinship ideologies inform and propel prospective parents in their 'quests for conception' (Storrow 2005; Inhorn 1994; Roberts 2012; see Nahman 2016 on 'reproscapes').⁶ Regionally, however, a form of academic pronatalism seems to mirror popular discourse, minimizing inquiry into the ways that perceptions of normality and desirability may limit or derail couples' reproductive aspirations.⁷ Researchers examining

6 The rapid uptake of non-invasive prenatal testing (NIPT) over the past seven years has generated a more extensive and targeted discussion on prenatal screening, diagnostics, and disability (Agarwal et al. 2013; Minear et al. 2015; Ravitsky 2017).

7 Unlike the rest of the region, research in Israel closely examines the intersections of race, ethnicity, and undesirability in the consumption of ARTs (Birenbaum-Carmeli et al. 2002; Kahn 2000; Nahman 2006; see Weiss 1994 on Israeli parents' reactions to postnatally diagnosed disabilities). Mandatory and optional premarital screening programs for inherited blood disorders, particularly

the impacts of selective reproductive technologies, especially those working in South and Southeast Asia, have closely followed the ethical and demographic consequences of sex selection, a practice usually employed to enact son preference (Croll 2000; Miller 2001; Patel 2007; Whittaker 2010, 2011). While the looming possibility of ‘gendercide’ (Warren 1985) has raised considerable offense in the liberal imagination, the impact of selective reproduction on disability generates considerably more ambivalence (Asch 2001; Parens and Asch 1999; Wong 2002). When fetal impairments are discovered in utero, whether via screening or diagnostics, selective termination is often framed as the best or even the only solution – at least in North American contexts (Kafer 2013; Wong 2002).

While Jordanian women experience pregnancy as thoroughly medicalized, punctuated by doctors’ appointments, ultrasounds, blood tests, and surveillance, it nevertheless remains unevenly biomedicalized; the availability and implementation of new medical technologies are inconsistent.⁸ Cost may pose a significant hurdle; as of 2013, private insurance companies did not cover a second trimester ultrasound (Thekrallah et al. 2013, 76). For women covered by public insurance, limited availability of equipment and high demand present a similar hurdle (*ibid.*). According to the 2017–2018 Population and Family Health Survey, 98 percent of women in Jordan received prenatal care from a medical professional, and this same percentage gave birth in a medical facility during the previous five years (Department of Statistics and ICF 2019, 143). Over the course of pregnancy, 82 percent of Jordanian women made seven or more antenatal care visits during this time, although this number fell to 74 percent among ‘other nationalities’ and dropped to 62 percent among Syrian women (*ibid.*, 145). The Survey reports nearly universal coverage for ‘key antenatal services’, which include blood pressure measurements, urine samples, blood samples, and weight measurements, but it does not specify beyond this (*ibid.*). In her research on childbirth in Jordan, Irene Maffi (2012, 140) described significant discrepancies between the procedures and tests available in private practices, which were usually offered on a monthly basis, and those available in public and NGO-based clinics. Furthermore, even when prenatal diagnostic tests are available, doctors may avoid promoting them, as Tsipy Ivry (2006) has shown in the case of Japan. My interlocutors routinely engaged with biomedical institutions during their pregnancy and thus expressed surprise that doctors did not ‘catch’ their child’s Down syndrome beforehand. Some women specifically mentioned ultrasounds or lab work as part of their antenatal care routine,

thalassemia, have been implemented across several Middle Eastern countries (Beaudevin 2013; Saffi and Howard 2015), but carrier screening can only be effective for certain conditions.

8 For example, while the World Health Organization’s range for safe C-section rates falls between 5 to 15 percent, Jordan’s stands at 28 percent (Department of Statistics and ICF 2019), a level comparable to the United States’ own elevated rate of 31.9 percent (Martin et al. 2018).

while others made vague references to the presence of medical experts without specifying tests or technologies.

Legal structures and moral norms shape the very realms of possibility that prenatal diagnostics are capable of conjuring. Abortion in Jordan is regulated by Article 12 of the Public Health Act, Law No. 47 of 2008, and Article 21 of the Medical Constitution, both of which recognize danger to the mother's health as legitimate grounds for termination (Ministry of Health n.d.; Nimri 2016). According to United Nations sources, fetal impairment was added to the list of existing criteria in 2005, and the termination of a pregnancy resulting from rape or incest became legal in 2015 (UN DESA n.d.). More recent English and Arabic language publications, however, disagree with this account, maintaining that abortion can only be performed if the mother's life is in danger (Abdo et al. 2018; Nimri 2019). Contradictory interpretations and variable public perceptions reflect ongoing legal debates and the impact of contemporary *fatwas*, or legally non-binding edicts issued by religious scholars. *Fatwas* carry notable moral authority and are meant to guide and inform the spirit of the law.⁹

The field of Islamic bioethics encompasses a wider range of stances on the permissibility of abortion than the national laws operating across the Middle East and North Africa region, reflecting the dynamic reasoning that religious scholars employ as they weigh the benefits and risks of new medical technologies. Different understandings of the process of ensoulment – recognized as occurring at either forty, ninety, or 120 days after conception – are key to these discussions (Hessini 2007; Rispler-Chaim 2007). Historically, ‘for abortion before 120 days, various opinions have been expressed which can be summed up into three or four main contentions, viz., unconditionally permissible, permissible in case of having an excuse (*‘udhr*), and generally reprehensible and forbidden’ (Ghaly 2008, 116). Scholars today largely conform to these positions, but they must address questions raised by the expansion of prenatal diagnostics. Deliberations focus on the stage of pregnancy at which termination can occur and the kinds of impairments that justify this outcome, as guided by principles of mercy, suffering, and social protection for the mother and family (Ghaly 2008).

As early as 1993, for example, Jordan's Council of *Ifta'* ruled it permissible to terminate a fetus prior to four months of gestation, with both parent's consent, if doctors determined that it suffered from an impairment that would ‘make its life unstable’ (Al-Ifta' [1993] 2015). Medicalization of the fetus – and of disability by extension – plays an increasing role in these arguments across the Middle East and North Africa. Jess Marie Newman (2018), for example,

9 In the case of a pregnancy resulting from rape, Jordan's Council of *Ifta'* ruled in 2014 that it would assess requests for termination on a case-by-case basis (Al-Aifta' 2014).

describes how fetal impairment has become a compelling ‘middle ground’ for Moroccan activists seeking to reduce existing restrictions on abortion, efforts that should not be equated with liberalizing access to abortion. While *fatwas* can influence both legal strictures and the moral deliberations of Muslims in daily life, they are not synonymous with law, nor do their subtleties always permeate the realms of popular discourse. Equally as important, ostensible legality does not equate to practical accessibility (Dabash and Roudi-Fahimi 2008). Shifting hospital policies and spousal consent laws mean that abortion formally unfolds as a collective decision belonging to medical practitioners, husbands, and extended family members in addition to pregnant women. Moreover, hospitals or individual doctors may follow policies that remain internal to their places of work.

The accessibility and effects of selective reproductive technologies also depend on the gender and kinship structures that shape family planning, local political economies of healthcare, and moral economies of suffering. The families that Duana Fullwiley (2004) met during her research on sickle cell disease in Senegal, for example, drew on the temporally sensitive process of ensoulment to make space for selective abortion as distinct from the crime of ending a human life. Not all families viewed termination as ‘the barely hidden interlocutor of all prenatal testing’ (Rapp 1999, 129). Some felt that prenatal diagnosis could provide time to prepare for a sick child (Fullwiley 2004). Those who did connect prenatal testing with selective abortion pointed to religious distinctions between human-ness and non-human-ness and Islamic scholars’ concern for the burdens of disease and illness (ibid.). Both these perspectives, noted Fullwiley (2004), also depended on individuals’ lived experiences with sickle cell disease and whether they watched their children thrive in spite of their sickle cell status or suffer because of it. It is the swirling force of these different components, grounded in the ways that people make sense of circumstance and destiny, that informed women’s confrontations with these technologies of subjunctivity.

It’s better not to know

A week after the global event of World Down Syndrome Day, held every year on 21 March, I sat with Umm Kawthar¹⁰ comparing notes on the different events included in the 2015 celebrations. During a panel on Down syndrome and medical issues, held at a large hospital

10 Here I employ the teknonym formula of address and naming that my interlocutors used, known in Arabic as *kunya*. It consists of the parental category of *Umm* (mother) or *Abu* (father) + name of child. Traditionally, parents take the name of their firstborn child (and for some, their firstborn son, if and when a son is born). In everyday interactions, parents might assume the name of the child present with them or being discussed in conversation. In the interactional fields of my research, parents often assumed the name of their child with Down syndrome.

in Amman, a young woman stood up to ask the panel of health professionals a question. How was it possible, she wanted to know, that despite attending consistent appointments throughout her pregnancy, doctors never diagnosed her baby with Down syndrome. The panel equivocated and generally tried to sidestep providing a definitive response. I subsequently brought up this exchange with Umm Kawthar, as I was curious to hear her perspective on this moment and the many issues it raised. ‘It’s impossible’, she told me. ‘Aside from it being expensive, we cannot have these tests here because abortion is *haram*’.

I countered her argument by pointing out that screening and diagnosis do not necessarily lead to abortion. They could, I reasoned, be used to better prepare families for the medical, emotional, and financial demands that raising a disabled child can entail. Umm Kawthar brushed this aside as nonsense and countered back:

If a mother knows beforehand, even if she doesn’t abort, she will be so sick with worry – What will her husband say? How will the children find out? What will the neighbors say? – that she will not take care of herself properly... In America, it’s not very important what people say, but here it is very, very important. Through her anxiety, the mother may harm the fetus. Unless there is a danger to the mother, there shouldn’t be any knowledge beforehand. This is something up to God. God creates what exists in this world.

In explaining her opposition to the prospect of prenatal diagnosis, Umm Kawthar raised three points. First and foremost, she connected prenatal diagnosis with selective abortion. Yet ‘even if’ a woman chose not to abort, the diagnosis itself could cause damage. The socially embodied and collective dynamics of pregnancy and reproduction became clear in Umm Kawthar’s response, which highlight the potential impacts of spouses, children, and neighbors on a pregnant woman’s wellbeing. The importance of these social relations – for both mother and fetus – were such that, given my outsider status, Umm Kawthar worried I could not possibly understand the full weight of their impact.

Describing this damage, Umm Kawthar’s hypothetical situation focused on the potentially destructive words, thoughts, and actions of others, as well as the dangers a pregnant woman in distress can pose to herself. These forces were, in her opinion, more consequential and threatening than the actual diagnosis and its ramifications. Umm Kawthar was a woman of determination and steely grit, but receiving her now-toddler’s postnatal diagnosis had been an incredible shock. Beyond her very acute fears about family and community responses, the doctors’ grim and wildly aggressive prognostications about Kawthar’s allegedly profound impairment and impending early death left a deep mark on her younger self. One of the most consistent and radical claims she made to her peers and in more general audiences was that

Down syndrome, in so many ways, says very little about the individuals who live ‘under its description’ (Martin 2009).

It was the contested moral status of prenatal diagnostics itself around which Umm Kawthar formed her third point, which ultimately returns to its debatably inevitable motivation of selective abortion. Acquiring diagnosis prenatally links knowledge to action in a way that violated the boundaries of human agency she considered acceptable. If ‘God creates what exists in the world’, prenatal diagnosis opens up the possibility of this being otherwise. Through diagnostic technologies, creation and its counterpart of selection are subjected to the whims of subjunctive human logic and reason, capacities widely regarded as incomplete and flawed. Apart from the morally contested act of terminating a fetus, diagnostics posed further harm by enabling the subjunctive narratives of others. Like the ambivalent possibilities made thinkable by testing, the ambivalent narratives produced by others posed direct risks to a pregnant woman’s health and wellbeing, and that of her family. ‘It’s very important what people say’ – and that is precisely what remains hard to predict, despite the considerable energy people spent attempting to do so.

It was my right to know

Umm Dunia did not agree that it was better not to know. She candidly described the shock of her daughter’s postnatal diagnosis to me in terms similar to many other mothers. Days after returning from the hospital, Dunia developed a bad cold, so an older sibling volunteered to take her back to the hospital. When they arrived, Umm Dunia explained, ‘the doctor took one look at Dunia and said she was *mongholi*?’. Reeling from this public and abrupt announcement of their sister’s Down syndrome, Dunia’s sibling decided to try to keep the news from their mother until further tests could be run. They enlisted their father’s help to make appointments for Dunia at other local hospitals. Umm Dunia learned what was going on when one of her husband’s relatives called to ask whether she was ‘going crazy’ waiting to hear if her daughter was *mongholi*. When her children later informed her that they were taking Dunia to another appointment for her illness, Umm Dunia intervened.

I said that they were all liars and they would do nothing of the sort. ‘She’s MY daughter. I’ll take her!’ We went to four different hospitals, and they all said the same thing: ‘Your daughter is *mongholi*’. At the last clinic, I was speaking with a young doctor. ‘Please don’t tell me Dunia is *mongholi*’, I said. The doctor responded that Dunia definitely was *mongholi* and that she would probably die as a baby. If not, she said that Dunia would live to be twenty-five at most, with a mental age of four. And death would be better.

Umm Dunia recounted this memory with a sad smile. She struggled after receiving Dunia's diagnosis, crying, overwhelmed, and angry. 'My husband was more accepting than I was', she recalled with a small laugh. 'He would tell me "*Alhamdulillah* [Thank God]. Some people have cerebral palsy, or autism! *Alhamdulillah*".'¹¹

I asked Umm Dunia if she wished she had known about the Down syndrome during her pregnancy. She paused and thought about the question. 'I'm not sure, if I had found out beforehand. [...] But it was my right to know'. Umm Dunia clearly felt that this information was wrongly withheld from her, although I was not sure whether she meant to imply that her doctor knew and did not tell her, or that he did not know but should have. 'It would have been my decision', she continued. 'And I had a right to make it. I don't know. Maybe I would have terminated, or maybe I would have feared God. But it was my right to know. Dunia's birth was a cruel surprise; a mother is free [*al-umm hiyya hurra*].' Umm Dunia clearly disagreed that it was better not to know, but she nevertheless shared many of the same key assumptions as her peers. The two options she presented, in the aftermath of knowing, were either terminating a pregnancy or 'fearing God', the latter being the morally superior alternative. She remained focused, however, on her own relationship to diagnostic knowledge and her own relationship with God. What mattered most was being given the chance to know and to choose. Concerned less with the question of whether or not one should know and more with the reality that people can and do know, she embraced the subjunctive possibilities engendered by prenatal diagnosis. The choice itself and the right to choose both emerge from the subjunctivity brought into being by these new diagnostic technologies.

Umm Dunia was a fierce advocate for her daughter. Dunia had transformed her world, bringing her new burdens and responsibilities, but also new opportunities. She was a beloved family member and created new identities and perspectives for her parents and siblings. Yet, Umm Dunia was the first to admit that she was devastated by the 'cruel surprise' of her daughter's diagnosis. She talked about the stigma she and her family encountered, stigma that she too had perpetuated before her own daughter was born with Down syndrome only a few years ago. The process of caring for her daughter launched Umm Dunia into an unexpected – and initially undesired – project of moral becoming, to paraphrase anthropologist Cheryl Mattingly (2014). And yet, the question remained: what would she have done, if she had

11 Throughout my research, I often encountered strong everyday typologies of disability, with certain features and characteristics linked to specific diagnostic labels. Comparisons between Down syndrome and autism were not infrequent, and many families saw Down syndrome as a foil for autism, linking the latter to stereotypes of violent and antisocial behavior.

known? Well aware of the problematic choices that knowing would enable, Umm Dunia desired access to them nonetheless; ‘a mother is free’.

Conclusion

In this article, I use the concept of subjunctivity to draw attention to the ways that uncertainty infiltrates the pasts, presents, and futures of mothers raising children with Down syndrome in Amman. Their concern and speculation over forms of prenatal diagnosis reveals how subjunctivity itself can develop into an object of social discourse and evaluation. It also reveals how, at least from the perspective of the mothers I met during my research, prenatal screening and diagnostics cannot be separated from the issue of selective reproduction. Many of these women shared the perspective that pursuing testing beyond that of basic health information (a standard open to debate) indicated a lack of faith in God and an inability to recognize the proper limits of human agency. Embracing their children, prenatal diagnostics challenged their identities as good mothers. Accepting or longing for testing felt tantamount to rejecting Down syndrome and, by extension, rejecting their own child. To suggest as much runs counter to widespread ideals of maternal and feminine subjectivity, and to articulate this desire would be particularly painful for women who expended considerable time and energy attempting to make space for their children in a world that remains hostile to disability.

Some of my participants supported Umm Kawthar’s position, asserting not only that it was better not to know but also that one *should not* know. The technological refusal advocated by Umm Kawthar places the destinies of kinship and disability beyond the subjunctive realms of ‘what-if’ that prenatal diagnostics bring into being. Others, however, disagreed. For Umm Dunia, conflicting moral principles came into view. While she worried about making the right choice, it was equally important to her that she be given the choice to make. Prenatal diagnosis is creating new possibilities and expectations for pregnancy in Jordan. One of my interlocutors, for example, told me she would leave the country to pursue testing for any subsequent pregnancies after her child was born with Down syndrome. For these women, new technologies surface competing expectations – to know their bodies, to embrace biomedicine, to protect their (unborn) children, and to carefully navigate the kinship structures and relationships that render reproduction as anything but autonomous.

Even when they remain underused, whether by choice or due to structural constraints, prenatal diagnostics work as technologies of subjunctivity. They become part of how women in Jordan, as elsewhere, construct themselves as responsible women, as good mothers, and as moral persons. Prenatal diagnostics are by no means the only arena in which mothers of children with Down syndrome confront uncertainty and wrestle with hypotheticals. Will they be able to find a school that welcomes their child? How will their son or daughter make a living and

a life when they are grown but lack access to support systems outside the family? What will happen when – inevitably – parents can no longer provide care? The future-oriented anxieties that swirled around my participants were not necessarily different in kind from general parental anxieties, but they intensified in degree. And the very relationships that women formed to navigate the world as the mother of a child with Down syndrome in turn amplified their musings about ‘what-if’ and ‘what-when.’ My interlocutors found themselves navigating rapidly changing narratives of human reproduction and of disability that are powered by globalizing technological and biomedical forces beyond their control. As they attempt to locate themselves and their children in these shifting moral terrains, subjunctive pasts and futures continue to emerge.

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