“This is an active one,” the sonographer says, nodding approvingly. Susan and Peter nod enthusiastically too, and Susan exclaims, “He looks like a little boy, doesn’t he.” Peter laughs: “It is obvious that he has my talent for football.” We are in a Danish ultrasound clinic. Susan and Peter have come for a routine pregnancy check-up which today also includes a nuchal translucency scan. The result shakes them: “Hmm,” the sonographer looks up from the documents in her lap. “Your risk is quite high. It’s well beyond the cut-off point. This means that you can have an invasive examination if you like. There’s a small risk of miscarriage though, but then you’ll have a clearer result. It’s your decision.” The atmosphere in the room changes completely. Peter and Susan look puzzled. “No, thank you,” Susan exclaims, speaking quickly and in a firm tone, “We’re not ready to take that risk.” Two weeks later, they return to the ultrasound clinic, asking for the invasive test. “Now that I’ve seen the little miracle in there,” Susan says, “I just don’t want anything to happen with it.” Peter adds, “We would never forgive ourselves if anything went wrong. The last two weeks have been a roller coaster.”

The above scene unfolded during Nete’s research among pregnant women in Denmark in (2005–2010). This scene is far from unique—the doubts and questions that this young Danish couple had to confront resemble those faced by millions of other women and men who live through technologically mediated pregnancies. In the twentieth century, technological capacities to surveil and monitor pregnancies have expanded dramatically: New technologies for prenatal screening and testing were increasingly incorporated in routine pregnancy care in affluent parts of the world in the 1980s and 1990s and are currently routinizing across the globe. Prenatal screening refers to systematic, population-wide efforts to identify problems during the development of a fetus, while prenatal diagnosis refers to clinical interventions that aim to obtain accurate assessments of fetal problems identified by screening. In its early years, prenatal diagnosis relied mainly on invasive tests such as amniocentesis, which involved risks of unwanted, spontaneous abortion and could only be performed in the second or third trimester of pregnancy. More recently, non-invasive prenatal testing (NIPT) that is less risky and performed earlier has become available, thereby increasing the scope of technology use significantly. Within the anthropology of reproduction, the study of prenatal screening and diagnosis has attained a central place, as anthropologists have investigated how advancing technologies of pregnancy are
experienced and used, how they are incorporated into day-to-day clinical routines, how they tend to provoke deep moral and ethical dilemmas, and how they set off cascades of sometimes mundane sometimes dramatic social events within and beyond clinical settings.

In this chapter, we offer an overview of key themes in anthropological studies of prenatal screening and diagnosis, showing how these technologies have become not only sites for pregnancy surveillance, but also for anthropological thinking. Spanning more than three decades, anthropological research on prenatal screening and diagnosis has covered all the world’s continents, highlighting the social, cultural, political, and economic processes through which the surveillance of fetal development has become a routine part of antenatal care for women all over the world. The first ethnographic account of pregnant women’s experiences with amniocentesis was published in 1986 (Rothman 1986). This ethnography was later followed by Rayna Rapp’s landmark study of amniocentesis practices in New York City (Rapp 1999) and by research on prenatal screening and testing conducted in other countries in the Global North, including Canada (Mitchell 2001), Australia (Brookes 2001), the United Kingdom (France et al. 2011; Thomas 2016; Williams et al. 2002), the Netherlands (Rothman 2000), Finland (Helen 2004; Meskus 2009), Greece (Mitchell and Georges 2000), Denmark (Heinsen 2018; Lou et al. 2017; Schwennesen and Koch 2012), Iceland (Gottfredsdottir et al. 2009), Germany (Erikson 2009), Israel (Ivry et al. 2011; Remennick 2006), and France (Ville and Lafarge 2020). As technologies for pregnancy surveillance were increasingly taken up also in the Global South, ethnographic studies expanded to consider Asian countries such as Pakistan (Bryant et al. 2011), India (Gupta 2010a; Unnithan-Kumar 2010), Japan (Ivry 2006; Kato 2010; Tsuge 2010), China (Qiu 2019; Zhu and Dong Dong 2018; Zhu 2013), Hong Kong (Pilnick 2012; Pilnick and Zay 2012), Vietnam (Gammeltoft 2014), and Taiwan (Shih 2018); African countries such as Tanzania (Müller-Rockstroh 2012) and Botswana (Tautz et al 2000); and Latin American countries such as Brazil (Chazan 2007) and Mexico (Tinoco-Ojanguren et al. 2008). These ethnographic accounts map the terrain of a period in the history of childbearing when prenatal screening and testing have become global phenomena, marking the experience of pregnancy for women all over the world. In some cases, technologies for prenatal screening and testing are used to ascertain the health and biomedical normality of the child-to-be; in other cases, they are used to identify the sex of the fetus, often with a view to sex-selective abortion if the fetus turns out to be female. Globally, millions of female fetuses are aborted each year, with drastically skewed sex ratios at birth as a result (e.g., Greenhalgh 2012; Lock and Nguyen 2010).

In this chapter, we divide the literature on prenatal screening and diagnosis into three main themes—pregnancy experiences, reproductive decision-making, and pregnancy governance—showing how anthropological contributions to our understanding of these reproductive interventions have entailed both a finely tuned attention to the socio-emotional dilemmas experienced by technology users and critical analyses of the political and economic forces that underpin practices of pregnancy surveillance and monitoring.

Pregnancy experiences: The search for reassurance and the production of uncertainty

Pregnancy has always been a liminal and risky endeavor, fraught with uncertainty and danger (cf. Rapp 1999: 104). Pregnancy outcomes are inherently uncertain, as is the fate of the mother as she brings a new life into being, reshaping her own life in the process. In the course of history, human beings have sought to influence and control the outcomes of pregnancies in multiple ways (cf. Gammeltoft and Wahlberg 2014). These efforts gained new momentum in the 1970s and 1980s when obstetric ultrasound scanning and genetic testing were introduced
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into pregnancy care in affluent parts of the world, changing practices and experiences of pregnancy. In the mid-1980s, Rothman (1986) documented how amniocentesis rendered pregnancies tentative: The notion of a “tentative pregnancy” refers to the ambivalence that pregnant women may experience when confronted with the possibility that something may be wrong with the fetus they are carrying, and that the pregnancy may not be carried to term. Since the 1980s, technologies for prenatal screening and diagnosis have expanded from invasive examinations (amniocentesis or chorionic villus sampling performed in the second or third trimester of pregnancy) to include noninvasive prenatal testing examinations (ultrasound scans, blood tests) performed in the first trimester of pregnancy (e.g., Schwennesen and Koch 2012; Thomas et al. 2019). As a consequence, users are now not only selected high-risk women in the Global North, but pregnant women across the world, and prenatal screening and testing now tend to take place earlier in pregnancy than in the initial years of prenatal diagnosis (Browner and Press 1995; Browner and Sargent 2011; Ginsburg and Rapp 1995; Sleeboom-Faulkner 2010; Wahlberg and Gammeltoft 2018). Earlier interventions, however, do not necessarily offer more reassurance. Ethnographic studies indicate that the notion of the tentative pregnancy remains highly relevant, capturing the experiences of pregnant women who seek certainty, yet often end up finding themselves confronted with deep uncertainties when a screening or testing result indicates an unwanted pregnancy outcome—whether in the form of a fetal anomaly or unwanted fetal sex (e.g., Erikson 2007; Tautz et al. 2000; Thomas 2017; Tran 2018).

Being relatively low-cost, ultrasound scans are the most widely used technologies for prenatal screening, and ultrasonography has by now become an almost mandatory passage point for mothers-to-be in many countries across the globe. Even though ultrasound imaging is widely perceived as a non-invasive “window” to fetal life, ethnographic studies show that ultrasound imaging may also significantly change the social experience of pregnancy (Mitchell 2001; Rapp 1997; Taylor 1998, 2008). As Janelle Taylor has emphasized, ultrasound imagining can be considered a “hybrid practice” that substantiates the woman’s relationship to the fetus at the same time as it renders it ambiguous and uncertain (Taylor 1998, 2008). On the one hand, ultrasound imaging has the capacity to establish the fetus as a real child-to-be, enabling prospective parents to meet their child-to-be face to face for the first time (Gammeltoft 2007; Howes-Mischel 2016; Lie et al. 2019; Rapp 1997; Taylor 1998, 2008). Through a collective interpretation of what is seen on the screen, the child-to-be is often brought into being as a real person and a potential family member during ultrasound. The moment in which the sonographic image of the fetus on the screen is turned into “baby’s first picture” (Mitchell 2001) entails not only the social birth of a child, but also a transformation in the identity of the pregnant woman and her partner who come to experience themselves as responsible mothers or families in the making (Gammeltoft 2007; Sandelowsky 1994; Schwennesen and Koch 2009). This symbolic meaning of ultrasound images as “baby’s first picture” and as social markers of parenthood are further enforced as sonographic images are today widely distributed on social media and saved for posterity in albums and baby books (Han 2009; Roberts 2012).

Yet, while ultrasound imaging may conjure a child-to-be as real, this technology, like amniocentesis, also reminds parents-to-be that something may be wrong with the fetus and that the pregnancy may end pre-term. The contemporary advancement of 2D imaging into 3D/4D provides a better capacity to detect fetal malformations while offering even more photographic-like images of the fetus (Gammeltoft 2013; Roberts 2012; Thomas 2017). Ironically, studies have shown that uncertainty produced through ultrasound may compel women and partners to seek numerous ultrasounds in the hope of having the normality of their child-to-be confirmed either inside or outside the established healthcare system (Gammeltoft 2013; Gammeltoft and Nguyên 2007b; Thomas et al. 2017). Commercial clinics offering 3D/4D ultrasound “reassurance” scans
and DVD movies of fetal life further the ambivalent character of ultrasound, as simultaneously a social ritual and a medical practice (Gammeltoft and Nguyén 2007a; Roberts 2012; Thomas et al. 2017).

Adding to the contingent nature of ultrasound imagining, in many countries women are offered a blood test which together with the woman’s age and the ultrasound scan provides the basis for a numerical risk assessment (Schwennesen et al. 2010; Thomas et al. 2019). These techniques are used early in pregnancy (eight to ten weeks of gestation) to predict the risk of a fetus having an abnormal condition. The blood test is non-invasive, based on maternal blood testing, and presents no risk of miscarriage or physical risk to the health of the mother or the fetus. In recent years, the uptake of maternal blood testing has expanded rapidly, with estimates that more than half a million procedures have been performed in 61 countries (Warsof et al. 2015). While these techniques are most often presented as technologies that will provide reassurance and control, pregnant women—again—rarely find firm answers. The ambiguity of the results produced by these techniques often generates new doubts and unknowns and new and perhaps intensified reproductive anxieties and uncertainties (Sargent 2020; Schwennesen et al. 2010; Tautz et al. 2000; Zhu 2013).

When prenatal screening is performed, hypothetical future events of childhood disability often loom large. While pregnancy in itself is a condition predicated on the future event of giving birth to a child, the future child enters the present life of women and families via its diagnostic categorization. The projected life of a child is suffused with the social imaginaries and conditions that prevail in particular social settings. Some studies have therefore suggested that we might understand the existential experience of uncertainty and the ambivalence that these technologies generate through the analytical lens of potentiality (Gammeltoft 2013; Zhu 2013). Potentiality arises from a disjunction between the present and the future and points to a fundamental uncertainty regarding the future. In the case of an abnormal finding, the pregnant woman projects herself and her child-to-be into the future, and the haunting fear of the possibility of carrying an abnormal fetus may cause women to look for additional tests. This constant projection of possible futures that may emerge through these technologies, Zhu (2013) argues, produces an uncertain and worrying self. Such self-experience, anthropologists have shown, always takes form within local moral worlds, intertwined with specific meanings of a “good pregnancy outcome,” a “normal baby,” or an “at-risk pregnancy” (Gammeltoft 2007; Müller-Rockstroh 2012; Sargent 2020).

Anthropological studies have also demonstrated how gender makes a difference to the social imaginaries of disability and experience of these technologies (Browner 2000; Browner and Preloran 2000; Dudgeon and Inhorn 2004; Rapp 1999). For example, Rapp found that women’s experiences and decisions about testing were formed through gendered relationships of domination, negotiation, and sometimes resistance to male partners and their stances toward disabled children (Rapp 1999: 98–100; see also Powis, this volume, and Layne, this volume, on the roles of men in reproduction). These studies show that technology experiences are also shaped through the gendered relationships within which a specific pregnancy is embedded.

Pregnancy decision-making: The sociality of choice and enactments of belonging

Despite the desires for certainty that drive the uptake of technologies for prenatal diagnosis, the use of these technologies is steeped in uncertainty. Screening and testing results are hardly ever clear-cut: In the case of fetal anomalies, a screening result will most often present the pregnant woman with a risk figure that can be difficult to interpret (Schwennesen et al. 2012), and even
an apparently clear prenatal diagnosis will most often be fraught with ambiguity, as a general disease label may say very little about the potential nature and life of the specific child-to-be in the womb: “Some of those with Down syndrome do not survive the pregnancy long enough to become people; some go on to graduate school and become spokespeople as part of disability advocacy” (Thomas et al. 2019: 5; see also Gammeltoft 2014; Rapp 1999).

When confronted with a high-risk screening result, women and their partners must decide whether to move on to more invasive forms of testing. Some refuse—due to fears of miscarriage, due to religious beliefs, or due to skepticism regarding the accuracy of results or technical approaches to pregnancy (Ivry et al. 2011; Markens et al. 1999, 2010; Rapp 1998). However, across all societies, ethnographic studies show, the vast majority of women are inclined to accept the possibilities for prenatal diagnosis they are offered. Besides having to make decisions regarding whether to proceed with further clinical examinations, a high-risk screening result also confronts the woman and her partner with the prospect of child disease and disability. In these situations, women are confronted with deep existential questions concerning the meaning and value of life and concerning our responsibilities to one another as human beings. As Rapp has put it, these decisions turn women into “moral pioneers” (Rapp 1999: 3), as they are asked to “make concrete and embodied decisions about the standards for entry into the human community” (Rapp 1999: 306). Reflecting liberal values such as choice and value neutrality, screening/testing results are most often presented to the pregnant woman and her partner as individual choices to be made on the basis of facts about the fetus communicated through “non-directive” counseling—i.e., counseling that encourages people to come to their own decisions regarding clinical pathways, rather than pushing them down specific pathways. However, studies have documented how so-called personal reproductive decisions are always embedded in larger social collectives, their use arising out of social interactions and relationships in lived worlds (France et al. 2011; Gammeltoft 2014; Gupta 2010a; Ivry 2006, 2007; Kato 2010; Lou et al. 2016; Markens et al. 1999, 2010; Rapp 1998; Schwennesen et al. 2010; Ville and Lafarge 2020).

Anthropologists have studied how high-risk screening results are practiced, interpreted, and acted upon in clinical encounters (e.g., Markens et al. 2010; Schwennesen and Koch 2012; Ville and Lafarge 2020). In these processes, the prognosis of the future child is at the center of attention. Scholars focusing on the mundane messiness of everyday clinical interaction have documented how clinical risk communication is shaped not only by a rationality of choice, which demands that women and their partners make decisions on the basis of ambiguous risk knowledge, but also by a rationality of care, whereby complexity is reduced and statistics is transformed by emphasizing certain interpretations and leaving others unspoken (Lou et al. 2016; Schwennesen and Koch 2012). Other studies have shown that pregnant women and their partners only reluctantly make choices (Tsuge 2010), feeling left in a limbo when they are forced to take on the responsibility for future fetal life, while at the same time having difficulties comprehending complex risk figures (Rapp 2000; Schwennesen et al. 2010).

Moreover, anthropologists have drawn attention to what is made absent in high-tech reproductive decision-making processes. Gareth M. Thomas (2016) identified a “remarkable absence” of discussions of Down syndrome during mundane clinical interaction in prenatal screening consultations in the UK. This relative silence was upheld and created by the idea that British people would know about Down syndrome, while at the same time, it was talked about through universalizing discourses of “risk.” This contributed to an understanding of Down syndrome as a negative pregnancy outcome and masked the variability and complexity of the condition (Thomas 2016). In these and other clinical interactions, the elusive character of the “prognosis” of the fetus and the apparent absence of discussions about it leave much space for fears and stereotypical images of disability (Gammeltoft and Nguyễn 2007b). At the same time, studies have
shown that pregnant women and partners often get little time for reflection before they have to make decisions (Gammon et al. 2016; Gottfredsdottir and Arnason 2011).

Recent scholarship has extended the trope of moral pioneering to analyze also how moral reasoning operates within social and global collectives discussing how to appropriately respond to a situation (Meskus 2012). Mianna Meskus (2012) emphasizes that women today may turn to peers and other social collectives (for instance, through social media) to find shared ethical grounds to cope with the complex decisions expected of them. Also pointing toward the soci-ality of choice, studies from South and East Asia have found that women handle uncertainties by placing themselves in the hands of others, turning choice into enactments of belonging (Gammeltoft 2007a, 2014; Gupta 2010a; Kato 2010). In these political terrains, such enactments are represented as collective endeavors, as markers of belonging to larger familial, social, and national communities, rather than as matters of individual preference and choice.

Ethnographic studies show that questions of care are also of central importance when prospective parents have to decide for or against the continuation of pregnancy in cases where prenatal examination detect a fetal anomaly (Brookes 2001; Gupta 2010a; Kato 2010; Remennick 2006). How much care a child will require, how much care a woman feels confident to provide, and the level of care available for children with genetic conditions and families from their communities are all important questions in deciding for or against the continuation of pregnancy in these situations. When a decision is made not to carry a pregnancy to term, these study show, it is usually based on woman’s or the couple’s expectation that the potential child’s needs for support will exceed the care that they are able to provide (Gammeltoft 2014; Pilnick and Zayts 2012; Rapp 2000). Gendered moral expectations toward care and family formation in local settings also play a prominent role in decision-making, and studies show that the moral expectations placed on women as primary caretakers are of central importance (Ivry et al. 2011; Remennick 2006; Unnithan-Kumar 2010). Hereby decision-making also reaffirms and consolidates local normative expectations and gender-specific reproductive responsibilities towards family formation and care.

Pregnancy governance: The political economy of prenatal screening and testing

Technologies for prenatal screening and diagnosis are, anthropologists have shown, inherently political projects in more than one sense. In some cases, technologies for reproductive selection have been mobilized with explicitly political aims, seeking to enhance the health and strength of a nation’s population (e.g., Dikötter 1998; Löwy 2017; Sleeboom-Faulkner 2010). In the twentieth century, eugenic practices aimed at “better breeding” proliferated across the world, reaching an extreme in Hitler’s Germany. This troubled political past continues to haunt present-day practices of prenatal screening and testing, raising vexed questions regarding the political and ethical implications of selective reproductive practices (e.g., Gammeltoft and Wahlberg 2014; Gupta 2010b; Lock 2007; Taussig et al. 2003). In some parts of the world, and particularly in Europe, North America, and Japan, contemporary practices of prenatal screening and testing continue to take place in the shadow of eugenics: Historically driven ethical doubts, anthropological studies show, are voiced with particular force in settings where eugenic policies prevailed (cf. Erikson 2003; Hubbard 1986; Ivry 2006; Shakespeare 2010).

In other parts of the world, anxieties regarding eugenics are expressed with less vigor, as other political questions tend to take precedence when prenatal screening is practiced. In the 1990s and the first decade of the twenty-first century, anthropologists documented how governments in East Asian countries such as China and Vietnam began to include screening and testing technologies in routine pregnancy care programs as part of political strategies to reduce
the number of children born with disabilities, thereby seeking to enhance “population quality” (e.g., Anagnost 2004; Gammeltoft 2014; Phinney et al. 2014; Wahlberg 2018). Such concerns rarely belong to governments alone, but often strike chords among ordinary citizens as well (e.g., Qiu 2019; Shih 2018; Zhu 2013). In China, anxieties regarding population quality tapped into more general fears regarding the nation’s development potential (e.g., Anagnost 1995), and in Vietnam, practices of prenatal screening were driven by political desires to reduce the reproductive damage done by the spraying of toxic herbicides during the Second Indochina War (the war that is known in the US as “the Vietnam War”) (Fox 2003; Gammeltoft 2013). In other words, whereas prenatal screening in some parts of the world is intimately associated with a dark history of eugenics, in other parts of the world, practices of selective reproduction tend to be seen as necessary political responses to historical wounds and traumas.

Besides being implicated in nationwide political efforts to enhance the strength of populations, technologies for prenatal screening and testing are also placed at the heart of the intersecting politics of abortion and disability. Given that a pregnancy termination is often the consequence if a fetal problem is found—as therapies are either not known or not accessible—prenatal screening and testing raise difficult moral-political questions regarding how to draw boundaries for the normal and where to set limits for human life (e.g., Landsman 2009; Löwy 2017; Rapp 1999; Simpson 2007). Disability rights activists have set forth trenchant critiques of selective reproductive practices, arguing that the search for fetal “defects” tends to reinforce societal discrimination of people with disabilities (e.g., Parens and Asch 2000; Shakespeare 2010), and anthropologists have pointed to the “laizzez-faire eugenics” (Lock 2007; see also Taussig et al. 2003) that may result when reproductive selection is placed in private hands. Further, feminist scholars have shown how, in societies with male-oriented kinship systems, technologies for prenatal screening and testing are often used for sex-selective purposes, thereby aggravating already existing gender-based discrimination (e.g., Khanna 2010; Tran 2018; van Balen and Inhorn 2003). While recognizing the ethical dilemmas at issue, other studies have pointed to the continued personal and political importance of women’s access to induced abortion as a reproductive rights issue (e.g., Morgan 2015; Morgan and Michaels 1999; Singer 2019), and scholars examining reproductive justice problems have drawn attention to people’s uneven access to high-cost technologies of pregnancy and to the “stratified reproduction” that such uneven access produces (Colen 1995; see also Ginsburg and Rapp 1995). Technologies for prenatal screening and testing are, in short, important political tools, operating along already existing ethical fault lines within a society.

Such political dynamics, the anthropological literature shows, often intertwine with economic forces, shaping the reproductive terrains in which people are navigating. In many countries, the use of new technologies of pregnancy is governed not merely by decisions made by governments or health authorities but also by market forces, as pregnancy interventions constitute important sources of economic revenue for healthcare providers operating in liberalized healthcare systems (e.g., Gammeltoft and Nguyễn 2007b; Zhu 2013). Due to the possibilities that they offer for encountering the child-to-be before birth, ultrasounds in particular have become important sites of consumption and revenue-generation across countries, offering prospective parents “keepsake imaging” (e.g., Chisholm 2011; Denbow 2019; Thomas 2017). These intersecting political and economic forces place prenatal screening technologies at the heart of what Lynn M. Morgan and Elizabeth F. Roberts (2012) have termed “reproductive governance,” referring to the mechanisms through which “different historical configuration of actors—such as state, religious, and international financial institutions, NGOs, and social movements—use legislative controls, economic inducements, moral injunctions, direct coercion, and ethical incitements to produce, monitor, and control reproductive behaviors and population practices”
(2012: 243). Across the globe, in short, practices of prenatal screening and testing have become significant sites for the exercise of political power and economic interest, while also serving as vital fields for symbolic struggles over the meanings of life, health, and normality.

Conclusion

This chapter has provided an overview of the rich literature on the use of prenatal screening and diagnosis that anthropologists have produced over the past three decades. These studies offer detailed ethnographic accounts of the ways in which prenatal interventions change pregnancy experiences, often deepening the uncertainties that surround childbearing. Despite the advent of earlier and less invasive methods of screening and testing, this literature shows, the ambivalence and uncertainties that suffuse technologically mediated pregnancies do not seem to have diminished. Providing insights into the existential dilemmas that pregnancy entails under conditions of technological surveillance, these studies have added significantly to our knowledge of the contingencies that suffuse reproductive medicine in the world today. Further, anthropological studies have documented the—sometimes excruciating—decision-making processes that prenatal screening and diagnosis entail. By documenting how personal reproductive decisions are always embedded in larger social collectives, this literature has also advanced anthropological thinking on decision-making, intersubjectivity, and belonging. Finally, anthropological studies have provided critical analyses of the political and economic forces at play when prenatal screening and testing are practiced. Framing technologies of pregnancy as political tools, this research has contributed to enhancing our understanding of the complex ways in which intimate lives are governed in the contemporary world. Overall, in other words, this body of literature has attended not merely to reproductive practices and experiences, but also to the varied forms of contingency, vulnerability, and exposure that human existence entails. Research on the myriad ways in which new technologies of pregnancy transform social and political lives in and beyond clinical settings has been central to the anthropology of reproduction, contributing to placing this field at the heart of anthropological scholarship. Since advancing technologies of pregnancy have proven to be an unusually privileged site for the understanding of social life across different scales—from ethics to politics, from intimate lives to mechanisms of governance—keeping track of developments within this field remains an important task for an anthropology of the twenty-first century.

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