

ABSTRACT

Non Invasive Prenatal Testing (NIPT) based on the detection of cell free fetal DNA in maternal blood has transformed the landscape of prenatal care by offering clinical benefits (non-invasive, high specificity and sensitivity, early detection of abnormalities) over existing prenatal screening tests. NIPT has expanded rapidly and is currently commercially available in most of the world. As NIPT spreads globally, culturally sensitive and ethically sound implementation will require policies that take into consideration the social and cultural context of prenatal testing decisions.

In a Western context, the main ethical argument for providing access and public funding of prenatal tests is the promotion of reproductive autonomy (also referred to as “procreative liberty” and “reproductive freedom”), by enabling pregnant women and couples to access information about the fetus in order to choose a certain course of action for pregnancy management (continuation of pregnancy and preparation for birth or termination). So how is the framework of reproductive autonomy operationalised in non-Western cultural contexts? We used Quebec, Canada and Beirut, Lebanon as case studies to explore what ethical considerations related to reproductive autonomy should guide the implementation of the test in various cultural contexts. To answer this question, we conducted a qualitative study to 1) explore the perceptions, values and preferences of pregnant women and their partners about NIPT and 2) to examine how these values and perceptions influence reproductive autonomy and decision-making in relation to NIPT in these two different cultural settings, Lebanon and Quebec.

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MANUSCRIPT

1. Introduction

Healthcare decisions related to testing, treatment and care are strongly influenced by individuals' attitudes, beliefs and experiences, which are in turn shaped by their cultural context. Culture is characterized as “the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs”(UNESCO, 2002). Culture creates the environment within which a person lives, interacts and takes decisions that have ethical dimensions.

Considering their significant role, cultural perspectives have recently garnered a greater attention as an important factor in the provision of healthcare services, as well as analyses. In part, this increased attention comes in response to the challenges and ethical dilemmas faced by healthcare professionals providing services for people from different cultural backgrounds. Moreover, globalization and migration result in increased cultural diversity in those seeking care, making cultural sensitivity a requirement for high quality patient-centered care (Andrews, 2013). For instance, in certain cultures, sharing information about a terminal diagnosis with family members and withholding it from the patient may be considered to be in the patient's best interests. However, in Western culture,

such a scenario is viewed as a breach of the patient's right to know (Chattopadhyay & Simon, 2008) .

In the field of prenatal testing, remarkable technological developments are reshaping the landscape of prenatal care while raising ethical, social and legal issues for pregnant women and their families, healthcare professionals, and society at large, including cultural communities (Rapp, 1999; Rothman, 1994; Shakespeare, 1998). While much bioethical attention has been dedicated to the challenges of prenatal testing, most studies to date, have been conducted in Western countries (Floyd, Allyse, & Michie, 2016; Kuppermann, Gates, & Washington, 1996; Learman et al., 2003) and they have been mainly framed from a Western perspective focusing on mainstream bioethical concepts such as “reproductive autonomy”, “individual choice” and “informed consent”(Hewison, 2015; Munthe, 2015; Rolfes & Schmitz, 2015). Our cross-cultural study on couples' and pregnant women's decision-making regarding a new testing technology, Non-Invasive Prenatal Testing (NIPT), thus provides an opportunity to gain new insights into how other values such as those emanating from religious and cultural contexts come into play. It shows how various values have significant importance in the process of decision-making in a specific context but less consideration in another. It thus sheds light on our understanding of how and why couples and pregnant women approach NIPT differently in different cultures.

These cultural perspectives matter as well for healthcare professionals offering care for people from diverse cultures, religious backgrounds and countries since they sometimes find their own held beliefs, ethical norms and values challenged by those of their patients. Therefore, in the context of prenatal testing, cultural perspective might assist them in coping with challenges they might encounter in their clinical practice when counseling patients about prenatal testing. An approach that is known as “culturally- appropriate care”, which takes into account patients’ cultural nuances (Truong, Paradies, & Priest, 2014), may allow the provision of care adapted to their needs, preferences and expectations and in this context, may support women and couples in their decision to accept or decline testing.

Based on an empirical qualitative study, this paper addresses cross-cultural perspectives on decision-making surrounding NIPT that focused on pregnant women and their partners in Lebanon and Quebec. We begin by justifying the choice of NIPT and of these two specific cultural contexts. We then present empirical findings, identifying factors that shape pregnant women and couples’ decision-making regarding NIPT, with a focus on similarities and differences between these two different contexts. We use the conceptual framework of the contextualized view of reproductive autonomy to discuss these findings and conclude with some implications of our findings for practice and policy.

2. Background

Rationale for choosing NIPT¹

Since its inception in 1970s, the field of prenatal testing has seen a tremendous evolution (Cuckle & Maymon, 2016). A variety of prenatal testing technologies have been developed and introduced into clinical use, including but not limited to prenatal screening tests such as maternal serum screening (MSS) and prenatal diagnostic tests such as amniocentesis and chorionic villus sampling (CVS). Based on the detection of biochemical markers in the mother's blood, screening tests offer an estimated risk calculation of fetal aneuploidy ("ACOG Practice Bulletin No. 77: screening for fetal chromosomal abnormalities," 2007). In contrast, prenatal diagnostic tests detect with theoretical 100% accuracy the actual presence of a genetic aneuploidy. They involve invasive procedures to sample chorionic villi or amniotic fluid in order to detect chromosomal abnormalities and therefore hold a risk of pregnancy loss ranging between 1 in 100 for CVS (RCOG, 2010) and 1 in 200-300 for amniocentesis (J. K. Morris, Waters, & de Souza, 2012; Wilson, Langlois, & Johnson, 2007). CVS is performed at 10-13 weeks' gestation whereas amniocentesis is performed after 15 weeks' gestation.

Recently, the development of a new prenatal technology known as Non-Invasive Prenatal Testing (NIPT) has changed the landscape of prenatal screening. Based on the analysis of cell-free DNA fragments in the maternal plasma (Lo et al., 1997), NIPT is used

¹ In this paper, we use the term NIPT (non-invasive prenatal testing) rather than NIPS (non-invasive prenatal screening) to refer to cell-free DNA (cfDNA) since it is an established term in the literature. We clarify that it is currently used as a screening test.

as a screening test and has been commercially available in the United States since 2011. Currently used to detect fetal aneuploidies (such as trisomy 21, 13 and 18) as early as the 10th week of gestation, NIPT involves a single blood draw with results turnaround time of about two weeks, although in some cases, women receive a no-call result and the test needs to be repeated (Scott et al., 2017). The same technology can be used to test the fetus for other types of genetic information, such as fetal sex, paternity and fetal Rhesus D status (Wong & Lo, 2015). It is noteworthy that these different types of genetic information have different goals. For instance, the use of NIPT to determine fetal sex could either be purely for information i.e. pregnant women or couples want to find out the baby's fetal sex or for medical reasons such as identifying sex-linked diseases in order to take a certain course of action with respect to the pregnancy.

Originally validated in a population at high risk for aneuploidies, NIPT is being assessed in order to be validated in the general or low-risk population (Bianchi et al., 2014; Zhang et al., 2015b). More recently, the American College of Medical Genetics and Genomics released a new statement recommending that all pregnant women be informed about NIPT (Gregg et al., 2016). Studies are underway to broaden the scope of conditions that can be detected to include microdeletion and duplication syndromes and other genetic conditions (Wong & Lo, 2015) such as Huntington's disease (van den Oever et al., 2015). In the future, NIPT might potentially be used to sequence the entire genome of the fetus, which has been demonstrated in a proof-of-principle study but is not yet clinically available (Fan et al., 2012; Hui & Bianchi, 2013; Lo et al., 2010).

NIPT differs from existing prenatal tests on both the clinical and the commercial levels. Similarly to noninvasive screening methods (e.g. MSS), NIPT carries no increased risk of pregnancy loss but yet is considered superior to them (Norton & Wapner, 2015). For instance, NIPT enables the screening of Down syndrome with 99.21% sensitivity (true positive rate) and 99.95% specificity (true negative rate) in high-risk populations vs. 98.97% and 99.95% respectively in low-risk populations (Zhang et al., 2015a). However, NIPT is not considered diagnostic and guidelines from all professional societies recommend that high-risk NIPT results be confirmed with an invasive diagnostic procedure before irrevocable decisions are made (Devers et al., 2013; Gregg et al., 2016; Langlois et al., 2013). Because of the improvement in detection rates and of the lower screen positive rate, NIPT has led to a significant decrease in invasive diagnostic procedures since its implementation (Platt et al., 2014; Warsof, Larion, & Abuhamad, 2015).

At the commercial level, the introduction of NIPT into clinical care was faster than that of previous prenatal tests. Its implementation was driven by market pressures accompanied by “aggressive advertising” (Norton, Rose, & Benn, 2013) by various companies wishing to capture market share. Further, in contrast to other tests that were developed in academic settings supported by public funding and that were gradually introduced into clinics following clinical trials and the publication of professional guidelines (ClinicalTrials.gov, 1996; Norton et al., 2013), NIPT’s development was rapidly licensed to companies supported by private funding and the test was introduced before professional guidelines were published (Morain, Greene, & Mello, 2013; Norton et al., 2013). This commercial

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pressure contributed to NIPT's fast global spread and the test is currently available in more than 60 countries (Chandrasekharan, Minear, Hung, & Allyse, 2014).

Bioethical discourse in prenatal testing, NIPT and the value of incorporating cross-cultural perspectives: Quebec and Lebanon as Case Studies

Developments in the field of prenatal testing technologies have been accompanied by an important body of literature related to the ethical, legal and social issues raised by these technologies, touching on issues such as abortion, eugenics and disability rights. A significant body of empirical work has been performed to date with respect to parental perceptions, attitudes, and experiences towards prenatal testing, such as maternal serum screening and amniocentesis. However, the prevailing discourse has focused mainly on mainstream bioethical concepts from a Western perspective, such as “reproductive autonomy”, “informed choice”, “informed decision-making”, “individual choice” and “informed consent” (Benn, Cuckle, & Pergament, 2013; Davis, 2013; Deans & Newson, 2012; Dondorp et al., 2015; Hewison, 2015; Silcock, Liao, Hill, & Chitty, 2015; Wright & Burton, 2009). In fact, the main ethical argument in favor of the implementation of prenatal tests and their public funding in Western countries is the promotion of reproductive autonomy, by allowing pregnant women or couples access to information about the fetus, which in turn allows them to prepare to parent a child with special needs or to terminate the pregnancy (Rolfes & Schmitz, 2015).

As for NIPT, the ethical, legal and social debate surrounding the test has been evolving since the earliest stages of the development of NIPT technology (Haidar, Dupras, & Ravitsky, 2016). The empirical studies performed to date involved a diversity of stakeholders such as pregnant women, their partners, genetic counselors, physicians and the public. They were predominantly conducted in Western countries including the UK, USA and Europe and with much of the Ethical, Legal and Social Implications' (ELSI) discussion framed from the perspective of reproductive autonomy and choice (Benn, Chapman, et al., 2013; Horsting et al., 2014; Kelly & Farrimond, 2012; van Schendel et al., 2016; van Schendel et al., 2014). Further, while some studies have been conducted on the cultural implications of NIPT (Minear, Lewis, Pradhan, & Chandrasekharan, 2015; Mozersky et al., 2017), they tackled ELSI discussions without delving into the way couples and pregnant women make their decision about NIPT. Therefore, it appears there remains a gap in understanding the prenatal testing decision-making processes from a comparative cultural perspective.

Cross-cultural perspectives are receiving more attention in bioethical discussions given the significance of culture in individuals' lives, especially in the context of healthcare. Cross-cultural research provides insights into how the same value or concept (such as "reproductive autonomy", "choice" or "informed consent") is contextualized and prioritized differently when a decision is made with respect to the same technology. For instance, while the value of reproductive autonomy - notably when considering prenatal

tests² - finds its primacy in the Western setting, this might not be the case when considering non-Western contexts such as Lebanon, where the emphasis might be placed on other values (such as religious values or trust in the healthcare professional) that play an important role in reproductive decision-making.

Healthcare professionals are faced with increasing challenges and cultural dilemmas when providing care to patients from diverse backgrounds and cultures. To fulfill their ethical obligation, they need to offer culturally-appropriate care, to support patients in their decisions. Referred to in the literature with terms such as ‘culturally sensitive’ or ‘competent care’ (Truong et al., 2014), culturally appropriate care reflects the ability to respond effectively to the attitudes, feelings, and circumstances of people that share common and distinctive characteristics such as, race, religion, language, and socioeconomic status (HHS, 2011). It has also been described as a care in which healthcare providers offer services in a way that is concordant with patients’ cultural values, beliefs, needs and expectations (Majumdar, Browne, Roberts, & Carpio, 2004). For instance, in a Western context, when a non-Western patient’s culture clashes with this of the ruling medical establishment, the patient’s culture should generally prevail ("Committee Opinion No. 493: Cultural Sensitivity and Awareness in the Delivery of Health Care," 2011). A culturally-appropriate care offers a way to address cultural clashes or tensions between patients and their providers by promoting an approach that encourages professionals to

² To avoid repetition, in this paper ‘reproductive autonomy’ refers to the context of prenatal testing.

respond to patients' request in a manner that is appropriate to their needs and preferences.

In ~~reality, within clinical practice Western culture and a specific clinical context where~~ the norms of the Western medical establishment ~~often take precedence over~~ clash with the values of non-Western patients and take precedence over them, ~~which such situation~~ might lead to negative outcomes³ such as loss of trust in the medical team (Weil, 2001). This paper attempts, amongst other things, to encourage change by arguing in favor of – and informing – a culturally appropriate care approach.

Providing culturally appropriate-care can thus seem a daunting task, considering the vast knowledge required regarding various cultures, which in turn, is amplified by the fact that within every cultural community, there are sub-groups and within these groups each individual is unique. Research integrating cross-cultural perspectives thus sheds important light on the importance of culture in ethical decision-making and has the potential to inform clinical practice and policy recommendations.

For these reasons, we chose to address decision-making surrounding NIPT across two jurisdictions Quebec and Lebanon. These two locations represent interesting case studies because they have different cultures and religions, health care systems, policies and regulations surrounding prenatal testing and abortion, as well as different resources and social supports for people with disabilities. These factors have been identified as potentially influencing the reproductive choices of pregnant women and their partners (Lawson &

³ We thank the reviewer for this suggestion.

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Pierson, 2007; Learman et al., 2003). This paper offers a summary of these factors in the two contexts, as a background for our study (Table 1).

Our goal in this paper is not to promote the normative claim that reproductive autonomy is ‘one size fits all’ and should be adopted as such in every context, Western and non-Western alike. Rather, we strive to understand how different factors are taken into consideration in decision-making surrounding NIPT. To do this we adopt the contextualized view of reproductive autonomy proposed by Erin Nelson, who suggests the need to consider the broader context in which reproductive decisions are made and the different influences that shape them. According to Nelson (Nelson, 2013a):

‘A contextualised conception of autonomy demands that we consider the range of decisions that must be permitted to be made autonomously. But unlike most accounts of reproductive autonomy, it also focuses our attention on the question of whether conditions exist that actually permit (or foster) the meaningful exercise of reproductive choice. In addition to directing our focus more broadly, a deeper, contextualised understanding of reproductive autonomy directs us to consider the social, institutional and policy contexts that play a role in shaping reproductive decisions.’

4. Methodology

Research design

Our qualitative study used a Qualitative Description (QD) Methodology. This design enables researchers to provide direct information about a topic/event as well as a comprehensive explanation of events as experienced by the study participants (Sandelowski, 2000). QD is congruent with empirical bioethics because it provides an opportunity to explicitly describe the perspectives and values of participants, allowing the author to provide her interpretation and application of ethical theories separately (i.e. not embedded in the analysis, as with other more interpretive methodologies). This permits readers to examine the ethical argumentation and interpretation separately from the available participant data. This research methodology was essential to this study, as it allows the description of different factors that are taken into consideration when pregnant women and couples make a decision about NIPT, as well as an understanding of how these elements influence this decision.

Ethical considerations

Approval for this study was obtained from [institutional name deleted for peer review] in Montreal, Quebec, Canada in September 2014 and from the Institutional Review Board (IRB) at the [institutional name deleted for peer review], Beirut-Lebanon in June

2015. Written informed consent was obtained from all study participants prior to data collection and all data were anonymised. Participants received 30\$ in a gift voucher to compensate them for the time dedicated to the interview.

Sampling, recruitment and data collection

Participants were recruited through the [institutional name deleted for peer review] in Montreal, Quebec. Potential participants were approached by a study coordinator or nurse after their clinical consultation about prenatal testing and the available prenatal tests. Potential participants included pregnant women at low and high risk of having a child with Down Syndrome, who were identified by recruiters through their medical records. Women were classified as high risk either because of their maternal age, medical history with previous pregnancies, or because their MSS result was positive for Down syndrome. Women chose whether or not they wished to include their partner in the interview. In Lebanon, participants were recruited at the department of Obstetrics and Gynecology at the [institutional name removed for peer review]. Potential participants were approached by a nurse or a physician at the [Institutional name removed for peer review] (See Table 2 for information regarding testing history).

One-on-one or one-on-two semi-structured interviews were conducted with pregnant women or couples (pregnant woman and her male partner). To ensure the feasibility of the study and in order to have a homogeneous sample in both contexts, the recruitment included only heterosexual couples (i.e. these couples could be found in both settings). Interviews with pregnant women and couples were audiotaped, transcribed

verbatim and anonymized (for details please see Table 3). It is worth noting that during the interviews, we relied on the participants' information and what they knew themselves about NIPT in both contexts. The semi-structured interview guide can be found in Appendix 1.

In Montreal and Beirut, the semi-structured interview protocol explored the same topics including: general attitudes regarding NIPT, informed consent for NIPT, time needed for decision-making, NIPT coverage by the healthcare system and insurance companies, current and future NIPT uses and social impact of NIPT. A few questions were adjusted to fit the context. For example, since Quebec has a public healthcare system and Lebanon has a hybrid system (private and public), the question related to NIPT coverage was reformulated in order to refer to the appropriate healthcare system.

Data analysis

Data analysis was conducted using thematic analysis, facilitated through the software package NVivo version 11. To ensure uniform coding, transcripts for interviews in Montreal were coded independently by two researchers (H.H. and G.B.) and another two researchers (H.H. and C.H.) coded the Arabic transcripts. Coded transcripts were then compared between researchers, and discrepancies were discussed until a consensus was reached. HH translated all themes and selected quotes from the interviews into a common language (English), so authors could confer on the developing analysis and for English manuscript preparation. Translations were validated by G.B. (French-English) and C.H., a research assistant bilingual in Arabic and English.

5. Results

Participant Characteristics

In total, 61 individuals were approached: 11 Quebecois couples, 12 Quebecoise women, 8 Lebanese couples and 11 Lebanese women. However, 43 individuals participated in the interviews: 7 Quebecois couples, 8 Quebecoise women, 6 Lebanese couples and 9 Lebanese women (Table 2).

Key findings

All participants in Quebec and Lebanon (except one Lebanese couple) considered NIPT to be a positive advance for prenatal testing technology, emphasizing the benefit of obtaining accurate information early in the pregnancy without the risk of miscarriage. When comparing decision-making processes about NIPT between Quebec and Lebanon, we identified several significant differences and some important similarities with respect to the different factors deemed to influence couples' and pregnant women's decision-making surrounding NIPT. Those factors are presented as themes, discussed as follows: factors related to a) the technology itself, including the features of the test; b) personal

beliefs or views, including couples' and pregnant women's personal views on abortion and pregnancy management; c) the relationship with others, including potential disagreement with the partner and the healthcare professional's recommendation; and d) financial resources, including NIPT cost and its coverage by the healthcare system or insurance companies.

Factors perceived to influence pregnant women's and couples' decision-making surrounding NIPT

a) Features of NIPT

When asked to think about the features of NIPT that would influence their decision to accept or decline the test, responses from Quebecois and Lebanese participants were similar. We identified four common factors that couples and pregnant women cited as key elements in considering NIPT: the 1) risk-free nature of the test (non-invasive); 2) the ease of the procedure; 3) its accuracy; and 4) the fact that it is performed earlier than other prenatal tests. The most commonly cited benefit of NIPT was its non-invasive nature and the lack of miscarriage risk. The majority of Quebecois and Lebanese interviewees perceived this feature as a key element in their decision-making, with some going so far as stating that there is no reason to decline a 'non-invasive test'. When compared to amniocentesis, NIPT was described as a 'simple' and 'easy' blood test (see Table 3). It should be noted that the way participants perceive the risk of miscarriage for amniocentesis

might influence their decision-making. For instance, if a woman perceives this risk as significantly higher than it actually is (i.e. 1 in 200-300), she might decide to accept NIPT. Or the other way around, that is, if she perceives the risk as minimal, she might decline NIPT. Our study didn't assess how women understood such risk however, only one participant stated that she considers the "risk with amniocentesis as minimal" and preferred this option.

As for the test's accuracy, participants showed two conflicting opinions: some of them had high confidence in the reliability of NIPT and considered it to be near diagnostic with a 99.9% detection rate. These participants were likely to state that follow-up invasive testing was not necessary if a positive result was returned after NIPT. Lebanese participants were especially enthusiastic about the 'high accuracy' or the 'certainty' of the test results' that are 'nearly diagnostic', and linked this accuracy with their decision to take the test. However, some Quebecois interviewees stated that their decision to decline NIPT was based on the fact that it is not 100% accurate and its results 'are comparable to a Prenatest [the MSS used in Quebec]', reflecting a probability of risk rather than a confirmed diagnosis. This opinion was linked to the need for amniocentesis to confirm NIPT results (see Table 3 for quotes).

The earlier timing at which NIPT detects abnormalities was cited less frequently than the non-invasive feature as an element facilitating the acceptance of the test. Some participants associated the timing of NIPT with the decision to terminate a pregnancy, stating that 'earlier is better' because it would be medically easier and safer for the pregnant woman in case she wants to consider a termination (see Table 3 for quotes).

b) Abortion and pregnancy management

In Quebec, termination of pregnancy is not legally restricted at any point during the pregnancy. Early term abortions are the norm, but terminations after 24 weeks occur in rare cases, in a limited number of institutions (CHUSJ, 2007) . In Lebanon, abortion is illegal except in cases where the mother's life is at risk. In practice, termination is frequently performed clandestinely in private clinics up to 24 weeks of the pregnancy.

It should be noted that among all participants: only three women decided to perform NIPT: one Quebecoise among the ten who had high-risk pregnancies (with the other nine decided to have amniocentesis), and two Lebanese one of the five who had high-risk pregnancies (with the other four declining any further testing including NIPT and amniocentesis) and one woman with a low-risk pregnancy.

When talking about their decision to perform NIPT, many Lebanese participants explicitly stated their positions about pregnancy termination, while Quebecois participants rarely brought up this issue, and when they did they were more likely to refer to abortion in a more general way, without stating their own opinion.

Lebanese participants who stated that they decided to perform NIPT stated that they want to prepare for the birth of their child, because they 'do not want to abort' or they are 'against abortion'. Participants who stated their opposition to abortion often invoked religion to discuss this stance: *"At all cases, even if I did the NIPT and God forbids the baby had any abnormality, I will prepare myself throughout the pregnancy. I am against*

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abortion. It is against religion... I will accept whatever God gives me.” “(Lb 14 Cp F) Only one couple talked about considering abortion in the event of a positive finding from NIPT: “It would be better that she aborts the baby than to keep it if there is any malformation or any developmental problems.” (Lb 3 Cp H).

Because most Lebanese participants stated they would not consider abortion, they were more likely to decline NIPT or any further invasive procedure when there was a high-risk pregnancy. Only one of the five pregnant women with a high-risk pregnancy decided to perform NIPT whereas the other four declined any further testing. Moreover, one Lebanese couple even refused to have any prenatal testing for conditions for which there is no ‘cure’, saying that since abortion is not an option, they preferred not to be ‘anxious’ throughout the pregnancy. When unwilling to terminate for any reason, the cost of NIPT made this a very unappealing test. However, despite the trend to decline NIPT when abortion was not an option, many couples were willing to pay for other prenatal tests (e.g. MSS) that detect similar conditions, saying it was important to ‘do all the available tests’ only ‘for information’ in order to be prepared for the birth of their child.

“If it is necessary and there is a high-risk pregnancy, the person would pay no matter what. The doctor told me about the Verifi⁴ and about its cost. It’s not covered by insurance or social security and the reason we didn’t do it is that if God forbids and there is something or any abnormality with the baby we are not gonna abort

⁴ Verifi is a brand name given to NIPT, marketed through a company called Verinata (other brand names, given by other companies, include MaterniT21, Harmony and Panorama).

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so we'll go with the usual trend. I'll do the usual test, the triple screen. I simply will not go further with any other tests [...] I am doing the test to get peace of mind. I would like to do all the available tests simply to get more information and to prepare myself psychologically.” (Lb 8 Cp F)

As for the Quebecois participants, one pregnant woman of the ten identified with a high-risk pregnancy decided to perform NIPT, while the other nine decided to have amniocentesis. Further, when discussing their decision, Quebecois participants rarely related their own views on abortion. Only one Quebecois couple explicitly reported their personal opinion about pregnancy termination. The pregnant woman from this couple, a physician, stated that “I could have a dilation then a curettage or a dilation and an extraction, rather than a procedure which is much more traumatizing” (*Qc 8 Cp F*). More commonly, interviewees discussed termination more generally by referring to the opinions of hypothetical others.

“I think that the more we wait the more the baby grows. So if someone were to know that his or her child has Down syndrome at 12 weeks, I think that it would be less difficult than to wait 18 or 20 weeks. So the earlier one knows, the more it is possible for it to be less difficult for those who decide against keeping the child.”
(Qc 7 Cp F)

c) Influence of others: partner and healthcare professional

Implications of potential disagreement within the couple

We asked both pregnant women and their partners about the influence that ‘potential’ disagreement over NIPT testing would have on the pregnant woman’s decision to accept or decline the test. Although some participants in Lebanon and Quebec did not see how there could be a potential for disagreement over a non-invasive test, others offered diverse opinions of the impact of a disagreement within the couple. The main difference was noted among male partners’ replies. For instance, the majority of Quebecois male partners agreed that it is the woman’s decision whether to accept or refuse testing, evoking terms such as ‘it is her own body’ and she has the ‘last say’ (see Table 4). In contrast, the majority of Lebanese male partners were inclined to have a discussion with their female partner in order to reach a consensus about NIPT.

Two different views were noted among Quebecois and Lebanese pregnant women: some of the Quebecois and the majority of Lebanese women reported that they will ‘deliberate until they find a consensus’, whereas few Lebanese and most Quebecois women affirmed that disagreement about NIPT with their husbands would not impact their decision to accept or decline the test. These women stated that they would follow their own opinion (see Table 4).

Role of healthcare professional's recommendation

The majority of Lebanese participants mentioned the 'recommendation' of their physician as a key factor in their decision to accept or decline NIPT. They stated that if the physician 'requested the test', 'recommended it' or if he believes that it 'should be done' or 'it's a must do', then they would accept testing: *"If the doctor says that medically he believes that the test should be done, it should be done like any other test and definitely there is no reason to decline it."* (Lb 14 Cp M) Quebecois participants, in contrast, did not mention their healthcare professional in relation to their decision to consider NIPT.

d) Financial resources: cost of NIPT and the role of coverage

The Cost of NIPT as a financial barrier

Both Lebanese and Quebecois participants cited cost as a significant influence on their decision to accept or decline NIPT. Currently, in both countries NIPT is paid for out-of-pocket. Other prenatal tests in Quebec are publicly funded, whereas most Lebanese women expect to pay out-of-pocket for prenatal tests. While cost was an important decision-making factor in both countries, the importance accorded to it varied. For instance, the majority of Quebecois participants mentioned cost as the principal element in their decision-making when considering NIPT:

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“Me, I would certainly have done it if it was not about the \$800.00. I would have done the blood test without any hesitation [...] But of course I will not pay for it out of my pocket. I had the choice to do the test for \$800.00, I could never afford to pay it, for sure.” (Qc 7 Cp F)

The significance of cost is inextricable from the availability of a publicly funded diagnostic test (amniocentesis). Many participants referred to amniocentesis as they discussed the cost of NIPT, either referring to the availability of more accurate results, or the public funding of amniocentesis. For example:

“Amniocentesis is free and for the other one you have to pay, and then the result is not 100%... I prefer to do the amniocentesis, and yes, there is a risk, but it is minimal. Besides, we are dealing with qualified professionals. I prefer to ...have my result 100%, and it's free.” (Qc 4 Cp F).

For others, NIPT would be more appealing only if amniocentesis were not available:

“Me, I cannot afford to pay 800.00\$ and do the test, this why I did the amniocentesis. [...] If I did not have the choice, yes. Let's say I cannot do the amniocentesis for a certain reason, then I will do the NIPT. I would do it. I will find a way to.” (Qc 6 F)

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Although in Quebec the cost was mentioned as a financial barrier to accept NIPT, one Quebecois couple mentioned that it is the last thing (i.e. least important) considered by them in order to consider the NIPT:

“There is the monetary aspect, but honestly for us it was not the..., it was in the end, the last aspect to consider.” (Qc 5 Cp F)

Compared to Quebecois participants, few Lebanese participants mentioned the cost of NIPT as a significant influence on their decision-making process. Additionally, while some participants acknowledged the high cost of the test and its inaccessibility for individuals of average and low-income, several stated that if their risk level were high, the cost barrier would be less important to them:

“If a person has a high risk, I don't think any mom or any parent, if put in a place where they have to pay money for the sake of their kids, they would say no. [...] probably if I knew I have a high risk, and I needed to take the test then of course I'll be paying for it.” (Lb 4 F)

In this instance, when NIPT is perceived to be necessary or recommended by a health care professional, several participants stated that they ‘would borrow money’ or ‘would be ready to pay for it out-of-pocket whatever it costs’:

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“I don’t believe that if you say to anyone that your wife or your baby has a high risk factor, they will not be ready to pay for the test whatever its price is. But again, it depends if this person could afford to pay for the test or not. There are a lot of people who cannot pay for it.” (Lb 14 Cp M)

NIPT reimbursement by the healthcare system and/or insurance companies

The reimbursement of NIPT by the healthcare system or by insurance companies seemed to influence decision-making surrounding NIPT by sending an implicit recommendation to pregnant women and couples to accept NIPT: [...] *the availability and coverage of NIPT brings an implicit pressure on parents to take the test (Qc 8 Cp F)*. Further, when we asked participants how they would feel if NIPT were covered by the healthcare system or by private insurance companies, participants from both contexts said they would feel enthusiastic because public coverage would ensure access to the test for all, regardless of ability to pay:

“That would allow all classes of society to access all of that. For sure people who have less money don’t have all these choices. At \$ 800.00, it limits to pass up [the opportunity] and wait for nature and they feel anxiety. Then for sure if everyone could have access, the rich as well as the poor, well at least everyone would be equal and everyone would have the peace of mind.” (Qc 7 Cp M)

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However, some Lebanese as well as Quebecois participants raised concerns regarding NIPT coverage and the temptation or ‘the subtle pressure on women to consider testing’ and the fact that ‘the coverage might render the decision to accept the test easier’. Those interviewees linked the coverage of NIPT also to its routinization, by arguing that NIPT coverage might create a perception that the test is ‘medically necessary’ and is not considered to be an ‘added’ or a ‘complementary test’. Therefore, women might ‘feel that they have to take the test’, as exemplified by the following quotes:

“I think that if it is covered, people in general will be more willing to do it of course, I think that it will become a routine test. I think that’s it definitely.” (Qc 3 F)

“If the NIPT is reimbursed this means that it will become a part of the routine tests, then sure women might feel that they have to take it. [...] And personally, I would not miss anything that I have to do for the sake of my baby and when it is covered it means that you ‘must do the test’ and it is not an extra test added to the others.” (Lb 13 F)

6. Discussion

This study provides one of the first accounts of how pregnant women and couples make decisions about NIPT in two different contexts: a Western context (Quebec) and a Non-Western context (Lebanon). We noted several similarities and significant differences

between Quebecois and Lebanese participants. Our results are congruent with those of other studies reporting that NIPT is generally viewed by pregnant women and their partners as a positive advancement in the prenatal care pathway, because of its non-invasive nature, simple procedure, high accuracy and earlier availability of results when compared to current prenatal tests (Lewis, Silcock, & Chitty, 2013; van Schendel et al., 2014; Vanstone, Yacoub, Giacomini, Hulan, & McDonald, 2015). However, some participants in Quebec and Lebanon raised concerns related to the lack of 100% accuracy and therefore the need to follow up with an invasive testing.

Quebecois and Lebanese interviewees presented different opinions regarding several aspects of decision-making surrounding NIPT. For instance, NIPT is not publicly funded in either location, but participants in Lebanon and Quebec described different influences of the lack of coverage on their decisions about the test. In Quebec, cost⁵ was frequently mentioned as a barrier to testing. This might be explained by the norm of not paying for health services, including prenatal tests, out-of-pocket. However, in the Lebanese context, cost - although perceived as high by participants - was mentioned to a lesser extent as a barrier. The Lebanese healthcare system is a hybrid one, and people must pay for prenatal tests out of pocket if they do not benefit from any form of health insurance. This could explain the lesser impact of cost on the decision-making processes of Lebanese couples, who do not share Quebec participants' expectation of publicly funded prenatal services. From a contextualized view of reproductive autonomy which invites us to

⁵ At the time of data collection, the cost of NIPT was around 800 CAD in Montreal and 800 USD in Lebanon.

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consider the social, institutional and policy contexts -- whether in Lebanon or in Quebec - - an absence of NIPT coverage undermines women and couples' reproductive choice by creating a barrier to access and thus allowing only those who can afford it to use it. Nevertheless, the finding that NIPT reimbursement is viewed by both groups as an implicit recommendation to accept the test implies that patient counseling and education surrounding NIPT testing should be greatly enhanced in order to promote pregnant women and couples' decision-making surrounding NIPT. In that respect, and independently from the context in which NIPT is offered, healthcare professionals should emphasize the fact that NIPT reimbursement or coverage does not underlie an obligation or a recommendation to accept the test and that couples or pregnant women have the choice to decline testing.

Further, the influence of others, including the healthcare professionals and the partners on decision-making regarding NIPT reflects the different dynamics of their roles in both contexts. In Lebanon, a communitarian society where an individual is rooted in the family and community, the family plays an important role and is actively involved in decision-making processes in general, and as well specifically as related to healthcare (Abou Mrad & Tarabey, 2012). It may thus be the reason why Lebanese participants indicated a preference for making decisions about NIPT testing by consensus. Our findings are congruent with the results of previous studies conducted in Lebanon (Eldahdah, Ormond, Nassar, Khalil, & Zahed, 2007) showing that the partner's preference is an influential factor in prenatal testing decisions.

As for the role of healthcare professionals, in Lebanese culture, the physician is held in high regard and is sometimes a friend or a part of the family⁶ (Fathallah, 2012). As trust is at the core of the relationship between the physician and pregnant woman or couple, in general, patients do not tend to question the recommendation provided by healthcare professionals (Abou Mrad & Tarabey, 2012). Moreover, patients in the Lebanese setting express a cultural preference for a firm recommendation from health care professionals and consider that the provision of alternatives represents lack of self-confidence and medical knowledge on the part of the physician (Eldahdah et al., 2007).

In Quebec, in contrast, the patient-family-healthcare professional relationship is characterized by a different dynamic. The findings that Quebec men's opinions were considered by both men and women to be secondary to the woman's preferences, are supported by literature from other Western countries, where male partners agreed that the woman should make the final decision regarding prenatal testing (Dheensa, Metcalfe, & Williams, 2013; Kenen, Smith, Watkins, & Zuber-Pittore, 2000; Williams, Dheensa, & Metcalfe, 2011). This might be interpreted based on the emphasis placed on reproductive autonomy, which impacts the level of influence and involvement of others (the partner or the family) in reproductive matters. Further, in Quebec women's reproductive rights are

⁶ Following the recorded interview, I had an opportunity to have some informal discussions with a few couples and pregnant women who told me about the good, long relationship they have with their physician "friend". Further, a couple told me that their "well-known physician" was recommended by one of their family members and a woman told me that she trusts her physician since he is her mother's cousin. However, these exchanges were reported by me on my research notebook, they were not recorded.

well entrenched and protected, both legally and socially (Nelson, 2013b) as is the case regarding access to abortion. The view of reproductive autonomy as grounded in legal rights may influence the extent to which the partner (or other family members) feels able to be involved in these reproductive choices, and the extent to which the pregnant woman expects and invites involvement from her partner.

The fact that most participants did not mention the healthcare professional as having a role in their decision to accept or decline NIPT might be explained by a cultural context that emphasizes patient autonomy by offering choices and avoiding recommendation of any specific course of action, particularly in the sensitive area of prenatal testing. Although, the emphasis on patient autonomy is visible in professional guidelines such as the Society of Obstetricians and Gynecology in Canada (SOGC) (Chitayat, Langlois, & Wilson, 2011) that recommends and endorses the non-directive counseling approach aiming to help patients achieve an informed and autonomous decision by offering “information in a clear and neutral manner...leaving clients free to interpret this information according to their own values”(Jansen, 2001), the literature on prenatal testing shows that the mere offering of screening, independently from the way it is framed, may be perceived as a recommendation to accept testing (Seavilleklein, 2009).

Finally, since prenatal testing is inevitably tied to the abortion debate (because it leads couples and pregnant women to consider whether to continue or terminate a pregnancy), policy and legal contexts are a critical consideration when discussing decision-making surrounding NIPT in both cultures. In Lebanon, women’s reproductive rights are

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still constrained by legal and social barriers because under the Lebanese penal code, abortion is prohibited at any point in time except to save the mother's life. Notwithstanding the law, it is offered as an option for patients with "fetal indications" (such as trisomy 18, 13 and 21) and is regularly practiced clandestinely in clinics with some regularity (Abu-Musa, Nassar, & Usta, 2008). The price of abortion is high, ranging from 300 USD up to 5 000 USD, depending on whether it is performed in a clinic or a hospital operating room. Therefore, the introduction of NIPT into the Lebanese healthcare system does not influence women and couples' reproductive choice in so far as it expands their testing options without changing their choices regarding pregnancy management. At the same time, the earlier detection of abnormalities by NIPT followed by an earlier diagnosis, might offer a better option for patients who face an unsafe abortion, since illegal terminations are less risky when performed earlier in pregnancy (Otaño & Igarzábal, 2015; Wyszynski, Perandones, & Bennun, 2003) .

As for Quebec, the introduction of NIPT expands the reproductive choice of couples and pregnant women, because a possible decision to consider testing accompanied with a decision to terminate a pregnancy is legal at any point in time and covered by public health insurance (Auger & Denis, 2012).

From empirical findings to actionability of findings: some practical implications of our study

Our study of cross-cultural perspectives on decision-making regarding NIPT in Quebec and Lebanon reveals differences related to the importance of several factors. Moreover, it shows the role that social, policy and institutional contexts play in shaping reproductive choice and autonomy. Consequently, practical and clinical implications of our findings vary. For instance, where a direct counseling approach and guidance from healthcare professionals may enhance couples' and pregnant women's decision-making in Lebanon, it might be perceived as an unjustifiably paternalistic approach and as an invasion of patients' autonomy in Quebec. Translating this finding into the clinical encounter, how should a Canadian healthcare professional or counselor respond to a clinical situation where a Lebanese couple consults him/her and requests directive counseling on whether to perform NIPT? A similar question can be raised, of course, regarding other countries of origin that present similar cultural differences. Based on a culturally-appropriate care approach, the Canadian counselor should provide direct guidance and recommendation to meet the couples' request. One proposed way of doing so is to first determine that the issue underlying this request is based on a cultural expectation to take a certain course of action because according to Weil: "Many [directive counseling] requests are not cultural in origin, but reflect instead issues such as confusion, a disagreement between members of a couple, or a desire to understand how others have dealt with the situation. If the situation involves a dynamic of this sort, it creates an opportunity to address the underlying issue" (Weil, 2001). Therefore, once the source of the request is clarified, Weil suggests such a request "is best met by framing a recommendation in terms of the information and values presented by the counselee(s) (e.g, 'Based on what you have told me...')" (Weil, 2001). While such

an approach might have limitations, such as missed or unshared information by the couple, it fulfills the couples' request by providing them with a recommendation for a certain course of action that is in accordance with their beliefs, values, needs and circumstances.

As Chattopadhyay states it: “the challenge for the bioethicists in the twenty-first century is to explore the possibility with an open mind of finding a common ground of morality across different cultures while acknowledging, and respecting cultural diversity” (Chattopadhyay & De Vries, 2013). Taking this into consideration, the “common ground of morality” in the present context is to help pregnant women and couples make an informed choice regarding NIPT, a choice that is congruent with their values and preferences. Further, the awareness of healthcare professionals regarding the differences in family-patient relationships, and therefore family involvement in healthcare decision-making, might help them in providing patient-centered care. For instance, in Lebanese culture, family or/ and community members might be included in the couple's decision with regard to medical treatment or reproduction (Fathallah, 2012). Thus, a Canadian healthcare professional meeting a Lebanese couple, who is aware of these culturally-based dynamics and the role of family or community in supporting the couple's decision, should allow and/or support the inclusion of these individuals in the decision-making process surrounding NIPT. While such situations may create discomfort for the healthcare professional in a culture where genetic counseling focuses primarily on the couple, the counselor should allow, and be receptive to, the inclusion of family members (B. Morris,

2014). Further, the professional may judge that it is important to meet alone with the couple in order to allow them to express their own preferences as well as their potential disagreements with other family members.

Similarly, a Lebanese healthcare professional meeting a Canadian couple, who is familiar with the family dynamics in a Canadian setting and with the culture of genetic counseling, should provide nondirective counseling and support the couple if they do not wish to involve family members in their decision-making process.

Whether in a Lebanese or a Canadian setting, the sensitivity of healthcare professionals to patients' cultural contexts may help in facilitating the clinical relationship and in guiding the offer of culturally-appropriate care. At the same time, healthcare professionals should be aware of the risks of generalizing their knowledge regarding cultural approaches to all the individuals of a particular group. Such generalization may promote a stereotypical attitude that can constrain the healthcare professional's perceptions and way of thinking, which in turn may impede the patient's decision-making process (Weil, 2001). Therefore, paying attention to individual differences and intragroup variation is a crucial element in offering an appropriate counseling (Bhogal & Brunger, 2010).

Another practical implication of this comparative approach can be found in similarities in the findings from both countries. For example, a decision to publicly fund NIPT in both contexts, although perceived as providing equitable access to all pregnant women, might be viewed as an implicit recommendation to consider NIPT. This finding implies that whether in Lebanon or in Quebec, patients' education and counseling should

emphasize that NIPT is an option that is offered and not a routine test that should be performed without much consideration.

Strengths, limitations and future research

This qualitative study explores and compares views and perceptions of pregnant women and couples regarding decision-making surrounding NIPT in two different countries with different cultures. Beyond identifying similarities and differences, this comparative approach provides a deeper understanding of factors that are of importance for decision-making surrounding NIPT in each context.

In addition, we noted that study participants in Lebanon and Quebec were predominantly white, older (in Quebec 95% and in Lebanon 66% of the participants were 33 years and above) and highly educated, demographic variables that are associated with higher levels of interest in NIPT, which could have influenced the results in favor of the test (Tischler, Hudgins, Blumenfeld, Greely, & Ormond, 2011). In addition, most Lebanese women (N=9 or 9 out the total of 15 Lebanese pregnant women interviewed) were pregnant for the first time, while this was true for only a small number of Quebecois women (N=5 or 5 out the total of 15 Quebecois pregnant women interviewed). This difference might have influenced study participants' attitudes toward prenatal testing, their decision-making

surrounding NIPT, as well as the relationship with their healthcare professional. Although the link between primigravida status and attitudes toward NIPT was not explored in this study, it may be of interest in future investigations.

Since pregnant women in our study were recruited either as low-risk or high-risk, and before going through invasive testing, they were all interviewed before invasive testing. Therefore, our sample by definition did not include women with a confirmed diagnosis of a child with Down Syndrome or any other aneuploidy (like trisomies 13 or 18). The views of women with a fetus with an aneuploidy may be different and are not included in our study results. Furthermore, pregnant women and couples' attitudes toward NIPT might not be necessarily translated to actual behaviors (Silcock et al., 2015): pregnant women and couples might record a view or an opinion that is different from how they eventually choose to act. Finally, the fact that participants who visit the (institute name removed for peer review) have an average to a high socioeconomic status (including education level, income and occupation), may have limited the socioeconomic diversity of our sample and entailed an underrepresentation of those of low socioeconomic status.

Conclusion

NIPT may soon be offered to all pregnant women (low as well as high risk)(Griffin, Edwards, Chitty, & Lewis, 2017; Minear, Alessi, Allyse, Michie, & Chandrasekharan, 2015). The challenge is to enable prospective parents to come to an informed decision that is congruent with their own values, preferences, beliefs and sociocultural contexts on

whether or not to undergo NIPT.

A contextual view of reproductive autonomy posits that one must consider the social, cultural, institutional, and policy contexts that play a role in shaping reproductive decisions. Applying this view to decision-making surrounding NIPT, our study elucidates how pregnant women or couples are embedded in larger societal contexts (medical, social, legal norms) that influence their decision-making. Therefore, the understanding of how social and cultural factors inform individual preferences holds the potential to identify diverse avenues for facilitating decision-making surrounding NIPT. It may help guide healthcare professionals in providing counseling and helping women and their partners make better informed prenatal testing decisions. Further, at a policy level, such understanding might inform the development of local guidelines and policies that are appropriate to each context.

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Conflicts of Interest

The authors declare no conflict of interest

Ethical Approval

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

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