

# Ethical Issues at the Beginning of Human Life Towards a Contextualized Islamic Understanding of Prenatal Diagnosis and Termination of Pregnancy

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*Abstract. — Medical advances have given rise to several ethical dilemmas at the beginning of life. To date, however, hardly any attention has been paid to the attitudes, beliefs, and decision-making processes of religious minorities in Europe, including Muslims, in relation to beginning-of-life issues. The examination of moral approaches to these issues usually starts from Western (secular) or Christian bioethical positions, while normative Islamic positions are comparatively under-researched. In our inaugural lecture we address this lacuna within ethical discourse by focusing on three aspects of the discussion of beginning-of-life issues. First, it sheds a light on Islamic normative sources on these issues, particularly on the question of when human life starts and on the moral status of the fetus, which plays an important role in the permissibility of termination of pregnancy. Second, it calls for the study of lived experiences/lived religion in ethical approaches to prenatal diagnosis and termination of pregnancy in cases of severe anomalies, by conducting an empirical study among Muslim couples, Muslim medical professionals, and Muslim religious professionals. Third, it advocates the need for the development of a contextualized Islamic ethical framework regarding prenatal diagnosis and termination of pregnancy, based upon a strong dialogue between Islamic normative sources and the lived experience of Muslims.*

## 1. Introduction

Many new ethical dilemmas have emerged as the technology used in medical treatment and research rapidly evolves. Technological advances in medicine have placed an increased responsibility on the patient, the

\* This text is an elaborated version of the inaugural lecture “Ethical Issues at the Beginning of Human Life: Towards a Contextualized Islamic Understanding of Prenatal Diagnosis and Termination of Pregnancy” held at the Faculty of Theology and Religious Studies, KU Leuven, on April 27, 2021.

family, and health care providers when it comes to making decisions at the beginning of life.<sup>1</sup> Prenatal screening, used for the detection of a malformation or anomaly in the fetus, is a practice which plays an important part in antenatal care in modern societies.<sup>2</sup> Discussions on biomedicine, including beginning- and end-of-life care, are still deeply influenced by contemporary secular Western<sup>3</sup> and/or Christian approaches, overshadowing the perspectives of other traditions. In this respect, the voices of Muslims, who form the largest religious minority in many Western European countries, are largely absent. Given the fact that Europe is becoming more multicultural and religiously pluralistic as society undergoes radical demographical, cultural, and religious changes, care can no longer be provided solely within a secular or Christian framework. Several studies argue that the way people view and deal with ethical issues at the beginning and end of life are likely to be related to and influenced by their religious beliefs.<sup>4</sup> More specifically, religion seems to play an important role in the decision-making process regarding prenatal screening.<sup>5</sup> However, the number of empirical studies that deal with the views of the rapidly growing number of Muslims living in the

1. Ruth M. Farrell and Megan A. Allyse, "Key Ethical Issues in Prenatal Genetics: An Overview," *Obstetrics and Gynecology Clinics of North America* 45, no. 1 (2018): 127-141.

2. Elisa Garcia, *In Search of Good Motherhood: How Prenatal Screening Shapes Women's Views on Their Moral Duties to Their Family*, unpublished PhD diss., Radboud University, Nijmegen, 2012.

3. Modern bioethics was born in the West and thus reflects, not surprisingly, the traditions of Western moral philosophy and political and social theory.

4. Joris Gielen, *Ethical Attitudes and Religious Beliefs at the End of Life: A Study of the Views of Palliative-care Nurses and Physicians in Flanders (Belgium) and New Delhi (India)*, unpublished PhD diss., KU Leuven, Leuven, 2010; Stef Van den Branden, *Islamitische ethiek aan het levenseinde: Een theoretisch omkaderde inhoudsanalyse van Engelstalig soennitisch bronnenmateriaal en een kwalitatief empirisch onderzoek naar de houding van praktiserende Marokkaanse oudere mannen in Antwerpen*, unpublished PhD diss., KU Leuven, Leuven, 2006.

5. Elisa Garcia, Danielle R. M. Timmermans, and Evert Van Leeuwen, "The Impact of Ethical Beliefs on Decisions about Prenatal Screening Tests: Searching for Justification," *Social Science & Medicine* 66, no. 3 (2008): 753-764; Janneke T. Gitsels-van der Wal, Judith Manniën, Lisanne A. Gitsels, Hans S. Reinders, Pietermel S. Verhoeven, Mohammed M. Ghaly, Trudy Klomp, and Eileen K Hutton, "Prenatal Screening for Congenital Anomalies: Exploring Midwives' Perceptions of Counseling Clients with Religious Backgrounds," *BMC Pregnancy Childbirth* 14, 237 (2014). <https://doi.org/10.1186/1471-2393-14-237>; Janneke T. Gitsels-van der Wal, Judith Manniën, Mohammed M. Ghaly, Pietermel S. Verhoeven, Eileen K. Hutton, and Hans S. Reinders, "The Role of Religion in Decision-making on Antenatal Screening of Congenital Anomalies: A Qualitative Study amongst Muslim Turkish Origin Immigrants," *Midwifery* 30, no. 3 (2014): 297-302; Matthijs van den Berg, Danielle R. Timmermans, Leo P. ten Kate, John M. van Vugt, and Gerrit van der Wal, "Are Pregnant Women Making Informed Choices about Prenatal Screening?" *Genetics in Medicine* 7, no. 5 (2005): 332-338.

West on the beginning of life is very limited. The role of religion in empirical ethics is often only briefly mentioned as an explaining factor; studies often lack an encompassing descriptive and in-depth analytic account of the (religious) rationale behind certain attitudes or practices.

There are very few academic studies that specifically examine prenatal diagnosis and termination of pregnancy in cases of (severe) anomalies from an Islamic ethical perspective. However, increasing efforts are being made from an Islamic ethical perspective to explore both the empirical reality and religious normativity surrounding end-of-life issues. It is striking that this trend applies less so for issues at the beginning of life, including prenatal diagnosis and termination of pregnancy in cases of anomalies. Not only is this topic an unexplored area from an academic perspective, these questions also matter to the larger society. Muslim couples, hospitals, and social organizations have many questions and are in need of information on what “the Islamic stances” are regarding termination of pregnancy in cases of (severe) genetic defects. To respond to these needs, this article first sheds a light on Islamic perspectives on issues at the beginning of life and more specifically on the moral status of the fetus and the question of when human life starts. Second, it gives attention to the need for the study of lived experiences/lived religion in the normative ethical approach of questions at the beginning of life, by conducting an empirical study among Muslim couples, Muslim medical professionals, and Muslim religious professionals. Third, this article demonstrates the need for the development of an ethical framework regarding prenatal diagnosis and termination of pregnancy, in dialogue with text (religious sources) and context (lived experience).

## 2. Muslims in Europe: Giving a Voice to the Unheard

The number of Muslims in Europe is growing. In just a few decades, Islam has become the second largest religion in many European countries.<sup>6</sup> In countries like Belgium, where I work as a researcher, mass migration of Muslims began in the 1960s, with the large-scale settlement of guest workers, mainly from Morocco and Turkey. They were driven by a shortage of workers in the coal, steel, and automobile industries in European countries. In 2019, sociologist Jan Hertogen estimated that

6. Pew Research Center, “Europe’s Growing Muslim Population,” November 29, 2017, <https://www.pewforum.org/2017/11/29/europes-growing-muslim-population/> (accessed 1 September 2021).

Muslims counted for 8.2 percent of the Belgian population, of which the Moroccan and Turkish communities are by far the two largest Muslim communities. However, it is also important to devote attention to the recent influx of Muslim refugees coming from Syria, Iraq, Afghanistan, and Somalia, as a result of which the number of Muslims in Belgium is rapidly growing.<sup>7</sup> This increasing Muslim presence has led to many challenges in the context of healthcare, including pre- and post-natal care, end-of-life care, and bereavement care, and also within the burial landscape.

To date, in European debates on prenatal diagnosis and termination of pregnancy, hardly any attention has been paid to the views and attitudes of religious minorities, including Muslims. In the academic literature, we find significantly more publications dealing with end-of-life issues than with beginning-of-life issues.<sup>8</sup> In addition to this, most academic works focus more on theoretical/normative approaches to the beginning and end-of-life issues; empirical studies focusing on the actual views, experiences, and perceptions of Muslims are less common.<sup>9</sup> A significant portion of the available normative/theoretical studies limit their focus to a legal perspective on abortion in several Muslim-majority countries, including Saudi Arabia, Pakistan, Indonesia, Turkey, and Iran.<sup>10</sup> Moreover, among the few

7. Jan Hertogen, "Waar woont een groot deel van 'onze mensen?," *Non-Profit Data*, April 25, 2020, <http://www.npdata.be/BuG/448-Moslms/> (accessed 1 September 2021).

8. Fuusje M. De Graaff, *Partners in Palliative Care? Perspectives of Turkish and Moroccan Immigrants and Dutch Professionals*, unpublished PhD diss., University of Amsterdam, Amsterdam, 2012; Abdulaziz Sachedina, *Islamic Biomedical Ethics: Principles and Application* (New York: Oxford University Press, 2009); Mohammed Ali Al-Bar and Hassan Chamsi-Pasha, *Contemporary Bioethics: Islamic Perspective* (Cham: Springer, 2015).

9. A similar gap in the available literature on issues at the end of life has been filled in with my doctoral research. This research, which involved an interdisciplinary study, explored how religion shapes the attitudes and practices regarding death and dying among middle-aged and elderly Moroccan Muslim women in Antwerp (Belgium) by providing a detailed and rich account of actual Muslims' lines of reasoning and practices, taking into account the diversity within the Muslim population. In my doctoral research, I presented a review based on the available normative/theoretical and empirical literature on these topics, and I conducted a qualitative empirical study consisting of semi-structured, in-depth interviews (from 2014-2016) with specialists in the field and middle-aged and elderly Moroccan Muslim women living in Antwerp, Belgium. See Chaïma Ahaddour, "Surely We Belong to God and to Him Shall We Return": Attitudes, Beliefs and Practices regarding Death and Dying among Middle-aged and Elderly Moroccan Muslim Women in Antwerp (Belgium), PhD diss., KU Leuven, Leuven, 2018. For more information, see publications based on this PhD: <http://lirias.kuleuven.be/cv?Username=U0070795>.

10. Alireza Bagheri and Leila Afshar, "Abortion in Different Islamic Jurisprudence: Case Commentaries," *Asian Bioethics Review* 3, no. 4 (2011): 351-365; Perihan Elif Ekmekci, "Abortion in Islamic Ethics, and How It Is Perceived in Turkey: A Secular, Muslim Country," *Journal of Religion and Health* 56, no. 3 (2017): 884-895; H. Jafri, S. Ahmed, M. Ahmed, J. Hewison, Y. Raashid, and E. Sheridan, "Islam and Termination

empirical studies found on prenatal diagnosis and termination of pregnancy, hardly any research focuses on Muslims in the West, and, more specifically, in Europe.

Much more attention has been devoted to reproductive health matters, such as IVF, while abortion has been dealt with in a very general way, without delving too much into details. In particular, there has been very limited focus on prenatal diagnosis and termination of pregnancy in cases of malformations. After extensive study of the available normative literature and my own empirical research (on lived religion in a European Islamic context), I came to realize that there is a need for the development of an innovative normative Islamic discourse, which does not only take into account the classical Islamic sources, but also the real lived faith of people in a European context (*in casu* Muslims) – how Muslims experience and practice Islam in reality. Muslim couples, hospitals, and social organizations lack information on what “the Islamic stances” are on termination of pregnancy in cases of genetic defects. As a result, Muslims may experience difficulties in making medical decisions at the beginning of life, fearing that their choices and actions could possibly conflict with the Islamic faith and more specifically, could go against God’s will on questions of life or death. This line of thinking was also found in my doctoral research on views about withholding and withdrawing life-sustaining treatment as well as palliative sedation.<sup>11</sup> A normative ethical framework is needed to help Muslims make both end-of-life and beginning-of-life decisions, i.e. to guide Muslim families, health-care providers, and religious practitioners as they navigate these tricky ethical waters.

### 3. Prenatal Diagnosis and Termination of Pregnancy

Today, modern advances in science and biomedical technologies have led to the ability to provide accurate information about the fetus. Prenatal screening and diagnostics are aspects of prenatal care that aim to detect problems with the pregnancy as early as possible.<sup>12</sup> A congenital anomaly is often a structural or functional defect that occurs during intrauterine

of Pregnancy for Genetic Conditions in Pakistan: Implications for Pakistani Health Care Providers,” *Prenatal Diagnosis* 32, no. 12 (2012): 1218-1220; Gilla K. Shapiro, “Abortion Law in Muslim-Majority Countries: An Overview of the Islamic Discourse with Policy Implications,” *Health Policy and Planning* 29, no. 4 (2014): 483-494.

11. Ahaddour, “*Surely We Belong to God and to Him Shall We Return*”.

12. Garcia, *In Search of Good Motherhood*.

life and is identified prenatally or at birth.<sup>13</sup> Screening can detect problems such as chromosomal abnormalities and gene mutations that would lead to genetic disorders and birth defects, such as cleft palate, Down syndrome, cystic fibrosis, etc. In other words, a congenital anomaly is defined as an abnormality of the body's structure, function or metabolism that is present at birth and leads to physical or mental disability and/or is fatal. Distinction can be made between invasive and non-invasive prenatal procedures. The most common prenatal screening tests are ultrasound, maternal-serum screening, and blood pressure measurements. The non-invasive prenatal test (NIPT) has been shown to be highly accurate in the detection of common genetic defects (fetal trisomies).<sup>14</sup> From a simple blood sample, fetal genetic information can be provided from the mother's DNA. The prenatal test detects chromosomal abnormalities including trisomies 13, 18, and 21. In trisomy 21, or Down syndrome, the fetus has three copies of chromosome 21 in each cell, resulting in intellectual disability and other possible genetic defects of the heart, digestive tract, and other organ systems. Trisomy 13, or Patau syndrome, causes abnormalities in the brain resulting in severe intellectual and physical disabilities. Lastly, NIPT tests for Edwards syndrome (trisomy 18), which causes a severe intellectual disability. NIPT can also be used to screen for non-medical genetic information such as the sex of the fetus.<sup>15</sup>

As the procedure of NIPT consists of only drawing a blood sample, it eliminates the risk of miscarriage associated with invasive diagnostic procedures. Whereas historically decision-making about prenatal

13. Anat Gesser-Edelsburg and Nour Abed Elhadi Shahbari, "Decision-making on Terminating Pregnancy for Muslim Arab Women Pregnant with Fetuses with Congenital Anomalies: Maternal Affect and Doctor-patient Communication," *Reproductive Health* 14, no. 1 (2017): 49.

14. Frank Hulstaert, Mattias Neyt, and Wilfried Gyselaers, "The Non-Invasive Prenatal Test (NIPT) for Trisomy 21 – Health Economic Cspects," Health Technology Assessment (HTA) Brussels, Belgian Health Care Knowledge Centre (KCE), *KCE Reports* 222 (2014), [https://kce.fgov.be/sites/default/files/atoms/files/KCE\\_222\\_Non\\_invasive\\_prenatal\\_%20test\\_Report.pdf](https://kce.fgov.be/sites/default/files/atoms/files/KCE_222_Non_invasive_prenatal_%20test_Report.pdf) (accessed 1 October 2021); Anne H. Mardy, Julia Zachary, Rebecca Clifton, Karen Wou, Brynn Levy, and Ronald J. Wapner, "186: Non-Invasive Prenatal Testing (NIPT) versus Diagnostic Testing for Evaluation of Fetal Structural Anomalies," *American Journal of Obstetrics and Gynecology* 216, no. 1 (2017): S121; Greg Stapleton, "Qualifying Choice: Ethical Reflection on the Scope of Prenatal Screening," *Medicine, Health Care, and Philosophy* 20, no. 2 (2017): 195-205.

15. Bettina Blaumeiser, "Prenatale Screening en Diagnostiek," *Ethische Perspectieven* 26, no. 4 (2016): 305-314; M. M. Gil, M. S. Quezada, R. Revello, R. Akolekar, and K. H. Nicolaides, "Analysis of Cell-free DNA in Maternal Blood in Screening for Fetal Aneuploidies: Updated Meta-analysis," *Ultrasound in Obstetrics & Gynecology* 45, no. 3 (2015): 249-266; Hulstaert, Neyt, and Gyselaers, "The Non-Invasive Prenatal Test (NIPT) for Trisomy 21 – Health Economic Aspects."

screening was partly influenced by fear of miscarriage or the uncertainty of the test results, the introduction of NIPT allows women and their partners to make a decision on prenatal screening that is based solely on their wish to know or not to know whether their child has chromosomal anomalies.<sup>16</sup> In the Belgian context, the non-invasive prenatal test functions as a primary test in prenatal screening. Since July 1, 2017 the NIPT for Down syndrome and other chromosomal abnormalities are (nearly) fully reimbursed for pregnant women in Belgium, thus strengthening the impression that prenatal testing is a normal practice.

When screening tests indicate that a fetus is at increased risk of a specific condition, prenatal diagnostic tests, which are often invasive, may be performed to confirm the presence of a disorder and to obtain more accurate and detailed information.<sup>17</sup> The most common procedures are amniocentesis and chorionic villus<sup>18</sup> sampling (CVS), which carries a risk of procedure-related miscarriage.<sup>19</sup> These procedures involve obtaining genetic material from the fetus that is then examined in a laboratory. The material is processed in such a way that the chromosomes of the cells can be analyzed. The chorionic villus test is a procedure that removes villi from the placenta and may be performed as early as 11 weeks of pregnancy. Amniocentesis is offered beginning at 15 weeks of pregnancy. This procedure involves the removal of approximately 20 to 40 milliliters of amniotic fluid, which allows for an accurate diagnosis of the genetic profile of the fetus.<sup>20</sup>

16. Stapleton, "Qualifying Choice"; Rachèl V. van Schendel, Johanna H. Kleinveld, Wybo J. Dondorp, Eva Pajkrt, Danielle R. Timmermans, Kim C. Holtkamp, Margreet Karsten, Anne L. Vlietstra, Augusta M. Lachmeijer, and Lidewij Henneman, "Attitudes of Pregnant Women and Male Partners towards Non-Invasive Prenatal Testing and Widening the Scope of Prenatal Screening," *European Journal of Human Genetics* 22, no. 12 (2014): 1345-1350.

17. Van Schendel et al., "Attitudes of Pregnant Women and Male Partners towards Non-Invasive Prenatal Testing and Widening the Scope of Prenatal Screening."

18. The chorionic villi are wispy projections of placental tissue that share the baby's genetic makeup.

19. Hulstaert, Neyt, and Gyselaers, "The Non-Invasive Prenatal Test (NIPT) for Trisomy 21 – Health Economic Aspects."

20. Gesser-Edelsburg and Elhadi Shahbari, "Decision-making on Terminating Pregnancy for Muslim Arab Women Pregnant with Fetuses with Congenital Anomalies: Maternal Affect and Doctor-patient Communication"; Laura M. Carlson and Neeta L. Vora, "Prenatal Diagnosis: Screening and Diagnostic Tools," *Obstetrics and Gynecology Clinics of North America* 44, no. 2 (2017): 245-256; M. van Zwieten, "Het belang van een weloverwogen keuze – Maar wat behelst de keuze? De complexe besluitvorming bij prenataal onderzoek," *De Psycholoog* 43 (2008): 20-25.

The detection of a possible congenital anomaly in the fetus is a fundamental part of prenatal diagnostics, one that can influence the decision of whether or not to terminate the pregnancy. Choices regarding prenatal screening and diagnosis and termination of pregnancy are not neutral, technical decisions; they involve norms and values and generate questions as to what is considered right and wrong, ethical and unethical. This clearly implies that these tests and the decision-making process regarding termination of pregnancy do not only have a medical or psychological aspect, but also an ethical dimension.<sup>21</sup> It is precisely here that a challenge arises for Muslims to make an informed choice. Recent studies have shown that religious beliefs are likely to have an impact on the decision-making and attitudes towards prenatal diagnostics and termination of pregnancy. For instance, research by Hadar et al. shows that religious convictions of pregnant women and partners in Lebanon played an important role in accepting or rejecting NIPT.<sup>22</sup> More specifically, studies conducted among Muslim women in the Netherlands and in Australia have shown that Muslim couples often do not use these tests, or only opt for non-invasive tests, in order to be mentally prepared for what is coming, but not to go so far as to terminate the pregnancy.<sup>23</sup> A study by Gitsels-van der Wal *et al.* indicates that Muslims in the Netherlands often have a lack of knowledge of Islamic views on this subject, as a result of which they assume that they cannot or may not proceed to further testing and/or termination of pregnancy in cases of severe anomalies.<sup>24</sup>

21. Chris Gastmans, Yvonne Denier, and Pierre Degadt, "Het zorgproces inzake zwangerschapsafbreking na prenatale diagnostiek," *Zorgnet Icuuro* April 24, 2008, ([zorgnet-icuro.be](http://zorgnet-icuro.be)) (accessed 1 September 2021); Antina De Jong, Wybo J Dondorp, Suzanna G. M Frints, Christine E. M. De Die-Smulders, and Guido M. W. R. De Wert, "Advances in Prenatal Screening: The Ethical Dimension," *Nature Reviews Genetics* 12, no. 9 (2011): 657-663.

22. Hazar Haidar, Meredith Vanstone, Anne-Marie Laberge, Gilles Bibeau, Labib Ghulmiyyah, and Vardit Ravitsky, "Cross-cultural Perspectives on Decision Making regarding Noninvasive Prenatal Testing: A Comparative Study of Lebanon and Quebec," *AJOB Empirical Bioethics* 9, no. 2 (2018): 99-111.

23. Shenaz Ahmed, Hussain Jafri, Yasmin Rashid, Gerald Mason, Yasmin Ehsan, and Mushtaq Ahmed, "Attitudes towards Non-invasive Prenatal Diagnosis among Obstetricians in Pakistan, a Developing, Islamic Country," *Prenatal Diagnosis* 37, no. 3 (2017): 289-295; Gitsels-van der Wal et al., "The Role of Religion in Decision-making on Antenatal Screening of Congenital Anomalies"; V. Tsianakas and P. Liamputtong, "Prenatal Testing: The Perceptions and Experiences of Muslim Women in Australia," *Journal of Reproductive and Infant Psychology* 20, no. 1 (2002): 7-24.

24. Gitsels-van der Wal et al., "The Role of Religion in Decision-making on Antenatal Screening of Congenital Anomalies."

#### 4. Islamic Bioethics: What's in a Name?

Bioethics, as branch of applied ethics that deals with the philosophical, social, and legal issues arising in medicine and the life sciences, is primarily a secular field, in which God and revelation are placed on the margins.<sup>25</sup> Religious ethics involves theological reflection on a system of moral beliefs and practices and clarifies what is right or wrong. In essence, it is a guide to behavior, attitudes, and beliefs.<sup>26</sup> The discipline of Islamic bioethics, which involves the moral approach to issues related to the human body from an Islamic perspective, is quite young. It is widely recognized that bioethics in Islam is primarily a branch of Islamic law and ethics and thus, unlike in the Western world, is not (yet) an independent field of study. In Islam, bioethical thought is inseparable from religion itself, which emphasizes the continuity between body and mind, between the material and spiritual realms, and between ethics and jurisprudence.<sup>27</sup> Thus Islamic bioethics is linked to Islamic law (*Shari'a*), as Islamic law not only legislates but also assigns moral values. In other words, Islamic 'law' is understood as both a legal and ethical system.<sup>28</sup> Contemporary Islamic bioethics arose around 1950 and developed further from 1980 on, concurrently with the biotechnological revolution. Nevertheless, Islamic bioethics has not yet produced a substantial amount of research on the specific topics of prenatal diagnosis and termination of pregnancy.<sup>29</sup>

In light of rapid advances in biotechnology, whether in Muslim majority or diasporic contexts in a globalized world, there is an urgent need to create appropriate ethical responses to bioethical/social

25. Mohammed Ghaly, "The Beginning of Human Life: Islamic Bioethical Perspectives," *Zygon* 47, no. 1 (2012): 175-213.

26. Ross Moret, "Religious Ethics and Empirical Ethics," *Journal of Religious Ethics* 49, no. 1 (2021): 33-67.

27. It is noteworthy to mention that Islamic ethics as a cohesive discipline does not exist. Material on ethics is scattered throughout the Islamic sciences of *fiqh* (jurisprudential understanding), *tafsir* (Qur'anic exegesis), and *kalām* (scholastic theology). This is necessarily so since many Muslims when questioned about the source of their ethical code, to which they turn when facing ethical dilemmas, would point the questioner towards Islamic *fiqh* (jurisprudential understanding) and the *Shari'a* (Islamic law). Islamic *fiqh* scholars reflect on how people should live. Aasim Padela, and A. Siddiqui, "Ethics in Islam: Key Concepts and Contemporary Challenges," *Journal of Moral Education* 26, no. 4 (1997): 423-431. Aulad Abdellah Marzouk, "The Sources of Islamic Ethics and Fiqh," in *Looking Beneath the Surface*, ed. Hendrik M. Vroom, Petra Verdonk, Marzouk Aulad Abdellah, and Martina C. Cornel (New York: Brill, 2013), 25-40.

28. Abdallah S. Daar and A. Binsumeit Al Khitamy, "Bioethics for Clinicians: 21. Islamic Bioethics," *Canadian Medical Association Journal (CMAJ)* 164, no. 1 (2001): 60-63.

29. Ghaly, "The Beginning of Human Life."

problems.<sup>30</sup> An investigation into any Islamic concern begins with consulting the *Qur'ān* and the *Sunna*, which are the guiding texts of Islamic religious authority.<sup>31</sup> If Islamic scholars cannot derive an immediate ruling from these sources, secondary sources are used, i.e., *'ijmā'* (consensus of Islamic scholars) and *qiyās* (analogical reasoning/precedent-based analogy). While this process is largely the same for the Shiite denomination, there is one essential difference<sup>32</sup>: Shiites place *'aql* (the use of the intellect or logic to deduce law) before *'ijmā'*, while Sunnis maintain *qiyās* as the fourth source after *'ijmā'*.<sup>33</sup> During these deliberations, various ethical principles are taken into account, depending on the issue, including *maslahā* (common good), *'adl* (justice), *ḍarūra* (necessity) and *lā ḍarara w-lā ḍirār* (no harm shall be inflicted or reciprocated) etc. These ethical principles are often used to discover and promote the higher goals of Islamic law (*maqāṣid al-Sharī'a*), which entails preservation of faith, life, intellect, lineage, and property.<sup>34</sup> The *maqāṣid al-Sharī'a* is often used as a value framework, to discuss issues pertaining to bioethics.

In contrast with the Catholic tradition, Islam does not have a central authoritative religious body. For that reason, a variety of approaches to ethics are employed, forming varied (non-binding) opinions (*fatāwā*)

30. Aryn B. Sajoo, "Negotiating Virtue: Principlism and Maslahā in Muslim Bioethics," *Studies in Religion / Sciences Religieuses* 43, no. 1 (2014): 53-69.

31. Jonathan E. Brockopp, *Islamic Ethics of Life: Abortion, War and Euthanasia*, Studies in Comparative Religion (Columbia, SC: University of South Carolina Press, 2003).

32. On the whole, Shia bioethical rulings do not differ fundamentally from the Sunni positions. In some cases the Shia schools developed their own interpretations, methodology and authority systems. For Sunni Muslims, knowledge of rules of law and ethics is anchored in divine revelation and not in human intuitive reason (*'aql*). In Shiite theology, in contrast with the majority of Sunni schools, independent reason is accepted as a source of discovering moral goodness and badness. *Qiyās* provided classical Muslim jurists with a method of deducing laws on matters not explicitly covered by the *Qur'ān*. This means that a ruling of the *Qur'ān* or *Sunna* may be extended to a new problem provided the precedent and the new problem share the same effective cause. Not all Shia schools of law have accepted *qiyās*; some have replaced it by *'aql*. Kiarash Aramesh, "Normativity in Islamic Bioethics," in *Dealing with Bioethical Issues in a Globalized World*, ed. Joris Gielen, Advancing Global Bioethics (Cham: Springer, 2020), 13-29.; Daar and Al Khitamy, "Bioethics for Clinicians: 21. Islamic Bioethics"; Sachedina, *Islamic Biomedical Ethics*.

33. Shabbir Alibhai and Michael Gordon, "Islamic and Jewish End of Life Ethics," in *Muslim Medical Ethics: From Theory to Practice*, ed. Jonathan E. Brockopp and Thomas Eich (Columbia, SC: University of South Carolina Press, 2008), 182-193.

34. Al-Bar and Chamsi-Pasha, *Contemporary Bioethics*; Dariusch Atighetchi, *Islamic Bioethics: Problems and Perspectives* (New York: Springer, 2007); Vardit Rispler-Chaim, *Islamic Medical Ethics in the Twentieth Century*, Social, Economic, and Political Studies of the Middle East (Leiden: Brill, 1993); Sachedina, *Islamic Biomedical Ethics*.

within Islamic jurisprudence (*fiqh*).<sup>35</sup> Contemporary Islamic scholars do not practice independent legal reasoning (*ijtihad*)<sup>36</sup> unless they encounter new issues on which the main sources of Islam are silent.<sup>37</sup> The resolution of bioethical issues is left to qualified religious scholars who are called upon to provide rulings on whether a proposed act is prohibited, discouraged, neutral, recommended, or obligatory (*ahkām al-khams*). As a result, there are a variety of Islamic views on bioethical issues, thus showing that Islam is not a monolithic entity.<sup>38</sup> Normative bioethical deliberations in the Islamic tradition usually take two main forms. The first consists of perspectives developed by an individual Muslim scholar. This falls within the individual ethico-legal reasoning (*al-ijtihad al-fardī*). The second is collective *ijtihad* (*al-ijtihad al-jamā'ī*), consisting of interdisciplinary or collective reasoning in which religious scholars (of different denominations) and biomedical scientists from different parts of the world participate. This points to the importance of possessing the religious and biomedical knowledge needed to formulate an informed opinion on a particular issue. Leading Islamic biomedical organizations and *fatwa* centers consider it of great importance to involve both scholars of the text and scholars of the context in ethical discussions.<sup>39</sup> However, prenatal diagnosis and termination of pregnancy (in cases of anomalies) are some of the least discussed topics in contemporary Islamic bioethics.

Since the 1980s, rich and extensive discussions on Islam and medical ethical issues by physicians and religious scholars have been taking place at conferences on an annual basis, where positions are taken, with the agreement of all participants or the vast majority. These meetings are being held by leading Islamic biomedical organizations and *fatwa* centers that are pioneering the field of (bio)medicine, including Islamic Organization for Medical Sciences (Kuwait), Islamic *Fiqh* Council (Mecca, Saudi Arabia), International Islamic *Fiqh* Academy (Jeddah, Saudi

35. Al-Bar and Chamsi-Pasha, *Contemporary Bioethics*; Sachedina, *Islamic Bio-medical Ethics*.

36. The practice of independent legal reasoning (*ijtihad*) is a core tool for achieving the moral mission of the discipline of Islamic jurisprudence (*fiqh*); it generates juristic rulings that help people become morally committed humans.

37. Ghaly, "The Beginning of Human Life."

38. Atighetchi, *Islamic Bioethics*; Brockopp and Eich, eds., *Muslim Medical Ethics*; Daar and Al Khitamy, "Bioethics for Clinicians: 21. Islamic Bioethics."

39. Mohammed Ghaly, "Biomedical Scientists as Co-Muftis: Their Contribution to Contemporary Islamic Bioethics," *Welt des Islams* 55, nos. 3-4 (2015): 286-311; Mohammed Ghaly, Randi R. Diamond, Maha El-Akoum, and Azza Hassan, *Palliative Care and Islamic Ethics: Exploring Key Issues and Best Practice* (Doha, Qatar: Qatar Foundation, 2018).

Arabia),<sup>40</sup> and to a lesser extent European Council for *Fatwa* & Research (Dublin, Ireland).<sup>41</sup> According to Thomas Eich, the *fatwa* commissions – including representatives from all schools of law, both Sunni and Shi-ite – were a deliberate attempt to establish *sharīʿa* institutions with transnational authority and, consequently, to unify the rulings of religious scholars on a given issue.<sup>42</sup> However, despite their large contributions – primarily from the first three organizations listed above – these position statements do not seem to be reaching the many Muslims in the West, primarily because they are mainly published in Arabic.

### 5. Islam and the Beginning of Human Life

One of the most pertinent discussions around issues at the beginning of life is about when human life begins. While a detailed discussion of this complex issue is beyond the scope of this article, I will attempt to briefly outline the main points in this discussion. First, there is no specific definition of when life begins, neither in the *Qurʾān* nor in the *Sunna*. There are disagreements about the specific beginning of human life and the moment of ensoulment – the infusion of the soul into the body of the fetus, followed by the attribution of a moral status to the fetus. When is the fetus seen as a full human being with rights? Four perspectives exist on this matter: 1) from the moment of fertilization, the embryo is considered a person; 2) the baby is considered fully human from birth; 3) with each day the embryo gradually acquires a higher moral status and thus there is no way to pinpoint a specific moment for the beginning of human life; and 4) the fetus is not merely a living organism, but develops potentiality from the moment of ensoulment onward and thus acquires more human characteristics. The two most dominant views are that human life begins at conception (a view supported by religious scholars and physicians including Muḥammad Mukhtār al-Salāmī, Hassān Haṭḥūt, and Aḥmad al-Qāḍī), or that human life begins at the moment of ensoulment, which occurs later than the moment of conception. The latter position is defended by religious

40. Mutaz Al-Khatib, “Contemporary Ijtihād, Ethics and Modernity,” *Journal of Islamic Ethics* 2019, nos. 1-2 (2019): 1-7; Ghaly, “Biomedical Scientists as Co-Muftis”; Thomas Eich, “Decision-Making Processes among Contemporary ‘Ulama’: Islamic Embryology and the Discussion of Frozen Embryos,” in *Muslim Medical Ethics*, ed. Brockopp and Eich, 61-76.

41. Ghaly, “Biomedical Scientists as Co-Muftis.”

42. Eich, “Decision-Making Processes among Contemporary ‘Ulama.’”

scholars and physicians such as Muḥammad Na'im Yasīn, Yūsuf Al-Qaradāwī, and 'Abdallah Bāsālāma.<sup>43</sup> Both the *Qur'ān* and *ḥadīths* (prophetic traditions) shed light on the development of the human being. More specifically, the Qur'anic verses 23:12-14 discuss fetal developments:

And indeed We created man from a draught of clay. Then We made him a drop [*nutfā*] in a secure dwelling place. Then of the drop We created a blood clot [*'alaqa*], then of the blood clot We created a lump of flesh [*mudgha*], then of the lump of flesh We created bones and We clothed the bones with flesh; then We brought him into being as another creation. Blessed is God, the best of creators!<sup>44</sup>

The above Qur'anic verses mention three *main* stages of embryonic development including the stage of *nutfā* (drop), *'alaqa* (blood clot), and *mudgha* (lump). This is, according to Ghaly, understood by Muslim scholars as three successive stages in which the embryo increasingly shows features of the human form. After the lapse of these three *main* stages, "another creature" develops. The majority of Muslim legal scholars interpret this formation of another creature as the ensoulment of the embryo, making him or her a human being.<sup>45</sup> Although the verses mention the development of the fertilized oocyte, it does not give any indication of the duration of the various stages, nor does the *Qur'ān* mention the exact time of the ensoulment. For this, Muslim scholars make use of the prophetic tradition that gives interpretation to these different stages.<sup>46</sup> One of the most important *ḥadīths* regarding the ensoulment is the so-called Ibn Mas'ūd *ḥadīth*, a tradition canonized in the collections of al-Bukhārī and Muslim.

The creation of one of you is put together in his mother's womb in 40 days (*nutfā*), then he becomes a clot of congealed blood (*'alaqa*) for a similar period, then a little lump (*mudgha*) for a similar period. Then Allah sends an angel who is ordered to write four things. He is ordered to write down his (i.e., the new creature's) deeds, his livelihood, his (date of) death and whether he will be blessed or wretched. Then the soul is breathed into him (*Ṣaḥīḥ al-Bukhārī*: 3036).

43. Ghaly, "The Beginning of Human Life."

44. Seyyed Hossein Nasr, Caner K. Dagli, Maria Massi Dakake, Joseph E. B. Lumbard and Muhammed Rustom, *The Study Quran: A New Translation and Commentary* (New York: HarperCollins Publishers, 2015).

45. Ibid.; Eich, "Decision-Making Processes among Contemporary 'Ulama"; Melanie Guenon, "Abd Al-Majid Al-Zindānī's I'jāz 'ilmī Approach: Embryonic Development in Q. 23:12-14 as a Scientific Miracle," *Journal of Qur'anic Studies* 21, no. 3 (2019): 32-56.

46. Ghaly, "The Beginning of Human Life"; Guenon, "Abd Al-Majid Al-Zindānī's I'jāz 'ilmī Approach."

According to Ghaly, most Muslim scholars assess the status of the fetus based on the moment of ensoulment. The discussion of the moment of ensoulment is crucial when it comes to termination of pregnancy. Based on the above *ḥadīth*, there are two main interpretations. A minority view is that God breathes the soul into the fetus on the 40th day of conception. A majority view, based on a collective approach, indicates that ensoulment occurs 120 days ( $3 \times 40$ ) after conception. The passage above is usually interpreted to indicate that the three stages of embryonic development last 40 days and thus that the entire process until the soul is breathed into the embryo would take 120 days.<sup>47</sup> Yet there are several variants of the tradition; only the variants reported by al-Bukhārī support the view that the ensoulment of the embryo occurs on the 120th day.<sup>48</sup> A critical note in this regard is that, according to Thomas Eich, one of the problems of this embryological model is that it contradicts scientific observation. The final stage, in which “we develop into another creature,” is usually equated with the ensoulment on the 120th day after the *nutfā*, *‘alaqa*, and *mudgha* stages have passed. But the formation of bones in the body of the embryo, which according to the *Qur’ān* follows the *mudgha* stage, is said to occur around the thirty-fifth day after fertilization.<sup>49</sup> Muslim physicians such as Haṭḥūt have contended that the stages in the process of embryonic development as described in the *Qur’ān* passage should not be interpreted literally because that would conflict with the medical reality. Furthermore, Haṭḥūt and others argue that positing the moment of soul-breathing as the beginning of human life does not work from a medical perspective, because it relies upon a purely metaphysical concept that cannot be examined on scientific grounds. Hence, Ghaly contends that the text should be interpreted metaphorically. Other Muslim physicians, including Mukhtār al-Mahdī and Abdallah Bāsālāma, state that the moment of ensoulment – the start of a human life – can be linked to the functioning of the brainstem from 12 weeks of pregnancy onwards, which represents a turning point in fetal development. This interpretation is based upon analogic reasoning (*qiyās*): if brain death marks the end of the human life, the start of brain stem activity should be understood as the beginning of human life.<sup>50</sup>

Nonetheless, the majority of scholars view the moment of ensoulment as a marking point in which the embryo is seen as a full-fledged person with (fundamental) rights and thus possesses human dignity and

47. Eich, “Decision-Making Processes among Contemporary ‘Ulama’.”

48. Guenon, “‘Abd Al-Majīd Al-Zindānī’s Ijāz ‘ilmī Approach.”

49. Eich, “Decision-Making Processes among Contemporary ‘Ulama’.”

50. For more details, see Ghaly, “The Beginning of Human Life.”

sanctity.<sup>51</sup> This means that the unborn child receives the full respect of an adult human being. The different interpretations on the moment of ensoulment have led therefore to different rulings on whether or not to terminate pregnancy in the case of genetic abnormalities. Nevertheless, the interpretation of the ensoulment on the 120th day is generally accepted by the aforementioned biomedical organizations and *fatwa* committees. The Islamic *Fiqh* Council (*Majma' al-Fiqhī al-Islamī*), linked with the Muslim World League, issued a *fatwa* in 1990 that would permit termination of pregnancy in case of severe anomalies. According to this *fatwa*, termination of pregnancy before the 120th day of conception (corresponds to 19 weeks of gestation) is permissible if (a) the life of the mother is in danger; (b) the case involves severe fatal genetic malformation/serious congenital anomaly leading to a “non-normal” functioning or non-viability; (c) there are no options for treatment, (d) the diagnosis of a severe anomaly has been confirmed by a committee of at least two competent and trustworthy medical experts in the field, and (e) with consent of the parents.<sup>52</sup>

Religious opinions vary widely, but most Muslim scholars (both Sunni and Shiite) agree that termination of pregnancy due to severe fetal abnormalities is permissible before ensoulment. After ensoulment, however, termination of pregnancy is prohibited even in cases of severe fetal abnormalities. The only exceptions are when the mother's life is in danger or there is a confirmed intrauterine death.<sup>53</sup>

The purpose of my current research is to find answers to these complex issues, starting with an examination of Islamic perspectives and approaches towards prenatal diagnostics and termination of pregnancy as well as Western bio-ethical perspectives and approaches. As noted earlier, I am seeking to fill in glaring gaps in modern scholarship by investigating the ethical challenges at the beginning of life through approaches and tools rooted in the Islamic tradition. As bioethical issues are mainly addressed within Islamic *Fiqh* (jurisprudence), it is important to provide an extensive overview of the (diverging) legal opinions issued by Muslim scholars, influential national and international Islamic judicial bodies, and Islamic medical organizations (e.g., Islamic *Fiqh* Council, International Islamic *Fiqh*

51. Ibid.

52. Mohammed A. Albar, “Ethical Considerations in the Prevention and Management of Genetic Disorders with Special Emphasis on Religious Considerations,” *Saudi Medical Journal* 23, no. 6 (2002):627-632; Abdulrahman Al-Matary and Jaffar Ali, “Controversies and Considerations regarding the Termination of Pregnancy for Foetal Anomalies in Islam,” *BMC Medical Ethics* 15, no. 10 (2014): 1-10.

53. Rispler-Chaim, “Islamic Medical Ethics in the Twentieth Century.”

Academy, European Council for *Fatwa* and Research, and Islamic Organisation for Medical Sciences). What are the methods and frameworks that are deployed to answer contemporary issues such as prenatal diagnosis and termination of pregnancy? How are conclusions reached in the ethico-legal deliberation about issues at the beginning of life and in particular prenatal diagnosis and termination of pregnancy? The aim is to examine how different contexts and methodologies influence Islamic biomedical discourses and to assess the rules and principles that Muslim jurists/scholars apply to arrive at ethical or judicial decisions across the different schools of thought. Attention will be also devoted to Islamic ethical approaches to biomedical issues, focusing on the use of virtue ethics, *maqāṣid al-Sharī'a* (the objectives of Islamic law) and on secular bioethical approaches such as principlism (Beauchamp and Childress).

## 6. Need for the Study of Lived Experience/Religion

In addition to the importance of focusing on Islamic theoretical and normative perspectives, there is a great need for empirical study of how choices are made and the lived experiences and contexts in which they are made. This empirical approach forms the second part of the required research. It is especially important to focus on prenatal diagnosis and termination of pregnancy among Muslims, as studies among migrants in Brussels (Belgium) showed that North African and Turkish people have a higher rate of having a disabled child and have significantly increased risk of perinatal morbidity due to congenital anomalies.<sup>54</sup> The importance of paying attention to Islamic ethics and issues at the beginning of life is reinforced by the fact that consanguineous marriages are common among Muslim populations, resulting in a higher risk of having a child with genetic abnormalities.<sup>55</sup>

54. Anne-Marie Nybo Andersen, Anna Gundlund, and Sarah Fredsted Villadsen, MS, "Stillbirth and Congenital Anomalies in Migrants in Europe," *Best Practice & Research Clinical Obstetrics & Gynaecology* 32 (2015): 50-59. Judith Racape, Myriam De Spiegelaere, Sophie Alexander, Michèle Dramaix, Pierre Buekens, and Edwige Haelterman, "High Perinatal Mortality Rate among Immigrants in Brussels," *European Journal of Public Health* 20, no. 5 (2010): 536-542; Judith Racape, Myriam De Spiegelaere, Michèle Dramaix, Edwige Haelterman, and Sophie Alexander, "Effect of Adopting Host-country Nationality on Perinatal Mortality Rates and Causes among Immigrants in Brussels," *European Journal of Obstetrics & Gynecology and Reproductive Biology* 168, no. 2 (2013): 145-150.

55. Consanguinity, the situation in which parents are related as second cousins or closer, is a widespread practice among Muslims. Hanan Hamamy, "Consanguineous Marriages," *Journal of Community Genetics* 3, no. 3 (2012): 185-192; Andersen, Gundlund, and Villadsen, "Stillbirth and Congenital Anomalies in Migrants in Europe."

While there are a few empirical studies on prenatal diagnosis and termination of pregnancy among Muslims in the Middle East, Africa, and Asia, such studies are almost entirely absent in Europe as studies conducted in Europe on congenital anomalies often focus on migrants in general rather than Muslims.<sup>56</sup> A study by Hussain et al. found that female subjects in Islamic bioethics research in Muslim-majority countries were well represented over the past fifteen years, with a trend toward increasing participation. However, Muslim women in Muslim-minority countries, as well as Muslim men, remain under-researched.<sup>57</sup>

As we seek to develop a deeper understanding of Islamic bioethical discourses on prenatal diagnosis and termination of pregnancy and to create a contextualized ethical framework, we must also analyze the concrete lived realities of Muslims. The objective is to lift up voices that often go unheard in ethical debates. As mentioned earlier, hardly any research exists that gives a detailed and comprehensive picture of the (ethical) attitudes, views, and decision-making processes of Muslim couples, nor of Muslim medical professionals or religious professionals including imams in West-Europe. We aim to contribute to that knowledge within a Belgian context. In the future, with co-researchers at KU Leuven, we will identify how Muslim couples view and deal with these issues. To understand and obtain a deeper insight into Muslim couples' way of thinking and experiences of bioethical issues at the beginning of life, it is important to elicit their more general views on personhood, pregnancy, birth, illness, and disability. Moreover, we particularly aim to elicit their attitudes and decision-making processes regarding non-invasive prenatal tests and invasive tests. We seek to uncover the rationale for their decision (a) to choose or decline prenatal screening and diagnostics, and (b) to continue or terminate pregnancy following the detection of a congenital anomaly in the fetus. At the same time, we will also elicit the views of medical and religious professionals in Flanders (Belgium), since medical professionals are faced on a daily basis with ethically challenging situations by Muslim patients who seek not only their medical but also their religious opinions and are hoping for culturally sensitive medical care.

56. Andersen, Gundlund, and Villadsen, "Stillbirth and Congenital Anomalies in Migrants in Europe"; Racape et al., "High Perinatal Mortality Rate among Immigrants in Brussels"; Racape et al., "Effect of Adopting Host-country Nationality on Perinatal Mortality Rates and Causes among Immigrants in Brussels."

57. Zeenat Hussain, Edyta Kuzian, and Naveed Hussain, "A 15-Year Review of Trends in Representation of Female Subjects in Islamic Bioethics Research," *Journal of Religion and Health* 56, no. 1 (2017): 284-293.

It is important for genetic counselors to know how Muslim patients/couples perceive genetic counseling services in general, and how religion potentially shapes their decision-making processes. For many Muslims, religion plays an important role in their daily life. Given the lack of a central religious authority on these bioethical questions as aforementioned, we are particularly interested in how Muslim couples of different ethnicities view ethical issues at the beginning of life and in particular how the decision-making process might be influenced by religious factors. For instance, do Islamic scholars (mufti; imam) and/or religious opinions (*fatwa*) have a say or impact on the decision-making processes of Muslim couples? To what extent do they provide guidance for these couples? How do Muslim couples address this challenge/issue in a Western context that emphasizes self-determination and autonomy? This research will enable us to observe possible differences on these issues between Muslim couples of different ethnicities and between men and women, and help us to ascertain whether their adoption of a secular approach to bioethical issues at the beginning of life could have been the result of their interaction with Western culture and society. The objective is also to identify the Islamic discourse among Muslim medical professionals and imams in Flanders (Belgium) and examine how the views of these professionals and imams regarding ethical issues at the beginning of life is shaped and developed. The goal is to find out how and when scholars and professionals use certain Islamic sources of authority (*Qur'ān*, *ḥadīth*, tradition, contemporary scholars) in order to arrive at a decision, how and when they use Western bioethical theories and philosophies to construct or justify their answers.

As noted above, the central focus of my current research is on lived experience/religion. This entails the study of everyday aspects of religion as lived by ordinary people, shedding light on the ways in which Islam shapes Muslims' lives and how new technologies (e.g., prenatal screening tests) impact the relationship between Islamic knowledge and authority and how religion operates within this frame and plays out across them in the life trajectories of individuals. The Islamic tradition is a lived religious tradition that influences the way Muslims frame all kinds of questions of existence, ethical issues, and their practical actions. This approach will be a significant contribution to the contemporary studies of Muslims and Islam in Europe.<sup>58</sup>

58. Nathal M. Dessing, Nadia Jeldtoft, and Linda Woodhead, *Everyday Lived Islam in Europe* (Farnham: Routledge, 2013); Kim Knibbe and Helena Kupari, "Theorizing Lived Religion: Introduction," *Journal of Contemporary Religion* 3, no. 2 (2020): 157-176.

## 7. Need for a Contextualized Islamic Normative Ethical Framework

The third part of my ongoing research addresses the need for a contextualized normative Islamic understanding regarding prenatal diagnosis and termination of pregnancy. In order to develop a contextualized normative ethical view, not only does attention have to be given to normative Islamic sources, but also more importantly to lived realities of Muslims. The aforementioned objectives (the study of normative Islamic and secular bioethical perspectives, and interviews with Muslim couples, Muslim medical, and religious professionals) will culminate in the development of an ethical framework regarding prenatal diagnosis and termination of pregnancy that takes into account Islamic worldviews and traditions, the diversity within Muslim communities, and Western pluralistic society.

If normative ethics aims at offering a useful guideline for people to make informed decisions, we believe that its ethical framework should not merely be based on theoretical constructs, but also on lived experience/religion. For a proper analysis of an ethical issue, ethics should also listen to the views and experiences of the people directly involved in the ethical issues at stake.<sup>59</sup> This approach addresses the flexibility of normative ethics and reflects upon the relationship between empiricism (empirical reality) and normative ethics and how lived religion/experience can contribute to determining norms and guidelines for contemporary issues and contribute to our understanding of normative ethics. The social scientific observation of Muslim practices can be used as a source of Islamic normative thinking. The notion of context-based knowledge will serve its purpose in determining contemporary Islamic ethical practices. In other words, gaining an understanding of concrete situations is important in arriving at normative reflection. Our normative ethical view, we aim to develop, will not only refer to classical and contemporary Islamic sources, but will also build on decades of academic Western (bio)ethical reflection. Given the Western context in which many Muslims find themselves, specific attention will be devoted to Western bioethical discourses and approaches (including the principlism of Beauchamp and Childress, the participatory Catholic theological bioethics as elaborated by Catholic theologian Lisa Sowle Cahill, the personalistic tradition/personalism etc.).<sup>60</sup>

59. Linus, Vanlaere and Chris Gastmans. "A Personalist Approach to Care Ethics," *Nursing Ethics* 18, no. 2 (2011): 161-173.

60. Ibid.; Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 7th ed. (New York: Oxford University Press, 2013); Lisa Sowle Cahill, *Theological Bioethics: Participation, Justice, and Change*, Moral Traditions Series (Washington, DC: Georgetown University Press, 2005).

This twofold research focus can be seen as a good starting point for the development of a normative Islamic view on (bio)ethics that takes into account both the contemporary Western and European context in which it is functioning and the diversity within Muslim communities in European societies. It is exactly within this context that there is a need for a normative voice alongside descriptive research from an outsider perspective or a religious studies approach. The normative framework that we intend to develop would be helpful as a framework for Muslim patients and Muslim professionals (e.g., physicians, nurses) to develop their own informed opinion and to be able to make informed decisions around prenatal diagnosis and termination of pregnancy. What we intend, is exploratory normative research, opening up new ideas and discourses on Islamic ethics and issues at the beginning of life. More specifically, by offering insights and an analysis of the Islamic perspectives of biomedical issues at the beginning of life on the one hand, and actual attitudes, beliefs, and decision-making processes of Muslim couples as well as views of Muslim medical and religious professionals on the other, this study will offer tangible leads to the establishment of an Islamic approach to biomedical ethics in a Western-European context and a solid basis for further research for theoretical, normative, and empirical study of Islamic/Muslim views on ethical issues at the beginning of life.

## 8. Conclusion

The rapidly growing number of Muslims living in Western Europe poses significant challenges, particularly for health care, including prenatal and postnatal care. The need for creating cultural sensitivity in the health care system is pressing, as is need for the provision of adequate and respectful care and guidance in prenatal and postnatal care. On the one hand, more research is needed on Islamic and scientific sources pertaining to prenatal diagnosis and termination of pregnancy. In particular, the question on when human life starts and the moral status of the fetus play an important role in the discussion of termination of pregnancy in cases of severe anomalies. On the other hand, little is known about the actual attitudes, beliefs, and decision-making of Muslims in the West/Europe regarding prenatal diagnosis and termination of pregnancy. Our contribution has pointed out that research on this matter in dialogue with text and context is of great importance. In order to develop a contextualized normative ethical view, not only does attention have to be given to normative Islamic sources, but also – more importantly – to

lived realities of Muslims. The normative framework we hope to help develop should be useful as a framework for Muslim patients and Muslim professionals (e.g., physicians, nurses) to develop their own informed opinions and thus to be able to make informed decisions around prenatal diagnosis and termination of pregnancy.

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