The Influence of Experiential Knowledge and Societal Perceptions on Decision-Making Regarding Non-Invasive Prenatal Testing (NIPT)

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Sophie Montgomery
Dartmouth College

✉️ shmonty96@gmail.com **Corresponding Author**
ORCiD: https://orcid.org/0000-0003-2606-2042

Zaneta M. Thayer
Dartmouth College

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Abstract
Non-invasive prenatal testing (NIPT) allows women to access genetic information about their fetuses without the physical risk inherent to prior testing methods. The advent of NIPT technology has yielded concerns among bioethicists regarding the quality and process of informed consent, as the routinization of this technology could degrade the intentionality of women choosing whether to undergo testing. Prior studies evaluating the NIPT decision-making process have focused on the clinical encounter as the primary environment for acquisition of biomedical information and decision formation. While important, this conceptualization fails to consider how additional sources of knowledge, including both embodied and empathetic experiential knowledge, shape perceptions of risk and the societal use of NIPT. In order to address this issue, qualitative, semi-structured interviews with 25 women who had been offered NIPT were performed. Women were categorized by NIPT use/non-use, as well as whether their described decision-making process was routinized. Qualitative analysis of the data using a phenomenological approach was used to explore themes in the data, develop a framework of NIPT decision-making, and compare the perceptions of women with differential decision-making processes and outcomes. A framework for decision-making regarding NIPT was developed based on three emergent factors: perceptions of the societal use of NIPT, expected emotional impact of genetic information, and perceived utility of genetic information. Qualitative analysis revealed that perceptions of widespread use of NIPT, pervasive societal narratives of NIPT use as progressive and “forward-thinking,” and a perception of more information as anxiety-relieving contributed to routinized uptake of NIPT. In contrast, women who displayed a lack of routinization expressed fewer stereotypes regarding the audience for NIPT and relied on communication with their social networks in-person and online to consider how they might use the information provided by NIPT. The findings of this study reveal the societal narratives and perceptions that shape differential decision-making regarding NIPT. Understanding and addressing these perceptions that influence NIPT decision-making, especially routinized uptake of NIPT, is important as the use and scope of this technology increases.

Full Text
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