

Making Informed Decisions Regarding Prenatal Genetic Testing and the Health Literacy Barrier

Argument Essay

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As prenatal genetic testing advances, barriers in health literacy surface for women making it harder for them to find the resources to make an informed decision regarding these tests. The problem we face now is the lack of guidelines and support from primary care physicians to help expecting mothers make decisions regarding these tests (Rink & Kuller, 2018, p. 287). Educating primary care physicians on how to overcome the health literacy barrier to better counsel mothers, through the process of prenatal genetic testing, helps mothers to be better equipped to make these difficult decisions.

Mothers are faced with two decisions as it relates to prenatal genetic testing once they become pregnant, to be tested or not. The health literacy barrier exists because primary care physicians are unable to communicate results in layman terms, creating a barrier when counseling and advising women. Dr. Ruth Farrell (2013), Assistant professor of Surgery at Cleveland Clinic, believes if mothers are not informed accurately by their primary care physicians they are hypothetically led down two paths: going through with testing uneducated or not going through with testing when it could have had major benefits to the child (p. 7). As such, it can be logically argued that it is the job of the primary care physicians to be the initial source of information for women regarding these tests and in preparing them for the future of their pregnancy. It is critical that primary care physicians know their patients so that the patients are more comfortable in their ability to make decisions (Jun, Thongpriwan, J. Choi, K. Choi, & Anderson, 2018, p. 132).

Many primary care physicians are not prepared in communicating results of prenatal genetic testing to patients (Founds, 2014, p. 214), especially when trying to overcome the health literacy barrier. A study conducted by the Council of Academic Family Medicine Educational Research Alliance, or CERA, in 2013 had results that showed most primary care physicians did

not feel educated enough to discuss genetic tests with patients, in some cases leading to primary care physicians choosing not to order the test as a result (as cited in Brown, Metzler, Desjardins, & Seiler, 2017, p. 12). Contemporary studies have provided more evidence as to why this is a problem by shining a light on data that shows women are more likely to make uninformed decisions because of health literacy barriers and a lack of knowledge on the meaning of prenatal testing (Farrell, 2013, p. 8). Primary care physicians need to make guidelines to overcome the health literacy barrier so that women can be better informed on their right to autonomy, the risks and benefits and the possible results.

The health literacy barrier leads women to misinterpret information and make mistakes in the decisions they face regarding prenatal genetic testing. For example, in a case study funded by the Korean government, one woman was mistaken when thinking she legally had to get amniocentesis (Jun et al., 2018, p. 131). Mistakes like these have led the American College of Obstetricians and Gynecologist, or ACOG, to create recommendations, one being that primary care physicians should come up with a standard method that should be delivered to all patients (“ACOG recommends genetic screening in all women before pregnancy”, 2017, p. 13). Creating a set curriculum for primary care physicians would help them to feel less stress when trying to guide patients (Rink & Kuller, 2018, p. 287).

Whether a doctor, a researcher, or a patient; awareness of the lack of capacity that primary care physicians have on educating themselves and their patients remains an topic of interest. Many are also aware of the abilities of nurses to form relationships with their patients. As a counterargument, it can be argued that nurses are the roots of health care, therefore they should be educated on genetics to better communicate results and counsel patients (Founds, 2014, p. 212). GERALYN MESSERLIAN, a professor at Brown University for pathology and laboratory

medicine, adds to this point when saying that the average woman goes to their primary care physician as their initial resource, yet the primary care physician does not create the time to explain the tests to the women (as cited in Paxton, 2017, p. 42). It then stands to reason that nurses could provide a solution to the health literacy barrier by becoming more educated on the subject so that they can better counsel patients because primary care physician's lack the time.

However, it is the job of the primary care physician to explain the benefits and risk to a patient before counseling (Brown et al., 2017, p. 15). Primary care physicians need to provide counseling before, during and after prenatal genetic testing (Rink & Kuller, 2018, p. 287). Thus, nurses cannot be the solution because primary care physicians have the responsibility of forming relationships and counseling patients, not just through their pregnancy.

Primary care physicians are responsible for the many different available tests for women that can assess how at risk their pregnancy is, but each test has specific risks of which the patient is entitled to be made aware. For example, noninvasive prenatal genetic testing, or NIPT, screens for conditions that have no cure, which leaves women to face decisions regarding the results that may be unexpected (Van Bruggen, Henneman, & Timmermans, 2018, p. 93). Many primary care physicians feel unprepared in communicating results to women (Founds, 2014, p. 212). As such, many women felt overwhelmed with these potential risks to their pregnancies, the more they learned the more worried they became (Jun et al., 2018, p. 132). As a result of this worry about potentially facing several outcomes after prenatal genetic testing, many women end up refusing these tests (Farrell, 2013, p.11). Tests such as whole-exome sequencing, or WES, produce results that may present clinical phenotypes we are not yet aware of (Brown et al, 2017, p. 15). Unpredictability of results, such as the kind WES provides, add to the importance of counseling before receiving tests so primary care physician and patient are aware of the possible outcomes.

It can be argued that equipping these primary care physicians with information to help overcome the health literacy barrier would elevate the possibility for women to not refuse these tests based on a level of fear that might not be rational or well informed.

Overcoming the health literacy barrier results in understood communication between primary care physicians and women regarding prenatal genetic testing. Providing guidelines to educate the primary care physicians, who can then provide resources to educate expecting mothers results in informed decisions made by both parties. The purpose of prenatal genetic testing stands to advance the medical field by providing women with an assessment of how at risk their pregnancy is before their child has been born. However, this phenomenon has been disrupted by the health literacy barrier, creating challenges in communication between primary care physicians and women. Barriers are only made worse as technology advances (Farrell, 2013, p. 2), in part due to primary care physicians' inability to remain up to date with these advances. Creating guidelines for primary care physicians would provide them the necessary information to allow them to remain up to date as advances in prenatal genetic testing continue, as well as enhancing their abilities to sufficiently advise and counsel women through the possible outcomes of prenatal genetic testing (Rink & Kuller, 2018, p. 288). Primary care physicians are the ultimate source of information for women when seeking information. Primary care physicians' abilities to provide the resources and initial counseling is vital for women to make informed decisions regarding their pregnancy.

## References

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