

Sarah Lawrence College

DigitalCommons@SarahLawrence

Human Genetics Theses

The Joan H. Marks Graduate Program in
Human Genetics

5-2017

Knowledge and Attitudes After Using Videos to Educate a Non-Clinical Cohort About Prenatal Cell-Free DNA Screening

Teresa Cacchione
Sarah Lawrence College

Safa Yusuf
Sarah Lawrence College

Follow this and additional works at: https://digitalcommons.slc.edu/genetics_etd



Part of the [Genetics Commons](#)

Recommended Citation

Cacchione, Teresa and Yusuf, Safa, "Knowledge and Attitudes After Using Videos to Educate a Non-Clinical Cohort About Prenatal Cell-Free DNA Screening" (2017). *Human Genetics Theses*. 32.
https://digitalcommons.slc.edu/genetics_etd/32

This Thesis - Open Access is brought to you for free and open access by the The Joan H. Marks Graduate Program in Human Genetics at DigitalCommons@SarahLawrence. It has been accepted for inclusion in Human Genetics Theses by an authorized administrator of DigitalCommons@SarahLawrence. For more information, please contact alester@sarahlawrence.edu.

**Knowledge and Attitudes After Using Videos to Educate
a Non-Clinical Cohort About Prenatal
Cell-Free DNA Screening**

By

Teresa Cacchione & Safa Yusuf

Joan H. Marks Graduate Program in Human Genetics

Sarah Lawrence College

May 2017

Submitted in partial completion of the Master of Arts Degree at Sarah Lawrence
College, May 2017

Abstract

Prenatal cell-free DNA (cfDNA) screening is now offered to pregnant women of all risk categories, creating a challenge in providing informed decision-making on a broad scale. Resources to support patient education, such as short educational videos, have been created to help ameliorate this issue but have not been formally evaluated. Thus, we sought to investigate the utility of videos in educating women about prenatal cfDNA screening and whether there were differences in knowledge and/or attitudes after viewing a video created by a non-profit genetics organization (Video A) versus a similar video created by a commercial testing company (Video B). Participants were asked to view one of the two videos and complete a survey assessing take-home messages, knowledge, attitudes, and demographics.

A total of 207 individuals participated in the study; 106 viewed Video A (Group A) and 101 viewed Video B (Group B). Mean knowledge scores for both groups indicated sufficient education by their respective videos; however, Group A scored significantly higher (mean = 9.40) than Group B (mean = 8.99) ($p < 0.01$). Both groups had favorable attitudes towards prenatal cfDNA screening with no significant difference between them. Other significant findings included younger participants having more positive attitudes than older participants ($r(204) = -0.24, p < .01$), and those with a prior pregnancy having less favorable attitudes than those without ($(17.1 \text{ versus } 19.8) (204) = -3.09, p < 0.01$). There were also notable qualitative differences in reported take-home messages between the groups: Group A more often addressed technical aspects of testing whereas Group B highlighted fetal sex determination and the timeline for testing. This study demonstrates that videos can effectively educate patients about prenatal cfDNA screening and that attitudes towards prenatal cfDNA screening are generally positive. However, the focus and origin of educational videos should be considered carefully by providers as these factors may variably influence take-home messages and overall education.

Introduction

In the past several decades, prenatal screening options have grown from one available marker, maternal age, to many possible options for patients including nuchal translucency screening, maternal serum screening and, most recently, cell-free fetal DNA (cfDNA) screening, also known as non-invasive prenatal testing (NIPT) (ACOG Committee on Genetics, 2015; Rink & Norton, 2016; Russo et al., 2014; Wilson et al., 2013). As prenatal screening options continue to develop both in number and capability, patients are presented with an ever-increasing number of choices regarding the direction of their prenatal care. Currently, the American Congress of Obstetricians and Gynecologists (ACOG) recommends that all patients be offered the option of prenatal screening regardless of maternal age, meaning that an incredibly large number of women are faced daily with the decision of whether or not to undergo screening and what type to choose if they decide to do so (ACOG Committee on Practice Bulletins, 2016a, 2016b). Accurate explanation of various testing options and what each test can and cannot detect is vital in order for patients to make informed decisions, yet high patient volume, the brief time typically allotted for patient encounters, and other barriers often prevent appropriate pre-test counseling.

It has long been a goal of the health care community to encourage patients to take a more active role in decisions regarding their care, particularly in obstetrics given the personal nature of prenatal testing. However, if patients are expected to make their own choices about the direction of their care it is essential that those decisions are informed by accurate information. This is important not only for ethical reasons, but also because informed decision-making has been shown to improve outcomes such as anxiety, decision conflict (uncertainty), and decision satisfaction (Marteau & Dormandy, 2001; Woolf et al., 2005). Nonetheless, a number of studies have demonstrated that many women feel they receive inadequate information about their prenatal screening options and that providers are not appropriately facilitating informed decision-making (Green et al., 2004; van den Berg et al., 2005; van den Berg et al., 2006). In addition, providers themselves have reported difficulty explaining the complex nature of prenatal screening options to women, concern about making their patients more anxious, and difficulty

removing their own biases (Nagle et al., 2006; Nagle et al., 2008). Even those who do feel comfortable explaining prenatal screening options to their patients have cited multiple barriers to effective pre-test counseling including time, reimbursement, and lack of resources to assist in counseling (Farrell et al., 2016). Ideally, all prenatal patients would see a genetic counselor to discuss their various options, as genetic counselors have the skills to present complex information in a simple and understandable way, with the time to discuss each option thoroughly with the patient. However, the small number of available genetic counseling providers makes this option currently unfeasible (Fonda Allen, Stoll, & Bernhardt, 2016).

One option to help providers facilitate informed decision-making is the use of decision aids such as videos, pamphlets, and computer modules as they “offer clinicians a validated format for presenting facts that surpass conventional advice in terms of balance, accuracy, and consistency” (Woolf et al., 2005). Decision aids typically provide standardized information about treatment options and help patients to clarify their personal values as they may relate to possible outcomes, benefits, or risks. There have been several studies to date looking at the effectiveness of decision aids in facilitating informed decision-making in the context of prenatal screening and/or diagnostic testing, which have, in general, demonstrated an increase in knowledge and decreases in decision conflict, decision regret, and patient anxiety (Dugas et al., 2012; Graham et al., 2000; Hunter et al., 2005, Kupperman et al., 2009; Kupperman et al., 2014; Vlemmix et al., 2013; Yee et al., 2014). However, these previous studies did not address whether decision aids can help facilitate informed decision-making in regards to newer types of prenatal screening, particularly cfDNA screening.

Genetics professionals and prenatal testing companies recognize the difficulty of facilitating informed decision-making now that technologies such as prenatal cfDNA screening are being offered to the general population and are beginning to create various resources to aid providers in patient education. One resource that has become widely utilized is that of short educational videos which prospective patients can view online or be shown in their physician’s office. A variety of companies and organizations have created videos to help explain the option of prenatal cfDNA screening to patients, yet the utility of

these resources in effectively educating individuals has not been formally tested. In addition, the fact that many of the available videos have been created by the testing companies themselves poses an important question: does the fact that the video could also be used as a marketing tool (as opposed to a video created by a group without a financial stake in test uptake) affect the viewer's perceptions of the test and its benefits/limitations? A recent review of electronic resources and advertising for prenatal cfDNA screening found that while there were few instances of actual inaccuracy, there were multiple instances of the use of persuasive statements or arguments designed to appeal to the emotions of prospective mothers with concerns about risk. The study found that these statements often overstated the ability of the test to provide reassurance, aggressively promoted the safety of prenatal cfDNA screening, and were more likely to discuss test benefits than test limitations. In fact, only one third of the 40 resources analyzed were considered by the researchers to be "balanced" in the information they provided (Skirton et al., 2015). Thus, further investigation into the use of videos for patient education about prenatal cfDNA screening and the sources of those videos is warranted.

Given that prenatal cfDNA screening is still fairly new, there have been several studies looking at attitudes towards this type of testing in both populations of pregnant women and in the general population. Several studies of pregnant women in the UK by Lewis, Hill, & Chitty (2016a, 2016b) found that the main motivation for uptake of prenatal cfDNA screening was reassurance and that women were extremely positive about the opportunity to have procedurally safe testing that reduced the need for invasive testing but was more accurate than previous screening options. In fact, the majority of the women interviewed felt that prenatal cfDNA screening should replace serum screening as first line testing. In 2015 and 2016, Allyse et al. looked at attitudes towards prenatal cfDNA screening in a large population of US adults of reproductive age and found moderate support for it with a high projected test uptake. The most highly rated aspects of the testing were its higher accuracy than other forms of serum screening, the fact that it could be performed early in pregnancy, and that it could provide potentially reassuring information.

We therefore sought to investigate the utility of videos in educating women about prenatal cfDNA screening and whether there were any differences in consequent knowledge and attitudes when using a video created by a non-profit genetics organization versus a similar video created by a commercial testing company. Attitudes about prenatal cfDNA screening were investigated to see if they supported the findings of previous studies. While the majority of previous studies about prenatal screening looking at similar parameters have involved the use of cohorts of pregnant women, we chose to recruit a non-clinical cohort of women of childbearing age from the general population as they represent the future patient population that will be offered prenatal cfDNA screening as it becomes increasingly utilized by providers nationwide.

Methods

Study Design

Study design began with the selection of two videos about prenatal cfDNA screening, one created by a non-profit genetics organization (Video A) and one produced by a commercial testing company (Video B). The chosen videos were of a similar length and style, and covered similar content. We then customized a survey for the study, which was adapted from a validated instrument previously used to evaluate knowledge about NIPT amongst pregnant women (Lewis, Hill, & Chitty, 2015) and from the Maternal Serum Screening Knowledge Questionnaire (Goel et al., 1995). The original sources were adapted to reflect the fact that study participants were being drawn from a non-clinical cohort and did not have to be pregnant or have been pregnant previously in order to participate. The adapted survey included a ten question knowledge test about prenatal cfDNA screening, a five question attitude assessment, and questions regarding socioeconomic demographics and pregnancy history. We ensured that all ten questions on the knowledge test were answered by each video. In addition, an open-ended question inquiring about general take-home messages was included in an effort to probe more deeply into participants' attitudes and impressions (the final survey is included in the Supplementary Material). At the

end of the survey, participants were given the option of providing their email address in order to be entered into a raffle for a \$100 Amazon gift card.

The adapted survey was piloted in a group of ten individuals, after which a few small changes to survey wording and formatting were made in response to feedback. In addition, a comment box was added at the end of the survey and the option “Not applicable - pregnancy ended in termination or miscarriage prior to testing” was added to Question 27 (see Supplementary Material).

Recruitment and Randomization

Individuals eligible for participation included English-speaking women in North America between ages 20 and 45. There were no restrictions on current or prior pregnancy status. Recruitment took place on social media, email, and by word of mouth from January 26th, 2017 through February 10th, 2017 with the goal of recruiting at least 100 participants. After recruitment, participants were randomized into one of two groups: one group received Video A (Group A), and the other group received Video B (Group B). Each participant was sent an email with a link to their respective video and to the survey on SurveyMonkey. Both groups received identical surveys. Participants were asked not to watch their video again or use any other online resources once they began the survey.

Data Analysis

After the survey closed, the knowledge test and attitude assessment scores for each participant were calculated. A score of 6 or greater (out of 10) on the knowledge test reflected adequate education, and a score of 13 or greater (out of 25) on the attitude assessment demonstrated a favorable attitude towards prenatal cfDNA screening. Mean knowledge and attitude scores for each study group and for various demographic subgroups were determined and compared for relevant differences using t-tests, one-way ANOVA, and post hoc analysis. Relevant differences between each group in terms of percent correct for individual questions on the knowledge test were determined using chi square and Fisher’s exact test.

Qualitative data from the open-ended question assessing main take-home messages was evaluated via open coding. The data was then assessed for similarities and differences between the two groups.

This study was determined to be exempt by the Sarah Lawrence College Internal Review Board.

Results

A total of 207 individuals participated in the study; 106 participants viewed Video A (Group A) and 101 participants viewed Video B (Group B). Details of participant demographics can be found in Table 1. One participant was removed from the Group A dataset due to failure to complete the attitude assessment. In addition, six participants (two in Group A and four in Group B) did not provide their age and one individual in Group B did not provide her highest level of education completed. All seven participants were left in the dataset given that removal of these individuals did not significantly impact the results when analyses were rerun without their responses.

Table 1: Participant Demographics

	<i>Total</i>	<i>Group A</i>	<i>Group B</i>
Number of Participants	206	105	101
Age			
20-24	41	26	15
25-29	85	39	46
30-34	42	23	19
35-39	25	12	13
40-45	7	3	4
Ethnicity			
White/Caucasian	156	81	75
Black	8	1	7
Hispanic	9	5	4

Asian	14	6	8
Middle Eastern	5	2	3
Mixed/Other	14	10	4
Religion			
Yes	105	51	54
<i>Christian</i>	72	36	36
<i>Jewish</i>	14	7	7
<i>Muslim</i>	8	4	4
<i>Hindu</i>	2	1	1
<i>Other</i>	9	3	6
No	101	54	47
Highest Education			
High School	0	0	0
Partial College	18	11	7
College	92	46	46
Advanced Degree	95	48	47
Profession			
Health Care Worker (incl. students)	92	46	46
<i>Genetic Counselor</i>	34	17	17
<i>Doctor</i>	5	3	2
<i>Nurse</i>	12	4	8
<i>Other</i>	41	22	19
Not Health Care Worker	114	59	55
Pregnancy History			
Previous Pregnancy	54	24	30
<i>Previous Screening</i>	24	10	14
<i>No Previous Screening</i>	16	7	9

<i>Miscarriage or Termination Before Testing</i>	14	7	7
No Previous Pregnancy	152	81	71

Quantitative Data:

The mean knowledge test scores for Group A and Group B indicated that both groups were sufficiently educated (with a score of 6 or more out of 10 correct) about prenatal cfDNA screening by their respective videos. However, participants in Group A scored significantly higher on the knowledge test (mean = 9.40) than those in Group B (mean = 8.99) ($p = <0.01$). Mean attitude assessment scores for both groups indicated favorable attitudes towards prenatal cfDNA screening (with a score of 13 or more out of 25). There was no significant difference in mean attitude scores between the two groups in relation to the video watched (Table 2).

Table 2: Knowledge and Attitude Scores by Group

	Mean for Group A (n=105)	Mean for Group B (n=101)	Mean Difference	t value	p level*
Total Knowledge Score	9.40 (SD = 0.92)	8.99 (SD = 1.06)	0.41	2.97	<0.01
Total Attitude Score	19.32 (SD = 5.13)	18.87 (SD = 5.23)	0.45	0.63	n.s.

*for two-tailed test

Age

For the total sample, age was negatively correlated with attitude ($r(198) = -0.24, p = < 0.01$), meaning that younger participants had more positive attitudes than older participants (Table 3). This was true for those in Group A ($r(101) = -0.24, p = <0.05$) and Group B ($r(95) = -0.24, p = <0.05$). Age was not related to knowledge in the total sample ($r(198) = 0.05, n.s.$). However, in Group B age appeared positively correlated with knowledge, although the result was not statistically significant ($r(95) = 0.17, p = 0.10$).

Table 3: Attitude Score Correlated with Age

	Age	p level*
Total Sample (n=200)	r = -0.24	<0.001
Group A (n=103)	r = -0.24	<0.05
Group B (n=97)	r = -0.24	<0.05

* for two-tailed test

Education & Ethnicity

A one-way ANOVA indicated that there was no significant difference in knowledge or attitude scores by education or ethnicity. This was true for the overall sample and each group individually. Post hoc comparisons in the total sample and the two subsamples resulted in similar findings.

Health vs. Other Professions

For the total sample, participants identifying as health care professionals had significantly higher knowledge scores (mean = 9.52) than participants identifying as non-health care professionals (mean = 8.94) ($t(202) = 4.42, p = <0.001$) (Table 4). When examining the subsamples, it was found in Group A that being a health care professional was significantly related to knowledge, while this was not the case for Group B. For Group A, health care professionals had a mean knowledge score of 9.46 and non-healthcare professionals had a mean score of 8.60 ($t(89) = 4.58, p = <0.001$). For Group B, health care professionals had a mean knowledge score of 9.58 and non-health care professionals had a mean score of 9.25 ($t(103) = 1.87, n.s.$).

Table 4: Knowledge and Attitude Scores by Self-Identification as a Health Care Professional

	Mean Health Care Profession (N=92)	Mean Non-Health Care Profession (N=114)	Mean Difference	t value	p level*
Total Knowledge Score	9.52 (SD = 0.80)	8.94 (SD = 1.08)	0.58	4.42	<0.001
Total Attitude Score	19.57 (SD = 4.70)	18.72 (SD = 5.23)	0.85	1.18	n.s.

*for two-tailed test

The attitude scores of participants self-identifying as health care and non-health care professionals in the total sample were not significantly different ($t(204) = 1.18, n.s.$). This was true for both Group A ($t(103) = 1.08, n.s.$) and for Group B ($t(99) = 0.61, n.s.$).

There were no significant differences in knowledge scores by type of health care profession in the total sample ($F(5/79) = 0.75, n.s.$), in Group A ($F(5/36) = 0.70, n.s.$) or in Group B ($F(5/37) = 0.47, n.s.$). However, attitude was related to type of health care professional in the total sample ($F(5/79) = 3.78, p = <0.01$). Post hoc analysis showed that the difference was between second year genetic counseling students (mean = 24.7) and other health care professions (mean = 20.0, $p = <0.05$), and between second year genetic counseling students (mean = 24.7) and those training in another health care profession (mean = 19.8, $p = <0.05$). Attitude was also related to type of health care profession in Group A alone ($F(5/36) = 3.11, p = <0.05$). Post hoc analysis showed that the difference was between second year genetic counseling students, who had a mean score of 24.3, and those training for another health care profession, who had a mean score of 15.8 on the attitude assessment ($p = <0.05$). There was no relationship between attitude and type of health care professional in Group B ($F(5/37) = 1.36, n.s.$).

Previous Pregnancy

There was no relationship between knowledge and whether or not the respondent had a previous pregnancy. However, attitude was related to having a prior pregnancy. In the total sample, those who had

a prior pregnancy had significantly less favorable attitudes towards prenatal cfDNA screening than those who did not have a prior pregnancy (17.1 versus 19.8) ($t(204) = -3.09, p = <0.01$). The main source of this difference was in Group B where those who had a prior pregnancy had a mean score of 16.7 and those without a prior pregnancy had a mean of 19.8 ($t(99) = -2.80, p = <0.01$) (Table 5).

Table 5 : Attitude Score and Prior Pregnancy Status

	Mean for Prior Pregnancy	Mean for No Prior Pregnancy	Mean Difference	t value	p level*
Total Sample (N=206)	17.09 (SD = 5.81)	19.82 (SD = 4.74)	-2.72	-3.09	<0.01
Group A (N=105)	17.58 (SD = 6.39)	19.84 (SD = 4.61)	-2.26	-1.61	n.s.
Group B (N=101)	16.70 (SD = 5.38)	19.79 (SD = 4.92)	-3.09	-2.80	<0.01

*for two-tailed test

Religion

There was no significant difference in knowledge or attitude scores for those who had a religious faith and those who did not. This was true in the total sample and in both subsamples. For the total sample and Group A, there were no significant differences in knowledge or attitude scores by religious preference. However, in a one-way ANOVA for Group B, knowledge was related to religious preference ($F(3/50) = 5.82, p = < 0.05$). Post hoc tests revealed that the differences stemmed from Muslim participants with an average score of 7.00 versus Jewish participants with an average score of 9.57 ($p = <0.01$) and Christians with an average score of 8.94 ($p = <0.01$). Religion was not related to attitude score in Group B. There were no significant differences in knowledge or attitude scores by reported degree of religiosity in either the total sample or the subsamples.

Individual Knowledge Questions

There were five statistically significant associations between which video was watched and answering a specific knowledge question correctly. Four of the five associations showed Video A as being correlated with higher knowledge. More participants who viewed Video A knew that prenatal cfDNA screening does not look for all possible genetic conditions; 94.3% of those who saw Video A knew the correct answer while only 72.3% of those who saw Video B knew the correct answer (Chi-square(1) = 18.10, $p < 0.001$). More participants who watched Video A knew that women with a test result showing decreased risk cannot be sure that their baby will not have Down Syndrome; while only 9 people overall answered incorrectly, 8 of the 9 (88.9%) were those who saw Video B (Fisher's exact probability = < 0.05). More participants who viewed Video A knew that prenatal cfDNA screening cannot be done as early as six weeks of the pregnancy (86.7% versus 74.3%); 40 participants responded incorrectly and 26 of the 40 (65%) were those who viewed Video B (Chi-square(1) = 5.07, $p = < 0.05$). More participants who viewed Video A knew that prenatal cfDNA screening cannot cause a miscarriage (Chi-square(1) = 5.00, $p = < 0.05$); only 11 participants overall had the incorrect answer, but 9 of the 11 (81.8%) saw Video B.

Only one question was associated with a higher knowledge score after watching Video B; 97.0% of those who viewed Video B correctly knew that prenatal cfDNA screening can determine the sex of the fetus, while only 79.2% of those who saw Video A were able to answer the same question correctly (Chi-square(1) = 15.40, $p < 0.001$). Of the 25 participants who did not know that the test can determine the sex of the fetus, 22 of them (88.0%) were from Group A.

Qualitative Data

Our qualitative data was derived from the open-answer question inquiring about main take-home messages that was answered by all participants regarding their respective video. There were 206 responses in total. We began by reading over the responses multiple times to identify common themes and counted 14 separate themes. Each answer was then broken down into these separate themes and tallied. While these themes were distinct, many of them were linked and fell into overarching categories. We

decided upon three separate categories to address different aspects of the videos including: breadth of testing, decisional considerations, and video. Every response included at least one theme and then was placed into the larger category. We also had an additional comments section as part of the survey. These responses were not included as part of the qualitative data as they were repetitive and often provided summaries, and therefore did not represent any additional data.

Breadth of Testing

There were a number of similar concepts amongst the answers that participants in both groups provided regarding the coverage of prenatal cfDNA screening as well as its limitations. One such common theme was the fact that prenatal cfDNA screening is non-invasive and poses no risk to the fetus. Statements coded in this theme included words such as ‘safe,’ ‘not harmful,’ and ‘little risk,’ indicating the perceived belief that both groups considered prenatal cfDNA screening to be safe overall. Another common theme that was shared by both groups was the fact that prenatal cfDNA screening can assess the risk of the fetus having a genetic condition. Phrases that represented this theme ranged from quantifying a ‘low or high’ risk of the fetus having abnormalities, as well as the ‘probability’ or ‘likelihood’ that the fetus would have a genetic condition. Similarly, both groups identified that the test can only look for certain genetic disorders or conditions. Participants noted that there were ‘several’ or ‘certain’ genetic disorders that were screened for, with some specifying further with terms such as ‘Down syndrome’ or ‘trisomies.’

The two groups differed quite noticeably concerning a number of different themes in this category. One included the screening being able to determine the gender or sex of the fetus. Only two participants in Group A noted this concept as a takeaway after watching their specific video; conversely, almost half of the participants from Group B included a statement referencing this fact. Another area in which the two groups differed was the length of gestation at which the screening could be offered. Close to half of Group B noted that prenatal cfDNA screening is an option as ‘early as nine weeks,’ ‘early on in the pregnancy,’ or ‘before other tests.’ Less than five participants in Group A included a similar statement in their answers, indicating a clear difference in the strength of this message between the two groups.

Another prevailing difference between the two groups was in their focus on the diagnostic value of the screening. Participants in Group A frequently noted that prenatal cfDNA screening is not diagnostic, including phrases such as ‘false positives,’ ‘not a guarantee,’ ‘imperfect,’ and ‘not definitive,’ in their answers. Very few participants in Group B made similar statements in their responses.

Decisional Considerations

There was less overlap between the groups concerning prenatal cfDNA screening and additional decisional considerations. The one area in which there was a similarity was the belief that prenatal cfDNA screening is easy. Participants in both Group A and Group B included this theme in their responses. Most phrases included ‘quick and easy’ and ‘simple,’ with one participant writing that prenatal cfDNA screening is easier as ‘compared to traditional methods.’

For the remaining themes in this category, no participants in Group B included such statements in their answers, while a sizeable number of Group A did. Participants in Group A were cognizant of a number of considerations factoring into decisions about undergoing prenatal cfDNA screening. One such theme included the idea that screening is ‘optional,’ a ‘personal choice,’ or ‘may not be worth it for some people.’ This belief was supported by a number of participants in Group A who also cited that prenatal cfDNA screening is just one of many screening options available. Answers ranged from ‘one of many options’ to ‘different types of testing.’ Additionally, participants in Group A noted that prenatal cfDNA screening is not without risks; common responses included ‘risks and benefits’ or ‘limitations’ for prenatal cfDNA screening. This belief was encapsulated by the following statement: “Mothers should think about what the results of this test mean for them.” Participants also cited that prenatal cfDNA screening is a combination of interesting, informative, or some iteration of ‘useful’ in their opinion, with one respondent stating that it is ‘an important part of the pregnancy process.’ A few participants spoke of prenatal cfDNA screening providing reassurance, including phrases such as ‘helpful for worried mothers.’ About the same number of participants in Group A also made reference to the fact that they considered

prenatal cfDNA screening to be more accurate as compared to other screening tests, for example, ‘better than other blood screening tests.’

Video

Overall, in both groups A and B there was little written by respondents regarding the video itself. One specific phrase that was included in a few answers given by participants in Group B was the idea of the video being an ‘advertisement.’

Discussion

The purpose of our study was to determine if two separate educational videos about prenatal cfDNA screening would be able to adequately educate a non-clinical cohort of female participants from the general population and to determine what attitudes participants held towards prenatal cfDNA screening. Analysis was then performed to determine if the above measures differed depending on whether the participant viewed Video A (produced by a non-profit genetics organization) versus Video B (produced by a commercial testing company). Overall, the results from this study showed that participants in both groups were sufficiently educated about prenatal cfDNA screening and held favorable attitudes towards prenatal cfDNA screening after viewing their respective videos. However, participants varied substantially in their main take-home messages depending on the video they watched. Our study is also notable in that participants were drawn from the general population, in contrast to participants in the majority of similar previous studies who were pregnant and/or receiving care from providers or within hospitals.

Knowledge

Our study found that both videos were effective in providing participants with adequate information regarding prenatal cfDNA screening. This finding is consistent with those of previous studies which

showed that educational tools and decision aids can be effectively used as a means of educating patients about prenatal screening options (Dugas et al., 2012; Graham et al., 2000; Hewison et al., 2001; Hunter et al., 2005, Kupperman et al., 2009; Kupperman et al., 2014; Vlemmix et al., 2013; Yee et al., 2014). As prenatal cfDNA screening is a relatively new technology, no prior studies examined the utility of videos about prenatal cfDNA screening in effectively educating patients. In addition, no previous studies compared two different videos in their quality as educational tools. Our study showed that while both videos were effective in educating participants, participants in Group A had a significantly higher mean knowledge score as compared to those in Group B. This could speak to earlier research which showed that while there is not misinformation in videos produced by commercial testing companies, they often limit focus or place more emphasis on certain factors (Skirton et al., 2015). More research needs to be done comparing the effects of commercial videos versus non-commercial videos on patient education and attitudes.

The results also showed that health care professionals had significantly higher knowledge scores when compared to non-health care professionals in both Group A and Group B, which were each roughly comprised of the same number of health care professionals. Previous similar studies did not include this demographic in their analyses. It stands to reason that prenatal cfDNA screening is a newer prenatal screening technology and therefore may not be as widely used or known by the general public. Health care professionals may have had more knowledge about prenatal cfDNA screening prior to watching the videos. They may also have been more familiar with similar screening methods and therefore were able to apply that knowledge when answering the survey questions.

When the results from comparison of individual questions on the knowledge survey were analyzed, clear differences between the two groups in their answers to five specific questions were identified. Of the five questions, a significant number of respondents from Group A responded correctly to four of the questions, while those from Group B performed better on one question. The content of these specific questions suggests this finding could be explained by a difference in focus between the two videos. Group A performed significantly better on questions that addressed the scope of and technical

aspects of testing, such as the range of conditions screened for, while Group B performed significantly better when asked whether prenatal cfDNA screening could determine the biological sex of the fetus. One possible explanation for this finding is that prenatal cfDNA screening is advertised strategically to appeal to pregnant women, and such advertisements may be less focused on the technical aspects of testing and more focused on the positive aspects of testing such as early sex determination. In fact, prenatal cfDNA screening is commonly referred to as the ‘gender test’ by women seeking to pursue it. Thus, our findings indicate clear differences in the focus of information between the two videos. More research needs to be done to determine the informational focus of videos produced by commercial testing companies and to assess whether they provide balanced information to women seeking prenatal cfDNA screening.

Attitudes

Attitude assessment results showed that respondents from both groups viewed prenatal cfDNA screening favorably after watching their respective videos and that there was no significant difference in attitude scores between the two groups or between any of the demographic subgroups. This finding is similar to other studies concerning prenatal cfDNA screening, which found that most participants viewed this type of prenatal screening favorably (Allyse et al., 2014; Georgsson et al., 2016; Kelly & Farrimond, 2011; Lewis et al., 2014; Lewis et al., 2016; Sahlin et al., 2016). However, several trends in attitudes amongst respondents were noted. One trend was that lower age corresponded to a more favorable attitude towards prenatal cfDNA screening. While there are no conclusive explanations for this phenomenon, younger respondents may be more receptive to genetic screening as it has recently become a more prevalent practice in the general population. Younger respondents may also be more likely to view screening as a mode of reassurance. In addition, older respondents could be cognizant of the fact that they are more likely to receive positive results and thus may feel more apprehensive towards screening tests. Another correlation was that participants with previous pregnancies held a less favorable attitude towards prenatal cfDNA screening. This hesitancy could be due to the newness of the screening and the fact that participants may not have had this specific type of screening in their previous pregnancies. Participants

with a prior pregnancy may also feel that they were able to have successful pregnancies without prenatal cfDNA screening and therefore consider it unnecessary. More research needs to be done to examine the reasons underlying these two trends.

Qualitative Data

There was a clear difference in the main take-home messages reported by the two groups after watching their respective videos. Despite the fact that both of the videos contained the same information necessary to answer the knowledge portion of the survey, respondents appeared to place importance on different aspects of the videos. Those in Group A often addressed the informative portions of the video such as the breadth and depth of testing. In contrast, respondents in Group B tended to focus on specific catch phrases, such as ‘gender’ or how early in pregnancy the screening could be performed. These findings reflect the trends seen in terms of performance between the two groups on certain knowledge test questions, and thus speak to the focus of the videos themselves. The main take-home messages reported by the participants also suggest that Video B (created by a commercial genetic testing company) functions as more of an advertisement than Video A (created by a non-profit genetics organization). This is something that should be considered by providers considering offering either of these videos as a means of patient education. Providers themselves often rely on commercial testing companies for education regarding prenatal cfDNA screening, so consideration of the source and potential slant of a video employed with patients is important (Farrell et al., 2016).

Study Limitations

There were some inherent limitations to our study. One limitation is that the sampling methodology resulted in a demographically homogeneous study sample. Most of the participants were Caucasian and college-educated. It could be said that the recruitment methods were not sufficient for representation of the general population; however, it could also be argued that this is the most relevant population to study currently because, as noted by Allyse et al. in their 2015 publication, this group is currently the population

with the most access to prenatal cfDNA screening. While our study cohort may not be as representative of the general population as desired, it serves as a foundation for more research.

Another limitation is that videos alone are unable to address all of the relevant components that comprise informed consent, particularly in ensuring that women are making choices that are consistent with their values. Multiples prior studies have mentioned the importance of using educational tools that also take into account patient values, therefore acting as a more comprehensive decision aid (Lewis et al., 2016; Stefansdottir et al., 2010; van den berg et al., 2005; van den berg et al., 2006; Vanstone et al., 2014). While it would be ideal for patients to speak to their provider or a genetic counselor before seeking screening in order to clarify which options align with their values, the purpose of this study and previous similar studies has been to educate a population that may not have access to a genetic counselor or are considered low-risk. For this purpose, a solution would be to include videos like the ones in this study as part of a comprehensive interactive tool that both educates and enables participants to interact meaningfully in the decision-making process. This is doubly important given that multiple studies have cited concerns that prenatal cfDNA screening will become a part of routine blood work because of its non-invasive nature, thereby diminishing attention to informed consent as a result. (Allyse et al., 2015; Allyse et al., 2016; Dondorp et al., 2015). Without informed consent regarding prenatal cfDNA screening, women may have no preparation for the results they could receive.

One potential limitation that could explain the significant difference in knowledge scores between the two groups is the particular videos that were included in this study. While they were matched to ensure a similar length and baseline amount of knowledge, there were aspects of each video that could not be controlled. The distinct focus of each video could also account for the varied qualitative responses, as previously discussed.

Areas for Future Study

While this study has contributed to a better understanding of patients and their experiences being educated about prenatal cfDNA screening at the present time, more research needs to be done in this area. One area

for future research would be comparison of knowledge gained by patients during counseling sessions in clinic versus knowledge gained from videos alone. There has been a dearth of studies comparing clinical, provider-based experiences and educational tool-based knowledge, particularly for prenatal cfDNA screening; such studies could be very illuminating and potentially useful. In addition, as mentioned before, educational videos could be part of a comprehensive decision aid that assists patients in making informed choices by including a values alignment component; further research should be done to test the impact of such a tool once it is developed. Lastly, another area of potential study is determining the impact of videos created by commercial testing companies on patient education. Countless videos about prenatal cfDNA screening have been produced by commercial testing companies and are available online. For a number of people, these videos could be their first encounter with information about prenatal cfDNA screening and thus could form the basis for the rest of their experience.

Conclusions

Our study suggests that videos can in fact effectively educate patients about prenatal cfDNA screening and that patients' attitudes about prenatal cfDNA screening are positive overall. However, the focus and origin of a video should be carefully considered by providers prior to use as those factors seem to variably influence main take-home messages. Given that an increasing number of providers will likely be pursuing the use of alternative counseling aids such as videos to help facilitate informed consent and decision-making, it is crucial that those resources provide a balanced view of the testing in question.

References

- ACOG Committee on Genetics. (2015). Committee Opinion No. 640: Cell- free DNA Screening for Fetal Aneuploidy.
- ACOG Committee on Practice Bulletins. (2016a). Practice Bulletin 162: Prenatal Diagnostic Testing for Genetic Disorders.
- ACOG Committee on Practice Bulletins. (2016b). Practice Bulletin 163: Screening for Fetal Aneuploidy.
- Allyse, M., Sayres, L. C., Goodspeed, T. A., & Cho, M. K. (2015). Attitudes Towards Non-Invasive Prenatal Testing for Aneuploidy Among United States Adults of Reproductive Age. *J Perinatol*, 34(6), 429–434. <http://doi.org/10.1038/jp.2014.30>.
- Allyse, M., Sayres, L. C., Goodspeed, T., Michie, M., & Cho, M. K. (2016). Public Understandings of the Risks and Benefits of Non-Invasive Prenatal Testing in the United States. *AJOB Empir Bioeth*, 6(1), 5–20. <http://doi.org/10.1080/23294515.2014.994722>.
- Dondorp, W., de Wert, G., Bombard, Y., Bianchi, D. W. Bergmann, C., Borry, P., et al. (2015). Non-invasive prenatal testing for aneuploidy and beyond: challenges of responsible innovation in prenatal screening. *Eur J Hum Genet*, 23, 1438-1450. <http://doi.org/10.1038/ejhg.2015.57>
- Dugas, M., Shorten, A., Dubé, E., Wassef, M., Bujold, E., & Chaillet, N. (2012). Decision aid tools to support women’s decision making in pregnancy and birth: a systematic review and meta-analysis. *Soc Sci Med*, 74(12), 1968–1978. <http://doi.org/10.1016/j.socscimed.2012.01.041>
- Farrell, R. M., Agatista, P. K., Mercer, M. B., Mitchum, A. G., & Coleridge, M. B. (2016). The use of noninvasive prenatal testing in obstetric care: Educational resources, practice patterns, and barriers reported by a national sample of clinicians. *Prenat Diagn*, 36(6), 499–506. <http://doi.org/10.1002/pd.4812>
- Fonda Allen, J., Stoll, K., & Bernhardt, B. A. (2016). Pre-and post-test genetic counseling for chromosomal and Mendelian disorders. *Semin Perinatol*, 40(1), 44–55. <http://doi.org/10.1053/j.semperi.2015.11.007>

- Georgsson, S., Sahlin, E., Iwarsson, M., Nordenskjöld, M., Gustavsson, P., & Iwarsson, E. (2016). Knowledge and Attitudes Regarding Non-Invasive Prenatal Testing (NIPT) and Preferences for Risk Information among High School Students in Sweden. *J Genet Counsel*.
<http://doi.org/10.1007/s10897-016-9997-y>
- Goel, V., Glazier, R., Holzapfel, S., Pugh, P., & Summers, A. (1996). Evaluating Patient's Knowledge of Maternal Serum Screening. *Prenat Diagn*, 16, 425–430.
- Graham, W., Smith, P., Kamal, A., Fitzmaurice, A., Smith, N., & Hamilton, N. (2000). Randomised controlled trial comparing effectiveness of touch screen system with leaflet for providing women with information on prenatal tests. *Br Med J*, 320, 155–160.
- Green, J. M., Hewison, J., Bekker, H. L., Bryant, L. D., & Cuckle, H. S. (2004). Psychosocial aspects of genetic screening of pregnant women and newborns. *Health Technol Assess*, 8(33).
- Hewison, J., Cuckle, H., Baillie, C., Sehmi, I., Lindow, S., Jackson, F., & Batty, J. (2001) Use of videotapes at home to inform choice in Down syndrome screening: a randomised controlled trial. *Prenat Diagn*, 21, 146-149.
- Hunter, A., Cappelli, M., Humphreys, L., Allanson, J., Chiu, T., Peeters, C., et al. (2005). A randomized trial comparing alternative approaches to prenatal diagnosis counseling in advanced maternal age patients. *Clin Genet*, 67, 303–313. <http://doi.org/10.1111/j.1399-0004.2004.00405.x>
- Kelly, S.E., & Farrimond, H.H. (2012). Non-invasive prenatal genetic testing: a study of public attitudes. *Public Health Genomics*, 15(2), 73-81. <http://doi.org/10.1159/000331254>
- Kupperman, M., Norton, M., Gates, E., Gregorich, S., Learman, L., Nakagawa, S., et al. (2009). Computerized Prenatal Genetic Testing Decision-Assisting Tool. *Obstet Gynecol*, 113(1), 53–63.
- Kuppermann, M., Pena, S., Bishop, J. T., Nakagawa, S., Gregorich, S. E., Sit, A., et al. (2014). Effect of Enhanced Information, Values Clarification, and Removal of Financial Barriers on Use of Prenatal Genetic Testing. *J Am Med Assoc*, 312(12), 1210–1217.
<http://doi.org/10.1001/jama.2014.11479.Effect>

- Lewis, C., Hill, M., & Chitty, L. S. (2016a). A qualitative study looking at informed choice in the context of non-invasive prenatal testing for aneuploidy. *Prenat Diagn*, *36*, 875–881.
<http://doi.org/10.1002/pd.4879>
- Lewis, C., Hill, M., & Chitty, L. S. (2016b). Women ' s Experiences and Preferences for Service Delivery of Non-Invasive Prenatal Testing for Aneuploidy in a Public Health Setting : A Mixed Methods Study. *PLoS ONE*, *11*(4), 1–16. <http://doi.org/10.1371/journal.pone.0153147>
- Lewis, C., Hill, M., Skirton, H., & Chitty, L. S. (2015). Development and validation of a measure of informed choice for women undergoing non-invasive prenatal testing for aneuploidy. *Eur J Hum Genet*, *24*(6), 809–816. <http://doi.org/10.1038/ejhg.2015.207>
- Marteau, T. M., & Dormandy, E. (2001). Facilitating informed choice in prenatal testing: How well are we doing? *Am J Med Genet - Semin Med Genet*, *106*(3), 185–190.
<http://doi.org/10.1002/ajmg.10006>
- Nagle, C., Lewis, S., Meiser, B., Gunn, J., Halliday, J., & Bell, R. (2008). Exploring general practitioners' experience of informing women about prenatal screening tests for foetal abnormalities: a qualitative focus group study. *BMC Health Serv Res*, *8*(114). <http://doi.org/10.1186/1472-6963-8-114>
- Nagle, C., Lewis, S., Meiser, B., Metcalfe, S., Carlin, J. B., Bell, R., et al. (2006). Evaluation of a decision aid for prenatal testing of fetal abnormalities: a cluster randomised trial. *BMC Public Health*, *6*(96).
<http://doi.org/10.1186/1471-2458-6-96>
- Rink, B. D., & Norton, M. E. (2016). Screening for fetal aneuploidy. *Semin Perinatol*, *40*(1), 35–43.
<http://doi.org/10.1053/j.semperi.2015.11.006>
- Russo, M. L., & Blakemore, K. J. (2014). A historical and practical review of first trimester aneuploidy screening. *Semin Fetal Neonatal Med*, *19*(3), 183–187. <http://doi.org/10.1016/j.siny.2013.11.013>
- Skirton, H., Goldsmith, L., Jackson, L., Lewis, C., & Chitty, L. S. (2015). Non-invasive prenatal testing for aneuploidy : a systematic review of Internet advertising to potential users by commercial companies and private health providers. *Prenat Diagn*, *35*, 1167–1175.
<http://doi.org/10.1002/pd.4673>

- Vanstone, M., King, C., de Vrijer, B., & Nisker, J. (2014). Non-Invasive Prenatal Testing: Ethics and Policy Considerations. *J Obstet Gynaecol Can*, 36(6), 515-526.
- van den Berg, M., Timmermans, D. R. M., ten Kate, L. P., van Vugt, J. M. G., & van der Wal, G. (2006). Informed decision making in the context of prenatal screening. *Patient Educ Couns*, 63, 110–117. <http://doi.org/10.1016/j.pec.2005.09.007>
- van den Berg, M., Timmermans, D. R. M., Ten Kate, L. P., van Vugt, J. M. G., & van der Wal, G. (2005). Are pregnant women making informed choices about prenatal screening? *Genet Med*, 7(5), 332–338. <http://doi.org/10.1097/01.GIM.0000162876.65555.AB>
- Wilson, K. L., Czerwinski, J. L., Hoskovec, J. M., Noblin, S. J., Sullivan, C. M., Harbison, A., et al (2013). NSGC practice guideline: Prenatal screening and diagnostic testing options for chromosome aneuploidy. *J Genet Couns*, 22(1), 4–15. <http://doi.org/10.1007/s10897-012-9545-3>
- Woolf, S. H., Chan, E., Harris, R., Sheridan, S. L., Braddock, C. H., Kaplan, R. M., et al. (2005). Promoting Informed Choice: Transforming Health Care To Dispense Knowledge for Decision Making. *Ann Intern Med*, 143, 293–300.
- Yee, L. M., Wolf, M., Mullen, R., Bergeron, A. R., Bailey, S. C., Levine, R., et al. (2014). A randomized trial of a prenatal genetic testing interactive computerized information aid. *Prenat Diagn*, 34, 552–557. <http://doi.org/10.1002/pd.4347>

Supplementary Material: Survey Questions

Section One

1. Open Question: What is your main takeaway after watching this video (1-2 sentences)?
2. How many times did you watch the video?
 - 1
 - 2
 - 3
 - 4
 - 5 or more

Section Two: Knowledge Test

For each of the following questions, please answer with one of the following options: True/False/Not Sure

3. Prenatal cfDNA screening involves taking blood from a pregnant woman's arm.
4. Prenatal cfDNA screening can tell you the sex of your baby (boy vs. girl).
5. Prenatal cfDNA screening gives a Yes or No answer regarding if the baby has a genetic condition.
6. Prenatal cfDNA screening looks for all possible genetic conditions.
7. If a woman receives an "increased risk" result on prenatal cfDNA screening, further tests are needed in order to be able to tell if anything is truly wrong.
8. Women who have a "decreased risk" result on prenatal cfDNA screening can be sure that their baby will not have Down syndrome.
9. Prenatal cfDNA screening can test for chromosomal abnormalities other than Down Syndrome.
10. Prenatal cfDNA screening is optional.
11. Prenatal cfDNA screening can be done as early as 6 weeks of pregnancy.
12. Having a test like prenatal cfDNA screening performed can cause a miscarriage.

Section Three: Attitude Assessment

For each of the following five questions, please circle the number from 1 to 5 that best describes how you feel at about each statement provided. If you are not currently pregnant, please answer the way you *think you would feel if you were currently pregnant*.

13. For me, having prenatal cfDNA screening would be beneficial:

Strongly Disagree 1 2 3 4 5 Strongly Agree

14. For me, having prenatal cfDNA screening would be important:

Strongly Disagree 1 2 3 4 5 Strongly Agree

15. For me, having prenatal cfDNA screening would be a good thing:

Strongly Disagree 1 2 3 4 5 Strongly Agree

16. For me, having prenatal cfDNA screening would be reassuring:

Strongly Disagree 1 2 3 4 5 Strongly Agree

17. For me, having prenatal cfDNA screening would be desirable:

Strongly Disagree 1 2 3 4 5 Strongly Agree

Section Four: Demographic Survey

18. How old are you?

- 20-24
- 25-29
- 30-34
- 35-39
- 40-44

19. What is your highest education completed?

- High School
- Partial College
- College Degree
- Advanced Degree

20. Which of the following best describes you?

- White/Caucasian
- Black
- Hispanic
- Asian
- Other: _____

21. Do you have a religious faith? Yes/No

22. If Yes, which faith?

- Christian
- Jewish
- Muslim
- Hindu
- Buddhist
- Sikh
- Other: _____

23. If Yes, how religious are you?

- Very
- Somewhat
- Not at All

24. Do you work or are you you training to work in a healthcare related profession?

- Yes
- No

25. If yes, what best describes your profession or training?

- Genetic counselor
- Genetic counseling student
- Physician
- Medical school student
- Nurse
- Nursing student
- Other health profession
- Training for another health profession

26. Have you ever been pregnant?

- Yes
- No

27. If yes, did you have a screening test for Down Syndrome in any of those pregnancies?

- Yes
- No
- Not Sure
- N/A - Pregnancy ended in termination or miscarriage before testing

28. If yes, what best describes the circumstances in which you underwent screening for Down syndrome:

- My healthcare provider *offered* the option of screening and I elected to undergo it
- My healthcare provider *recommended* that I undergo screening
- I requested screening for Down syndrome during my pregnancy

29. If no, what best describes the reason that you did not undergo screening for Down syndrome:

- My healthcare provider *offered* screening for Down syndrome but I chose not to have it.
- My healthcare provider told me about the screening but did not recommend it for me
- I was never told about prenatal screening for Down syndrome during my pregnancy

30. If you were offered screening for Down Syndrome in a prior pregnancy, and you decided not to have it done, what was the reason (check all that apply)?

- I did not feel a screening test would be helpful for me because I knew I wanted to have a diagnostic test (amniocentesis or CVS)
- I would never terminate an affected pregnancy so did not feel the information would be helpful for me
- If positive, I would never have an invasive test to confirm and put my pregnancy at risk
- It would have caused a lot of anxiety if I found out I was high risk
- Screening wouldn't have given me a definite result
- My partner or family did not want me to
- I preferred not to know

31. Were you found to be high risk in any of those pregnancies? (only ask those who said they underwent screening)

- Yes
- No
- Not Sure

32. Did you have an invasive test (CVS or amniocentesis)?

Yes

No

Not Sure

33. What was the outcome?

Diagnosis of Down Syndrome

Diagnosis of another condition

Normal result

Miscarriage as the result of an invasive test

Not Sure