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Assessing Social Media for Themes of Trisomy 18 and 13

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ASSESSING SOCIAL MEDIA FOR THEMES OF TRISOMY 18 AND 13

by

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ABSTRACT

Themes within virtual communities have been explored examining topics such as prenatal diagnosis and termination for fetal anomalies, and it is known that when receiving a diagnosis of trisomy 18 or 13 parents may turn to online resources for information and emotional support. Knowledge of what content patients may encounter on various social media platforms about prenatal testing for trisomy 18 and 13 at large has not yet been established. However, this information would aid healthcare professionals in providing anticipatory guidance for patients using social media.

This study is a preliminary scan of social media to identify content areas and topics within posts regarding prenatal testing for trisomy 18 and 13. It is the first, to the researcher's knowledge, to use monitoring software and artificial intelligence within the field of genetic counseling to quickly analyze a large number of posts using the Crimson Hexagon platform.

A total of 26,740 posts were retrospectively collected from January 1, 2018 until August 30, 2019 from publicly available social media sources. Posts considered Off-Topic were excluded from analysis. The remaining 15,748 posts were placed into one of three categories: Experience (52%), Support/Emotion (25%), or Information (23%).

Experiences described involved ultrasound findings, test results, a previous affected pregnancy, and pregnancy management decisions. The category of Support/Emotion was comprised of others' reactions to pregnancy management

decisions, risk perception analysis for other users, and sympathetic or empathic responses. Information within posts included screening and testing options, procedure risks, and the accuracy of testing.

Based on the content areas and topics of conversation identified in this study, healthcare providers should anticipate that patients may turn to social media as an important source of support and information for their patients who are faced with a positive prenatal screen or diagnosis of trisomy 18 or 13.

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CHAPTER 1

BACKGROUND

1.1 Trisomy 18 and Trisomy 13

Trisomy 18 and trisomy 13 are chromosomal conditions that are the result of an additional chromosome and occur with a frequency of 1/6,670 and 1/12,240 livebirths, respectively (Meyer et al., 2016). Trisomy 18 (i.e., Edward syndrome) and trisomy 13 (i.e., Patau syndrome) are associated with congenital anomalies in multiple organ systems. Common features of trisomy 18 and 13 include: prenatal onset growth retardation, cardiac anomalies, microcephaly, digestive system anomalies, urinary anomalies, and limb anomalies (Springett et al., 2015). Additionally, hydrocephalus, esophageal atresia, and omphalocele are common in trisomy 18, while central nervous system anomalies and polydactyly are common in trisomy 13 (Springett et al., 2015). Approximately 10-15% of children with these conditions survive past one year of age. Children living longer are able to vocalize or use purposeful eye gaze in order to make choices, show preferences for family members, engage in social play, explore objects with their hands, and sit independently for several minutes at a time (Bruns, 2015). Additionally, older children with trisomy 18 may be able to ambulate with gait trainers and similar mobility devices (Bruns, 2015).

Trisomy 18 and 13 have high mortality rates. Approximately half of the pregnancies affected by trisomy 18 or 13 end in spontaneous fetal death or death during delivery (Houlihan & O'Donoghue, 2013). In a large population-based study of survival

among children with trisomy 18 or trisomy 13, Meyer et al. (2016) found that the survival rate for trisomy 18 was 37.2% at 28 days and 13.4% at a year; the survival rate for trisomy 13 was 25.5% at 28 days and 11.5% at a year. For infants surviving to a year, survival to 5 years was 86.8% for those with trisomy 18 and 82.5% for those with trisomy 13 (Meyer et al., 2016). It is possible that these numbers will increase if more infants are receiving full interventions; however, there are reasons, such as insufficient respiratory drive and comorbid conditions, such as complex heart abnormalities, that may make intervention more likely to harm than benefit an infant (Brosco & Feudtner, 2017). It was first demonstrated that interventions including cesarean delivery, resuscitation by intubation, mechanical ventilation, and surgical operations had an impact on infant mortality when Kosho et al. (2006) found that maximum interventions increased the usual 1-year survival rate from 5-8% to 25% in 24 infants with trisomy 18.

1.2 Prenatal Screening for Trisomies

The American College of Obstetricians and Gynecologists (ACOG) and the Society for Maternal-Fetal Medicine (SMFM) recommend all pregnancies be offered screening for common aneuploidies (American College of Obstetricians and Gynecologists [ACOG], 2016b). Prenatal screening for these conditions can be accomplished via maternal blood sampling and/or ultrasound screening in the first or second trimester of pregnancy. When prenatal screening is accomplished by maternal blood sampling, analytes are measured during the first or second trimester of pregnancy and compared to the values from other pregnant women of the same gestational age to give an individualized risk estimate for the chance that the pregnancy is affected by the conditions being screened for. Analytes measured include: PAPP-A, β -hCG, hCG, AFP,

DIA, and uE3, as well as nuchal translucency measurement by ultrasound in the first trimester of pregnancy (10-13 weeks). Screening may also be accomplished by measuring the levels of cell-free DNA from the placenta in maternal blood; this is non-invasive prenatal screening (NIPS). The detection rate for NIPS lies close to 98-99% for trisomy 21, 18, and 13 (Yu et al., 2017). Trisomy 21, 18, or 13 may be suspected by abnormal values identified through the above screening methods or when fetal structural anomalies and/or “soft markers” are observed on first or second trimester ultrasound. “Soft markers” may be seen in healthy pregnancies; however, they are seen in higher frequencies in affected pregnancies. These include increased nuchal measurement, absent nasal bone, shortened long bones, renal pyelectasis, and echogenic focus. The most common structural defects reported on ultrasound for trisomy 18 include ventricular septal defect and abnormal posturing of the hands or feet (Houlihan & O'Donoghue, 2013). The most common structural defects reported on ultrasound for trisomy 13 include cleft lip and/or palate, holoprosencephaly, and rocker bottom feet (Houlihan & O'Donoghue, 2013).

1.3 Prenatal Diagnostic Testing for Trisomies

Chorionic villus sampling and amniocentesis are two procedures that allow for definitive prenatal diagnosis of trisomy 18 and trisomy 13. Chorionic villus sampling, CVS, may be pursued between 10 and 13 weeks. In CVS, chorionic villi are biopsied from the placenta. Amniocentesis may be pursued beginning at 16 weeks, and involves collecting cells of fetal and amniotic origin from the amniotic fluid. Cells collected from CVS and amniocentesis are used to perform karyotype and chromosome microarray analysis, making these tests diagnostic. These tests have a high sensitivity, and may be

used to diagnose or rule out trisomy 18 or 13. However, they are also associated with a 0.1-0.3% risk for miscarriage, with the risk for miscarriage from CVS being slightly higher than that for the risk of miscarriage due to an amniocentesis (ACOG, 2016a).

1.4 Decisions Following a Prenatal Diagnosis

When there is a positive prenatal diagnosis of trisomy 18 or 13, in addition to an emotional response, parents are also faced with multiple medical management decisions. Depending on gestational age, one of the first decisions parents may face is whether to continue or terminate the pregnancy. Parents may consider moral, religious and ethical beliefs, views on perceived quality of life with the condition, severity of anomalies found on ultrasound, financial concerns, and their personal situation in making pregnancy management decisions. In a study of parents electing to terminate an affected pregnancy, it was found that parents may make this decision based on their personal perception of decreased quality of life for the baby, mortality of the condition, medical considerations for the baby, their inability to cope with continuing the pregnancy, or family issues (Bet, 2008). Additionally, it was found that parents may experience relief or regret in regards to their decision (Bet, 2008). In another study looking at parents' reasons for continuing a pregnancy affected by trisomy 18 or 13, it was found that parents may do so based on moral beliefs, child-centered, parent-centered, or practical reasons (Guon, Wilfond, Farlow, Brazg, & Janvier, 2014). Medical management decisions related to delivery and neonatal care must be made if the baby is not stillborn. Some parents may choose aggressive medical intervention in order to prolong their child's life, while others may use palliative care as a means to minimize the suffering of their child and maximize the experience they have with their child.

Parents may decide to continue a pregnancy for various reasons, and the reason they continue the pregnancy may determine what interventions they choose for their child. Guon et al. (2014) examined reasons for continuing the pregnancy, interactions with health care providers, parents' hopes and plans for their child, and outcomes and family consequences for parents receiving a prenatal diagnosis of trisomy 18 or 13. They found that parents continuing the pregnancy for child-centered reasons were more likely to choose full interventions than those continuing for parent-centered reasons. Parents continuing for child-centered reasons chose full interventions, doing everything deemed medically necessary to keep their child alive 40% of the time, while those continuing for parent-centered reasons never opted for full interventions. Parents selected interventions based on their child's specific anomalies. The researchers of this study also found that the most common hope described by parents at the time of the diagnosis was that their child would be born alive and they would have a modest amount of time with their child; this was 80% of the parents surveyed. The other 20% hoped their child would be one of the exceptions, one of the survivors. Other hopes were that their child would not suffer, that they would know that they were loved, and that a miracle would occur or that it was a misdiagnosis. (Guon et al., 2014)

In a study of parents who continued their pregnancy after a positive prenatal diagnosis of trisomy 18 or 13, Janvier, Farlow, and Wilfond (2012) found that parents generally feel that taking care of a child with disabilities was harder than they anticipated, but that they believed their child was happy and enriched their lives. Another study found that for parents deciding between medical intervention and palliative care, they unanimously agreed that their child's quality of life was improved by the treatment

selected and that they would choose the same course of treatment again (Davisson, Clark, Chin, & Tunks, 2018).

According to the National Society of Genetic Counselor practice guidelines, when parents are given a diagnosis of Down syndrome, they should be provided with accurate, up-to-date information in a balanced perspective using neutral language (Sheets et al., 2011). These same principles should be applied when providing parents with a diagnosis of trisomy 18 or 13. However, in a study of parents of children diagnosed with trisomy 18 or 13, Wallace, Gilvary, Smith, and Dolan (2018) found that parents felt that their child's diagnosis was not discussed in a nonbiased way, they felt pressured to terminate, and receiving accurate information about the spectrum of the condition was helpful. This is important because the information parents receive regarding a diagnosis is influential to their decision-making (Hall, Abramsky, & Marteau, 2003). When parents don't receive all of the information they want from their healthcare provider, they may turn to social media to provide the answers (Gardner, Carter, & Enzman-Hines, 2016; Juul, Tausch, & Ballard, 1998).

1.5 Social Media

Increasing access to the internet provides individuals with an immense variety of information at their fingertips. In particular, social media allows for greater and more readily available opportunities to communicate with other individuals and communities. Social media comes in a variety of forms including blogs, discussion forums, and social networking.

Blogs can act as an online journal for one to share their experiences and create a community linking the blogger to the reader (Gurak & Antonijevic, 2008). Blogging may

serve as a way for participants to extend their support network or reinforce connections with family and friends (Rains & Keating, 2011). In a survey of the authors of 100 health blogs, researchers found that bloggers felt comfortable discussing their condition on the blog and that they provided support to their readers (Rains & Keating, 2011). Those who blog more frequently feel a greater level of support (Rains & Keating, 2011). Blogs may also be used to gather information and for advocacy purposes (Hamill & Stein, 2011).

Online discussion forums are sites that enable participants to seek answers to their questions from other participants in the form of posted messages. Participants can also hold conversations by posting more messages in a thread linked to the original post. Discussion forums are a way for participants to gather information from others who may be more knowledgeable on a subject.

Social networking sites enable users to connect with one another. This includes sites such as Facebook and Twitter. Groups or topic threads may be formed where individuals can connect based on common experiences or interests. Individuals can post, comment, and interact with posts by other users.

1.6 Social Media Use Surrounding a Trisomy 18 or 13 Diagnosis

In a recent study, Crabbe, Stone, and Filoche (2019) evaluated what women said about NIPS on online pregnancy discussion forums. Women early in their pregnancy or those planning a pregnancy were posting questions trying to decide whether or not to undergo NIPS, and their questions were answered by women who had undergone NIPS, who were further along in their pregnancy, or who had already given birth. Many women posting to these discussion forums were attempting to process varying information from previously read sources. The users appeared to value others' experiences and opinions as

a part of their own decision-making process. Advice given on the forums was sometimes direct and other times passive. Direct advice included parents giving recommendations to consider what the implications of a result would be before pursuing testing and parents providing a cost-benefit analysis about testing. Passive advice included respondents sharing their reasons for selecting NIPS. Common reasons respondents elected for NIPS were to alleviate anxiety or for reassurance. The authors found that when women reported a high-risk result, responders would offer anecdotal evidence to discredit the result, even though participants of these forums highly regarded NIPS for its accuracy pre-test (Crabbe, Stone, & Filoche, 2019). These findings predict some of the themes we can expect to see when looking at social media use in the context of a trisomy 18/13 diagnosis.

In her unpublished thesis from 2013, Ginger Edwardsen surveyed 179 people who had a family member with a diagnosis of trisomy 18, 13, or 21 and completed five phone interviews with mothers to learn about how they use social media as a platform for building a support network and for gathering information. She found that the social media website most often used was Facebook, followed by obtaining information from blogs and pregnancy websites. On reasons for using social media, 90% of surveyed participants used social media to connect with others in a similar situation, 81% used social media to gather information, and 73% used social media to share information. Nearly 80% of participants said that the information they gathered on social media was more useful than the information provided by their healthcare professional. Twelve percent found social media sites through suggestions from their healthcare professional and 66% found sites through an internet search. Sixty-three percent of participants believed providers should

be sharing information about these sites to their patients. These findings indicate areas of need that healthcare professionals could be addressing in their practice. (Edwardsen, 2013)

Additionally, Edwardsen (2013) found that family members of children with trisomy 18 or 13 believed social media was better for providing information about the condition, but many did not feel that social media aided them in making decisions about their pregnancy. However, of parents of children with trisomy 18 or 13, parents of children with trisomy 13 were more likely to believe that social media was useful for this purpose. (Edwardsen, 2013)

Participants in Edwardsen's thesis turned to social media because they felt that there was a lack of information elsewhere. Specifically, they found social media beneficial for providing them with information about how to care for their children born with trisomy 13 or 18. This included types of surgeries and therapies that they should consider for their children. All of this was information that participants felt they were not receiving from members of the medical community. Participants believed social media gave them a more realistic expectation of medical problems to anticipate and when to expect their children to reach certain developmental milestones. They felt that they were able to gain a better understanding of what life is like with a child with trisomy 18 or 13 through social media. The author speculated that this picture may be a bit skewed to promote somewhat unrealistic optimism because most individuals completing the survey had children who were still alive. It may be that these are the individuals who are more likely to be using these social media sites; therefore, they are the individuals who were more likely to complete the survey. (Edwardsen, 2013)

1.7 Themes on Social Media Regarding Diagnoses of Fetal Anomalies

In 2016, two studies were completed in Sweden that looked at virtual community messages for pregnancies diagnosed with fetal anomalies. One study focused on experiences described before, during, and after termination for fetal anomalies while the other surveyed the communication of support and critique about prenatal diagnoses of fetal anomalies.

Carlsson, Bergman, Karlsson, Wadensten, and Mattsson (2016a) explored experiences communicated online about terminations and found themes of emotional shock and feeling it was a difficult decision conveyed prior to the procedure. The theme of emotional shock included feelings of anxiety and unfairness. The difficult decision was conveyed as a choice between continuing the pregnancy and allowing the child to suffer versus terminating the pregnancy with feelings of guilt and emotional pain. Themes described during the termination were a need for compassion care, an experience of intense emotional and physical pain, a lack of understanding about the procedure, and varied feelings about the option to view the fetus. Opinions expressed about viewing the fetus included: finding closure viewing the fetus, content with decision not to view fetus, and regret over decision not to view the fetus. In discussions about an induction, some feared seeing fetal life signs after the induction. Themes for after the termination included: grief and emotional scars; sleeping difficulties; use of objects, events, and dates to mourn; challenges of being reminded of their loss; social withdrawal due to difficulty breaking the news to others; feeling lonely and empty; and a desire for expanded prenatal testing in future pregnancies. This study also mentioned health professional-launched websites as a potential solution for difficulty finding reliable information. They also

suggested that such websites could include film clips about patient experiences. Such web pages should include information that is consistent with a practice's messages and policies in order to be in alignment with the ACOG committee opinion on professional use of digital and social media (ACOG, 2019; Carlsson, Bergman, Karlsson, Wadensten, & Mattsson, 2016a).

The other study reviewed support and critique regarding prenatal diagnoses of fetal anomalies. It assessed four types of support from previously presented theories. The types of support were affirmational support, emotional support, informational support, and instrumental support. Affirmational support was described as affirming emotions, thoughts, and behaviors (Dennis, 2003). Emotional support was described as conveying caring and concern (Helgeson & Cohen, 1996). Informational support was providing information to guide or advise (Helgeson & Cohen, 1996). Instrumental support was defined as practical support, such as reaching out to the poster to offer to talk to them outside of the thread (Carlsson, Landqvist, & Mattsson, 2016b; Dennis, 2003). Carlsson et al. (2016b) found that 54% of support posed was emotional, 22% was affirmational, 22% was informational, and 2% was instrumental. They described 343 meaning units that were words, sentences, or paragraphs exemplifying a given concept. Thirty meaning units voiced critique against termination of pregnancy stating it was ending a life or not giving the fetus a chance to live. Critique of choosing to continue a pregnancy, 6 meaning units, included bringing a disabled child into the world and causing unnecessary suffering and potentially death. Responses to critique, which consisted of 142 meaning units, were all defending the decision to terminate stating that this was a personal decision that was carefully considered. (Carlsson et al., 2016b)

1.8 Crimson Hexagon

Crimson Hexagon (Crimson) was founded in 2007 at Harvard University's Institute for Quantitative Social Science, and is powered in part by IBM AI, International Business Machines-Artificial Intelligence. Crimson is a professional-grade monitoring software that allows one to monitor all publicly-available social media, online news, blogs, and forums. Through another software program called Brightview, Crimson allows a user to collect mentions of words and phrases from these sources and sort them according to parameters that are established by the user. This training allows the user to sort the information by overall tone of the post, emotions associated with the post, or whether it is on or off topic. This software is trainable, so the user can teach Crimson's artificial intelligence exactly what to search for in order to aid in the sorting process.

Previously, Crimson has been used to analyze audiences, track brand perceptions, monitor campaign performance, and detect trends. Using Crimson, it is possible to sort information collected from public forums into categories based on topics of interest within the conversation, such as prenatal screening or testing. This allows one to gather quantitative data about topics that are being discussed on social media. Information may also be organized into categories based on content source, or where the information is coming from: parents or outside sources. Outside sources posting content on trisomy 18 and trisomy 13 can be identified and the form of social media they are using can be tracked. This would identify the forms of social media most likely to contain information presented to promote an agenda.

1.9 Need for Study

Healthcare professionals should be aware of the information and support that is available to their patients via social media, since it is known that patients turn to social media for information and support when they receive a diagnosis of trisomy 18 or 13. To date, there have been no known studies categorizing information presented about trisomy 18 or 13 on social media on a broad scale. With the advent of software that can scan the internet for mentions of a given word or phrase, such as in Crimson Hexagon, this is now an easier task to accomplish. This study is a preliminary scan of social media at large to identify categories of content presented about trisomy 18 and 13 on social media and can highlight the content areas that healthcare professionals should be aware. Providing healthcare professionals with awareness of what patients may be encountering across various social media platforms can aid them in providing anticipatory guidance to their patients.

CHAPTER 2

ASSESSING SOCIAL MEDIA FOR THEMES OF TRISOMY 18 AND 13¹

¹ Metcalf, F., Vincent, V., Park, K., Hill-Chapman, C. To be submitted to *Journal of Genetic Counseling*

2.1 Abstract

Themes within virtual communities have been explored examining topics such as prenatal diagnosis and termination for fetal anomalies, and it is known that when receiving a diagnosis of trisomy 18 or 13 parents may turn to online resources for information and emotional support. Knowledge of what content patients may encounter on various social media platforms about prenatal testing for trisomy 18 and 13 at large has not yet been established. However, this information would aid healthcare professionals in providing anticipatory guidance for patients using social media.

This study is a preliminary scan of social media to identify content areas and topics within posts regarding prenatal testing for trisomy 18 and 13. It is the first, to the researcher's knowledge, to use monitoring software and artificial intelligence within the field of genetic counseling to quickly analyze a large number of posts using the Crimson Hexagon platform.

A total of 26,740 posts were retrospectively collected from January 1, 2018 until August 30, 2019 from publicly available social media sources. Posts considered Off-Topic were excluded from analysis. The remaining 15,748 posts were placed into one of three categories: Experience (52%), Support/Emotion (25%), or Information (23%).

Experiences described involved ultrasound findings, test results, a previous affected pregnancy, and pregnancy management decisions. The category of Support/Emotion was comprised of others reactions to pregnancy management decisions, risk perception analysis for other users, and sympathetic or empathic responses. Information within posts included screening and testing options, procedure risks, and the accuracy of testing.

Based on the content areas and topics of conversation identified in this study, healthcare providers should anticipate that patients may turn to social media as an important source of support and information for their patients who are faced with a positive prenatal screen or diagnosis of trisomy 18 or 13.

2.2 Introduction

Trisomy 18 and trisomy 13 are chromosomal conditions resulting from an additional copy of their respective chromosomes and are associated with congenital anomalies in multiple organ systems. Common features of trisomy 18 and 13 include: prenatal onset growth restriction, cardiac anomalies, microcephaly, digestive system anomalies, urinary tract anomalies, and limb anomalies (Springett et al., 2015). These trisomies involve high morbidity and mortality with approximately half of affected pregnancies ending in spontaneous fetal death or death during delivery and approximately 10-15% of individuals surviving after their first birthday (Bruns, 2015; Houlihan & O'Donoghue, 2013).

Trisomy 18 and trisomy 13, as well as trisomy 21, compose the most common autosomal chromosome conditions likely to result in live birth and prenatal screening for these conditions is available to all pregnant women. Prenatal screening methods include first or second trimester screening through maternal blood sampling (maternal serum analytes or cell free placental DNA in maternal blood) as well as ultrasound during the first and second trimester. Prenatal diagnosis may also be accomplished during a pregnancy through chorionic villus sampling (CVS) and amniocentesis. While these diagnostic procedures have a high sensitivity, they are also associated with a 0.1-0.3%

risk for miscarriage (ACOG, 2016a). Postnatal diagnosis is typically performed on cord or peripheral blood and/or tissue biopsy to confirm by chromosome analysis.

When there is a positive prenatal result of trisomy 18 or 13, expectant parents are faced with multiple medical management decisions. If there is a positive prenatal screen, they must decide if they want to follow up with diagnostic testing. When the diagnosis is confirmed by prenatal testing during the pregnancy, the decisions faced may include continuation or termination of the pregnancy depending on gestational age. Many factors may be considered when making this decision including: moral, religious and ethical beliefs, views on perceived quality of life with the condition, severity of anomalies found on ultrasound, financial concerns, and their personal situation (Bet, 2008; Guon, Wilfond, Farlow, Brazg, & Janvier, 2014).

Another decision parents may face is whether and what types of intervention they would like for their infant with trisomy 18 or 13 when they decide to continue the pregnancy or learn of the diagnosis at birth. Interventions such as cesarean, resuscitation by intubation, mechanical ventilation, and surgical operations may increase survival for some infants (Kosho et al., 2006). Palliative care aims to increase quality of life while medical interventions often aim to increase the life span. Based on a retrospective survey of parents, they unanimously agreed that their child's quality of life was improved by the treatment selected, whether that was medical intervention or palliative care, and that they would choose the same course of treatment again (Davisson, Clark, Chin, & Tunks, 2018).

It is known that patients faced with a diagnosis or possible diagnosis of trisomy 18 or trisomy 13 use social media to build a support network and to gather information

(Edwardsen, 2013). Crabbe, Stone, and Filoche (2019) explored 13 open-access discussion forums to evaluate for themes about non-invasive prenatal testing (NIPT). The researchers found women early in their pregnancy asked others on the forum about their decision to pursue NIPT. They were answered by women who were further along in their pregnancy or who had given birth who had undergone NIPT screening. Women asking about NIPT valued the other women's experiences as part of their decision-making process. Women responding gave either direct recommendations or aimed to provide a cost-benefit analysis. Another study by Carlsson et al. (2016b) reviewed support and critique in regards to prenatal diagnosis of fetal anomalies within virtual communities.

While themes related to prenatal decision making have been documented in previous studies, none have explored the information presented about trisomy 18 and 13 on social media on a broad scale. Software advances make this an easier task to accomplish. This study aims to identify categories of information about trisomy 18 and 13 on social media related to the prenatal decision-making process. This is the first study known to the researcher to use monitoring software and artificial intelligence for research within the field of genetic counseling to identify content areas and topics within a large number of posts. Surveying the discussion around trisomy 18 and 13 on social media can help healthcare professionals to be aware of what patients may encounter if they were to turn to social media sites for information, guidance, or support related to their own situation.

2.3 Materials and Methods

Software

Crimson Hexagon (Crimson) is a Harvard engineered, professional-grade monitoring software that uses Boolean methodology to identify phrases and collect posts (posts and their related comments on discussion forums or blogs, Tweets, and news articles) from publicly available sources on the Internet. Boolean phrases are either true or false, and the software will collect posts where the Boolean phrase is true. For example, if the Boolean phrase used is “trisomy 18 OR trisomy 13” then all of the posts containing either of the phrases will be included. Boolean phrases can be combined to generate a query. The software will collect, or pull, all of the posts for which the phrases included in the query are true. See Appendix A for the query used in this study.

Once posts have been collected, the user can explore posts by reading through a list of the posts or by viewing word clouds or topic wheels generated by Crimson. Word clouds and topic wheels are visual ways to represent words and phrases that are common within the posts with words or phrases that are in more posts taking up more space in the image. When a word or phrase is selected from the word cloud or topic wheel, Crimson generates a list of posts containing these words or phrases for the user to review. This allows the user to explore topics generated within Crimson. This feature was used by the researcher to identify common concepts within the posts without having to read all of the posts collected. This was done twice. The first run was to identify the main categories and the second run, performed after training the software, was to identify subcategories. The word cloud and topic wheel generated for all of the posts collected by the query were

used to systematically explore posts and identify categories; these are included in Appendix B and C respectively.

After categories are identified by the user, Crimson allows the user to train the artificial intelligence software, Brightview, to sort posts into categories according to established parameters. Parameters are a list of words or concepts common within posts that may be used to identify the category where a post belongs. Training is accomplished and parameters established by providing Brightview with posts that represent the categories provided by the user. When Brightview is categorizing posts, the posts cannot be placed into more than one category. Posts used for training were those that represented only one category because using a post that could be placed into more than one category in training can confuse the software, which may mean parameters are not clearly defined and posts may be arbitrarily placed into categories. The process of exploring posts to identify categories and training Brightview to categorize posts is considered one run through Brightview. Two runs through Brightview were completed for the current study: once to generate categories and second to generate subcategories. Brightview allows for the organization of categories into groups to allow numerical analysis of both, so when subcategories were created, they were generated as categories within Crimson and organized into their respective category by treating that category as a group.

Procedure and Content Source Breakdown

Crimson was used to collect mentions of trisomy 18 and trisomy 13 from publicly available sources online from January 1, 2018 until August 31, 2019. The query identified 26,740 posts related to trisomy 18 and 13. Crimson categorized each post according to the site and source type. Posts were collected from over 100 different sites.

Top sites (Figure 2.1) included: babycenter.com (37%), whattoexpect.com (22%), and Twitter (16%). The remaining 25% of posts were from over 97 different sites. The majority of posts were from forums (71%), with the remaining posts from Twitter (16.3%), news outlets (8.8%), and other source types (3.9%). (See Figure 2.2)

After exploring posts gathered by Crimson the researcher created four main categories representing content areas that were the focus of posts: Experience, Support/Emotion, Information, or Off-Topic. The first three categories were posts that were considered on-topic and included in the study. Training posts were selected that resembled the main intent of the post. The Off-Topic category was used to exclude posts from the study when trisomy 18 or 13 was mentioned but not the main focus of the post. This was the first run through Brightview.

The second run through Brightview generated subcategories. To create subcategories, posts considered “on-topic” by the first run were explored by the primary investigator. Subcategories were created to represent content matter within categories. Subcategories were meant to answer what type of experience the author of the post (PA) was describing, what the emotions/support shared was related to, and what type of information was being provided. Crimson was trained to place the posts into each of the subcategories or into the Off-Topic category in the second run through the software. The posts placed into one of the subcategories were considered “on-topic” and included in the study, while those placed into the Off-Topic category were excluded. The second run through Brightview could place posts which were considered off-topic in the first run into an “on-topic” category in the second run. The number of posts considered “on-topic” or Off-Topic could change between the first and the second run. A similar concept applies

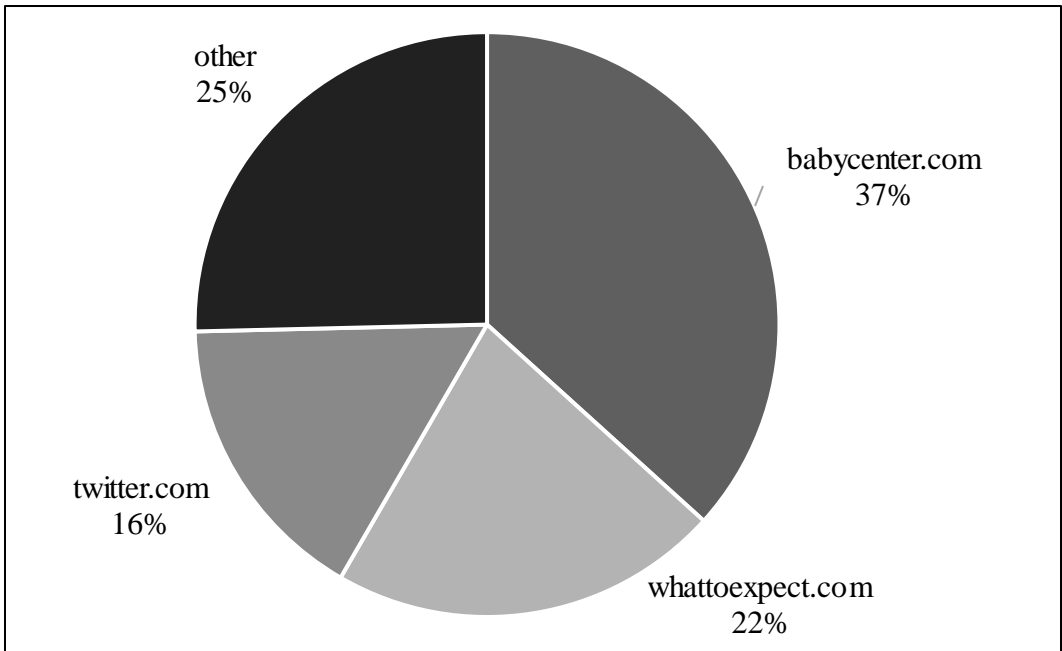


Figure 2.1. Percent of posts from top websites.

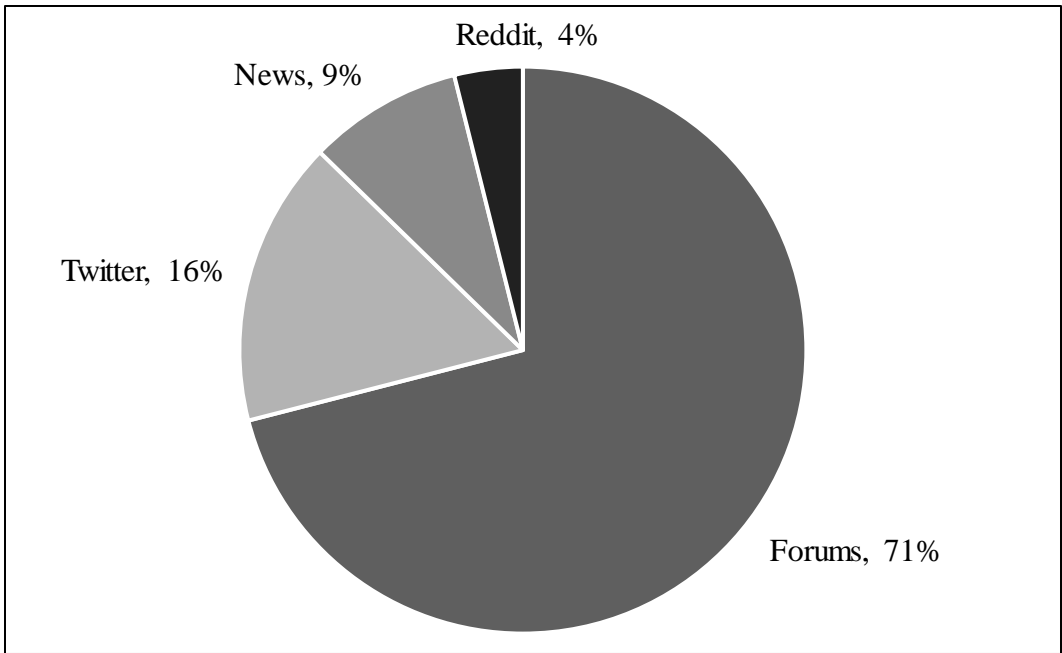


Figure 2.2. Percent of posts from source type.

for the number of posts within each category. For this reason, quantitative results were collected from the second run through the software and exported to Microsoft Excel. The 15,748 posts still considered “on-topic” after the second run through Brightview were those included in analysis for this study. For a visual representation of workflow through Crimson see Figure 2.3.

It is important to note that the number of categories that can be created in Crimson is limited, so this is not an exhaustive list of themes identified. Instead the categories and subcategories created serve to provide a framework for grouping posts based on the primary content area of the post and topic within a given content area.

2.4 Results

The number of posts varied month to month, with the largest amounts of posts seen in January 2018, April 2018, August 2018, January 2019, May 2019, and August 2019. These trends were seen both in the total number of posts and, specifically, on-topic posts. Volume of posts over the 20-month period is included in Figure 2.4.

The three main categories analyzed were Experience (52%), Support/Emotion (25%), and Information (23%). The first category, Experience, was further divided into four subcategories: Ultrasound Findings, Test Results, Previous Affected Pregnancy, and Pregnancy Management Decisions. The second category, Support/Emotion, was divided into three subcategories: Reaction to Pregnancy Management Decisions, Risk Perception, and Sympathetic/Empathic Responses. The last category, Information, was divided into three subcategories: Screening and Testing Options, Procedure Risks, and Accuracy of Testing. See Table 2.1 for a breakdown of the amount of posts within each category.

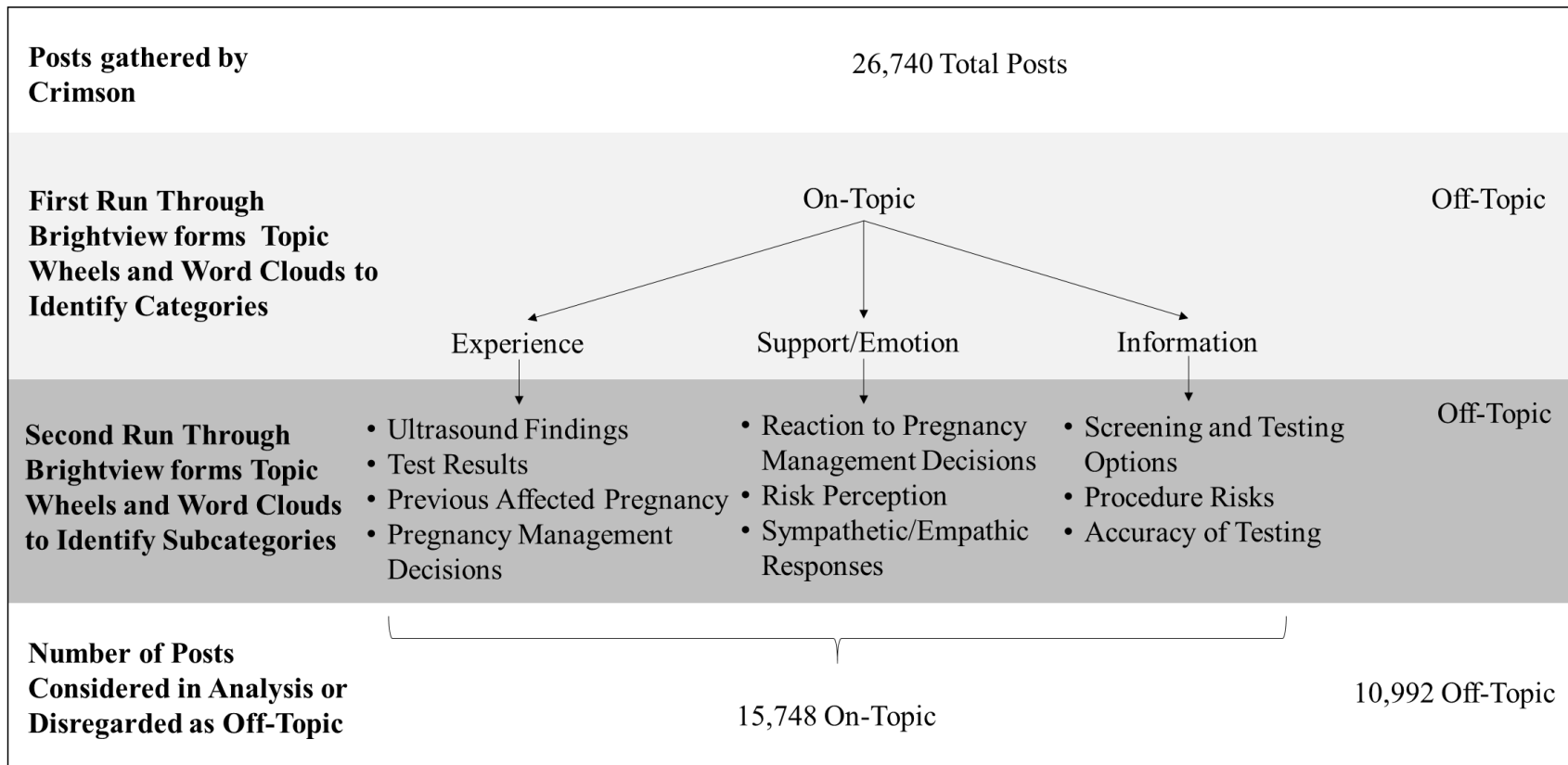


Figure 2.3. Workflow in Crimson for categorizing posts.

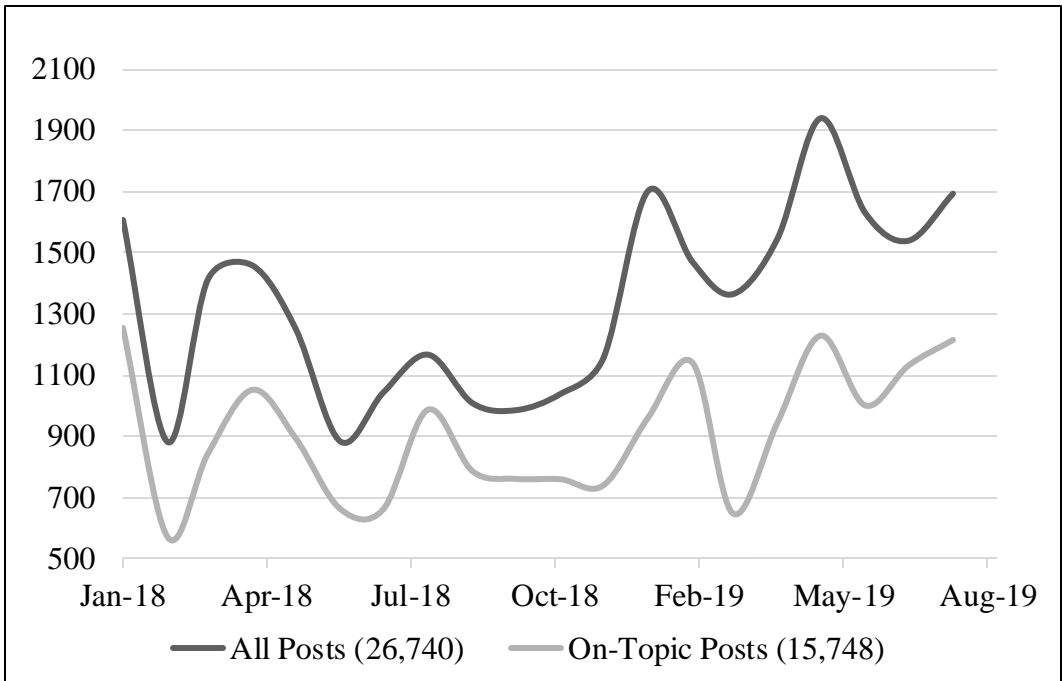


Figure 2.4. Volume of posts between January 1, 2018 and August 31, 2019.

Table 2.1. Quantifying posts within each category.

Category/Subcategory	N	% of Total
<u>Experience</u>	8172	51.9%
Ultrasound Findings	3040	19.3%
Test Results	2065	13.1%
Previous Affected Pregnancy	1541	9.8%
Pregnancy Management Decisions	1526	9.7%
<u>Support/Emotion</u>	3961	25.2%
Reaction to Pregnancy Management Decisions	1657	10.5%
Risk Perception	1475	9.4%
Sympathetic/Empathic Responses	829	5.3%
<u>Information</u>	3615	23.0%
Screening and Testing Options	1677	10.6%
Procedure Risks	1140	7.2%
Accuracy of Testing	798	5.1%
Total On-Topic Posts (N=15,748)		

Experience

The category of Experience comprised of descriptions of ultrasound findings, tests results, a previous affected pregnancy or child, and making pregnancy management decisions. Posts describing experience with ultrasound focused on soft markers identified, primarily choroid plexus cysts, and the use of ultrasound to identify anomalies.

Is this a choroid plexus cyst? If so, they're not uncommon, they generally go away, and they're just a soft marker for Trisomy 18. SOFT marker. Most babies with a choroid plexus cyst are normal.

I had my anatomy scan last week and just got to see my full report. They said they noticed bilateral cysts in her choroid plexus. My NIPT test was normal and so was my AFP [alpha fetoprotein] so my dr didn't mention them to me. I found the report in my patient portal and went on a google hunt. I'm just wondering if anyone else here had these on their scans and if they went away or anything. The only thing that made me nervous was i read that they can be associated with trisomy 18 when other factors are also spotted on ultrasound. Namely malformed feet, low amniotic fluid, clenched fists, and heart defects. Her feet and my fluids were fine, but they couldn't get a good look at her heart and fingers. She was making a fist. I thought fists and such were normal.. it's likely nothing, but it has given me pause. I suppose I'm looking for a bit of reassurance. Thanks.

The experience of test results was shared in two main formats, either being identified as "high" or "low" risk, or given numerically.

My last pregnancy came back as high risk for trisomy 18 from the nipt test. I opted to do the cvs testing to test further.

The probability was showing 1 in 17 chance that our baby has Trisomy 13 and Trisomy 18.

The experience of a previous affected pregnancy was met with three main responses.

Some individuals expressed a strong desire to have a healthy pregnancy.

I understand the feelings of wanting to be pregnant again soon. We lost our son Elijah in March, full term, due to Trisomy 18. I'm not pregnant yet, but we are also TTC [trying to conceive].

Some individuals shared ways they were able to cope with their loss.

I terminated at 16 weeks in September of last year for Trisomy 18. I was devastated. There is a group here called 'D&E' [dilation and evacuation] that helped me get through and be mentally prepared as to what to expect.

Other individuals shared a desire for increased screening in subsequent pregnancies.

My husband and I lost our sweet baby to trisomy 18 last October, so this time we are doing the NIPT right away.

Experiences around pregnancy management decisions included discussions about how they made their choice and what the consequences were, which were sometimes brought up in relation to a decision another author was about to make.

The decision to end a much wanted baby due to trisomy 18 still haunts me even though I know we made the right decision. Just know that you took on a lifetime of pain so your baby never has to.

I lost my daughter due to Trisomy 13 which has a similar life expectancy and comes with similar deformities as Trisomy 18. We found out much earlier than you did because of NIPT testing but chose to continue with the pregnancy

knowing that at some point we would most likely lose her. Of course it was very painful to lose her but I will never regret the decision to give her a fighting chance at life...

Support/Emotion

Posts in the category Support and Emotion included reaction to pregnancy management decisions, perception of risk based on another PA's test or screening results, and sympathetic or empathic responses to another PA's post. Reactions to pregnancy management choices may be that the PA made the best decision that they could in a difficult situation or that the PA was wrong to terminate their pregnancy. Often posts that criticized the PA's right to terminate were followed by posts that defended or supported the PA's right to make that decision.

The point is parents have to make the decision that is right for themselves and their own families. Whether others disagree with their reasons or not is irrelevant. It's such a personal decision...

...Termination isn't for everyone but it is the right decision for some. I hope you get answers and can find peace with whatever decision you make.

Make a decision you are comfortable with. YOU are the one that has to live with your choices, and you are not required to justify or explain yourself to anyone.

Posts regarding risk perception dealt with risk in a variety of ways from sentiments like "most likely everything is fine" to breaking down the numbers to consider what the chances for a given result look like logically.

I'd feel pretty confident in those results. They catch 99% of trisomy 21, and upper 90% for trisomy 18 and 13.

With odds like this, it's like taking a whole deck of cards (minus 10) and saying you're going to pull out a 2 of clubs and then actually pulling out that exact card.

That's one in 42. Your odds are good, Mama!

Sympathetic and empathic responses were given in a variety of situations to offer support to the PA.

I am so sorry to hear this. My heart is breaking for you.

I can only imagine how scary that must be. I have no advice or answers for you, Just hugs and prayers.

I am so sorry this is happening. We TFMR [terminated for medical reason] our baby boy in 10/17 for T21. It is a life changing experience and I understand the pain and shock you are going through...

Information

Individuals provided information about the accuracy of screening and testing options, the risks related to diagnostic procedures, and the screening and testing options available. The detail given for the accuracy of testing ranged from explaining the difference between screening and diagnostic testing to providing the sensitivity/detection rate or positive predictive value of a given screening option.

It is a SCREENING not a diagnostic test. So if the result comes back positive it does not guarantee your child has Down syndrome or Edwards. A positive result means you should consider doing a diagnostic test such as a CVS or an amnio but again you do not have to do a diagnostic or screening test.

NIPT is 99% accurate.

The positive predictive value is low (38%) on Panorama screening.

Procedure risks examined numerical values as well as the emotional response to procedures.

I would do the CVS, as long as the person performing the test has significant experience there is extremely small risk- the risk statistics commonly stated (1 out of 300) are very outdated.

Personally I'm opting in to screening for Edward's and Patau's syndrome only.

This is because I wouldn't terminate in the event that my child had Down syndrome and therefore wouldn't risk a miscarriage from an amnio.

Posts involving screening and testing options varied in detail from "NIPT is the blood test that gives gender" to full descriptions of all screening and testing options available.

NIPT is a DNA test on maternal blood to screen pregnancies for the most common fetal chromosome anomalies: trisomy 21 (Down syndrome), trisomy 18 (Edwards syndrome) and trisomy 13 (Patau syndrome). Also the gender of the fetus is determined.

Any NIPT testing does produce false positives, and they're more common for T18 and T13 than for T21. Only an amnio or CVS can be diagnostic.

2.5 Discussion

Categories and Themes

Past studies have shown that social media can provide information or support to patients and families about all kinds of medical or genetic conditions. Using Crimson software, online posts from a 20-month period were analyzed to determine types of posts on social media related to prenatal screening or diagnosis of trisomy 18 and 13. Posts were sorted into three categories of interest. A little over half of the posts were

categorized as Experience with the remaining half split almost evenly between Information and Support/Emotion. The number of posts describing experience suggest that people turn to social media to share their experience with others or to elicit information or support from other users.

While categories analyzed in this study provided structure to group the posts based on the primary content area and topics within a content area, this was not the only information gleaned from the posts. Posts identified in this study also represented themes described in previous studies.

One theme found in this study was also described in a recent study by Crabbe, Stone, and Filoche (2019) which found that when an NIPT comes back as high risk, anecdotal evidence may be provided to discount the result or to share mistrust in the results of testing.

I had high risk NIPT for trisomy 18, but NT scan looked fine. I opted for an Amnio with a specialist (lower risk for miscarriage depending on the expertise of the dr) and it came back all clear.

...But I must also stress my anger and frustration that everything with our baby was fine, and we went through a month of pure agony and a dangerous and invasive test to show that things were fine.... all because of an optional blood screen. An optional blood screen that was touted as being essentially foolproof. An EXPENSIVE optional blood screen that we have to pay for even after it scared the daylights out of us, and countless other expectant parents, by being WRONG...

In addition to finding posts providing anecdotal evidence of false positives, the current study also found that when a positive result was given the PA may attempt to elicit such responses in a search for hope that their own result was a false positive as well.

Has anyone received results like this that turned out to be fine with further diagnostic testing? I need some hope right now.

My doc called and told me there were abnormalities relating to Trisomy 18. Please tell me someone out there has had a false positive.

One post even reflects that the PA had searched for hope with her own positive result and wanted to share her experience to offer hope to others with positive screening results that this may be a false-positive.

So I am writing this to give someone that was in my shoes hope. If you are anything like me, you are Googling the heck out of Trisomy 18 and looking for any sort of hope that the "test" was wrong. We were extremely fortunate because in our case, it was a false positive...

Another PA shared that she believes the discussion forums are meant to be an avenue for helping others in a similar situation. She was sharing her experience with false-positive screening and how she wished she had known this was a possibility of screening before she had her testing.

...when we opted to have that test we had no idea of what it actually meant, and it took me a lot of time researching on the company's website to find any statistic other than the 99% accuracy one... It's about trying to help other women who might find themselves in a similar situation by sharing our experiences- aren't these Boards supposed to be about supporting each other!?

This supports the notion that individuals may turn to social media upon the receipt of positive NIPT screening in search of hope that this is a false-positive result and that they will find others who had that experience. Knowing this, healthcare providers may provide anticipatory guidance for their patients that when they turn to social media they should expect to see examples of a variety of outcomes for screening. They may find users who describe false-positive results, and this is expected because false-positives are an expected consequence of screening.

In a previous study by Carlsson, Landqvist, and Mattsson (2016b), it was found that within a virtual community there was criticism related to patients' decisions to either continue or terminate a pregnancy when fetal anomalies were detected. They also found that criticism of the PA's decision to terminate tended to be met with defense from other users that this was a personal decision that was carefully considered. The current study found posts consistent with Carlsson, Landqvist, and Mattsson's findings. However, in this study it was found that many posts criticizing the decision to terminate had been deleted from the discussion forums. These deleted comments (or posts) were identified on their original forums when the researcher viewed responses criticizing another user for their lack of compassion regarding another PA and found a note stating that the previous comment had been deleted. Quotes from this study that support the previous findings of Carlsson, Landqvist, and Mattsson have been included below.

There is absolutely no reason other than being completely selfish to bring a severely disabled child into the world. If the disability is detected in the womb, then an abortion should be had and you can try again.

The point is parents have to make the decision that is right for themselves and their own families. Whether others disagree with their reasons or not is irrelevant.

Carlsson, Landqvist, and Mattsson (2016b) also assessed four types of support found on social media. They identified affirmational, emotional, informational, and instrumental support within the threads. Examples of these forms of support were also identified within the current study. Affirmational support was found within the Sympathetic/Empathic Responses subcategory and represented by support for the decision-making process or through affirming emotions. Emotional support was also seen in many sympathetic and empathic responses. Posts within the Information category represented informational support. Instrumental support was also observed in the Information category and occurred when a PA offered resources to another user.

The intention of this study was not to assess the validity of the information presented about trisomy 18 and 13; however, there was some accurate information as well as misinformation found in the posts collected. One misconception observed in this study was that there should be a family history of a trisomy for a woman to be at risk of having an affected pregnancy. Another was that the positive predictive value given to one person would be the same for someone else. Healthcare providers may be concerned about what types of misinformation are propagated on social media, so assessing the types and prevalence of misinformation on pregnancy forums may be an area for future study.

Post Sources and Trends

Pregnancy forums such as babycenter.com, tended to focus more on experience while other sites, such as Twitter and those that contained news articles, may contain

more posts designed to promote an agenda. For example, some posts observed on news sites and shared through Twitter contained potentially inflammatory content around pro-life or pro-choice debates. Healthcare professionals should be aware that this is content that their patients may come across online and may wish to provide anticipatory guidance as appropriate.

There were multiple months with spikes in the amount of posts over the 20-month period with January 2019 and May 2019 representing the two months with the most posts. The researchers believed this might reflect current topics and represent temporal changes in the amount and content of the posts. To explore this idea, a list of posts during these months was generated within Crimson in an effort to identify recurring content. Exploration of these lists revealed news articles referenced within the posts that focused on the topic of women's termination rights that comprised almost half of the posts collected from Twitter during January and May of 2019.

In January 2019, an article was shared comparing one woman's experience with spontaneous abortion from trisomy 18 to her friend's experience terminating a pregnancy affected by trisomy 18. This article was shared on sites other than pregnancy forums and accounted for 45% of tweets that month. Additionally, a news article was released about a professional athlete whose daughter had passed away from complications related to trisomy 18. This news article was shared in 18% of all posts during January 2019.

Another noticeable spike in posts occurred in May 2019 around the time an article was released about a couple who almost terminated a healthy child based on a false positive screening result. This article was shared on sites other than pregnancy forums and accounted for 44% of tweets during May 2019.

Practice Implications

The emphasis of posts identified in this study tended to be the experience of prenatal testing for trisomy 18 and 13. Based on the content areas, topics of conversation, and themes identified in this study, healthcare providers should anticipate that when their patients turn to social media regarding prenatal testing for these conditions they will be able to find descriptions of others' experience with screening, diagnosis, and pregnancy management as well as information about these processes. They should also anticipate that patients will find support or criticism for their decision-making process.

Study Limitations

While Crimson allows the researcher to categorize posts, the number and types of posts collected are limited by capabilities of the software and input from the researcher. The monitoring software in Crimson is limited by the phrases submitted by the researcher in the Boolean query, so relevant posts not including one of the phrases submitted would not be collected and included in the study. The software also is limited to posts that are still publicly available when the monitoring software is run, so posts that were deleted before posts are collected cannot be included and important concepts from these posts may be missing. Once posts are collected, Brightview works to categorize posts through word choice instead of overall sentiment that can lead to a discrepancy between where the researcher and the program may categorize a given post.

Other limitations include the inability of a post to be placed into more than one category and a limit on the number of categories that may be created within the software. A post may fall into more than one category; however, Brightview will place it into the category where the artificial intelligence software determines it to fit the best. This means

there may have been more posts that contained sentiment that would fall into the categories of Information or Support/Emotion; however, they may have been placed in the Experience category because more content within that post would be classified as experience over information or support/emotion.

This study was limited to publicly available sites, where there did not appear to be many discussions about clinical features of the condition or caring for a child with trisomy 18 or 13. The researchers suspect this information was more likely to be found in private support groups, so this information was missing from this study.

Research Recommendations

This study examined the types of posts available on social media to gain insight regarding the types of information about trisomy 18 and 13 in pregnancy that is available to patients and the public. Using monitoring software and artificial intelligence the researcher was able to gather large amounts of data quickly. This or similar software that would allow for the creation of more categories could be utilized in future studies to assess public discourse about a variety of topics within the field of genetic counseling such as prenatal screening, genetic testing, and specific genetic conditions other than just those related to trisomy 18 and 13.

CHAPTER 3

CONCLUSIONS

Social media is a readily available resource that patients will continue to use. Healthcare providers should be aware of what their patients will find on social media. This study analyzed information presented about trisomy 18 and 13 on social media and public forums related to pregnancy and prenatal testing. Findings from this study inform healthcare providers to anticipate that when patients turn to social media regarding prenatal testing for these conditions, they will find an abundance of information about the experience of prenatal screening, diagnosis, and pregnancy management as well as support for their decision-making process.

This study was accomplished using monitoring software and artificial intelligence to gather and categorize a large number of posts. This is technology that could be applied to other questions in the field of genetic counseling to provide answers about what is being discussed on social media within the public domain to efficiently analyze a large amount of data.

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APPENDIX A

QUERY USED TO COLLECT POSTS IN CRIMSON HEXAGON

Trisomy_SOFT OR (trisomyawareness AND ("trisomy 18" OR "trisomy 13")) OR (HopeforTrisomy AND ("trisomy 18" OR "trisomy 13")) OR (TrisomyAdvocate AND ("trisomy 18" OR "trisomy 13")) OR (TrisomyHelp AND ("trisomy 18" OR "trisomy 13")) OR (TrisomySurvivor AND ("trisomy 18" OR "trisomy 13")) OR "Trisomy 18" OR edwardssyndrome OR trisomy18 OR trisomy18awareness OR trisomy13 OR patau OR PatauSyndrome OR ("trisomy 13" AND decision) OR ("trisomy 13" AND abortion) OR ("trisomy 13" AND discussion) OR ("trisomy 13" AND termination) OR ("trisomy 13" AND advice) OR ("trisomy 13" AND experience) OR (T13 AND "positive diagnosis") OR (T18 AND "positive diagnosis") OR ("trisomy 18" AND decision) OR ("trisomy 18" AND abortion) OR ("trisomy 18" AND discussion) OR ("trisomy 18" AND termination) OR ("trisomy 18" AND advice) OR ("trisomy 18" AND experience)

