

1-1-2013

Use of Social Media as a Support Network in Families with a Child Diagnosed with Trisomy 13, 18, or 21

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Use of Social Media as a Support Network in Families with a
Child Diagnosed with Trisomy 13, 18, or 21

by

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Submitted in Partial Fulfillment of the Requirements

For the Degree of Master of Science in

Genetic Counseling

School of Medicine

University of South Carolina

2013

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Dedication

For Grace: 46, XX

Acknowledgements

I would like to thank my family for all of their support and guidance over the last twenty years of school. You have constantly shown your support during times of frustration and times of success, and I cannot even begin to tell you how much your encouragement and belief in my abilities means to me. Mom and Dad, thank you for answering all of my panicked phone calls and helping me develop the skills that have led me to become a genetic counselor. Thank you to my baby sister, Grace, for always being my biggest supporter and more importantly, my biggest inspiration.

I would like to thank Jared, my partner and best friend, for all of your love and support. I truly could not have done any of this without you. Thank you for your wisdom and your strength throughout this process. I am truly grateful to have you in my life.

To my advisor, Andrea and my committee members, Cam and Rob – I would like to thank you for sharing your expertise and guidance throughout this project.

Thank you to the families that participated in this study for sharing your thoughts, time, and passion.

Finally, I would like to thank my classmates, “The Lucky Seven”, for filling our graduate school experience with love, laughter, and support. A special thank you to Cassie for your friendship and keeping me motivated over the last two years.

Abstract

Social media is a web based technology that allows individuals to communicate with other individuals, organizations, and communities about common interests and experiences. Recently, social media use has expanded into the healthcare field and many individuals are using social media to connect with others in similar situations and find support. Family members of children or pregnancies with trisomy 13, 18, or 21 were invited to participate in an online survey that explored the use of social media as a support network including their purposes for using social media as a support network, how often they use social media, and what information they gain from social media. Data from 94 trisomy 13/18 participants and 77 Down syndrome participants were used for statistical analysis while additional qualitative data was collected through ten telephone interviews. The majority of participants used Facebook (89%), blogs (59%), and pregnancy websites (39%) as their main forms of social media for support. Participants reported using social media for the purposes of gathering information (81%), sharing information (73%), connecting with others in a similar situation (90%) and because of the ease of use (56%). Seventy-nine percent (79%) of participants indicated that information gathered from social media was “much more helpful” or “more helpful” than information gathered from their healthcare professional. Qualitative data from the telephone interviews identified various themes related to social media use including the search for support, a sense of community, types of information gained from social media, and viewpoints on the healthcare community. Based on this information, a list of

recommendations was created for genetic counselors and other healthcare professionals on how to present social media to families as a support option, including discovering local support options, accessing families thoughts and feelings about using the internet for support, creating a list of appropriate social media and sites, and providing the list to the family at an appropriate time.

Keywords: Down syndrome, social media, support, trisomy 13, trisomy 18

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Chapter 1: Background

1.1 Social Media

Social media is web based and mobile based technology that allows individuals to interact and communicate with other individuals, organizations, and communities (Kietzmann, Hermkens, McCarthy, & Silvestre, 2011). Social media is a part of “Web 2.0”, in which content is created and continuously updated by multiple users in order to collaborate and improve the application (Kaplan & Haenlein, 2010). A certain aspect of Web 2.0 known as User-created Content (UCC) is the main platform in which much of social media is built upon. In order for content to be considered UCC, it must be made available publically over the internet, it must have a certain amount of creative efforts and it must be “created outside of professional routines and practices” (Vickery & Wunsch-Vincent, 2007; p.9).

Social media comes in a variety of forms, with the main categories including blogs, collaborative projects, and social networking (Kaplan & Haenlein, 2010). Blogs are webpages that allow individuals to journal about their experiences and interests as well as share and deliver information (Vickery & Wunsch-Vincent, 2007). Blogs are updated in regular intervals with entries that are date-stamped and presented in reverse chronological order (Gill, 2004). Blogs can be created by downloading blogging software and hosting them on a server (ex: Wordpress) or they can be created through blog hosting sites (ex: Blogger) (Vickery & Wunsch-Vincent, 2007). Blogs are generally

created and updated by a single individual but enable readers of the blog to comment, allowing there to be interaction between the blogger and the blog readers (Kaplan & Haenlein, 2010). Collaborative projects are webpages that allow multiple users to create and edit content. The most well-known form of collaborative project is Wikipedia, in which multiple users can edit information by adding or deleting content on a particular page. Collaborative projects allow many individuals to come together in order to provide information for the purpose of achieving an overall better outcome (Kaplan & Haenlein, 2010). Social networking sites are webpages that allow users to connect by creating profiles in which friends and colleagues can gain access to and communicate with the individual (Vickery & Wunsch-Vincent, 2007).

Social networking sites are one of the most widely used forms of social media and include websites such Facebook, YouTube, and Twitter. Facebook, founded in 2004, allows individuals to create profiles and share information with friends including photos, links, and videos (Facebook, 2012). Facebook is one of the most visited websites in the world connecting individuals across the globe. With the implementation of Facebook pages and groups, individuals who have a common interest can come together in one location to discuss their interest in a centralized location. YouTube, founded in 2005, allows individuals to “watch and share originally-created videos” about a variety of topics. YouTube can be used by anyone from major music artists to show music videos, to large corporations to display their latest products. As of 2011, YouTube had more than one trillion video views which is equivalent to 140 views for every person on earth (YouTube, 2013). Twitter is a “microblogging” website in which individuals share “small bursts of information called Tweets” (Twitter, 2012a). Each tweet is 140 characters long

or less and connects people to news, ideas, opinions, and thoughts. Individuals can add hashtags (#) to certain words in a tweet and it instantly becomes a searchable category on Twitter (Twitter, 2012b). These social networking sites create a unique opportunity in which individuals across the world can connect with one another to share common thoughts and feelings, all with the click of a mouse.

1.2 Trisomy 13, 18 and 21

Trisomy 13, 18, and 21 are chromosomal conditions caused by the addition of an entire chromosome. This addition of an extra chromosome is known as aneuploidy. These conditions generally result in some form of intellectual disability, growth restriction, and multiple congenital anomalies as a result of too much genetic information present in each cell of the body. The addition of an extra chromosome is due to an error during meiosis known as nondisjunction. Nondisjunction results when a pair of chromosomes fails to separate properly, yielding one cell to have two chromosomes of the pair and the other to have none. When the cell with two copies of the chromosome pair is fertilized it results in a trisomy of that chromosome (Nussbaum, McInnes, & Willard, 2007). Although all women are at risk, nondisjunction events occur more often in women as they age. Due to this risk, women are routinely offered screening and diagnostic testing options during pregnancy to screen for aneuploidy of chromosome 13, 18, and 21. Although all chromosomes are subject to nondisjunction, chromosomes 13, 18, and 21 are the most likely conditions to result in live birth. Due to the higher number of genes on the other autosomes, aneuploidy of these chromosomes are lethal prenatally (Nussbaum et al., 2007).

Trisomy 21, more commonly known as Down syndrome, is the most common of these chromosome conditions. In 95% of cases, Down syndrome is caused by an additional chromosome 21 and is the most common genetic cause for intellectual disability. Down syndrome prevalence is dependent on maternal age and gestation. Down syndrome accounts for one in every 150 first trimester spontaneous pregnancy losses and one in every 800 live births (Hunter, 2001). Down syndrome can be diagnosed either prenatally or postnatally through chromosome analysis by karyotype (Nussbaum et al., 2007). About 50% of pregnancies with Down syndrome have findings on ultrasound including single umbilical artery, intracardiac echogenic focus, echogenic bowel, and shortened long bones which may help lead to a diagnosis prenatally.

Physical features commonly observed in individuals born with Down syndrome include low muscle tone, up-slanting of the eyes, flat nasal bridge, mild to moderate intellectual disability and congenital heart defects in fifty percent of individuals (Hunter, 2001). Individuals with Down syndrome should undergo genetic evaluation in order to assess their physical and developmental needs. The implementation of early intervention along with regular visits with primary care physicians is suggested in order to maintain their developmental and physical health (Bull, 2011). Although mortality rates are still higher compared to the general population, especially during infancy, the majority of individuals with Down syndrome now live well into their sixties. Organizations such as the National Down Syndrome Society (NDSS) and the National Down Syndrome Congress (NSDC) seek to provide awareness and support for the Down syndrome community by providing information and resources. These organizations have continued

to grow and along with local Down syndrome organizations have continued to advocate and educate about individuals with Down Syndrome (NDSS, 2012).

In 94% of cases, Trisomy 18, also known as Edwards syndrome, is caused by an extra chromosome 18. Unlike trisomies 21 and 13, about 50% of nondisjunction events in trisomy 18 occur during meiosis II rather than meiosis I making its nondisjunction pattern unique (Carey, 2001). Trisomy 18 occurs one in every 5,000 births with the majority of pregnancies with trisomy 18 ending in spontaneous abortion. Prenatally, pregnancies with trisomy 18 may include choroid plexus cysts, polyhydramnios, intrauterine growth retardation, and a strawberry shaped calvarium. These ultrasound findings often lead to a prenatal diagnosis of trisomy 18 which can be confirmed with diagnostic testing before or after birth. Individuals born with trisomy 18 have severe intellectual disability, failure to thrive, restricted growth, and a severe heart defect. Other features that may be seen are overriding clenched fists, low set ears, rocker bottom feet, and a small receding jaw. Trisomy 18 is a lethal condition and most of these individuals do not live past the first year of life (Carey, 2001; NML-NIH, 2012b; Nussbaum et al., 2007).

In 80% of cases, Trisomy 13, also known as Patau syndrome, is caused by an extra chromosome 13, while 20% of cases are a result of a translocation involving the critical region located on 13q. About 80% of pregnancies with trisomy 13 are detected on ultrasound by the presence of polyhydramnios, clefting, single median central ventricle or a heart defect (Carey, 2001). Trisomy 13 occurs in one in every 15,000 to 20,000 live births with the majority of pregnancies affected resulting in spontaneous abortion. Individuals born with trisomy 13 have severe intellectual disability, extra fingers and toes, cleft lip and/or palate and overall problems in the central nervous

system. Like trisomy 18, trisomy 13 is considered a lethal condition with most of these individuals not living past the first year of life (NML-NIH, 2012a; Nussbaum et al., 2007). Organizations such as Support Organization for Trisomy 18, 13 and related disorders (SOFT) seek to offer support to parents who are expecting or parenting a child with trisomy 13 or trisomy 18. These organizations have a strong online presence and allow families from across the world to connect with each other and increase awareness and education related to these conditions for both families and professionals (SOFT, 2012).

1.3 Social Support

Social support can be defined as “an advocative interpersonal process that is centered on the reciprocal exchange of information and is context specific” (Finfgeld-Connett, 2005, p.5). There are two main types of social support: structural and functional. Structural support involves the presence of others in an individual’s life. This may include entities such as family, friends, religion, or organizations. Functional support can be further divided into instrumental and emotional support. Instrumental support is tangible support such as money and information, whereas emotional support involves support of an individual’s self-esteem by displaying compassion and comfort (Beeher & Glazer, 2001; Finfgeld-Connett, 2005). Social support in its various forms provides individuals with a way to cope with stress in their life, through the connection with others that are close to them.

When seeking social support in times of stress, many people turn to what is known as their strong-tie network, a group of people from which one draws support, usually family members and close friends. However, in certain situations, some

individuals find it difficult to seek support and comfort from someone in their strong-tie network. In this case, weak-tie support networks may be effective. Weak-tie networks are comprised of individuals that a person may interact with on a daily basis but with whom they do not have a strong connection (Adelman, Parks, & Albrecht, 1987; Albrecht & Adelman, 1987). With the introduction of the internet, individuals' access to weak-tie networks has expanded and allowed for social support for various reasons, including support for health conditions (Albrecht & Goldsmith, 2003; Wright & Bell, 2003).

While various events can trigger stress and the need for social support, diagnosis of a condition, especially a genetic condition, in a family can create unique challenges that can be addressed through the use of social support. The diagnosis of a genetic condition creates many different emotional reactions among family members. Although genetic conditions are diverse and have numerous outcomes and management strategies, many of the emotions that are experienced by families in which there is a genetic condition are similar. McAllister et al. (2007) identified eight emotional effects of genetic conditions on individuals and families with various genetic conditions: anxiety, worry about risk to children, guilt, anger, uncertainty, sadness and grief, depression, and redemptive adjustment. Genetic conditions have the unique emotions of guilt and worry about passing on the condition that many acquired conditions do not have. These emotions create added stress and need for additional support such as psychosocial counseling in order to address these feeling of guilt and worry in regards to having the condition in the family (McAllister et al., 2007). Additionally, due to the rarity of genetic conditions such as Down syndrome, trisomy 13, and trisomy 18, additional or similar emotions may be experienced by these families because of their inability to connect with

others in a similar situation. Although many of these emotions can be experienced in other situations, further understanding the emotions and need for support in families with genetic conditions can provide insight into how healthcare professionals can assist during these times of need.

One area in which individuals with various healthcare conditions, including genetic conditions, receive support is through in-person support groups. Support groups can offer an area in which both parents and affected youth are able to gain psychosocial support, participate in a social gathering, gain education and awareness of their conditions, or raise public awareness and funds for research (Plumridge, Metcalfe, Coad, & Gill, 2012). In a recent study by Plumridge et al. (2012) evaluations of genetic support groups were conducted in order to explore how parents and children communicate about genetic risk information as well as the role of support groups. Different models of family communications were considered in order to assess these roles. Support groups in this study offered support in a variety of ways including face to face visits, internet and telephone support, as well as having a worker come and visit with the family personally. Assessment of involvement of young people in the support groups was conducted and younger children were found to be more involved in support groups than teenagers, mainly because older teens were able to continue friendships without the formality of a support group. It was also found that many parents wanted their children to wait some time (6-12 months) after diagnosis to be involved in a support group in order for them to become more familiar and comfortable with their diagnosis. As expected, many families enjoyed the empathy and understanding of others in similar situations that attending a support group provides. However parents also expressed concern that regular attendance

to a support group would expose their children to some of the physical and mental manifestations of the disease, perhaps evoking anxiety. Last, parents felt more confident in talking with their children about their genetic condition after attending support groups, but felt that they still needed more information on how to discuss genetic risk information to their children (Plumridge et al., 2012). This study was the first study to explore support groups involving individuals with genetic conditions. Further studies are still needed in order to explore the role of support groups more fully and better understand the uniqueness that genetic support groups offer to individuals with genetic conditions.

1.4 Social Media in Health

While social media has grown exponentially in popularity for personal use, introduction of social media into the healthcare community is still in its infancy. Since the rise of social media has grown so rapidly over the last few years, healthcare providers quickly have had to learn how to bring social media into their daily practices in order to be more connected with their patients. It is becoming more evident that “Web 2.0” now has a subcategory of “Health 2.0”(Hackworth & Kunz, 2011). It is estimated that over 60 million Americans participate in “Health 2.0 resources” including video and photo sharing, user-driven rating systems, wikis and blogs (Kane, Fichman, Gallagher, & Glaser, 2009). It seems appropriate that if patients are consistently using social media in order to gain more knowledge about various aspects of health, healthcare providers also need to be a part of the online health community (Hackworth & Kunz, 2011).

Articles on how to best implement social media into health care practices have been published in a variety of disciplines including dermatology, oncology, and hand surgery. Common themes include ways to implement Facebook, Twitter, blogs, and other

social media venues to create a stronger online presence for their field in general. These articles describe ways these practices can better communicate with their patients through social media sites, including providing suggestions on how to present information that is accurate to the patient population (Anderson, 2012; Chen, 2012; Collier, 2012; Travers, 2012). Along with the benefits of social media use, these articles address ways in which the healthcare professionals maintain privacy and professionalism while participating in social media. The Health Insurance Portability and Accountability Act (HIPPA) prohibits releasing any medical information of a patient without authorization, allowing the patient to protect their own health information. Extreme caution is advised in order to maintain HIPPA requirements. In addition, the ethical dilemma on whether or not to allow patients to interact with healthcare professionals on their personal social media pages is of growing concern. Healthcare professionals are encouraged to make sure they are in control of their “social media footprint” by maintaining their privacy settings and remaining professional if they choose to include patients as a part of their personal social media (Travers, 2012, p. 172).

Recently, Fisher and Clayton (2012) sought to assess patient interest in the use of social media for healthcare by surveying patients’ social media preferences as well as their perceived barriers of social media used in a healthcare setting. Of the patients surveyed, e-mail, texting, and Facebook were the preferred venues of social media, with the younger generations favoring social media over the older population. In regards to social media’s use in healthcare, over half of the respondents specified that they would consider using social media if it were offered by their healthcare provider. Respondents felt that social media could be utilized for setting up appointments, communicating about

lab results, notifying the patient about prescriptions, education and health information, as well as a location in which they could ask their healthcare provider general questions. Respondents did express concern over the use of social media and their privacy and a lack of personal benefit as potential barriers of social media in healthcare. This study is one of the first to quantify the desire and preference of social media use in healthcare. Further research is still needed to determine how healthcare professionals feel about implementing social media into their practice. In addition, studies demonstrating satisfaction of social media implementation are also needed (Fisher & Clayton, 2012).

1.5 Social Media and Its Role in Social Support in Health

Every day the internet allows individuals to access information and other individuals with shared commonalities, such as a common disorder or condition. Research examining the use of social media for support by individuals with certain health concerns has started to surface within the last couple of years. Online communities have been shown to provide support and a sense of community among individuals with physical disabilities by increasing the availability of social and moral support to a community that has reduced mobility (Obst & Stafurik, 2010). Similarly, teens and young adults with attention-deficit/hyperactivity disorder (ADHD) have found a location in which they can discuss their thoughts, troubles, and insights into their disorder as well as identify as a group through the use of Facebook groups (Gajaria, Yeung, Goodale, & Charach, 2011). Children diagnosed with asthma found online support using e-mail, chat sessions, and online community bulletin boards allowed them to communicate more openly about their problems than they would be able to in a face-to-face conversation. They also enjoyed talking with other youth with similar conditions and it aided in

boosting some participants' low self-esteem (Letourneau et al., 2012). With the introduction of forums, blogs, and chat rooms, individuals in these various communities are able to come together for support without having to leave the comfort of their home. It provides them with a community in which they can discuss their feelings openly without fear of judgment or misunderstanding.

A large portion of health related social media centers around chronic disease and illness such as cancer, diabetes, and fibromyalgia. Research has shown that websites and social networking sites are becoming an increasingly more popular venue for information, especially among the younger generations (Lam, Roter, & Cohen, 2013). Prevention, information, and support are among the top three goals of many Facebook and Twitter groups centered on breast cancer, colon cancer, and diabetes (Chen, 2012). Discussion of treatment such as chemotherapy, surgical prevention, and coping skills are common among cancer online support groups, whereas depression and management of symptoms are common in diabetes and fibromyalgia online discussions. Social media has also acted as a venue of support for individuals with other healthcare concerns, including pregnancy loss. Common themes such as the feeling of not being alone, validation and safety, and the ease and convenience of the internet are all reasons that social media support has become increasingly more prevalent in this population. The internet provides an area in which these topics are more acceptable for discussion and where users' emotions are understood and accepted by individuals they have never met. Online support has also been found to help these individuals "move on" at their own pace by being able to communicate with others 24 hours a day instead of having to wait for

another in-person support group (Chen, 2012; Gold, Boggs, Mugisha, & Palladino, 2012).

Along with online support groups, one aspect of social media that has become prevalent in the health field is blogging about one's experience with a certain health condition. Blogs have the ability to be private or public. On one hand, blogs act as an online diary in which individuals can share their experiences. On the other hand, blogs create a community in which the blogger writes for the readers, and the readers become linked with the blogger (Gurak & Antonijevic, 2008). Recently, the social dimension of blogging about health has been studied in order to "examine the relationship among health blogging, social support and psychosocial well-being" (Rains & Keating, 2011, p.512).

Rains and Keating (2011) reviewed over 100 blogs whose main purpose was to discuss and share the author's experiences with certain health conditions. Authors of these blogs were asked to participate in an online survey that measured their social support and measures of well-being. Survey results indicated that bloggers who blogged more frequently reported greater levels of support. Information that bloggers' received from their readers had a positive association on their ability to manage their health condition. Blogging was also found to reinforce connections with family and friends by some bloggers, and many bloggers were able to extend their support network through blogging. Along the same lines, bloggers that lacked support from family and friends were found to be less lonely and gained personal growth from blog reader support. Additionally, the results showed that bloggers were comfortable discussing their health condition on their blog and were able to themselves provide support to their readers

(Rains & Keating, 2011). In addition to discussing and gaining support from blogs, blogs have been used for information gathering and advocacy in other disability communities (Hamill & Stein, 2011).

Although there have been studies that have examined social media in health settings, additional research is needed in order to better understand why families and individuals with health concerns choose social media as their way to find support. Additionally, studies involving the use of social media as a support network for individuals with genetic conditions have yet to be conducted. As stated previously, genetic conditions provide a unique set of emotions and challenges for families (McAllister et al., 2007). Therefore, understanding these families' reasons for using social media for support will perhaps provide the healthcare community with a better general understanding of the use of social media for support as a whole.

1.6 Need for this Study

Social media has provided a venue in which hundreds of thousands of individuals can connect with each other over a common network, a concept that even a few years prior was unattainable. Through the implementation of blogs, Twitter, Facebook, and other social networking sites, individuals from across the globe are able to communicate with each other about their common interests and find support and friendship with individuals with whom they might otherwise never have connected. In an era in which individuals tend to turn to their computers instead of turning to their doctors for information about their health, it seems necessary that the healthcare community become involved and aware of social media. While research has been conducted on healthcare professionals' involvement in social media in regards to professionalism and patient

privacy, little research has been done on how individuals use social media as a support system related to their health or how healthcare professionals can use social media to connect their patients with other individuals with similar diagnoses (Anderson & Klemm, 2008; Gabbard, Kassaw, & Perez-Garcia, 2011; Jent et al., 2011; Mansfield et al., 2011).

Genetic counselors serve a unique role by not only providing information about the underlying genetic etiology of genetic disorders, but also serving as a counselor to support and guide patients as they come to terms with their diagnosis. Genetic counseling is “ the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease” by integrating the “interpretation of family and medical histories...education about inheritance, testing, management, prevention, resources and research, [and] counseling to promote informed choices and adaptation to the risk or condition” (Resta et al., 2006; p. 77). Among many, trisomy 13, 18 and 21 are conditions that are routinely diagnosed in the prenatal and pediatric genetic counseling arenas. In families who have a child diagnosed prenatally with trisomy 13, 18, or 21, the genetic counselor is with them throughout the entire process of screening, testing, and diagnosis. This process allows the counselor to establish a relationship and provide support to the family during this time. Additionally, after a child is born with one of these conditions, they receive care from a multitude of healthcare professionals including but not limited to genetic counselors, geneticists, cardiologists, pediatricians, and physical therapists.

By surveying families of children diagnosed with a trisomy condition who are actively using social media as a support network, we hope to understand both how and why social media is currently being used for this purpose. We will be gathering

information from families who use social media in order to better understand its appeal and gain insight into how social media may be used as a support network in the future. The qualitative and quantitative information gathered from this study will allow us as genetic counselors to better understand the need and desire for social media for support and allow us to learn how to incorporate social media into our healthcare practices. This research will benefit us as genetic counselors, in particular due to the close relationships that are developed between the genetic counselor and the patient through the diagnostic process. Genetic counselors also have the opportunity to provide these resources directly to patients shortly after diagnosis.

1.7 Hypothesis and Study Objectives

We hypothesize that families with a child diagnosed with trisomy 13, 18, or 21 utilize social media because it allows them to seek support and guidance from individuals who have been through similar situations without the need to identify who they are. In addition, we hypothesize that social media provides a type of comfort that perhaps speaking with a genetic counselor does not.

The objectives of this study are to identify why families members of children diagnosed with trisomy 13, 18 or 21 are using social media as a support network, to identify what types of social media and how often these families are using social media as a support network, and to identify what information social media is providing these families with that they are not receiving from genetic counselors and other healthcare professionals.

Chapter 2: Manuscript

Use of Social Media as a Support Network in Families with a Child Diagnosed with Trisomy 13, 18, or 21¹

2.1 Abstract

Social media is a web based technology that allows individuals to communicate with other individuals, organizations, and communities about common interests and experiences. Recently, social media use has expanded into the healthcare field and many individuals are using social media to connect with others in similar situations and find support. Family members of children or pregnancies with trisomy 13, 18, or 21 were invited to participate in an online survey that explored the use of social media as a support network including their purposes for using social media as a support network, how often they use social media and what information they gain from social media. Data from 94 trisomy 13/18 participants and 77 Down syndrome participants were used for statistical analysis while additional qualitative data was collected through ten telephone interviews. The majority of participants used Facebook (88%), blogs (59%), and pregnancy websites (39%) as their main forms of social media for support. Participants reported using social media for the purposes of gathering information (81%), sharing information (73%), connecting with others in a similar situation (90%) and because of the ease of use (56%). Seventy-nine percent (79%) of participants indicated that

¹ Edwardsen, G.E., Sellers, A., Brasington, C.K., Hock, R.M., to be submitted to *[Journal of Genetic Counseling]*

information gathered from social media was “much more helpful” or “more helpful” than information gathered from their healthcare professional. Qualitative data from the telephone interviews identified various themes related to social media use including the search for support, a sense of community, types of information gained from social media, and viewpoints on the healthcare community. Based on this information, a list of recommendations was created for genetic counselors and other healthcare professionals on how to present social media to families as a support option, including discovering local support options, accessing families thoughts and feelings about using the internet for support, creating a list of appropriate social media and sites and providing the list to the family at an appropriate time.

2.2 Introduction

Every day the internet allows individuals to access an immense variety of information on various topics. Social media in particular allows for individuals to interact and communicate with other individuals, organizations, and communities (Kietzmann et al., 2011). Social media comes in a variety of forms, with the main categories including blogs, collaborative projects, and social networking (Kaplan & Haenlein, 2010). These social media venues create a unique opportunity in which individuals across the world can connect with one another to share common thoughts and feelings, all with the click of a mouse.

Over the last few years, social media has grown exponentially in popularity for personal use and more recently the introduction of social media into the healthcare community has created unique benefits and challenges in the healthcare field. With the introduction of “Health 2.0”, healthcare providers are quickly beginning to learn how to

bring social media into their daily practices in order to become more connected with their patients. While some efforts have been made in order to incorporate social media into healthcare, research in this area is still limited. Previous studies in this area have explored the use of social media by individuals with chronic conditions including cancer, diabetes, ADHD, and physical disabilities (Chen, 2012; Gajaria et al., 2011; Gurak & Antonijevic, 2008; Lam et al., 2013; Obst & Stafurik, 2010; Rains & Keating, 2011). With the introduction of forums, blogs, and chat rooms, individuals in these various communities are able to come together for support without having to leave the comfort of their home. It provides them with a community in which they can discuss their feelings openly without fear of judgment or misunderstanding.

One group of conditions that has a strong presence in social media are chromosome conditions including trisomy 13, 18, and 21. Trisomy 13, 18, and 21 are all chromosomal conditions caused by the addition of an entire chromosome, known collectively as aneuploidy. These conditions generally result in some form of intellectual disability, growth restriction, and multiple congenital anomalies as a result of too much genetic information present in each cell of the body. The conditions result from a failure of chromosomes to separate during meiosis known as nondisjunction. Although all chromosomes are subject to nondisjunction, chromosomes 13, 18, and 21 are the most likely conditions to result in live birth (Nussbaum et al., 2007). Due the varying severity of symptoms, family members of children and pregnancies with these conditions may turn to social media as a form of social support.

Social support in its various forms provides individuals with a way to cope with stress in their life, through the connection with others that are close to them. While

various events can trigger stress and the need for social support, diagnosis of a condition, especially a genetic condition, in a family can create unique challenges that can be addressed through the use of social support. The diagnosis of a genetic condition creates many different emotional reactions among family members (McAllister et al., 2007). Although genetic conditions are diverse and have numerous outcomes and management strategies, many of the emotions that are experienced by families in which there is a genetic condition are similar.

One emotion experienced by family members of children with a genetic condition is the unique emotions of guilt and worry about passing on the condition that many acquired conditions do not have. These emotions create added stress and need for additional support, such as psychosocial counseling, in order to address these feelings of guilt and worry in regards to having the condition in the family (McAllister et al., 2007). Due to the rarity of chromosome conditions, additional or similar emotions may be experienced by these families because of their inability to connect with others in a similar situation. Further understanding of these emotions and need for support in families with genetic conditions may provide insight into how healthcare professionals can assist during these times of need. One healthcare field that may benefit largely from understanding social media use by these families is genetic counseling.

Genetic counselors serve a unique role by not only providing information about the underlying genetic etiology of genetic disorders but also serving as a counselor to support and guide patients as they come to terms with their diagnosis. Trisomy 13, 18, and 21 are conditions that are routinely diagnosed in the prenatal and pediatric genetic counseling arenas. In families that have a child diagnosed prenatally with trisomy 13, 18,

or 21, the genetic counselor is with them throughout the entire process of screening, testing, and diagnosis. This process allows the counselor to establish a relationship and provide informational and emotional support to the family during this time. Additionally, after a child is born with one of these conditions, they receive care from a multitude of healthcare professionals including but not limited to genetic counselors, geneticists, cardiologists, pediatricians, and physical therapists.

This study gathered information from family members of children or pregnancies diagnosed with trisomy 13, 18 or 21 about their experiences and reasons for using social media as a support network. Given the unique challenges associated with raising a child with a genetic condition, identifying themes around reasons for using social media for support may allow healthcare professionals, including genetic counselors, to better serve these families by providing social media as a support to future patients.

2.3 Materials and Methods

This research study collected quantitative and qualitative data from family members of children or pregnancies diagnosed with trisomy 13 or 18 and family members of children or pregnancies diagnosed with Down syndrome who routinely use social media as a support network through an online survey and optional telephone interview. Participants were recruited by making the surveys available on various social media venues (blogs, websites, Facebook groups, etc.) that were targeted towards trisomy 13, trisomy 18, and trisomy 21. Individuals who were eligible to participate in this study were family members or guardians of a child or pregnancy diagnosed with trisomy 13, 18, or 21 who use social media as a support network. Individuals who were under the age of eighteen were excluded from this study.

A request to post a link to the survey was sent out via email (Appendix A) to seven blogs and websites (Appendix B), four of which agreed to post a link to the survey in various locations (Appendix C). This request explained the purpose of the research study and asked the recipients to post a link to the survey on their website or blog. Two versions of the online survey, one for families with a child diagnosed with Down syndrome and one for families with a child diagnosed with trisomy 13 or 18 were created for this study (Appendices F and G). Participants were informed about the survey through an invitation letter in the form of a blog post and provided with a link to participate in an online survey hosted on SurveyMonkey.com (Appendix D and Appendix E). Links to the survey were posted between October, 2012, and November, 2012. The surveys were available for completion from October, 2012, until January, 2013. This study was approved by the Institutional Review Board of the Office of Research Compliance, University of South Carolina, Columbia, in July, 2012.

The online surveys were nearly identical for family members of children or pregnancies with trisomy 13 or 18 and the family members of children or pregnancies with Down syndrome. The survey questions consisted of mainly multiple choice, Likert scale, and demographic questions that were designed to determine what types of social media they use, how often these families use social media, and their purposes for using social media as a support network. In addition, participants were asked open-ended questions in order to gain more detailed information about their social media use. A portion of the demographic information was collected prior to the qualifying question of the survey. Participants who did not qualify to take the rest of the survey were asked to provide their reasons for not using social media as a support network and were not

allowed access to the remainder of the survey. Participation in all questions of the survey were not required, thereby allowing participants to skip questions they were not comfortable answering. All qualifying responses to each question were gathered and included in the analysis of the study. At the end of the survey, participants were invited to provide their contact information if they were interested in participating in an optional phone interview.

For the qualitative portion of the study, telephone interviews were conducted to gain a more in depth understanding of how and why these families use social media as a support network. Participation in the telephone interview was voluntary and was not required in order to participate in the online survey. The principal investigator contacted willing participants by telephone during the designated timeframe they requested. Structured interviews were conducted with a series of predetermined open-ended questions that were aimed at answering the objectives of this study (Appendix H). All interviews were recorded using Audacity, an online voice recording software, and transcribed by the principle investigator for analysis. Each participant was informed of the purpose of the interview, reminded that their participation in the study was voluntary, and informed that they could withdraw from the interview at any time or choose not to answer a question based on their comfort level.

Quantitative analysis of the online surveys was conducted using SPSS version 21.0 statistical software (SPSS Inc., Chicago IL). Chi-square, independent T-tests, and ANOVA analyses were used to determine statistically significant relationships within each survey group as well as between each survey group. In addition, frequencies and percentages on each question were calculated. Qualitative data was reviewed by the

principal investigator and overlying themes pertaining to social media were identified. Overlying themes were identified based on two or more responses fitting into a particular category. These themes and subcategories were reviewed by committee members and reported. Personal information including names and telephone numbers were gathered only for the purpose of contacting willing participants and were discarded after the completion of the telephone interview.

2.4 Results

2.4.1 Quantitative Results. One hundred and nine (109) participants started the trisomy 13/18 survey. Ninety-five ($N = 95$) surveys were completed. Five surveys were incomplete, and the remaining nine surveys were not eligible for inclusion as the participant reported no using social media as a support network. A portion of the demographic information was collected prior to the inclusion criteria resulting in a difference in sample number for the demographic information *compared* to the total number of completed surveys. The majority of participants were Caucasian ($n = 78$, 83%) female ($n = 92$, 97%) parents ($n = 86$, 91%) who had at least some college education ($n = 80$, 46%). Participants were relatively equally distributed among regions and age range (Table 2.1).

Table 2.1 Trisomy 13/18 Participant Demographics (N = 95)

	Frequency	Percentage
Age	<i>n</i> = 94	(%)
18-25 years	5	5.3
26-32 years	27	28.7
33-39 years	24	25.5
40-46 years	24	25.5
47 years or older	14	14.9
Gender	<i>n</i> = 95	
Male	3	3.2
Female	92	96.8
Relationship to the individual diagnosed with trisomy 13/18	<i>n</i> = 95	
Parent	86	90.5
Grandparent	5	5.3
Aunt/Uncle	2	2.1
Sibling	2	2.1
Ethnicity	<i>n</i> = 95	
Caucasian	78	82.1
African American	3	3.2
Asian	5	5.3
Hispanic/Latino	6	6.3
Native American	1	1.1
Other	2	2.1
Education Level	<i>n</i> = 95	
Less than high school	1	1.1
High School/GED	14	14.7
Some College	25	26.3
College Degree (Associates or Bachelors)	44	46.3
Professional Degree (Master's, Doctorate, MD, JD)	11	11.6
Region	<i>n</i> = 94	
Rural	27	28.7
Suburb	29	30.9
City	38	40.4

The majority of total participants have a family member with Trisomy 18-Edward's syndrome ($n = 89/109$, 82%). The majority of pregnancies resulted in live birth ($n = 90/105$, 86%) with the majority of those children currently still living ($n = 51/90$, 57%). The diagnosis of trisomy 13/18 was evenly distributed before and after

birth. In addition, the number of participants who did and did not speak to a genetic counselor about the diagnosis before and after birth was also evenly distributed (Table 2.2).

Table 2.2 Trisomy 13/18 Participant Demographics Continued (N = 109)

	Frequency	Percentage
Which trisomy was/is your family member diagnosed with?	<i>n</i> = 109	(%)
Trisomy 18 (Edward's Syndrome)	89	81.7
Trisomy 13 (Patau Syndrome)	20	18.4
Was the diagnosis made before birth?	<i>n</i> = 109	
Yes	59	54.1
No	50	45.9
How did the pregnancy end?	<i>n</i> = 105	
Miscarriage	1	1.0
Termination	2	1.9
Stillbirth	11	10.5
Live Birth	90	85.7
How long did your family member with trisomy 13/18 survive?	<i>n</i> = 90	
Hours	7	7.8
Days	8	8.9
Weeks	12	13.3
Years	12	13.3
Still Living	51	56.7
Did you speak with a genetic counselor about the diagnosis of trisomy 13/18 <i>before</i> birth?	<i>n</i> = 108	
Yes	52	48.2
No	56	51.9
Did you speak with a genetic counselor about the diagnosis of trisomy 13/18 <i>after</i> birth?	<i>n</i> = 106	
Yes	68	64.2
No	38	35.9

Eighty-eight (88) participants started the Down syndrome survey. Seventy-seven participants completed the survey. Seven surveys were incomplete, and the remaining four surveys were not eligible for inclusion as the participant reported not using social media as a support network. A portion of the demographic information was collected prior to the inclusion criteria resulting in a difference in sample number for the demographic information compared to the total number of completed surveys ($N = 76$). The majority of participants were Caucasian ($n = 67, 88\%$) female ($n = 71, 93\%$) parents ($n = 75, 99\%$) between the ages of 33-46 years ($n = 67, 88\%$) who had earned at least a college degree ($n = 67, 88\%$). Approximately one third of participants received the diagnosis of Down syndrome prenatally ($n = 31, 35\%$) and spoke to a genetic counselor about the diagnosis of Down syndrome prenatally ($n = 30, 35\%$). While the majority of participants did not speak to a genetic counselor prenatally, there was a 20% increase in the number of participants who spoke with a genetic counselor about the diagnosis of Down syndrome after birth compared to prenatally (Table 2.3).

Table 2.3 Down syndrome Participant Demographics (N = 88)

		Frequency	Percentage
Age		<i>n</i> = 77	(%)
	18-25 years	2	2.6
	26-32 years	11	14.3
	33-39 years	32	41.6
	40-46 years	25	32.5
	47 years or older	7	9.1
Gender		<i>n</i> = 76	
	Male	5	6.6
	Female	71	93.4
Relationship to the individual diagnosed with Down syndrome		<i>n</i> = 76	
	Parent	75	98.7
	Sibling	1	1.3
Ethnicity		<i>n</i> = 76	
	Caucasian	67	88.2
	Asian	1	1.3
	Hispanic/Latino	5	6.6
	Other	3	4.0
Education Level		<i>n</i> = 76	
	High School/GED	2	2.6
	Some College	7	9.2
	College Degree (Associates or Bachelors)	35	46.1
	Professional Degree (Master's, Doctorate, MD, JD)	32	42.1
Region		<i>n</i> = 76	
	Rural	10	13.2
	Suburb	38	50.0
	City	28	36.8
Was the diagnosis made before birth?		<i>n</i> = 88	
	Yes	31	35.2
	No	57	64.8
Did you speak with a genetic counselor about the diagnosis of Down syndrome <i>before</i> birth?		<i>n</i> = 86	
	Yes	30	34.9
	No	56	65.1
Did you speak with a genetic counselor about the diagnosis of Down syndrome <i>after</i> birth?		<i>n</i> = 85	
	Yes	49	57.7
	No	36	42.4

While individual data sets were analyzed, results of both the trisomy 13/18 survey and Down syndrome survey were combined ($N = 179$) in order to observe the use of social media across all three conditions. Participants of each survey were asked to select all social media venues they used for support purposes. Overall, the majority of participants used Facebook ($n = 159, 89\%$), blogs ($n = 106, 59\%$), and pregnancy websites ($n = 70, 39\%$) for support. Facebook is the most commonly used social media among both groups individually (trisomy 13/18: $n = 93/99, 94\%$; Down syndrome: $n = 66/80, 83\%$) but pregnancy websites were used more commonly among the Down syndrome population ($n = 50/99, 63\%$) than the trisomy 13/18 population ($n = 20/99, 20\%$) (Table 2.4). Of the individuals who used blogs as a form of support when combining both groups ($N = 107$), half of the participants had their own blog ($n = 53, 50\%$). Among the individuals who had their own blog, the majority of them used their blog to discuss life with their family member with trisomy 13/18 or Down syndrome ($n = 51/56, 91\%$). In addition, the majority of participants who used blogs as a support network read other individual's blogs as a form of support ($n = 105/108, 97\%$).

Table 2.4 Types of Social Media Used for Support Purposes ($N = 179$)

	Frequency			Percentage		
	Trisomy 13/18	Down syndrome	Total	Trisomy 13/18	Down syndrome	Total
	$n = 99$	$n = 80$	$N = 179$			
Blogs	53	53	106	53.54	66.25	59.22
Facebook	93	66	159	93.94	82.5	88.83
Twitter	4	10	14	4.04	12.5	7.821
CaringBridge	11	8	19	11.11	10	10.61
Pregnancy Websites	20	50	70	20.20	62.5	39.11
Forums	17	25	42	17.17	31.25	23.46
Other	17	8	25	17.17	10	13.97

Participants of each survey were asked to select all of their reasons for using social media as a support network that apply. Overall, the majority of participants ($N = 179$) used social media as a support network for information gathering ($n = 144, 80\%$), information sharing ($n = 131, 73\%$), connecting with others in a similar situation ($n = 169, 90\%$) and because of its ease of use ($n = 100, 56\%$). There were no major differences in reasons for using a particular social media between the trisomy 13/18 and Down syndrome groups except for ease of use, which was more important for Down syndrome participants ($n = 54/81, 67\%$). Due to the lethality of trisomy 13/18, the option of grief support was provided in the trisomy 13/18 survey with 39% ($n = 38/98$) of participants stating this as a reason for using social media. The option of emotional support was provided in replacement of grief support in the Down syndrome survey with 53% ($n = 43/81$) of participants stating this as a reason for using social media (Table 2.5)

Table 2.5 Reasons for Using Social Media as a Support Network ($N = 179$)

	Frequency			Percentage (%)		
	Trisomy 13/18 $n = 98$	Down Syndrome $n = 81$	Total $N = 179$	Trisomy 13/18	Down syndrome	Total
Anonymity	6	8	14	6.1	9.9	7.8
Information gathering	82	62	144	83.7	76.5	80.5
Information sharing	80	51	131	81.6	63.0	73.2
Ease of use	46	54	100	46.9	66.7	55.9
Connection with others in similar situation	89	72	161	90.8	88.9	89.9
Lack of personal support network	27	12	39	27.6	14.8	21.8
Grief support	38		38	38.8		21.2
Emotional support		43	43		53.1	24.0
Other	4	7	12	4.1	8.6	6.7

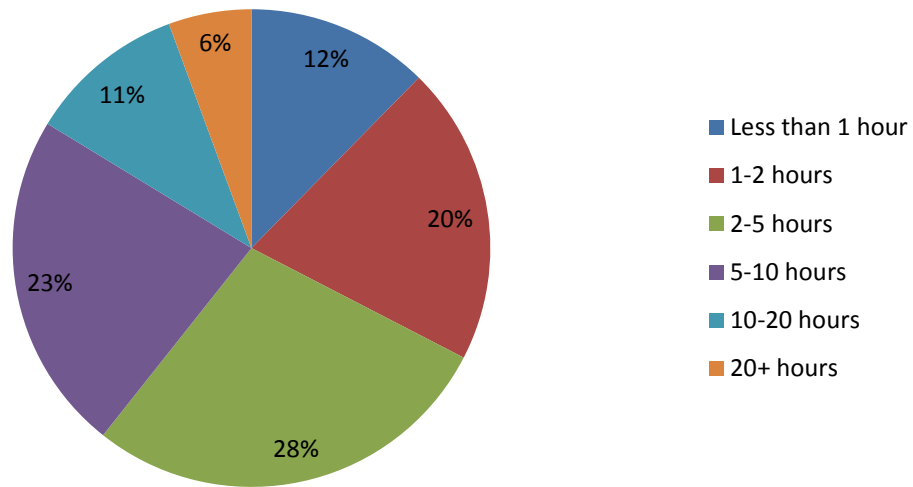
When asked how they heard about the type of social media they use for support purposes, overall, the majority of participants found their social media venue through an internet search ($n = 119, 66\%$) followed by family and friends ($n = 69, 39\%$) and local trisomy 13/18 or Down syndrome organizations ($n = 41, 23\%$). Only 12% of participants learned about social media via a healthcare professional ($n = 18$) (Table 2.6).

Table 2.6 How Participants Heard about the Type of Social Media They Use
($N = 179$)

	Frequency			Percentage (%)		
	Trisomy 13/18	Down syndrome	Total	Trisomy 13/18	Down syndrome	Total
	$n = 98$	$n = 81$	$N = 179$			
Internet Search	71	48	119	72.5	59.3	66.5
Advertisement	2	1	3	2.0	1.2	1.7
Healthcare professional	12	6	18	12.2	7.4	10.1
Different social media venue	9	13	22	9.2	16.1	12.3
Family or Friends	38	31	69	38.8	38.3	38.6
Local organization	21	20	41	21.4	24.7	22.9
Other	10	5	15	10.2	6.2	8.4

Participants of both surveys ($N = 179$) were asked to estimate how many hours per week they use social media as a support network. Overall, 71% of participants use social media for support purposes between 1-10 hours per week ($n = 121$). (Figure 2.1) The majority of trisomy 13/18 participants reported using social media for support between 2-5 hours per week ($n = 30/98, 31\%$), while the Down syndrome survey participants were evenly distributed between using 2-5 hours ($n = 20/81, 25\%$) and 5-10 hours ($n = 21/81, 26\%$) per week.

Figure 2.1 Number of Hours per Week Spent Using Social Media for Support for Both Trisomy 13/18 and Down Syndrome Families



Participants of the trisomy 13/18 survey were asked a series of Likert scale questions assessing how social media has aided them in their life with their family member with trisomy 13/18, their feelings towards social media, and their views on healthcare professionals suggesting social media as a support network. On Likert scale questions of zero (strongly disagree) to four (strongly agree), participants felt strongly that social media has provided them with information on trisomy 13/18 ($M = 3.62$), has provided them with an outlet in which they can express their feelings about their family in a way that may be helpful to other individuals or families ($M = 3.66$), and has allowed them to connect with others in a similar situation ($M = 3.69$). Although they felt social media had provided them with information on trisomy 13/18, participants did not feel as strongly that social media helped them feel prepared to have a child with these conditions ($M = 2.47$) or helped them accept their family members' diagnosis ($M = 2.54$).

In regards to their feelings towards social media, participants agreed that their use of social media has increased since their family member's diagnosis ($M = 3.23$) and

agreed that they would suggest social media to someone in a similar situation ($M = 3.53$). Participants agreed also that they have/will continue to use social media after the birth of their family member ($M = 3.52$). Participants disagreed that they used social media for support because it allows them to remain anonymous ($M = 1.23$). In addition, social media did not appear to be influential in aiding decisions regarding their pregnancy ($M = 1.66$). Finally, in regards to healthcare professionals suggesting social media as a support network to other families with family members with trisomy 13/18, participants felt strongly that healthcare professionals should be suggesting social media ($M = 3.66$) (Table 2.7).

Table 2.7 Likert Scale- Trisomy 13/18

	<i>n</i>	Mean	Range	Std. Deviation
Using social media has provided me with information on trisomy 13/18	92	3.62	0-4	0.724
I use social media because I can be anonymous	91	1.23	0-4	1.065
Social media has helped me to accept my family member's diagnosis of trisomy 13/18	91	2.54	0-4	1.177
My use of social media has increased since my family member's diagnosis with trisomy 13/18	92	3.23	1-4	0.915
Social media has aided me in decisions regarding my pregnancy	90	1.66	0-4	1.383
I feel more comfortable using social media for support over other methods of support	91	2.47	0-4	1.099
I would suggest the use of social media to someone in a similar situation as myself	90	3.53	2-4	0.64
Social media has made me feel more prepared to have a child with trisomy 13/18	89	2.74	0-4	1.039
Social media has allowed me to connect with others who also have a family member with trisomy 13/18	91	3.69	2-4	0.571
I have/will continue to use social media after the birth of my family member with trisomy 13/18 for support	89	3.52	0-4	0.785
Healthcare professionals should consider suggesting social media as a support network to family members that have a family member with trisomy13/18	91	3.66	2-4	0.619
Social media provides/has provided an outlet for me to express my feelings and experiences about our family in a way that may be helpful to other individuals or families	90	3.66	2-4	0.584

Participants of the Down syndrome survey were also asked a series of Likert scale questions assessing how social media has aided them in their life with their family member with Down syndrome, their feelings towards social media, and their views on

healthcare professionals suggesting social media as a support network. Participants felt strongly that social media has provided them with information on Down syndrome ($M = 3.55$) as well as has allowed them to connect with others who also have a family member with Down syndrome ($M = 3.66$). In addition, participants agreed that social media has provided them with an outlet in which they can express their feelings and emotions in a way that may be helpful to other families ($M = 3.34$). Although participants agreed that they have/will continue to use social media after the birth of their family member with Down syndrome ($M = 3.46$), participants did not feel as strongly that their use of social media has increased since their family members' diagnosis ($M = 2.76$) or that they felt more comfortable using social media over other forms of support ($M = 2.31$).

When asked if social media helped them to accept their family member's diagnosis of Down syndrome, participants were fairly neutral on the topic ($M = 2.64$). In contrast, participants disagreed that they used social media for support because it allows them to remain anonymous ($M = 1.74$). In addition, social media did not appear to be influential in aiding decisions regarding their pregnancy ($M = 1.56$). Finally, participants felt strongly that they would suggest social media to someone in a similar situation as themselves ($M = 3.40$) and also felt that healthcare professionals should be offering social media as a support network to families that have a family member with Down syndrome ($M = 3.45$) (Table 2.8).

Table 2.8 Likert Scale- Down syndrome

	<i>n</i>	Mean	Range	Std. Deviation
Using social media has provided me with information on Down syndrome	74	3.55	0-4	0.796
I use social media because I can be anonymous	74	1.74	0-4	1.123
Social media has helped me to accept my family member's diagnosis of Down syndrome	74	2.64	0-4	1.117
My use of social media has increased since my family member's diagnosis with Down syndrome	74	2.76	0-4	1.225
Social media has aided me in decisions regarding my pregnancy	71	1.56	0-4	1.010
I feel more comfortable using social media for support over other methods of support	72	2.31	0-4	0.988
I would suggest the use of social media to someone in a similar situation as myself	73	3.40	2-4	0.702
Social media has made me feel more prepared to have a child with Down syndrome	73	2.76	0-4	1.169
Social media has allowed me to connect with others who also have a family member with Down syndrome	73	3.66	1-4	0.628
I have/will continue to use social media after the birth of my family member with Down syndrome for support	74	3.46	1-4	0.706
Healthcare professionals should consider suggesting social media as a support network to family members that have a family member with Down syndrome	73	3.45	1-4	0.727
Social media provides/has provided an outlet for me to express my feelings and experiences about our family in a way that may be helpful to other individuals or families	74	3.34	0-4	0.896

Participants of both surveys were asked a series of questions on their thoughts and suggestions for healthcare professionals in regards to offering social media to families that have children with trisomy 13, trisomy 18, or Down syndrome. Fifty five percent of

participants felt that the information they gather from social media was much more helpful than the information they gathered from their healthcare professional ($n = 91/165$) (Figure 2.2). As previously stated, participants of both surveys felt strongly that healthcare professionals should offer social media as a support network (See Table 2.6 and Table 2.7). Related to when healthcare professionals should offer social media, the majority of participants felt it should be offered on the same day of diagnosis ($n = 105/162$, 65%) or at a follow up appointment ($n = 34/162$, 21%) (Figure 2.3).

Figure 2.2 Views on Information Gathered from Healthcare Professional vs. Information Gathered from Social Media for Trisomy 13/18 and Down syndrome Participants

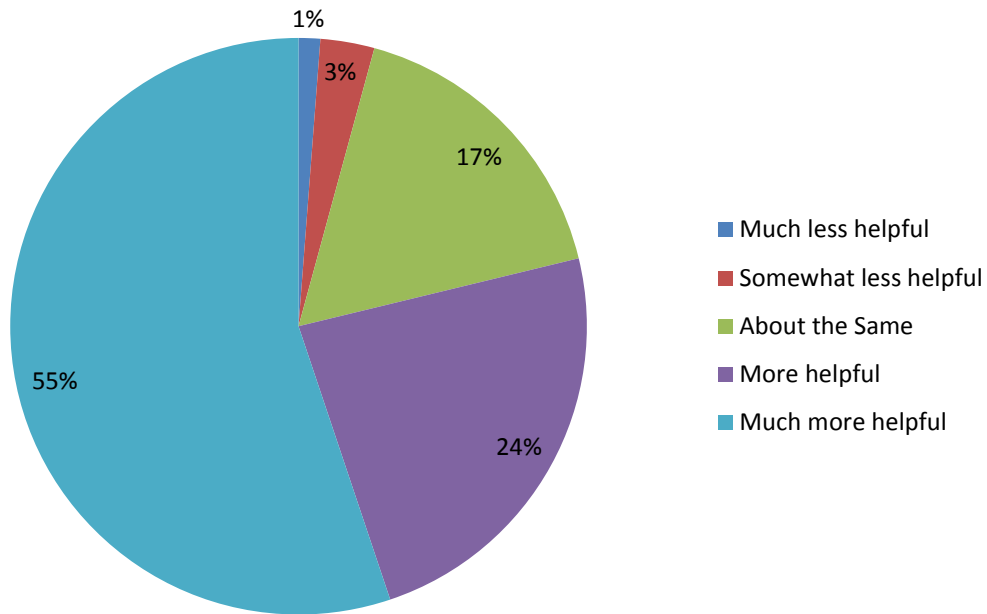
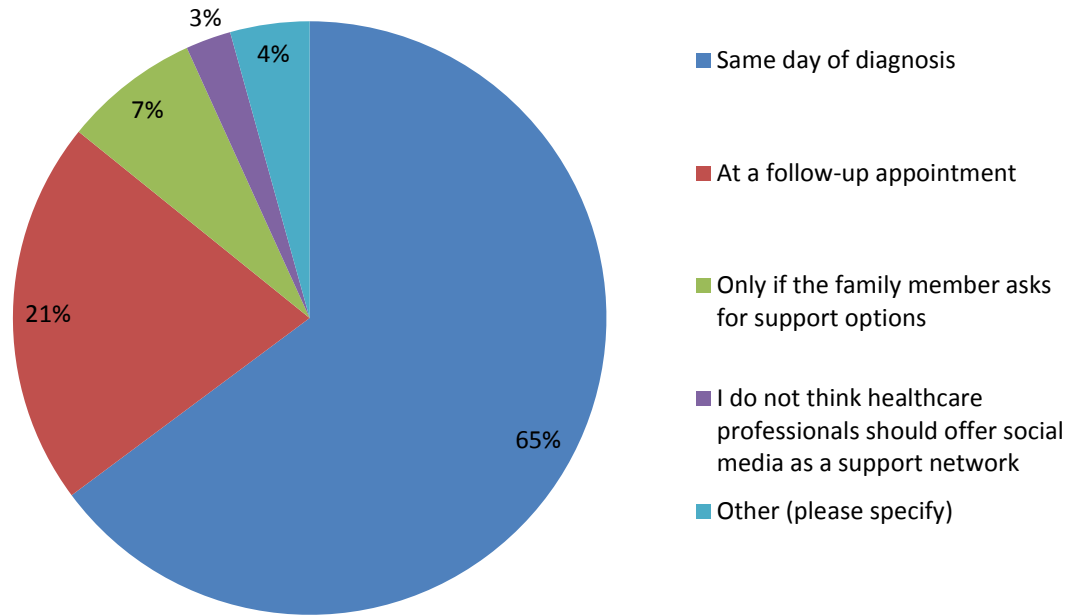


Figure 2.3 When Healthcare Professionals Should Offer Social Media



Participants were asked to provide suggestions on how healthcare professionals should offer social media of families with a similar diagnosis. A majority of participants ($n = 17/27$, 63%) responded that healthcare professionals should provide a list or pamphlet filled with helpful websites, Facebook groups, and blogs. Many participants also stressed the importance of providing this information both verbally and in written form. Participants also suggested providing families with contact information for both local and national support organizations and if possible, the contact information of a family that has a child with the same diagnosis. Participants were then asked to provide a list of social media sites that they think healthcare professionals should provide to families (Table 2.9 and Table 2.10).

Table 2.9 List of Social Media Sites Suggested by Trisomy 13/18 Families for Healthcare Professionals to Offer

Websites

Australian Rare Chromosome Awareness Network <http://www.arcan.org.au/>
Baby Center Carrying Pregnancy to Term Despite Fatal Prenatal Diagnosis Community http://community.babycenter.com/groups/a6711405/carrying_pregnancy_despite_poor_or_fatal_prenatal_diagnosis
Be Not Afraid <http://www.benotafraid.net/resources.asp>
CaringBridge <http://www.caringbridge.org/>
Chromosome 18 Registry & Research Society <http://www.chromosome18.org/Genetics/FactsAboutGenetics/tabid/132/Default.aspx>
Chromosome Disorder Outreach <http://www.chromodisorder.org/CDO/>
Family Voices <http://www.familyvoices.org/>
Hope for Trisomy 13 & 18 <http://www.hopefortrisomy13and18.org/>
Mommies Enduring Neonatal Loss (M.E.N.D.) http://www.mend.org/support/resources_organizations.asp
Perinatal Hospice and Palliative Care <http://perinatalhospice.org/>
Support Organization for Trisomy (SOFT) <http://trisomy.org/>
Noah's Never Ending Rainbow <http://noahsneverendingrainbow.org/>
Now I Lay Me Down To Sleep <https://www.nowilaymedowntosleep.org/>
Living with Trisomy 13 <http://www.livingwithtri13.org/>
Living with Trisomy 13 Archive <http://trisomy13archive.com/>
String of Pearls <http://stringofpearlsonline.org/>
T18 Moms <http://www.t18moms.com/>
Trisomy 18 Foundation <http://www.trisomy18.org/site/PageServer>
Unique <http://www.rarechromo.org/html/home.asp>

Facebook Groups: Trisomy 13/18 Families

Faces of Trisomy <https://www.facebook.com/groups/facesoftrisomy/?ref=ts&fref=ts>
Hope For Trisomy <https://www.facebook.com/HopeForTrisomy13and18>
Kinley Noelle Mitchell <http://www.facebook.com/KinleyNoelleMitchell>
Living with Trisomy 13 <https://www.facebook.com/LivingWithTrisomy13>
Mommies of Miracles <http://www.facebook.com/MommiesofMiracles?fref=ts>
Support Organization for Trisomy (SOFT) <https://www.facebook.com/groups/TrisomySOFT/>
Trisomy 18 Foundation Parents Connect <http://www.facebook.com/groups/ExpectingTrisomy18/?fref=ts>
Trisomy 18 Mommies <http://www.facebook.com/groups/T18Mommies/?fref=ts>
Trisomy Angel Parents <https://www.facebook.com/groups/TrisomyAngelParents/?ref=ts&fref=ts>
Trisomy Families <http://www.facebook.com/trisomyfamilies.hope.18.13.awareness?fref=ts>

Blogs: Trisomy 13/18 Families

Compatible with Joy <http://compatiblewithjoy-trisomy18.blogspot.com/>
Eva's Gifts <http://www.evasgifts.org/>

Table 2.10 List of Social Media Sites Suggested by Down syndrome Families for Healthcare Professionals to Offer

Websites: Down syndrome Families

Baby Center Down Syndrome Pregnancy Community
http://community.babycenter.com/groups/a14515/down_syndrome_pregnancy
Baby Center Down Syndrome Community
http://community.babycenter.com/groups/a315/down_syndrome
Circle of Moms <http://www.circleofmoms.com/>
Down Syndrome Pregnancy <http://downsyndromepregnancy.org/>
Down Syndrome Prenatal Testing <http://www.downsyndromeprenataltesting.com/>
Einstein Syndrome <http://einstein-syndrome.com/category/down-syndrome/>
A Heartbreaking Choice <http://www.aheartbreakingchoice.com/>
International Down Syndrome Coalition <http://www.theidsc.org/>
Lettercase <http://lettercase.org/>
National Down Syndrome Society <http://www.ndss.org/>
SMILE Support <http://www.smilesupport.org.uk/>
Twitter <http://www.twitter.com> (#downsyndrome)

Facebook Groups: Down syndrome Families

Bethany and Company <https://www.facebook.com/pages/Bethany-and-Company/250516025012902?fref = ts>
Downs Designs <https://www.facebook.com/downsdesigns?ref = ts&fref = ts>
National Down Syndrome Society
<https://www.facebook.com/NationalDownSyndromeSociety>
Our Adventures with Down Syndrome
<http://www.facebook.com/groups/ouradventures/?fref = ts>

Blogs: Down syndrome Families

A Perfect Lily <http://babynumber10.blogspot.com/>
Big Blueberry Eyes <http://mdbeau.blogspot.com/>
Down Syndrome Blogs <http://downsyndromeblogs.blogspot.com/>
Down syndrome: A day to day guide <http://dsdaytoday.blogspot.com/>
Down Syndrome New Mama <http://downsyndromenewmama.blogspot.com/>
Enjoying the Small Things <http://www.kellehampton.com/>
Everything and Nothing from Essex <http://www.deannajsmith.com/>
Noah's Dad <http://noahsdad.com/>

Data from both surveys were analyzed via comparative statistical tests individually as well as a combined group. Comparative t-tests and chi square tests were run on both data sets individually comparing nominal data to trisomy type as well as Likert scale data to trisomy type. No statistically significant relationships were identified.

ANOVA tests were run comparing Likert scale questions to demographic information of the participants including age, education level, gender, region, relationship and ethnicity. In the trisomy 13/18 participant group, there was a statistically significant relationship between age of the participant and their likelihood to suggest the use of social media to someone in a similar situation ($p = 0.008$). No additional statistically significant relationships were identified for each survey group individually.

Comparative t-tests and ANOVA tests were run on the combined data comparing demographic, nominal, and Likert scale data against trisomy type (Trisomy 13, 18 or 21). Family members of children with Down syndrome felt more neutral about using social media to be anonymous compared to trisomy 13 and trisomy 18 family members ($p = .012$). Family members of children with trisomy 13 were more neutral on the topic of using social media to make decisions regarding their pregnancy ($p = .057$) and family members of children with trisomy 18 felt more strongly when compared to family members of children with trisomy 13 or Down syndrome about how social media allows them to express their feelings and emotions. No additional statistically significant relationships were identified for the combined survey groups.

2.4.2 Qualitative Results Thirty-four out of the 94 participants (36%) who completed the trisomy 13/18 survey responded that they would be willing to participate in a telephone interview and provided their contact information. Ten of the participants were contacted at the designated time frame they requested and five telephone interviews were completed in which saturation was achieved. All participants were female parents of children with either trisomy 13 or trisomy 18. Additional demographic information

such as age, education, ethnicity or region was not collected during the interview. The length of the interviews ranged between 10 minutes to almost 14 minutes.

Twenty-eight out of 77 (36%) participants who completed the Down syndrome survey also responded that they would be willing to participate in a telephone interview and provided their contact information. Six of the participants were contacted at the designated time frame they requested and five telephone interviews were completed in which saturation was achieved. All participants were female parents of children with Down syndrome. Additional demographic information such as age, education, ethnicity or region was not collected during the interview. The length of the interviews ranged between 5 minutes to almost 11 minutes.

Participants of both surveys were asked five open ended questions that focused on determining their reasons for using social media as a support network, how soon after their child's diagnosis they began using social media, and what types of support and information they have gained through the use of social media in regards to their child's diagnosis. Three main themes were identified for both participant groups which were further broken down into three to four subcategories.

In the trisomy 13/18 survey group the three main themes that were identified included the search for support, information gained from social media, and thoughts about the medical community. The first theme, "The Search for Support" was broken down into four subcategories: time frame/social media type used, convenience, lack of information elsewhere, and social media awareness. Participants used Facebook as their main source of social media support and time frames ranged from one month after diagnosis to several years after diagnosis. Two parents expressed that they used social

media because it is always available and because it allows them to connect with other people who have children with the same diagnosis. Lack of information elsewhere was a common response among participants as to why they began looking for information via social media. Participants stated that there is currently not a lot of information about these conditions and they needed to find it somewhere in order to take care of their children. Finally, two parents also expressed that although they use social media for support, they believe there are many individuals who are not aware of social media as a source of support. One parent of a child with trisomy 18 commented on how she wished she had known about social media for the first few months after her child's diagnosis saying "had I known beforehand that 6 to 8 months would have not been so stressful in the beginning."

"Information Gained from Social Media" was further broken down into the subcategories of support and encouragement, connection with others in a similar situation, and daily life information. Participants discussed the sense of support they gained from the greater social media community through the sharing of encouraging words and stories as well as seeing pictures of these children. A parent of a child with trisomy 18 commented "I can be an encouragement to them as well, and sharing my story will hopefully encourage them as well, so it works both ways." Participants described that the connection with others who also had children with the same condition provides them with a sense of normalcy and gives them a location in which they can communicate about various experiences and gather and give advice. Finally, participants discussed how they were able to find out specific information on how to take care of children with these conditions including types of surgeries and therapies they should be considering. The

final theme of ‘Thoughts about the Medical Community’ was identified based on participants’ feelings about how the medical community treats their children as well as what the medical profession needs to do in order to learn more about their children. Participants expressed that the medical profession lacks humanity when interacting with their children as well as adequate information on how to take care of their children. One parent of a child with trisomy 18 commented “...the medical profession has to start acting human and that is the component that we get from social media.”

Three major themes were also identified for the Down syndrome survey participant group which includes the search for support, discoveries through social media and medical advice. The first theme “The Search for Support” was broken down into three subcategories: discovering social media, convenience, and drawbacks of social media. Overall participants in this group discussed how they came about finding social media and the benefits and drawbacks of using social media for support. Participants used both Facebook and BabyCenter forums boards for support beginning at the time of diagnosis to about a year and a half after diagnosis. Participants expressed that one main reason they began using social media was the convenience it provided and the immediacy of responses they would receive when they posted a question or concern. One parent commented “if you need support or are looking for support you are able to give it and it’s instantaneous, it’s not like you have to wait for a meeting once a month and go in.” Finally, participants also discussed the negative sides of social media including increased anxiety and comparisons among other children. Also included as both a benefit and a drawback to social media was the ability to remain anonymous or not remain anonymous on various social networking sites.

The theme “Discoveries through Social Media” was further divided in two subcategories: a sense of community and awareness about Down syndrome. Participants expressed experiencing many emotions when communicating with other Down syndrome families including support, acceptance, connection, inspiration, and hope. Overall participants repeatedly expressed how connection with other families provided them with a sense of a community in which they could actively participate at any given time. In addition, participants expressed how social media serves as a venue in which they can create and spread awareness about the diagnosis of Down syndrome. Participants discussed that social media is a place in which families who do and do not have children with Down syndrome can come together and learn more about life with a child with Down syndrome. One parent also commented on how she hoped that social media may serve as a venue in which teenagers and young adults with Down syndrome can communicate with one another and become self-advocates.

Finally, the theme of “Medical Advice” was divided into two subcategories of medical advice learned via social media and medical advice learned via medical professionals. In general, participants felt that they received more accurate information about medical complications and developmental milestones from other parents via social media than they did from medical professionals. Participants discussed that parents on social media have lived and experienced what is like to have a child with Down syndrome and therefore they can provide advice and answer questions with more experience. Participants expressed that medical professionals can provide statistical data on when to expect certain developmental milestones but lack the personal experience of raising these children, with one parent saying “there was so much more that [my

geneticist] could have been able to give me.” Participants also commented that medical professionals lack compassion when it comes to interacting with these families.

2.5 Discussion

Throughout this study, social media has proven to provide many forms of support to family members with children with trisomy 13, trisomy 18, or Down syndrome.

Participants of both surveys shared which types of social media they use for support, how often they use social media for support, and their thoughts and feelings on how healthcare professionals should provide social media as a support to other trisomy families. In general, Facebook, blogs, and websites served to be the most used social media sites by family members in both participant groups. This was expected given that links to the survey were posted on these social media venues. Many participants that reported using blogs for support not only read other individual’s blogs but many had blogs of their own in which they discuss life with their family member with trisomy 13, 18 or 21.

In general, participants spent between one to ten hours per week using social media for support. Contrasted with traditional support venues, such as speaking with a genetic counselor or attending an in person support group which may only provide a few hours of support monthly or even yearly, social media allows individuals to access support more often (Chen, 2012; Gajaria et al., 2011; Gold et al., 2012; Obst & Stafurik, 2010). When asked how they discovered the particular social media venue they used, the large majority found it through internet searching. This was to be expected given how the internet has become such a large part of daily culture (Lenhart, Purcell, Smith, & Zickuhr, 2010). More and more individuals are gaining access to the internet and are able

to utilize it in order to find out more information on a variety of topics as well as to locate options for support.

Social media use is generally higher among younger individuals as compared to elder individuals. More specifically, social media use is generally highest in individuals aged 12 to 29 with approximately 73% of teens and young adults in this age group participating in social networking sites as compared to only 39% of individuals over the age of thirty (Lenhart et al., 2010). Interestingly, in the trisomy 13/18 participant group of our study the older the participant was, the more likely they were to suggest social media as a support network. It could be expected that younger family members would offer social media more readily than older family members as they have incorporated social media into their lives to a greater degree than older family members. Perhaps the younger population may not suggest social media to others in a similar situation assuming that others will have already explored the option of social media or already have access to social media. Since social media is in general a large component to this population's daily life, it may be that the idea of suggesting social media is not thought of as necessary in contrast with the older family member population.

2.5.1 The Search for Support While identifying how individuals discovered and use social media, an overlying theme identified in both participant groups was their journey in the search for support. Participants discussed how they came to find social media for support and the benefits they gained once they became a part of the online community. For some individuals, social media was the first venue they turned to for support. For others, however, the struggle to find social media took longer or wasn't available to them at the time of diagnosis: "My son was diagnosed in 1997 and at that

time there wasn't social media...there was the internet but not the social media component to it....” – parent of a child with trisomy 18; “...[I used social media] that day, prenatally at about 18 weeks and it was really helpful”-- parent of a child with Down syndrome; “Well I guess what took me so long to get into Facebook was that I wasn't even really familiar with it at the time, it was kind of still new.”-- parent of a child with trisomy 18; “Social media (FB, webpages, and blogs) was the first thing [we] turned to when we found out our son could [have] Trisomy 13 or 18”-- parent of a child with trisomy 13.

Furthermore, once participants become a part of social media, they reported being continuously drawn back to it for support due to the immediacy of responses they received from other parents. Not only are they able to connect with others instantly but they are also able to connect with people from all areas of the country and the world.

Well, I live out in the country. ...It's convenient and there is more. There's thousands and thousands and hundreds of thousands of people versus the smaller groups here ... it's just easier and more convenient.... -- parent of a child with Down syndrome.

Although the overwhelming majority of participants spoke highly of social media and all of the support it has provided, a few parents discussed the negative aspects of social media. Previous studies have discussed the negatives aspects of support groups including the fear of exposing their children to other children with the same genetic condition. Some parents felt seeing children that had the same condition as their child served as a constant reminder of the potential physical or mental deterioration that was possible with the condition (Plumridge et al., 2012). Similarly, one parent in our study

expressed that social media, in addition to providing her with so much support, it has also provided her with anxiety.

It creates a little bit of hysteria sometimes like ‘Oh am I missing something?’ ‘Oh you are taking your kid to the doctor and I'm not.’ And also I think there is a comparison and I hate this but I do it. I have had to block people because they become braggy and if there is a kid that is a little bit younger than my son whose doing a lot more than he is and I get stressed out and I get upset and I get worried and it makes me anxious -- parent of a child with Down syndrome.

Outside of the realm of support, the internet gives individuals the opportunity to ask questions that perhaps they would not feel comfortable asking in person, including questions about their health. Naturally, forums that allow individuals to post questions and answer questions anonymously are appealing for many as they allow them to gather information without having to identify themselves (Lenhart et al., 2010; Wallace, 2001). It was hypothesized in this study that many of our participants would choose social media for support as it provides a relatively safe environment that would allow them to ask questions anonymously. Generally speaking, however, participants disagreed or felt neutral about social media’s ability to allow them to be anonymous. One parent expressed that she does not feel the need to be anonymous when using social media:

I am never anonymous I don't feel like. I mean on Facebook certainly my full name is out there and [there are] local groups that I am involved in so there is really no anonymity there -- parent of a child with Down syndrome.

The ability for a family member to remain anonymous is dependent upon which social media venue they use. Social media sites such as Facebook use your full name and identifying factors. Although individuals can express as much or as little information as they choose on Facebook, the ability to be anonymous is essentially removed due to the nature of site. Other social media venues such as blogs or forums allow them to post or discuss life with their family member without needing to reveal their identity with individuals they have never met in person (Gurak & Antonijevic, 2008; Obst & Stafurik, 2010; Rains & Keating, 2011). When comparing all three trisomies to a question regarding anonymity, there was a statistically significant relationship between the three groups. For family members of children with trisomy 13 and trisomy 18 being anonymous on social media was not as important for them as it was for family members of children with Down syndrome. One parent of a child with Down syndrome described her fears associated with using her real name on social media:

Facebook always makes me a little nervous because everything is linked back to your profile, and so there is that certain amount of anonymity, you can remain anonymous on BabyCenter. And it wasn't necessarily a level of embarrassment, its more I am really careful about trying to keep our personal information protected online, and Facebook makes me nervous because even if you make everything private your picture and your name are still there. So BabyCenter is great because you can be as anonymous as you want to be and...really protect your information.-- parent of a child with Down syndrome

One parent even felt that the need to be anonymous changed for her as her child grew older. Anonymity was important when she needed support during her pregnancy, but now she is more comfortable using her name to provide support to other parents.

My prenatal diagnosis was 8 years ago, so I was anonymous then, which was very important to me. In the ensuing years, I have used my name as I became a leader in this community ... When I was pregnant, I very much needed the support. Years later I don't 'need' the support but I still use social media to give support to expectant parents. -- parent of a child with Down syndrome

2.5.2 Discoveries and Information Gained through Social Media. Similar to many other studies exploring support and social media use for support, another main theme identified in both participant groups in this study was that social media provided them with an entire network of families who were going through similar situations as themselves (Chen, 2012; Gajaria et al., 2011; Gurak & Antonijevic, 2008; Letourneau et al., 2012; Obst & Stafurik, 2010). The majority of participants responded saying that the main reasons they use social media for support are to both gather (80%) and share (73%) information about their family member's condition. In addition many participants spoke about the comfort they received by speaking with others who also have family members with the same condition. These are a few of their voices:

I am able to speak directly to parents who have children with the same diagnosis as my son and benefit from their experiences and what they have gone through -- parent of a child with trisomy 18;

I realized that looking online that I just found a whole support network and I go there because of the fact that I am getting information, opinions, and support from people that actually walk down the same path as I do, from moms and dads who have children with Down syndrome. -- parent of a child with Down syndrome;

I think that it's important for parents even to be able to share their stories with others; it just gives them that sort of outlet into a community that is willing to listen and understand. You know those kinds of things. It's wonderful to establish friendships with people who are walking the same journey that you are and can understand what is taking place -- parent of a child with trisomy 18.

Participants also spoke about how social media and speaking with other families about their family member's condition brings a sense of normalcy to the diagnosis. In a review of several studies exploring online support groups and their link with social support needs, empathetic support from others with similar diagnoses provided a sense of comfort and understanding (Wright & Bell, 2003). Participants in this study expressed how when they post to social media they do not have to explain certain frustrations because the community already understands what they are going through on a regular basis. Social media allows these families to connect with other families and learn about what daily life is like for them, such as these comments: "It is the breath of fresh air that we have all been looking for. A place to reference to so that our kids are not always a diagnosis, they are kids."- parent of a child with Down syndrome; and, "I see these pictures of these

babies each day and rejoice when one is born and we grieve when one dies. It's just unbelievable..."-- parent of a child with trisomy 18.

Although participants generally disagreed that social media had an influence on helping them make decisions regarding their pregnancy, family members of children with trisomy 13 remained more neutral on the topic than trisomy 18 or Down syndrome families. Although there were not many participants who had a family member with trisomy 13 that participated in this study, one trisomy 13 parent spoke about how social media helped her decide to continue her much wanted pregnancy.

Social media helped me choose to carry on my pregnancy when my doctors urged termination. I will forever be grateful for finding out it was safe to carry on with the pregnancy. My baby boy was born still at 32 weeks. [I] would never change my decision. -- parent of a child with trisomy 13.

One additional theme that was identified in the Down syndrome participant group was how social media has allowed them to raise awareness about the condition, not only within the Down syndrome community but also with others. Participants remarked that social media allows them to communicate efficiently and quickly to people within and outside the Down syndrome community about what their life is like with a child with Down syndrome. It allows them to share their viewpoints on the condition and promote general acceptance and understanding towards their children.

Parents are able to see, and just people in general, that Down syndrome is not a big deal it's just a part of a person and social media defiantly helps to reduce ... the focus on the diagnosis and highlight more of the individual

characteristics of the person. I hope with increased awareness that people look at our kids as just typical people, they are just a little different. I mean everyone is a little different... I think I had my son at the best time because of social media and the help. -- parent of a child with Down syndrome

I think the more awareness is raised with social media because it is out there for everyone to share. And when I am sharing it, I am not just sharing it to my special needs group, I am sharing it to all of my 475 Facebook followers so it defiantly creates awareness... -- parent of a child of Down syndrome.

One parent even commented on how social media may become an outlet for self-expression and advocacy for her daughter by allowing her to communicate with other children with Down syndrome and teach other's about her condition.

I am very curious to see how social media plays a role in [my daughter's] life. ...a lot of kids with special needs don't have the typical friend groups and so maybe they are in or at home on a Friday or Saturday night and they watch a lot of movies or they play the Wii. I am hoping that maybe social media will be able to get them to interact a little bit more and become self-advocates. So I am curious to see what happens now going forward. -- parent of a child with Down syndrome.

2.5.3 Medical Advice and Thoughts about the Medical Community. An objective of this study was to identify what information these families were gaining from social media that they perhaps were not gaining from their healthcare professionals or other forms of support. One theme that was identified in both participant groups was that social media provides a lot of medical advice about how to take care of children with these conditions, especially in the trisomy 13/18 participant group. As stated earlier, trisomy 13 and trisomy 18 are considered lethal conditions and many children born with these conditions do not survive past the first year of life. Although there have been some guidelines on how to counsel families and take care of children with trisomy 13 and trisomy 18, limited information is available for healthcare professionals (Carey, 2012). Many participants in the research study did have children that have been surviving for years after birth. Participants discussed that currently there is not a lot of information available on how to take care of children with these conditions that continue to live.

Well these babies weren't supposed to be born alive and then they say the ones that do live, 90% of them die by the age of one and she is three and a half... -- parent of a child with trisomy 18;

The reality is that [trisomy] 13 and 18 is just like Down syndrome... there is a wide spectrum of severity and yes a lot of kids pass away through miscarriage or right after birth but there are still a lot of kids out there who do survive... so there really needs to be that information to be able to take care of these kids. -- parent of a child with trisomy 18.

In both survey groups, participants responded that social media gives them a more realistic expectation of what medical problems to anticipate as well as when to expect certain developmental milestones. The overwhelming majority of participants (79%) stated that the information they gained about the conditions from social media was “much more helpful” or “more helpful” than the information they gained from their healthcare professional. Participants in the qualitative portion of the study again reiterated that by communicating with these families on social media, they gain a better understanding of what life is like with a child with one of these conditions; information that often cannot be given from medical professionals.

I learned basically everything there was to know about dealing with a child with trisomy 18... [I learned] that they can survive....[and I learned] how to take care of my daughter...health wise -- parent of a child with trisomy 18;

...Comparisons for mile markers as far as things like teeth. I could ask what their experiences were with it. Doctors tell you 'oh anywhere from three to five'... they can give you statistics [or] I can get real life statistics from people that are going through it.... -- parent of a child with Down syndrome;

Symptoms on different things like GI issues, heart problems, if other kids have had surgeries, different medications just looking for answers that I felt like that when I would take him to a specialist they just didn't know because they didn't have the experience with the kids with trisomy 18 -- parent of a child with trisomy 18.

In the process of learning what information families are gathering about these conditions via social media, many family members expressed negative feeling towards the healthcare community. Recounting of what medical professionals have said to these families was not explored from the medical professionals' viewpoint in this study. Parents from both interview groups described that not only do healthcare professionals not have accurate information about their children's conditions, but they also have skewed perceptions on how to properly convey compassion and respect to them and their children.

As soon as [my son] was diagnosed [with trisomy 18]...the geneticist tried to make him fit the description. So all of a sudden his ears were in the wrong place, his forehead was wrong, his head. And if you look at my son none of that holds true but she tried to make my child fit the description of what a typical child [with trisomy 18] should look like... -- parent of a child with trisomy 18;

Well the genetic counselor was basically like 'He's got Down syndrome'... well we knew that already.... I mean it was the stupidest appointment I have ever been to, they could have e-mailed me that information. -- parent of a child with Down syndrome;

I asked my geneticist after how she would have counseled me [if she knew my pregnancy was affected], and she said 'Well to terminate the pregnancy' and I said 'Yeah but you would have advised me to terminate

[my son]you would have advised me to abort [my son]' and her comment was 'Yes, but statistics show...' Well I'm sorry, children are not statistics. --parent of a child with trisomy 18.

As stated previously, information on how to take care of children with these conditions has been rather limited, especially in regards to how to take care of children with trisomy 13 and trisomy 18. With advances in medical care, more children with these conditions are surviving and healthcare professionals are learning more information on how to provide adequate and accurate health information (Bull, 2011; Carey, 2012). Guidelines on communicating a diagnosis of these three conditions and recommendations to healthcare professionals, including genetic counselors, have recently been published (Carey, 2012; Sheets et al., 2011). These guidelines provide suggestions on how to counsel and interact with families that have children with these three conditions and will hopefully aid in better communication and care.

Another objective of this study was to identify family members' thoughts and feelings about healthcare professionals suggesting social media as a support option. The majority of participants of both surveys felt strongly ($M = 3.45$; $M = 3.66$) that healthcare professionals should be suggesting social media to other trisomy families. Participants revealed that social media allowed them to express their feelings and emotions in ways that would be helpful to others and it has allowed them to connect with other trisomy families.

I think that [doctors] should let [parents] know that there is more information out now than there was years ago and that there [are] a lot of people that are on the social media that are dealing with it and that they

probably know more about how to take care of the child than the doctors really do. -- parent of child with trisomy 18.

Upon further investigation, family members expressed that not only does the healthcare profession need to suggest social media as an option for these families, but that they also need to be aware of what information is being shared on social media sites in order to learn more about living children with these conditions. One parent of a child with trisomy 18 stated the following: “The more [healthcare professionals] are a part of [social media] the more that they can learn and the more they can help the patients that are going through it.”

As a healthcare profession, genetic counseling has the unique opportunity to interact with these families during various stages of their children’s lives. Whether the diagnosis of these conditions are made before or after birth, genetic counselors serve as a resource to these families by providing them information about the conditions and various resources for support. Data collected from this research revealed that these families perceive they are not receiving all the information they need in order to truly understand what daily life is like with these children. This study has shown that these families feel social media provides them with more accurate and up to date information on how to take care of these children medically than information they have gathered from their healthcare professional and provides them with support by allowing them to connect with others who are experiencing the same emotions, joys, and challenges that they are.

2.5.4 Recommendations on How to Provide Social Media as a Support

Network. Based on the information gathered in this study, a list of recommendations has

been compiled on how and when to provide social media to trisomy families. A list of recommended social media venues are provided earlier in this study (Table 2.9 and Table 2.10).

1. Discover local support groups that are available online and in person for families with family members with these conditions.

Many participants of this study expressed that having the ability to connect with local families that have the same condition as their family member was very important and helpful. In addition to facilitating a connection with another family member that has a child with one of these conditions, genetic counselors can also provide a list of local resources. Many local trisomy organizations now have Facebook pages or groups which can allow these families to interact. Providing them with a local online resource may allow these families to begin interactions in a more open location and allow them the option to participate based on their comfort level.

2. Ask local families that have children with these conditions what social media resources they use and have found to be helpful in providing accurate information and support.

In addition to the list of social media venues provided in this study (Table 2.9 and Table 2.10), asking local families about their experiences with social media use for support may provide a more personalized list that is applicable to patients in the region being served.

3. Discuss the option of online support with the family verbally and assess their thoughts and feelings about using the internet for support.

Although the majority of participants agreed that healthcare professionals should be providing social media as an online support, social media may not be right for all families. Discussing the options of social media as a support option with the family and exploring their thoughts and feelings towards it may give genetic counselors and other healthcare professionals a better idea on whether offering social media is appropriate. In addition, discussing with patients about their access to the internet is also important in determining whether or not providing social media is appropriate.

4. Take the time to view each social media site and create a list of appropriate social media sites that includes blogs, Facebook groups, websites, and forums to provide the family.

Just as genetic counselors provide families with accurate information about genetic conditions in the form of books, handouts, and pamphlets, it is also important to view each of the social media sites that are being suggested and determine whether or not to include them as a resource to the patients. The list of social media sites provided in this study were all suggested by participants as sites they found to be helpful and that they would recommend to their healthcare professional to share with other trisomy families. Some of these social media sites may not be applicable to all patient populations; therefore, healthcare providers should view these sites and determine their comfort level with them prior to creating their own list of social media support sites. In addition,

participants felt strongly that a variety of social media should be provided to families including blogs, forums, websites and Facebook groups on a local and worldwide level.

When creating a list, healthcare providers may wish to think about dividing the social media sites into applicable categories. For example one may wish to separate the list based on the types of social media they are such as Facebook groups, websites, blogs or forums. Additional ways to provide a list would be to categorize resources based on the type of support they provide. (i.e., support to families that have terminated, had stillbirths, or have living children with these conditions). Another option would be to divide the list based on whether or not the online resources are local or if they are on a national or worldwide level.

5. Provide the families with the list of appropriate social media site in the form of a handout or pamphlet

In addition to discussing social media as a resource with these families, the overwhelming majority of participants said providing families with a list of social media resources in the form of a handout would allow these families to have a physical list of references that they could refer back to after the appointment. Some participants also suggested providing a small description of each site along with the web address.

6. Provide the list of social media sites at the time of diagnosis or at a follow up appointment

The majority of participants (65%) felt that providing a list of social media support on the same day as diagnosis would be most beneficial. While some participants disagreed, many felt that families would feel the most support by having the resource

available to them soon after the diagnosis would provide the most support. Participants suggested providing the list along with other national and local recourses and some suggested even physically showing families some of these sites if possible. Twenty one percent of participants suggested offering social media at a follow-up appointment. Receiving a new diagnosis invokes many emotions and individuals are receiving a lot of information all at one time. Some families may benefit from having time to process all the information that is provided to them at the time of diagnosis. Therefore accessing a family's emotional needs at time of diagnosis may be beneficial in determining when it would be appropriate to provide a list of social media support sites.

7. Discuss the benefits and drawbacks of social media with families.

As previously stated, while social media can provide a large network of support, there are some drawbacks to using social media. It is important to discuss that many families feel social media has provided them with a lot of support at various times during their journeys. On the contrary, some families have experienced negative aspects. It is also important to inform families that some of these social media sites are not created, written or endorsed by medical professionals. Many of these are created by individuals that have family members with these conditions and therefore they may not provide accurate medical information about these conditions. It is important that families continue to seek medical advice from healthcare professionals.

2.5.5 Limitations and Future Research. One limitation of the study was the homogenous participant sample. The majority of both surveys were taken by Caucasian college educated female parents of individuals with trisomy 13, 18, or 21. Variations in gender, relationship, ethnicity, and education level may have provided a broader

understanding as the use of social media as a support network. Participants for these surveys were contacted and asked to participate through a limited number of social media venues which may have biased the results of which social media venues were most favorable.

In addition, the majority of parents who responded to the trisomy 13/18 survey had living children with these conditions that had/have been living for several years after birth. While gaining insight into why these families use social media and learning what information they gather from social media is helpful, such a population did not allow us to observe how families who have lost a child with these conditions use social media for support. Surveys were posted on trisomy 13 and trisomy 18 Facebook groups that mainly provide support for living children with these conditions and did not include Facebook groups or other social media that were developed for grief or bereavement support for these families. This may explain some of the results observed. Given the lethality of trisomy 13 and trisomy 18, understanding the support needs of families who decided to terminate pregnancies or who have lost family members with these conditions may also provide valuable information. Finally, an additional limitation includes the limited number of responses from family members that have a child with trisomy 13. This could be expected given that it is the rarest out of the three conditions this study explored. The limited quantitative and qualitative data from these families may have not provided all the reasons these particular families use social media for support.

Future research could focus on families with family members with other genetic conditions in order to understand their reasons for using social media for support. As previously stated, understanding how families that have lost a child with one of the

conditions examined in this study may also provide some insight into how they view social media as a support network. Further areas that could be explored in more detail also include how social media aids these families in making decisions regarding their affected pregnancies, how it aids them in deciding to have more children in the future and how their need for social media support has changed over time. Furthermore, distributing the survey through national organization electronic mailing lists or in a clinical setting may allow for more of an unbiased sampling. Additional areas of research could include assessing genetic counselors and other healthcare professionals' knowledge of social media as a source of support including how often they suggest social media as an option, as well as their viewpoints on providing social media to their patients.

2.6 Conclusion

This study focused on determining reasons why families of children with trisomy 13, trisomy 18, and Down syndrome use social media for support purposes, how often these families use social media for support, which types of social media they use, and their thoughts and feeling towards healthcare professionals suggesting social media in the future to other trisomy families. Overall, both the trisomy 13/18 and the Down syndrome group felt that social media has allowed them to gather and share information, express their emotions openly and freely, and provided a sense of community in which they can connect with other families that have children with these conditions. Given the rarity of these conditions, connection with other families that also have children with trisomy 13, trisomy 18 or Down syndrome provides these families with social support as well as information and advice on how to take care of children with these conditions

Based on their responses, participants felt that healthcare professionals should be providing social media as a support option. Suggestions on how to present social media to families with children with one of these conditions has been provided.

The hope is that by providing this resource, genetic counselors and healthcare professionals will become more aware of social media use by these families and begin to feel comfortable providing and suggesting social media as a support option to other trisomy families.

Chapter 3: Conclusions

This study focused on determining reasons the families of children with trisomy 13, trisomy 18, and Down syndrome use social media for support purposes, how often these families use social media for support, which types of social media they use, and their thoughts and feeling towards healthcare professionals suggesting social media in the future to other trisomy families. Overall, both the trisomy 13/18 and the Down syndrome group felt that social media has allowed them to gather and share information, express their emotions openly and freely, and provided a sense of community in which they can connect with other families that have children with these conditions. Given the rarity of these conditions, connection with other families that also have children with trisomy 13, trisomy 18 or Down syndrome provides these families with social support as well as information and advice on how to take care of children with these conditions

Based on their responses, participants felt that healthcare professionals should be providing social media as a support option. Suggestions on how to present social media to families with children with one of these conditions has been provided.

The hope is that by providing this resource, genetic counselors and healthcare professionals will become more aware of social media use by these families and begin to feel comfortable providing and suggesting social media as a support option to other trisomy families.

References

- Adelman, M. B., Parks, M. R., & Albrecht, T. L. (1987). Beyond close relationships: Support in weak ties. In T. L. Albrecht & M. B. Adelman (Eds.), *Communicating social support* (pp. 126-147). Newbury Park, CA: Sage.
- Albrecht, T. L., & Adelman, M. B. (1987). Communicating social support: A theoretical perspective. In T. L. Albrecht & M. B. Adelman (Eds.), *Communicating social support* (pp. 18-39). Newbury Park, CA: Sage.
- Albrecht, T. L., & Goldsmith, D. J. (2003). Social support, social networks, and health. In T. L. Thompson, A. M. Dorsey, K. I. Miller & R. Parrott (Eds.), *Handbook of health communication* (pp. 263-284). Mahwah, NJ: Lawrence Erlbaum Associates.
- Anderson, A. S., & Klemm, P. (2008). The internet: Friend or foe when providing patient education? *Clinical Journal of Oncology Nursing*, *12*(1), 55-63.
- Anderson, K. (2012). Social media a new way to care and communicate. *Australian Nursing Journal*, *20*(1), 22-25.
- Beeher, T. A., & Glazer, S. (2001). A cultural perspective of social support in relation to occupational stress. In P. Perrewe, D. C. Ganster & J. Moran (Eds.), *Research in occupational stress and well being* (pp. 97-142). Greenwich, CO: JAI Press.
- Bull, M. J. (2011). Health supervision for children with Down syndrome. *Pediatrics*, *128*(2), 393-406. doi: 10.1542/peds.2011-1605
- Carey, J. C. (2001). Trisomy 18 and trisomy 13 syndromes. In S. B. Cassidy & J. E. Allanson (Eds.), *Management of genetic syndromes* (pp. 417-436). New York: Wiley-Liss.
- Carey, J. C. (2012). Perspectives on the care and management of infants with trisomy 18 and trisomy 13: striving for balance. *Current Opinion in Pediatrics*, *24*(6), 672-678.
- Chen, A. T. (2012). Exploring online support spaces: Using cluster analysis to examine breast cancer, diabetes and fibromyalgia support groups. *Patient Education and Counseling*, *87*(2), 250-257.
- Collier, R. (2012). Professionalism: Social media outreach. *Canadian Medical Association Journal*, *184*(11), E587-588.

- Facebook. (2012). Facebook Retrieved May 28, 2012, from <http://www.facebook.com/facebook>
- Finfgeld-Connett, D. (2005). Clarification of social support. *Journal of Nursing Scholarship*, 37(1), 4-9.
- Fisher, J., & Clayton, M. (2012). Who gives a tweet: assessing patients' interest in the use of social media for health care. *Worldviews on Evidence-Based Nursing*, 9(2), 100-108.
- Gabbard, G. O., Kassaw, K. A., & Perez-Garcia, G. (2011). Professional boundaries in the era of the internet. *Academic Psychiatry*, 35(3), 168-174.
- Gajaria, A., Yeung, E., Goodale, T., & Charach, A. (2011). Beliefs about attention-deficit/hyperactivity disorder and response to stereotypes: youth postings in Facebook groups. *Journal of Adolescent Health*, 49(1), 15-20.
- Gill, K. E. (2004). *How can we measure the influence of the blogosphere*. Paper presented at the WWW 2004 Workshop on the Weblogging Ecosystem: Aggregation, Analysis and Dynamics.
- Gold, K. J., Boggs, M. E., Mugisha, E., & Palladino, C. L. (2012). Internet message boards for pregnancy loss: who's on-line and why? *Womens Health Issues*, 22(1), e67-72.
- Gurak, L. J., & Antonijevic, S. (2008). The psychology of blogging: you, me, and everyone in between. *American Behavioral Scientist*, 52(1), 60-68.
- Hackworth, B. A., & Kunz, M. B. (2011). Health care and social media: Building relationships via social networks. [Article]. *Academy of Health Care Management Journal*, 7(2), 1-14.
- Hamill, A. C., & Stein, C. H. (2011). Culture and empowerment in the Deaf community: An analysis of internet weblogs. *Journal of Community & Applied Social Psychology*, 21(5), 388-406.
- Hunter, A. G. W. (2001). Down syndrome. In S. B. Cassidy & J. E. Allanson (Eds.), *Management of genetic syndromes* (pp. 103-129). New York: Wiley-Liss.
- Jent, J. F., Eaton, C. K., Merrick, M. T., Englebert, N. E., Dandes, S. K., Chapman, A. V., & Hershorin, E. R. (2011). The decision to access patient information from a social media site: what would you do? *Journal of Adolescent Health*, 49, 414-420.
- Kane, G. C., Fichman, R. G., Gallagher, J., & Glaser, J. (2009). Community relations 2.0. *Harvard Business Review*, 87(11), 45-50.
- Kaplan, A. M., & Haenlein, M. (2010). Users of the world, unite! the challenges and opportunities of social media. *Business Horizons*, 53(1), 59-68.

- Kietzmann, J. H., Hermkens, K., McCarthy, I. P., & Silvestre, B. S. (2011). Social media? get serious! understanding the functional building blocks of social media. *Business Horizons*, 54(3).
- Lam, C. G., Roter, D. L., & Cohen, K. J. (2013). Survey of quality, readability, and social reach of websites on osteosarcoma in adolescents. *Patient Education and Counseling*, 90(1), 82-87.
- Lenhart, A., Purcell, K., Smith, A., & Zickuhr, K. (2010). *Social media & mobile internet use among teens and young adults: Pew internet & american life project* Washington, DC.
- Letourneau, N., Stewart, M., Masuda, J. R., Anderson, S., Cicutto, L., McGhan, S., & Watt, S. (2012). Impact of online support for youth with asthma and allergies: pilot study. *Journal of Pediatric Nursing*, 27(1), 65-73.
- Mansfield, S. J., Stephens, H. O., Bonning, M. A., Wang, S.-H., Withers, A. H. J., Olver, R. C., & Perry, A. W. (2011). Social media and the medical profession. *Medical Journal of Australia*, 194, 642-644.
- McAllister, M., Davies, L., Payne, K., Nicholls, S., Donnai, D., & MacLeod, R. (2007). The emotional effects of genetic diseases: implications for clinical genetics. *American Journal of Medical Genetics Part A*, 143A(22), 2651-2661.
- NDSS. (2012). National Down Syndrome Society Retrieved May 25, 2012, from <http://www.ndss.org/>
- NML-NIH. (2012a, January 2009). Genetic home reference: trisomy 13 Retrieved May 18, 2012, from <http://ghr.nlm.nih.gov/condition/trisomy-13>
- NML-NIH. (2012b, March 2012). Genetic home reference: trisomy 18 Retrieved May 18, 2012, from <http://ghr.nlm.nih.gov/condition/trisomy-18>
- Nussbaum, R. L., McInnes, R. R., & Willard, H. F. (2007). *Thompson & Thompson genetics in medicine* (7th ed.). Philadelphia, PA: Saunders Elsevier.
- Obst, P., & Stafurik, J. (2010). Online we are all able bodied: online psychological sense of community and social support found through membership of disability-specific websites promotes well-being for people living with a physical disability. *Journal of Community & Applied Social Psychology*, 20(6), 525-531.
- Plumridge, G., Metcalfe, A., Coad, J., & Gill, P. (2012). The role of support groups in facilitating families in coping with a genetic condition and in discussion of genetic risk information. *Health Expectations*, 15(3), 255-266.
- Rains, S. A., & Keating, D. M. (2011). The social dimension of blogging about health: Health blogging, social support, and well-being. *Communication Monographs*, 78(4), 511-534.

- Resta, R., Biesecker, B. B., Bennett, R. L., Blum, S., Hahn, S. E., Strecker, M. N., & Williams, J. L. (2006). A new definition of genetic counseling: National society of genetic counselors' task force report. *Journal of Genetic Counseling*, 15(2), 77-83.
- Sheets, K. B., Crissman, B. G., Feist, C. D., Sell, S. L., Johnson, L. R., Donahue, K. C., . . . LaGrave, D. (2011). Practice guidelines for communicating a prenatal or postnatal diagnosis of Down syndrome: Recommendations of the national society of genetic counselors. *Journal of Genetic Counseling*, 20(5), 432-441.
- SOFT. (2012). SOFT support organization for trisomy 18, 13 and related disorders Retrieved May 19, 2012, from <http://www.trisomy.org/>
- Travers, R. L. (2012). Social media in dermatology: moving to Web 2.0. *Seminars in Cutaneous Medicine and Surgery*, 31(3), 168-173.
- Twitter. (2012a). Twitter Retrieved May 28, 2012, from <https://twitter.com/about>
- Twitter. (2012b). Twitter help center: What are hashtags ("#" symbols)? Retrieved May 28, 2012, from <https://support.twitter.com/articles/49309-what-are-hashtags-symbols>
- Vickery, G., & Wunsch-Vincent, S. (2007). Participative Web and User-Created Content *Web 2.0, Wikis and Social Networking* (pp. 124). Retrieved from <http://www.sourceoecd.org/scienceIT/9789264037465>
- Wallace, P. (2001). *The psychology of the Internet*: Cambridge University Press.
- Wright, K. B., & Bell, S. B. (2003). Health-related support groups on the internet: Linking empirical findings to social support and computer-mediated communication therapy. *Journal of Health Psychology*, 8(1), 39-54.
- YouTube. (2013). Statistics Retrieved January 14, 2013, from http://www.youtube.com/t/press_statistics

Appendices

Appendix A – Request for Hosting Research Survey

Dear _____

My name is Ginger Edwardsen and I am currently a genetic counseling graduate student at the University of South Carolina School of Medicine. As a part of my Masters' thesis, I am conducting research on the **use of social media by families with a child diagnosed with (trisomy 13/18 or Down syndrome) as a support network.**

I am very interested in gathering information about the use of social media as a support network from the members of your online community. I am writing to ask if you would consider posting a link to my survey on your (website/blog/forum). I have attached a copy of sample post which includes all the information about my research and a link to the survey that you would be able to post.

I would greatly appreciate the opportunity to ask your community to participate in this survey.

If you have any additional questions, please feel free to contact me or my thesis advisor.

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If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803) 777-7095.

Thank you so much for your time and consideration,

-Ginger Edwardsen

Appendix B – List of Social Media Sites Contacted

1. Down Syndrome Pregnancy (<http://www.downsyndromepregnancy.org>)
2. Living with Trisomy 13 (<http://www.livingwithtri13.org>)
3. Trisomy 18 Foundation (<http://www.trisomy18.org>)
4. “I See Love” blog (<http://www.iseeloveblog.blogspot.com>)
5. “Enjoying the Small Things” blog (<http://www.kellehampton.com>)
6. “Carrie with Children” blog (<http://www.carriewithchildren.com>)
7. Support Organization for Trisomy (<http://www.trisomy.org>)

Appendix C – List of Social Media Sites Where Survey Links were Posted

1. Down Syndrome Pregnancy website (<http://www.downsyndromepregnancy.org>)
2. Trisomy 18 Mommies Facebook group (<http://www.facebook.com/groups/T18Mommies/>)
3. Trisomy 13-Patau Syndrome-Living with Trisomy 13 Community Facebook group (<http://www.facebook.com/groups/Trisomy13/>),
4. Down Syndrome Pregnancy Inc. Facebook group (<http://www.facebook.com/pages/Down-Syndrome-Pregnancy-Inc/126178450781951?fref=ts>),
5. Lettercase Facebook group (<http://www.facebook.com/pages/Lettercase/166808796678498?fref=ts>)
6. “I See Love” blog (<http://www.iseeloveblog.blogspot.com>)

Appendix D – Invitation to Participate for Down Syndrome Survey

Hello Everyone,

My name is Ginger Edwardsen and I am currently a second year student in genetic counseling program at the University of South Carolina School of Medicine.



_____ has graciously allowed me to introduce myself to your community and explain my current research.

As a part of my Masters' thesis, I am conducting research on the **use of social media by families with a child diagnosed with Down syndrome.**

Like many of you, I use social media in my everyday life and find it to be an integral part of the online community today. I am interested in seeing how families such as you use social media to gather information and support about Down syndrome.

I would like to invite you to participate in an online survey about your use of social media. You are being asked to participate in this study because you have a family member or are a caregiver of an individual with Down syndrome. This survey should take around 10-15 minutes to complete. At the end of the survey, you will be given the option to provide your contact information for a follow-up phone interview at your convenience. I would love the opportunity to talk with you briefly about the specific ways in which you find social media helpful regarding your family member with Down syndrome.

To complete this survey please click the link below:

<http://www.surveymonkey.com/s/socialmediads>

Your time and involvement would be greatly appreciated. If you would like more information or have any questions please feel free to contact me or my faculty advisor with the contact information below.

If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803) 777-7095.

I would like to thank _____ for allowing me to share my research with you today and I would like to thank you all in advance for your consideration.

Sincerely,

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Appendix E - Invitation to Participate for Trisomy 13/18 Survey

Hello Everyone,

My name is Ginger Edwardsen and I am currently a second year student in the genetic counseling program at the University of South Carolina School of Medicine.



_____ has graciously allowed me to introduce myself to your community and explain my current research.

As a part of my Masters' thesis, I am conducting research on the **use of social media by families with a child diagnosed with either trisomy 13 or trisomy 18.**

Like many of you, I use social media in my everyday life and find it to be an integral part of the online community today. I am interested in seeing how families such as you use social media to gather information and support about trisomy 13 or trisomy 18.

I would like to invite you to participate in an online survey about your use of social media. You are being asked to participate in this study because you have a family member or are a caregiver of an individual with trisomy 13 or trisomy 18. This survey should take around 10-15 minutes to complete. At the end of the survey, you will be given the option to provide your contact information for a follow-up phone interview at your convenience. I would love the opportunity to talk with you briefly about the specific ways in which you find social media helpful regarding your family member with trisomy 13 or trisomy 18.

To complete this survey please click the link below:

<http://www.surveymonkey.com/s/socialmediatri13or18>

Your time and involvement would be greatly appreciated. If you would like more information or have any questions please feel free to contact me or my faculty advisor with the contact information below.

If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803) 777-7095.

I would like to thank _____ for allowing me to share my research with you today and I would like to thank you all in advance for your consideration.

Sincerely,

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Appendix F – Down Syndrome Survey

Qualifying Questions

Was the diagnosis of Down syndrome made before birth?

Yes

No

Did you speak with a genetic counselor about the diagnosis of Down syndrome before birth?

Yes

No

Did you speak with a genetic counselor about the diagnosis of Down syndrome after birth?

Yes

No

Do you use social media to obtain support regarding your family member diagnosed with Down syndrome? (Social media examples: Facebook, Twitter, blogs, pregnancy websites, etc.)

Yes

No

If yes, continue on to survey questions

If No,

What are your reasons for not using social media as a support network?

I do not know what social media is

I do not have access to a computer

I do not feel using social media would be helpful for support

I have access to support networks elsewhere (Ex: in my community)

I know someone personally who has a family member with Down syndrome

I am too busy with family, friends, and other commitments to use social media

Other: _____

End of survey

Survey:

1. What types of social media do you use *for support purposes?* (check all that apply)
Facebook
Twitter
CaringBridge
Pregnancy Websites (ex: Baby Center, Down Syndrome Pregnancy)
Blogs (ex: Blogger, Wordpress, Tumblr)
Forums
Other:_____

If “blogs” is checked:

Do you have your own blog?

Yes

No

If No:

Do you read others’ blogs for support for your family member with Down syndrome?

Yes

No

If Yes:

Do you use your blog to discuss life with your family member with Down syndrome?

Yes

No

2. What are your reasons for using social media as a support network? (check all that apply)
Anonymity
Ease of use
Information gathering
Information sharing
Connection with others in similar situation
Lack of personal support network
Emotional support
Other:_____

3. About how many hours per week do you use social media *for support purposes*?
 - Less than one hour
 - 1-2 hours
 - 2-5 hours
 - 5-10 hours
 - 10-20 hours
 - 20+ hours

4. Where did you hear about the social media network you use? (check all that apply)
 - Internet Search
 - Advertisement (TV, Print, Radio)
 - Healthcare professional
 - Different social media venue
 - Family or Friends
 - My local Down syndrome organization
 - Other: _____

5. Have you used social media to tell others about your family member's diagnosis of Down syndrome?
 - Yes
 - No

Likert Scale (Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree)

6. Using social media has provided me with information on Down syndrome
7. I use social media because I can be anonymous
8. Social media has helped me to accept my family member's diagnosis of Down syndrome
9. My use of social media has increased since my family member's diagnosis with Down syndrome
10. Social media has aided me in decisions regarding my pregnancy
11. I feel more comfortable using social media for support over other methods of support
12. I would suggest the use of social media to someone in a similar situation as myself
13. Social media has made me feel more prepared to have a child with Down syndrome
14. Social media has allowed me to connect with others that also have a family member with Down syndrome

15. I have/will continue to use social media after the birth of my family member with Down syndrome for support
16. Healthcare professional should consider suggesting social media as a support network to family members that have a family member with Down syndrome
17. Social media provides/has provided an outlet for me to express my feelings and experiences about our family in a way that may be helpful to other individuals or families

If you wish to expand on your answers on any of the above questions, or have additional comments, please place them here:

18. When compared to the information I gained from my healthcare professional, the information I gained from social media about Down syndrome was:

- Much less helpful
- Somewhat less helpful
- About the Same
- More helpful
- Much more helpful

19. How would you like a healthcare professional to present social media to you as a support option?

20. When you think healthcare professionals should offer social media as a support option?

- Same day of diagnosis
- At a follow-up appointment
- Only if the family member asks for support options
- I do not think healthcare professionals should offer social media as a support network
- Other:

21. What are your favorite social media sites that you think healthcare professionals should offer as support options?

22. Would you be interested in participating in a telephone interview to discuss your experiences with social media as a support network in further detail?

Yes

No

If No:

Thank you for your time and participation in this research study.

If Yes:

Please fill out your contact information below. This information will remain private and be used only for the purpose of contacting you for participation in this research study.

Name:

Phone Number:

Best time to contact you at the phone number provided:

Morning (10am-12pm)

Afternoon (1pm-5pm)

Evening (6pm-8pm)

Weekend

Email (optional):

Thank you for your time and participation in this research study.

Demographics:

Your Age:

18-25 years

26-32 years

33-39 years

40-46 years

47 years or older

Your Gender:

Male

Female

Your Relationship to the individual diagnosed with Down syndrome:

Parent

Grandparent

Aunt/Uncle

Sibling

Guardian

Other: _____

Your Ethnicity:

African-American

Asian

Caucasian

Hispanic/Latino

Native American

Middle Eastern

Other:

Your Education Level:

Less than High School

High School/GED

Some College

College Degree (Associates or Bachelors)

Professional degree (Master's, Doctorate, MD, JD)

What region do you live in?

City

Rural

Suburb

Appendix G – Trisomy 13/18 Survey

Qualifying Questions:

Which trisomy was/is your family member diagnosed with?

Trisomy 13 (Patau Syndrome)

Trisomy 18 (Edward's Syndrome)

Was the diagnosis of trisomy 13/18 made before birth?

Yes

No

How did the pregnancy end?

Live Birth

Stillbirth

Miscarriage

Termination

If participant answers "Live Birth"

How long did your family member with trisomy 13/18 survive?

Still living

Hours

Days

Weeks

Years

Did you speak with a genetic counselor about the diagnosis of trisomy 13/18 before birth?

Yes

No

Did you speak with a genetic counselor about the diagnosis of trisomy 13/18 after birth?

Yes

No

Do you use social media as a support network in regards to your family member diagnosed with trisomy 13/18? (Social media examples: Facebook, Twitter, blogs, pregnancy websites, etc.)

Yes

No

If yes, continue on to survey questions

If No,

What are your reasons for not using social media as a support network?

I do not know what social media is

I do not have access to a computer

I do not feel using social media would be helpful for support

I have access to support networks elsewhere (Ex: in my community)

I know someone personally who has a family member with trisomy 13/18

I am too busy with family, friends, and other commitments to use social media

Other:_____

End of Survey

Survey:

1. What types of social media do you use for *support purposes*? (check all that apply)

Facebook

Twitter

CaringBridge

Pregnancy Websites (ex: Baby Center)

Blogs (ex: Blogger, Wordpress, Tumblr)

Forums

Other:_____

If “blogs” is checked:

Do you have your own blog?

Yes

No

If No:

Do you read others’ blogs for support for your family member with trisomy 13/18?

Yes

No

If Yes:

Do you use your blog to discuss life with your family member with trisomy 13/18?

Yes

No

2. What are your reasons for using social media as a support network? (check all that apply)

Anonymity

Ease of use

Information gathering

Information sharing

Connection with others in similar situation

Lack of personal support network

Grief support

Other:_____

3. About how many hours per week do you use social media *for support purposes*?

Less than one hour

1-2 hours

2-5 hours

5-10 hours

10-20 hours

20+ hours

4. Where did you hear about the social media network you use? (check all that apply)

Internet Search

Advertisement (TV, Print, Radio)

Healthcare professional

Different social media venue

Family or Friends

My local trisomy13/18 organization

Other:_____

5. Have you used social media to tell others about your family member's diagnosis of trisomy 13/18?

Yes

No

Likert Scale (Strongly Disagree, Disagree, Neither Agree or Disagree, Agree, Strongly Agree)

6. Using social media has provided me with information on trisomy 13/18
7. I use social media because I can be anonymous
8. Social media has helped me to accept my family member's diagnosis of trisomy 13/18
9. My use of social media has increased since my family member's diagnosis with trisomy 13/18
10. Social media has aided me in decisions regarding my pregnancy
11. I feel more comfortable using social media for support over other methods of support
12. I would suggest the use of social media to someone in a similar situation as myself
13. Social media has made me feel more prepared to have a child with trisomy 13/18
14. Social media has allowed me to connect with other that also have a family member with trisomy 13/18
15. I have/will continue to use social media after the birth of my family member with trisomy 13/18 for support
16. Healthcare professional should consider suggesting social media as a support network to family members that have a family member with trisomy13/18
17. Social media provides/has provided an outlet for me to express my feelings and experiences about our family in a way that may be helpful to other individuals or families

If you wish to expand on your answers on any of the above questions, or have additional comments, please place them here:

18. When compared to the information I gained from my healthcare professional, the information I gained from social media about trisomy 13/18 was:

- Much less helpful
- Somewhat less helpful
- About the Same
- More helpful
- Much more helpful

19. How would you like a healthcare professional to present social media to you as a support option?

20. When do you think healthcare professionals should offer social media as a support option?

Same day of diagnosis

At a follow-up appointment

Only if the family member asks for support options

I do not think healthcare professionals should offer social media as a support network

Other:

21. What are your favorite social media sites that you think healthcare professionals should offer as support options?

22. Would you be interested in participating in a telephone interview to discuss your experiences with social media as a support network in further detail?

Yes

No

If No:

Thank you for your time and participation in this research study.

If Yes:

Please fill out your contact information below. This information will remain private and be used only for the purpose of contacting you for participation in this research study.

Name:

Phone Number:

Best time to contact you at the phone number provided:

Morning (10am-12pm)

Afternoon (1pm-5pm)

Evening (6pm-8pm)

Weekend

Email (optional):

Thank you for your time and participation in this research study.

Demographics:

Your Age:

- 18-25 years
- 26-32 years
- 33-39 years
- 40-46 years
- 47 years or older

Your Gender:

- Male
- Female

Your Relationship to the individual diagnosed with trisomy 13/18:

- Parent
- Grandparent
- Aunt/Uncle
- Sibling
- Guardian
- Other: _____

Your Ethnicity:

- African-American
- Asian
- Caucasian
- Hispanic/Latino
- Native American
- Middle Eastern
- Other:

Your Education Level:

- Less than High School
- High School/GED
- Some College
- College Degree (Associates or Bachelors)
- Professional degree (Master's, Doctorate, MD, JD)

What region do you live in?

- City
- Rural
- Suburb

Appendix H – Phone Interview Introduction and Questions

Hello, may I please speak with Mr./Ms. _____

My name is Ginger Edwardsen and I am a genetic counseling student at the University of South Carolina School of Medicine. I am calling you in regards to an online survey you recently filled out about your use of social media as a support network for your family member diagnosed with (trisomy 13/18 or Down syndrome). Is this a convenient time for me to speak with you?

As you may remember from filling out the survey, I am interesting in understanding what types of social media are being used by families that have a family member with (trisomy 13/18 or Down syndrome) and how social media is being used as a support network. You are being asked to participate in this study because you have a family member or are a caregiver of an individual with (trisomy 13/ trisomy 18 or Down syndrome).

I will be asking you a series of questions about your use of social media for support in order to gain a more detailed understanding of your reasons for using social media and what you gain from using social media as a support network for (trisomy 13/18 or Down syndrome). This interview should take about 15-20 minutes of your time.

This interview will be recorded and transcribed for the purpose of the research study. All of the information gathered from this study will remain confidential and your contact information will be discarded upon completion of this interview.

Please feel free to ask me any questions you may have or express any concerns you may have during our conversation. Your participation in this phone interview is completely voluntary and you may stop the interview at any time. If you are uncomfortable with any of the questions I am asking or do not wish to respond, please feel free to let me know and I will move on to the next question.

Do you have any questions before we begin?

Phone Interview Questions

1. Why did you choose to use social media as a support network?
2. Why did you select the particular social media format that you use for support?
3. How soon after your diagnosis did you use social media for support?
4. What has social media provided you with that traditional forms of support have not been able to?
5. What type of information did you learn about your child's diagnosis through social media?

Mr./Ms. _____ , I would like to thank your time and participation in this research study. Your answers to these questions will provide us with better insight into social media use in the (trisomy 13/18 or Down syndrome) community and how we as healthcare professionals can inform our patients of social media support.

Do you have any questions for me?

Thank you again for your time and participation and have a wonderful day/evening.