

UTILIZING SOCIAL MEDIA TO CONNECT ADOLESCENTS AND YOUNG
ADULTS WITH HEARING LOSS

Capstone

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Abstract

The aim of the present study was to develop a social media network designed for adolescents and young adults with hearing loss. Five adolescents and young adults with hearing loss were recruited through central Ohio audiologists. Participants responded to two electronic surveys and took part in a focus group with their peers. Results indicated elements, or suggestions, that should be incorporated when designing a social media network for this population. A supplemental study was also conducted with four young adults with normal hearing who participated in a focus group and responded to the same questions relating to the social media network as the focus group of participants with hearing loss. Results indicated that the participants with normal hearing desired different resources and information on the social media network compared to the participants with a hearing loss. The results of the present study can be used to guide audiologists in the development of a social media network for adolescents and young adults with hearing loss.

Dedication

First and foremost, I would like to dedicate this document to my family. They have been supportive of my professional ambitions and dreams, and without their support I would undoubtedly not be where I am today. Second, I would like to dedicate this document to Dr. Gail Whitelaw. I have never in my life had a mentor who was so inspirational, and has taken such an interest in me as a person. She has had a profound impact on the way I approach the field of audiology, and has inspired me to want to do more for the profession. Lastly, I would like to dedicate this document to Dr. Larry Feth. If he had not provided me the opportunity to work in his research laboratory as a first year student, I would have never fallen in love with the research side of audiology. He trusted me to work with his subjects, allowed my involvement in the research process, and provided me with opportunities that I would have never experienced otherwise. He is without a doubt the main reason for my passion in research.

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Chapter 1

Introduction

Social media websites have become one of the most utilized forms of peer-to-peer interaction on the Internet. Each month, 90% of all Americans who use the Internet access a social media network, with Facebook being the number four most accessed website on the Internet (Comscore, 2010). Facebook, introduced in 2004, is a social media website that allow users to construct individual profiles that can be utilized to connect with online peers to enhance communication opportunities (McClard & Anderson, 2008).

The largest demographic age group to utilize social media networks are 18-24 years of age, with young adults 18-20 years of age the most likely to use the Internet for a means of mental health support (Chou et al., 2009; Townsend et al., 2012). Knowing that close to 90% of high school and college students access at least one social media website (Dowdell et al., 2011), it has been suggested that online social networks could be used to connect teens and young adults with similar types of health related conditions to form an online community (O'Dea & Campbell, 2011; Malik & Coulson, 2011).

When considering the use of social media and health related conditions, hearing loss may be a condition that lends itself well to development with social media. The incidence of infant hearing loss in the United States is 1.1 of every 1,000 births, and 3.1% of children have at least a mild unilateral or bilateral hearing loss (Mehra et al., 2009). It has been determined that 11.3-14.9% of school age children exhibit some degree of hearing loss, whether conductive or

sensorineural, in at least one ear (Niskar et al., 1998; Bess et al., 1998). Any degree of hearing loss can cause psychosocial issues during critical developmental periods. For example, by the time a child with a minimal sensorineural hearing loss reaches the ninth grade, they are more likely to have difficulties with social support, stress, and self-esteem compared to their normal hearing peers (Bess et al., 1998).

Knowing that 80% of Americans use the Internet (U.S. Department of Commerce, 2011), audiologists have a unique opportunity to use this means of communication to provide information and support for patients with hearing loss.

The purpose of this study was to explore the development of an online social media network for adolescents and young adults with hearing loss. It has been suggested that when constructing a website for a specific etiology, the designer should have knowledge of the intended audience and design it based on the population who will be using the website (MacCulloch et al., 2010). The social media network was designed using the input of adolescent and young adults with hearing loss. Because they were the intended population, they were able to provide valuable feedback that can be used in the development of social media networks that are constructed for other adolescents and young adults with hearing loss. The social media website was formed using a participatory design, which allows those who ~~will be use using these~~ means of technology to help shape the design (Mosavel et al., 2005). It is anticipated that the results of the electronic surveys and focus groups can be used to aid in the construction of a social media network designed for adolescents and young adults with hearing loss. A

secondary purpose was to compare the attitudes about hearing loss of normal hearing young adults with the attitudes of adolescents and young adults with hearing impairment. It was hypothesized that young adults with normal hearing were not going to have the same attitudes about hearing loss as adolescents and young adults with hearing impairment.

Chapter 2

Literature Review

2.1 Social Media

The social media phenomenon has revolutionized the way that people of all ages utilize the Internet. Social media allows users to connect with others, and share information in a virtual environment that can be accessed worldwide.

Current popular social media platforms include Facebook, MySpace, Twitter, and YouTube. To put the popularity of social media platforms into perspective, as of June, 2013, Facebook had 1.15 billion users worldwide (Facebook, 2013). The number of monthly Facebook users is 3.5 times greater than the entire population in the United States, which is close to 320 million people. With this growing technology available at our fingertips, health professionals have started to take advantage of social media networks that can be used to increase communication between professionals and patients, as well as communication between patients outside of the clinic or office.

For a website to be considered a social media network, three elements must be present: (1) users must have the ability to construct a profile, (2) users must be able to share a connection with other members of the network, and (3) users must have the ability to view their connections and connections made between other members of the network (Boyd & Ellison, 2007). Social media networks can be designed to appeal to broad audiences, such as working professionals (e.g., LinkedIn), or more narrow audiences, such as breast cancer patients and survivors (e.g., Pink-Link Breast Cancer Support Network).

Although the largest population that accesses social media networks are users between 18 and 24 years of age (Chou et al., 2009), there is evidence that social media is being adopted by all age demographics. For example, Facebook's fastest growing population is composed adults between 45 and 54 years of age, and Twitter's fastest growing demographic is comprised of adults between 55 and 64 years of age (Globalwebindex, 2013). Although still relatively new, social media has already had a significant impact on business, healthcare, and social communication. It is an area of continuous advancement that can be used in the audiology profession to enhance communication and build relationships within the hearing loss community.

Social media networks are websites that can be accessed using the Internet. They are member-driven virtual communities composed of content posted by its users. Social media networks provide a comfortable atmosphere for members to discuss views and information related to a variety of topics. Furthermore, based on its inherent design and purpose, social media networks have become an innovative tool of varying health professions to improve patient and professional communication, as well as provide increased opportunity for patient-to-patient interaction and support.

2.2 Social Media Networks and Healthcare Patients

Studies have been designed to improve the quality and accessibility of current health information through use of the Internet (Stvilia et al., 2009; Kwon & Kim, 2009). Eysenbach [and](#) Köhler (2002) focused on search engine habits of patients using the Internet to obtain health information. When searching for health information on the Internet, the average person assesses a website in one minute and nine seconds, and finds an answer to their inquiry in five minutes and 42 seconds. In addition, the same study found that most participants clicked on the first website that resulted from their search. Studies have also focused on Internet use habits for patients with specific diseases or health conditions.

Sterling et al. (2012) interviewed adolescents with [hemophilia](#) about using the Internet to search for information regarding their disease. The authors indicated that the adolescents used the Internet to address urgent issues, and to obtain information related to their chronic condition that they may not want to ask their health providers. Furthermore, subjects reported that they found the information easier to comprehend than if it had been provided by a healthcare provider.

The Internet habits of patients who were newly diagnosed with a health condition have also been studied. Bass et al. (2006) investigated Internet-use of cancer patients at initial diagnosis and after eight weeks. It was found that of the participants who had never used the Internet to access health information, 44.5% were using the Internet for this purpose at the eight-week point of diagnosis. It was also determined that compliance to physician recommendations was greater in patients who did not seek health information on the Internet compared to those

who access this information themselves. By developing a social media network, healthcare providers have the opportunity to provide accurate health information to patients who may be newly diagnosed with a health condition, and are seeking information to better understand the diagnosis. Therefore, a social media network may provide a central location for patients to access reliable information related to a health condition rather than relying on Internet search engines and unregulated websites, which may increase patient compliance to recommendations.

Additionally, some adults are more likely to use Internet support groups if they believe that their health/medical insurance will not cover the cost of an appointment with a medical professional (Townsend et al., 2012). Thus, there may be a place for social media networks in to aid patients with health disparities who are unable to afford costs associated with medical care.

2.3 Adolescents and Health Care

Some health professionals may have a disconnect when treating adolescents because they feel that they do not have the training needed to adequately serve this patient population (Blum & Bearinger, 1990). Jacobson et al. (2001) noted that some adolescents have reported that they do not feel respected by healthcare professionals, and they perceived that some health professionals and support staff only view them as “trouble makers” during appointments. Furthermore, some adolescents reported that when consulting with their attending primary care physician, they felt as though physicians were going to “lecture” or “talk down” to them. This may lead some adolescents to turn to the Internet for informational and emotional support. For example, Gray et al. (2005) reported that adolescents may use the Internet as a source of finding health information because it is convenient and does not involve scheduling an appointment with a medical professional. Additionally, adolescents preferred to use the Internet for sensitive health issues that they would be embarrassed to discuss with a health professional. If adolescent patients are not comfortable in a clinical setting with their healthcare professional, it may be more beneficial to connect with patients outside of this setting. Knowing that adolescents are least likely to turn to professionals for help regarding a health condition (O’Dea & Campbell, 2011), social media networks may provide a link to connecting with this population.

2.4 Social Media Networks and Adolescent/Young Adult Patients

When surveyed, 95% of adolescents have Internet access (Subrahmanyam & Lin, 2007). However, only 5% of Internet users who also access social media are participants in an online support group, whereas 23% of all Internet users participate in social networking sites such as Facebook. Furthermore, Internet users who are 18-24 years of age are the least likely to use online support groups (Chou et al., 2009). The formation of a social media network may increase the number of adolescents and young adults who access informational and social support in a virtual community on the Internet.

Examples of the use of “informal” support groups on the Internet are evident. For example, college students with depressive symptoms are more likely to frequently update their Facebook page compared to students who did not exhibit these symptoms, with sleep disturbance and depressive mood being the most commonly reported symptoms (Moreno et al., 2011). When utilizing Facebook, college students reported they perceive a greater amount of social support based on the volume of people who are giving attention to their postings (e.g., status updates; Manago et al., 2012). This may be a critical role of social media, and there is evidence that young adults between 18-25 years of age with greater amounts of social support are not as at risk for depression, and have a higher self-esteem (Galambos et al., 2006). If adolescents and young adults do not perceive support in their actual social environments, virtual environments may be used as a supplement to fulfill this need.

Online social media networks designed to provide emotional and informational support for patients with chronic conditions have been studied and implemented in various health-related fields. An example of emotional support is the sharing of personal experiences, which can have the most profound effect on other social media members with similar conditions. For example, in an online forum for adolescents and young adults with inflammatory bowel disease, the most common form of posting was sharing of a personal experience. The sharing of a personal experience was used when asking for advice, sharing advice or support, and when discussing negative feelings towards the disease. There were also postings related towards supporting other members with the same condition, as well as threads devoted to connecting outside the online support group (Malik & Coulson, 2011). A reported advantage of using an online support group is the population of people are all in a related situation to one another (Wright, 2002), which may explain adolescents are capable of providing support for their peers, including emotional and informational support (Fukkink, 2011).

There are various types of digital media formats that can be used to model story sharing. Furthermore, the purpose of story sharing can be interpreted differently based on the viewing audience. A study by Yu et al. (2011) focused on obtaining perspectives about sharing personal stories in digital format on a website that would be related to a specific health condition. Findings indicated that professionals viewed story sharing as an educational opportunity and young adults viewed it as an opportunity to increase awareness in the population of people who do not fully understand a disease or chronic condition. The young

adults also reported that the posted stories could provide a sense of hope for future website users. Thus, social media networks for chronic health conditions may have differing effects based on who is actively viewing the information that is posted.

Social media networks, compared to actual physical environments where networking may take place, such as a face-to-face support group, may allow for users to be more forthcoming with information. In an early study on electronic media, Sproull and Kiesler (1986) found that when using electronic mail as a form of communication, there was an increase in new information introduced compared to any other form of communication (e.g., face-to-face). Therefore, there is a belief that the anonymity of online support groups may be more beneficial than face-to-face interactions for some users. Furthermore, users benefit whether they are actively posting on a network or if they are information seeking. For example, when searching websites with a forum for discussion posts, three main categories emerge: users who mainly view the website and do not usually post, users who actively use the website to ask for advice or to offer support, and users who negatively reacted to others postings (Henderson et al., 2012). The majority of people who utilize social media websites designated for participants with a certain condition are “lurkers,” or people who never post on the website. Both active and passive users of online support groups were found to obtain some type of support from this mode of interaction (Setoyama et al., 2011).

Although adolescents and young adults may report difficulties as they experience new life events and changes, hearing loss can add another factor to

psychosocial well-being. Hearing loss can be related to an increased amount of distress, and feelings of depression and loneliness. Moreover, loneliness is a significant issue for young adults (18-30 years of age) with hearing loss (Nachtegaal et al., 2009). Adolescents with hearing loss have a lower self-esteem and exhibit greater feelings of loneliness compared to adolescents with normal hearing. However, adolescents with hearing loss did not feel as lonely and had greater self-esteem when they used the Internet as often as their normal hearing or hearing-impaired peers (Barak & Sadovsky, 2008).

Knowing that many patients with a chronic health condition would be willing to exchange information with others using a website dedicated to the condition (Shaw & Johnson, 2011), audiologists have an opportunity to implement social media networks to address the needs of their adolescent and young adult patients with hearing loss. Social media networks may be a tool that can improve the outcomes for adolescents and young adults with hearing loss. Furthermore, the ability to access this type of social network may provide an opportunity to this population to seek greater support. For example, compared to their peers with normal hearing, adolescents with hearing loss had a greater motivation to utilize the Internet, did so more frequently, and used the Internet for a greater length of time (Barak & Sadovsky, 2008). When children and adolescents are lonely, they are more likely to spend more time communicating with others using the Internet, and are more likely to communicate about social and personal topics (e.g. emotions; Bonetti et al., 2010). In addition, increased feelings of loneliness yield a greater likelihood that an adolescent will contact an

online friend when they are faced with an emergency (Subrahmanyam & Lin, 2007).

Social media networks may also provide a type of social support that adolescents and young adults with hearing loss are not receiving in their daily environments. For example, Cummings et al. (2002) noted that the results of a survey given to people with hearing loss who participated in an online support group indicated that participants exhibited greater involvement in the online group if they perceived a lack of social support in their actual environment.

Furthermore, outcomes also demonstrated that when family and friends in the participant's actual environment were involved with the online group, the participant perceived greater benefit. When participating in a social media network designed for adolescents and young adults with hearing loss, additional topics that may be introduced include issues related to communicating and interacting with their siblings (Bat-Chava & Martin, 2002), how to approach discussing their hearing loss with their pediatrician (Moeller et al., 2006), and coming to terms with the negative connotation that their family may assign to their hearing loss (Steinberg et al., 2007).

2.5 Social Media Network Development

When constructing a website related to a chronic health condition, adolescent or young adult patients and healthcare professionals may have differing perspectives about what should be included as well as what is important. For example, when asked about the construction of a website for younger patients with haemophilia, adolescents reported that a website should be geared not only towards the patient, but other contacts who may not fully understand the chronic condition (e.g., friends and teachers). It would also be beneficial in connecting parents of newly diagnosed patients with experienced parents to offer support, as well as provide an educational component for parents. Additionally, adolescents reported greater degree of comfort sharing their experiences with others online rather than in person (Sterling et al., 2012).

McCallough et al. (2010) conducted focus groups of health professionals to determine what should be included on a website geared towards adolescents and their families concerning surgical intervention of scoliosis. The professionals suggested that when constructing the website, the designer should have knowledge of the intended audience and design it based on the population who will be using the website, the layout of the website should be carefully determined, and the main page should specify the purpose of the website and who its intended population should be. The other areas of information should be determined and designed out based on importance towards the viewing population. An example provided by adolescents with [hemophilia](#) is the inclusion of social networking opportunities with other adolescents with the same chronic

condition (Sterling et al., 2012). Furthermore, other suggestions provided by McCallough et al (2010) include an area of the website dedicated to online support forums that included patient interactions as well as a professional interaction with patients. Patients would include those who were beginning the process of intervention with those who had already experienced the outcomes of the intervention.

Based on the studies referenced above, health professionals may believe that informational support is paramount when designing a website for a chronic condition; however, adolescents perceived emotional support as being the vital part of the website. Orizio et al. (2011) analyzed existing social networks created for health issues to determine the main features of the networks. Most websites ended in .com, had a search engine specific to that website, and included contact information. Almost all of the websites included a mission statement, privacy policy, terms and conditions of participation, and a discussion board. Most websites requested only an e-mail address in order to become a member. Slightly more than half of the websites included a listing of the moderators, which usually consisted of “doctors.” Furthermore, healthcare professionals may have a differing opinion as to what should be included. Thus, adolescents and young adults should be consulted about what they feel are the important features that should be available to network users.

Additional studies have addressed adolescents and young adults input as a consideration when composing a social media network. For example, Shoveller et al. (2012) reported that young adults are receptive to the idea of having a forum

moderated by a healthcare professional, which can be trusted to answer questions they may have. It was also noted that young adults are not as receptive to using e-mail when posing questions due to current technology, which allows instantaneous communication. The young adults reported that when utilizing e-mail as a means of communication, response time is not as immediate as the population would prefer. Additionally, when asked, most adolescents stated they would use a website connected to their geographic location for online services (O’Dea & Campbell, 2011). Thus, when constructing a website for adolescents and young adults with hearing loss, it is essential to take into consideration design, layout, and content that the intended population deems to be important in making the website feasible and user friendly as well as effective and engaging.

2.6 Focus Groups

As defined by Krueger [and](#) Casey (2009), “The purpose of a focus group is to listen and gather information...Focus groups are used to gather opinions (p. 2).” Essentially, a focus group is a carefully designed interaction through discussions with a group of individuals who possess certain characteristics. Each group will have five to 10 participants, and a moderator (or interviewer) encourages the sharing of individual opinions in a comfortable environment.

Krueger [and](#) Casey (2009) have also identified five characteristics of a focus group: they include “(1) people, who (2) possess certain characteristics, (3) provide qualitative data (4) in a focused discussion (5) to help understand the topic of interest (p. 6).”

A focus group is one method that can be used to obtain further information, and opinions, from this population regarding what are the important design elements of a social media network related to hearing loss. Focus groups can be used for both decision-making and program/product development purposes (Krueger & Casey, 2009). As described above, a participatory design allows those who will be using the means of technology to help shape the product or process (Mosavel et al., 2005), which is why a focus group can be used as a means of collecting data in participatory research. Focus groups are “a research technique that collects data through group interaction on a topic determined by the researcher (Morgan, 1996, p.130).”

Participatory designs have been used in healthcare to aid in developing approaches to improve patient health. Areas of health using this model include

reminders for mammogram screenings for underprivileged women (Lustria et al., 2010), website development for stroke patients (Kerr et al., 2010), website development for mental health issues (Barnes et al., 2011; Meyer, 2007), online individualized physical activity plans (Vandelanotte & Mummery, 2011), using a text message system to address HIV issues within the African-American community of young males (Wright et al., 2011), and the development of a DVD for patients with chronic obstructive pulmonary disease (COPD; Stellefson et al., 2010). Use of this type of technology in healthcare presents an opportunity for healthcare professionals to provide education and support to current patients.

2.7 Psychosocial Development

When designing a social media network for adolescents and young adults with hearing loss, it is important to include informational and emotional support that may aid in psychosocial development for this population. There is growing evidence that adolescents and young adults with hearing loss are at greater risk of developing issues as they progress through psychosocial stages. Thus, it is important for healthcare practitioners to consider psychosocial developmental periods when constructing and implementing tools to be used with this population. Erikson (1980) described eight stages of psychosocial development that an individual progresses through during their lifetime. He was the first to suggest that development is influenced by outside influences, such as culture and relationships. Furthermore, the eight stages coincide with psychological dilemmas faced by all humans as they age, which contributes to personality and identity formation throughout the lifespan. Erikson (1980) suggests that as an individual ages, social, societal, and cultural experiences influence the progression through each stage of psychosocial development. Erikson's eight stages of psychosocial development are described in Table 1. There are nine stages described, each coincide with psychological dilemmas faced by all humans as they age, which contributes to personality and identity formation throughout the lifespan. Essentially, if conflicts are not resolved, identity formation and internal conflict have lasting effects into adulthood.

Table 1: Erikson's Stages of Psychosocial Development	
Stage of Psychosocial Development	Description
Basic Trust Versus Basic Mistrust ⁷⁷	<ul style="list-style-type: none"> Resolved in the first year of a child's life Infant learns to trust others that are involved in his/her environment
Autonomy Versus Shame and Doubt	<ul style="list-style-type: none"> Resolved between the second and third years of a child's life The child develops independence and self-reliant tendencies
Initiative Versus Guilt	<ul style="list-style-type: none"> Resolved between the ages of four and five years of age The child develops their inner conscience
Industry Versus Inferiority	<ul style="list-style-type: none"> Resolved between age five and prior to adolescence Child develops a sense of purpose and what they can contribute to society
Identity Versus Identity Diffusion	<ul style="list-style-type: none"> Resolved throughout adolescence Adolescent develops their self-esteem and attempts to find their identity
Incarnation Versus Impudence*	<ul style="list-style-type: none"> Resolved during emerging adulthood “Acceptance of adult roles and responsibilities, realistic expectations for the future, and concrete plans to achieve goals (p. 23)”
Intimacy and Distantiation Versus Self-Absorption	<ul style="list-style-type: none"> Resolved in early adulthood Adult develops sexual and interpersonal intimacy with the opposite sex
Generativity Versus Stagnation	<ul style="list-style-type: none"> Resolved in middle adulthood Adult has the desire to procreate and raise children
Integrity Versus Despair and Disgust	<ul style="list-style-type: none"> Resolved in late adulthood Adult accepts and takes responsibility for one's own path in life

*Stage defined by Patterson (2012) to describe emerging adulthood.

2.7.1 Emerging Adulthood

Patterson (2012) suggests that Erikson's stages involving adolescents and young adults are partially outdated due to the fact that Erikson composed the stages based on his experiences throughout his lifetime, and that lifestyles have significantly changed since the stages were created. Erikson first published the stages of psychosocial development in 1950. The transition from adolescence to adulthood is significantly different in the current generation compared to the adolescent and young adult population in the 1950s.

Arnett (2000) introduced the term "emerging adulthood," which is a theory that those in their late teens and early twenties experience a period of exploration in multiple facets of life. In the course of this period, young adults begin to experience change in areas such as living arrangements, education (e.g. 4-year college), career options, and intimate relationships (Arnett, 2000). Essentially, emerging adulthood is a transition period between adolescence and young adulthood (Arnett, 1998); however, "young adulthood and emerging adulthood are not synonymous (p. 20; Patterson, 2012)."

Arnett (2004) suggested that the transition period of "emerging adulthood" takes place between 18 and 25 years of age following adolescence, which is 10 to 18 years of age. Emerging adulthood is the byproduct of four phenomena in current Western culture. The phenomena include the creation of birth control and the sexual revolution of the 1960s and 1970s, more young adults are pursuing a higher education following high school, the meaning of becoming an "adult", and

the role of the female from being a wife and caregiver to now pursuing higher degrees and careers. Furthermore, there are five characteristics to emerging adulthood. These five characteristics are: (1) identity explorations, (2) instability, (3) self-focused, (4) feeling in-between, and (5) the age of possibilities.

When incorporating Erikson's stages in current society, a ninth stage should be incorporated between stages four (adolescence) and five (young adulthood) that includes emerging adulthood. Patterson (2012) suggests that this stage could be "incarnation versus impudence." Incarnation would include "acceptance of adult roles and responsibilities, realistic expectations for the future, and concrete plans to achieve goals (p.23)." If incarnation is not resolved, the result is impudence, which is characterized by "shamelessness, immodesty, and a lack of realistic goals and concrete plans to achieve those goals (p. 23)."

Half of all adolescents and emerging adults, when asked if they believed that they had reached adulthood responded with "in some respects yes, in some respects no." To reach adulthood, the most highly ranked item by both adolescents and emerging adults was being held accountable for one's actions (Arnett, 2001). Furthermore, adolescents and young adults view themselves as being an "adult" when they become self-reliant, which includes controlling their own decisions and being able to support themselves financially (Arnett, 1998).

Based on viewing the older adolescent and emerging adult population as a separate developmental period, many young adults will be transitioning towards constructing one's identity, and will begin to progress into developing intimacy with a partner or reveling in isolation. If the individual is unsure of their identity,

then they are more likely to have adjustment issues when progressing through Erikson's stages (Jenkins et al., 2005). In addition, the development of one's ego in adolescence is positively correlated to identity resolution at 24 years of age, which led to higher levels of intimacy in emerging adulthood (Beyers & Seiffge-Krenke, 2010). Thus, psychosocial maturity is related to an individual's identity resolution (Adams et al., 2006).

Peer relationships are an important part of an adolescent's identity formation. It has been discussed that those who were adjusted to both intimacy and identity, or only adjusted in their identity, were more likely to report that they were satisfied with the closeness of personal friendships and placed value on those relationships. Those who had not adjusted to identity and intimacy were not satisfied with their friendship development (Moore & Boldero, 1991). Without the formation of a strong sense of identity, an individual is more likely to be self-conscious. While males develop a sense of identity in early adolescence whereas females are more likely to develop identity in later adolescence, females develop intimacy at a younger age than their male counterparts, specifically during emerging adulthood (Montgomery, 2005).

Rosenthal et al. (1981) noted that based on Erikson's theory, adjustment or conflict resolution may not be resolved until the end of each stage. There is also evidence to suggest that as an individual becomes older, they continue to resolve internal conflict related to each stage of psychosocial development (Whitbourne et al., 1992). Widick et al. (1978) described how Erikson's theory supported that the adjustment to later stages is based on the resolution of the earlier stages. It is also

known that it is possible for an individual to revert to an earlier developmental stage depending on life events. An example would be that an individual may return to the stage of industry versus inferiority upon graduation from high schools when determining what career they would like to practice when pursuing a higher education.

2.8 Psychosocial Development and Hearing Loss

As described by Moeller (2007), “many children with hearing impairment exhibit delayed communicative skills, limited access to communicative exchanges, and other environmental effects (e.g., noise, reverberation, and distance) that put them at risk in the area of psychosocial development (p.729).” There is evidence that children with hearing loss are 3.7 times more likely to have psychosocial difficulties compared to their normal hearing peers (Dammeyer, 2010). However, the same study reported that when an additional disability is included, which is fairly common, children and adolescents are three times more likely to have difficulties than peers without two or more disabilities. Deaf students, of all ages, may have more difficulty with psychosocial adjustment based on the severity of their hearing loss and age of onset (Polat, 2003). In addition, adolescents want to be similar to their peers, and some may feel that their hearing loss makes them different especially when they are the only person in their peer group with hearing loss (Clark & English, 2013).

With communication as an important predictor of psychosocial adjustment (Polat, 2003; Dammeyer, 2010), Deaf adolescents were more likely to have fewer close friendships and not feel as socially accepted as their hearing peers (van Gent et al., 1981). Similarly, adolescents with hearing loss who were in mainstreamed educational settings were more likely to form closer relationships, or desire greater contact, with their peers with hearing impairments, rather than peers with normal hearing (Stinson et al., 1996). This may be because their hearing loss

does not allow them to have the same mode of communication or the same social pragmatics as their hearing peers. However, a student with a less severe hearing loss who was diagnosed at a younger age will have greater psychosocial development compared to other Deaf peers. In addition, as a student becomes older, they are more likely to be adjusted compared to younger students (Polat, 2003). Thus, a social media network may help facilitate communication between adolescents with hearing loss, which may lead to social acceptance across peers in similar situations.

In adolescents and young adults, hearing loss and learning disabilities both provide an academic disadvantage. Adolescents with a learning disability are not as well adjusted to industry as determined by the Erikson Psychosocial Stage Inventory (EPSI; Rosenthal et al., 1981) compared to their peers without a learning disability (Pickar & Tori, 1986). It can be determined that due to lack of achievement in an educational setting, adolescents do not fully develop this sense of industry which leads to unresolved internal conflict. In early adolescence, if the individual does not feel that their academic performance is acceptable then they risk inferiority (Manning, 1988). This may develop from not performing as well as their peers academically, or not up to their inherent standards of performance. However, academic performance and use of hearing aids may aid in psychosocial development (Polat, 2003).

Although the life stage of “emerging adulthood” was initially designed for the individuals without hearing loss, the goals of transitioning through this stage are essentially the same whether an individual has a hearing impairment or

normal hearing acuity. For Deaf emerging adults, transitioning through this life stage may take a greater period of time (Zand & Pierce, 2011). Furthermore, when transitioning through emerging adulthood, individuals with hearing loss are just as likely to transition into an “adult social role” (e.g., post-secondary student, competitive occupation, caregiver) as individuals with normal hearing (Van Naarden Braun et al., 2006). There is limited evidence about emerging adulthood in individuals who have a hearing impairment, or are Deaf; however, there is evidence that in some areas there are significantly different between this population and their peers with normal hearing.

Lukomski (2007) found that emerging adults with hearing loss generally reported that they experience greater stressors at home, and they had greater difficulty with coping skills compared to their normal hearing peers. Furthermore, females with hearing loss ranked themselves as worrying significantly more than males with hearing loss, and their normal hearing peers of both genders. However, the same study also found that in domains such as discouragement, body image, anger, alcohol, overall trouble, and context school significant differences were not observed between emerging adults with normal hearing and those with a hearing impairment. This may suggest that although there are some differing internal conflicts that may result throughout emerging adulthood, there are also similarities within the life stage. This may support the notion that individuals with hearing loss transition through similar conflicts as those with normal hearing. A social media network may aid in resolving internal conflict associated with transitioning through emerging adulthood, due to

increased support and social interaction for individuals with hearing loss and their peers.

2.9 Psychosocial Adjustment and Social Media Network Design

Kane (2012) suggests that individuals may use social media networks differently depending on the psychosocial stage of which they are currently transitioning. For example, the most important feature for adolescents when using social media networks may not necessarily be peer relationships, but finding a group identity, or affiliation. When comparing transition periods, adolescents use social media to affirm or disaffirm others' ideas, whereas emerging adults may use social media to express independent opinions and perceptions. Social media may also be used to increase opportunities for exploration related to identity formation.

When reviewing the literature for opportunities presented by social media networking websites, Collin et al. (2011) found multiple positive effects that social media networks present for young adults. For example, young adults have the opportunity to use this type of network for identity formation. This type of social media networking also encourages interaction with peers, which helps facilitate psychosocial development. Furthermore, the same study presented evidence that social media networks can strength existing real-world relationships, and foster the development of relationships through a virtual environment. For some individuals, online relationships may be their primary source of socializing with other individuals. The opportunity to be part of a social media network also allows young adults to feel “connected” to others, which may help in the formation of a “collective identity.” In addition, there was also

mounting evidence that social media networks may enhance an individual user's overall well-being.

Knowing that there is the possibility of positive psychosocial and mental health effects for social media network users, a social media network for adolescents and emerging adults with hearing loss may be a valuable asset for this patient population. For individuals who may be socially isolated, social media networks may allow the opportunity for connecting with other similar individuals. Because peer relationships are such an important part of transitioning through Erikson's psychosocial stage associated with adolescence, social media networks provide the opportunity for a decreased sense of loneliness and isolation, and a greater feeling of support to aid in the transition. Furthermore, knowing that emerging adults with hearing loss may not be as versed in coping with difficult situations related to transitioning to adulthood, social media networks have the opportunity to provide increased peer-to-peer support for difficult situations that may prolong the transition to adulthood.

2.10 Purpose

The purpose of this study was to develop a social media network that could be used to connect adolescents and young adults with hearing loss. The network was designed through input obtained by means of electronic surveys and a focus group of participants with hearing loss. Furthermore, a focus group will be conducted of young adults with normal hearing to compare differences in perception of those with normal hearing acuity compared to participants with hearing loss. It was hypothesized that opinions of adolescents and young adults with hearing loss can be used to construct a social media network designed for this population. A secondary hypothesis was that perceptions of hearing loss would differ between participants with normal hearing and participants with hearing loss.

Chapter 3:

Methods

3.1 Overview for Initial Study

A social media network website was designed for adolescents and young adults with hearing loss. The website design was based on a transcript of a focus group conducted by Oticon Pediatrics, a worldwide manufacturer of hearing aids that develops products for children and adolescents with hearing loss, at The Ohio State University in Columbus, Ohio in June 2012. Following the development of the social media network, adolescents and young adults with hearing loss were recruited to provide feedback and suggestions related to improving the network's design. Participants had access to the secured social media network, and had the opportunity to evaluate design, features, content, and layout. Feedback was provided first through an electronic survey, followed by a focus group with other participants with hearing loss, and a final electronic survey to measure overall improvement in network design. Opinions and suggestions provided by participants may be used by audiologists in future social media network design concepts for adolescents and emerging adults with hearing loss.

3.2 Social Media Network Development

The social media network website was developed using <http://www.ning.com>, a social media website that allows users to develop their own social media network. Layout, color scheme, website theme, available applications, and other design features were customized through this website. The social media website for the study was titled "Ohio State Audiology" and the

URL was <http://www.ohiostateaudiology.ning.com>. When designing the social media network for adolescents and emerging adults with hearing loss, it was important to incorporate elements that are present in other social networking websites to increase user engagement. Elements that were incorporated included: blog posts, a discussion forum, user profiles, status updates, individual and group chat features.

“Ohio State Audiology” was designed to be a secure network that would only be accessible by study participants. To access the social media network, the investigator e-mailed a URL to each participant. Once the participant visited the social media network website, they were asked to use their initials for their first and last name, and they had to answer a security question. When the security question was answered correctly, the investigator was notified that the participant requested access to the social media network. The investigator then granted the participant access, which allowed open access to the social media network.

The design and content of the social media network was based on the transcript of a pilot study which was a focus group conducted by Oticon Pediatrics at The Ohio State University in June, 2012. The objective of the focus group was to use participant responses to a number of issues and concerns related to hearing loss and transition phases in adolescence, which then were used to aid in the development of materials designed to appeal to adolescents and young adults with hearing loss. For the Oticon Pediatrics focus group, there were four adolescent participants, one female and three males. The duration of the focus group was one hour and 45 minutes. Participants answered questions related to

hearing aid products, features, interest utilizing social media networks for hearing loss, and psychosocial issues related to hearing loss.

3.3 Subjects

The target subject population for this study included adolescents and young adults with hearing loss. Population characteristics included: individuals between 15-24 years of age, any degree of hearing loss, and an interest in social media network development for adolescents and young adults with hearing loss. The age range was chosen so that both adolescents and emerging adult populations would be included in the participant group. Although it was required that participants had hearing loss, this could include unilateral or bilateral, conductive or sensorineural, and did not require that the participant used amplification. It was important that the participants with hearing loss not be restricted. This was to allow the inclusion of any participant who could potentially become a user of a social media network for hearing loss, and to include various viewpoints based on participant characteristics

Audiologists in the Central Ohio area were contacted through e-mail with a letter outlining the details of the study, and an attached flyer that could be posted in audiology clinics and waiting rooms. The letter asked that audiologists post the flyer in a location where patients would have the opportunity to view the information. It was also requested that the audiologist forward the information to patients who had hearing loss and were within this age range to determine if they would be interested in participating. The study was designed to have between five and 10 adolescents and young adults with hearing loss. Once this number

had been reached, recruitment efforts were ceased. The recruitment letter and flyer are outlined in Appendix A.

Eight potential subjects were identified for the study. From these eight potential participants, five subjects were available for the study. Two participants were adolescents (17 years of age or younger), and three participants were young adults (18 years of age or older). Two subjects were within the age range requirements and were diagnosed with hearing loss; however, they no longer resided in the Central Ohio area and were unable to participate. A third subject had contacted the investigator to express interest, but was unable to participate in all aspects of the study due to a recent family issue.

The five participants resided in the Central Ohio area, and they were not compensated for their participation in this study. There were five total participants, with all five participating in the first electronic survey. However, one participant was unable to take part in the focus group, so there were only four participants in the focus group. In the final electronic survey, there were four participants who completed the survey and one participant who did not complete the electronic survey. There were two male and three female participants. One participant was not able to participate in the focus group, and it is unknown which participant did not participate in the final electronic survey because respondents are anonymous.

3.4 Procedures

Potential participants expressed interest in the study by contacting one of the investigators. Following the initial e-mail, a consent form (Appendix B) was

e-mailed to adult subjects and parents of adolescent subjects. The consent forms were then faxed or e-mailed to one of the investigators. Adolescent participants also had to complete an assent form (Appendix C) prior to receiving access. Following the receipt of consent form, the participant was e-mailed the URL to “Ohio State Audiology.”

Once a participant entered in the URL to their web-browser, they were routed to a secure webpage through the social media network. At this point, they were asked to enter their initials in order to identify them as a participant, and were asked the answer a security question (Where is the Ohio State University located?). At this time, the participant did not have website access. After answering the security question, the investigator was notified which participant attempted to access the website, and the participant was manually granted access.

The e-mail that contained the social media network website’s URL also had a link to an electronic survey developed using <http://www.surveymethods.com>. Once the participant had access to the website, they were asked to complete the electronic survey to provide feedback on the website’s design, content, and layout (Appendix D). Responses to the electronic survey were anonymous. All subjects were required to complete the electronic survey prior to participation in the focus group. Additionally, all participants had at least three days to complete the electronic survey. Two days prior to the focus group, each participant was sent a reminder e-mail asking that they complete the survey prior to the focus group, if they had not already done so.

Focus group questions were designed based on a number of factors. First, questions developed for the Oticon Pediatrics focus group, as described above, were used. In addition, questions asked in another study focused on social media network development for adolescents with [hemophilia](#) (Sterling et al., 2012) were also used for this focus group. Questions that were used from both of these focus groups are noted in Appendix E. Participants were reminded that their survey results had been anonymous, and that the results from the focus group would also remain anonymous. The first electronic survey and the focus group both consisted of questions with open-ended answers to obtain greater feedback about what modifications could be completed to improve website design and content. Following the completion of the first electronic survey and the focus group, the social media network was modified based on participant feedback.

Once modifications were completed, a second electronic survey was e-mailed to participants. The second electronic survey was designed for participants to evaluate the final design based on a bipolar 5-point Likert scale with verbal descriptors, and an additional area for comments if necessary (Appendix F). Verbal descriptors were used because verbal labels are cognitively less difficult to interpret compared to numerical labels when choosing a response option (Krosnick, 1991). Furthermore, Likert response scales have good internal validity (Flynn et al., 2004). Also, only five response options were used because although a greater amount of information can be collected with a greater number of response options, as the number of response options increase there is a greater possibility that response errors will be made (Cox, 1980).

Following the initial e-mail with the second electronic survey, participants were sent two reminder e-mails. The first reminder e-mail was sent eight days following the initial e-mail containing the final survey, and the second reminder e-mail was sent 20 days following the initial e-mail. The second electronic survey was also anonymous.

3.5 Supplemental Study: Addition of a Control Group

A control group of five young adults with normal hearing acuity was added as a supplement to the initial research protocol. The control group participants would only participate in a focus group. The rationale for conducting a focus group with this population is to have a control group (normal hearing) that can be used as a comparison to the experimental group (hearing loss) in relation to perceptions of the social media network design.

The control group consisted of four young adults who were recruited from an undergraduate introductory speech and hearing course (SHS 2230) at The Ohio State University. A slide with information related to the study was posted in a power point presentation for students, and the first five students to contact study personnel, and who were able to attend the focus group, were selected for participation. Five young adults confirmed normal hearing acuity through self-report and committed to attending the focus group; however, one did not attend. Control group subjects had normal hearing acuity, as self reported, to compare perceptions about the social media network website with those from the adolescents and young adults with hearing loss. The four control participants received extra credit in their introductory course for their participation. The four

participants were all female students who were pre-majors in the speech and hearing science undergraduate degree program.

The control group only participated in a focus group. Participants received access to the social media network website as described in the methods section. Each participant was asked to review the website prior to the focus group. Also, prior to answering questions, participants were asked to consider the questions from the perspective of a young adult with hearing loss. Participants were recruited from an introductory speech and hearing course to ensure that they would have some insight into living with hearing loss based on course lectures. The focus group was scheduled for a one-hour time frame and was completed within that hour. The focus group questions were the same as in Appendix E.

Chapter 4

Results of Initial Study

4.1 First Electronic Survey

The purpose of the electronic survey was to establish what information participants found useful, based on previous guidance from adolescents and young adults obtained as part of a focus group. When asked what they found useful liked about the website, participants responses were overall positive. Comments included how similar the website is to Facebook, which was viewed as a positive, that participants were able to connect with one another, and the “idea” of the website in general. For example, one participant responded:

“...it gives students who have a hearing loss a sense of family. I thought I was the only student that had hearing loss and just dealt with it for such a long time... I think this website will help a lot of students in the future who feel isolated because of their hearing loss.”

Participants reported that the content was well-organized, accessible, interesting, and that there were valuable links available. One participant commented that the material was very “clinical,” and another participant commented that they would like to see more resources for adults added to the website. There were also further recommendations for links to companies that manufacture hearing aids and accessories, as well as local audiology and otolaryngology services available in Central Ohio.

When asked about what information participants would like to be available about “hearing loss”, a variety of responses were obtained. Information they would want to have access to includes types and degrees of hearing loss, how

a person acquires a hearing loss, medical interventions for hearing loss, how to live with hearing loss, and how hearing is tested. One participant commented:

“I’ve had my loss all my life but I never fully understood why I sat in a booth repeating words and pressing a button so many times until I became a Speech and Hearing major.”

Further recommendations for information included being able to access others with hearing loss who might be viewed as “role models” for those who use the website, and more information about the profession of audiology.

When reviewing the layout, the website was described as “simplistic” and because it was like Facebook, the website was “appealing.” However the main criticism is that the website was “plain” and “not very exciting.” Furthermore, the participants requested more shortcuts to access different areas of the website in one-step rather than navigating through multiple pages. To make the website more appealing, it was recommended that there should be more pictures, more color, the inclusion of video, and less contrast in the background.

When asked about the ability to chat with other members, the response was that it was a very positive feature, and the best part of the website. One participant commented:

“It is very nice to know that I have others to relate to in the OSU community. I can get advice and tips from them specifically for our area which is great.”

Another participant stated:

“I thought that was the most important part of this website. I believe whenever a community is formed of people who all have something in common [it] bring[s] them closer together.”

When asked about what topics could be introduced to aid in information exchange, participants recommended areas such as “hearing aids and your experience,” and “how much do hearing aids really help?”

Participants were asked if this website would be beneficial for people their age who had newly identified hearing loss and/or were new to wearing hearing aids. Responses included that the website would be beneficial, however, the need for greater depth and specificity of information was noted. It was recommended that there could be a separate blog designed for people who were newly identified, and that there could be an area for people to share their experiences with one another. Furthermore, information that should be provided for newly identified could include: how to cope, how to explain their hearing loss to others, that they are not alone and should not be ashamed, what to do next, and services available for school and job situations. Discussions about newly identified were included to reflect what information should be available throughout the website for those who are not as familiar with hearing loss and its effects.

When asked about whether anonymity should be part of the website, participants had diverse opinions. One participant reported that it should be the website user’s personal choice as to whether they wanted to remain anonymous or provide personal information. However, another user stated that the website should remain anonymous, as they perceived that it would allow participants to be “more open” with one another. Also, another participant was not comfortable with every potential user being able to see his or her information, and that they would want to the option of deciding who can view their profile. Furthermore,

two of the participants were in favor of the website not remaining anonymous.

One user commented:

“The anonymity is very impersonal and not very comforting, this is a place where people should feel comfortable talking to others and that is sometimes easier when you know their name. It also provides opportunities to connect outside of the website as well.”

As to whether family members, such as parents, should be included on the website, the main responses were that this should only be a website for adolescents and young adults with hearing loss. Participants reported that they believed that their parents would find the information available on the website to be beneficial (e.g., communication strategies that could be incorporated with their son/daughter); however, participants stated that they believed parents would not benefit from a website designed for this population because they are in need of different information resources outside of the available links. One participant commented:

“...they should have a website of their own where they can chat with other families who have someone with a hearing loss... People with hearing loss have a different reason for being on a website with others like them from those who are family members of someone with a hearing loss.”

Furthermore, another participant added:

“I would not want my family on here because they truly would not be able to understand what we are going through unless they had hearing loss.”

One participant also noted that although they would not want family to be included on the website, they would still be able to show others content provided that they thought may be helpful (e.g., communication strategies). Also, all of the participants agreed that if their family was included on the social media website, they would be less likely to discuss certain topics.

All of the participants reported that it would be valuable to include an audiologist as a moderator on the website. Participants stated that the audiologist would be more knowledgeable about current technology, more reliable, and that it was be convenient to receive “quick” answers through the website. Furthermore, one participant noted that there may be some questions that adolescents and young adults may not feel comfortable asking while at an audiologist appointment or in a face-to-face environment, and the website would provide a way for users to have their questions answered.

When asked about what they considered to be the “best” aspect of the website, participants responded with “the open format,” the information available in the blog posts, and the links to other websites related to hearing loss. When asked what they viewed as the area of “greatest improvement” for the website, the participants responded with “the look and feel” of the website, and greater opportunities for interaction especially on topics related to their hearing loss.

4.2 Focus Group with Subjects who are Hearing Impaired

As described in the Methods section, a focus group was conducted with four adolescents and young adults with hearing loss. Focus group questions are listed in Appendix E, and are related to hearing loss, amplification, psychosocial issues, and social media network website development.

4.2.1 Hearing Loss and Hearing Aids

When asked what people are most likely to not fully understand about individuals with hearing loss, based on their own experiences, participants provided a range of answers. One participant reported that they have been

described as having “selective hearing”. Another participant commented that people do not seem to understand how difficult it can be to live with hearing loss at times. Another participant added that people can get frustrated when constantly asked to repeat themselves. This participant continued:

“...they seem to get kind of frustrated, like, ‘he just doesn’t want to pay attention to me.’ They don’t actually tell me that, but that’s kind of what their reaction is.”

It was also reported by another participant that because her hearing loss is invisible that her friends do not seem to see her as a person with a hearing loss. For example when talking about how she has to ask her friends to increase the volume of the television, she added:

“...they don’t really see me as having a hearing loss because mine is only mild to moderate. I don’t know, it’s not that bad, so they don’t really see me as having a hearing loss in everyday life. Then, that happens, and they get really frustrated with me because it’s fine for them, but it’s not fine for me. So I think if they had a better understanding of how, in different situations, why I can’t hear as well.”

Participants also commented that some friends and family point out their frustration at times because participants will not hear understand what someone is saying to them, while others will remain silent.

When asked what they would want others to know about hearing aids, participants responded that even while wearing hearing aids consistently, they are merely aids and do help them to hear in all listening environments or hear as well as they would without a hearing loss. One participant commented:

“...hearing aids sometimes don’t pick up everything, like, which is one of the reasons I sometimes have to ask people to repeat themselves because they’re not facing me so it’s harder to hear them.”

Other frustrations included what is audible when individuals with hearing loss are not wearing their hearing aids. As one participant stated:

“And I think like some of my friends think like ‘Oh, if you take your hearing aids out then you can’t hear me at all.’ They don’t understand that it’s not complete deafness.”

The topic of technology, other than hearing aids, was addressed in the focus group. One of the technology options discussed included the use of an FM device in the classroom. Two of the participants had previously used FM systems in the classroom. One participant commented how teachers would forget that the transmitter was on outside of the classroom. The other participant commented that some teachers were great about wearing the device and would try to not embarrass her in front of other students when she was asked about it; however, the same participant also noted that some teachers did not like having to wear the transmitter, which she perceived that the teachers were less patient or more frustrated with her in the classroom.

The use of streaming devices with hearing aids was also discussed. One participant reported trying a streaming device with her hearing aids, and another participant had used direct audio input cables coupled to hearing aids.

Participants recommended including information related to streaming devices, such as their function and available accessories, on the website. It was also requested the information about using FM systems outside of the classroom in different listening environments be included as well.

When researching hearing aids, the participants reported using Google to find information. However, it was noted that it would be helpful to have a blog to

compare technology, and use as a resource to compare different hearing aids rather than determining hearing aid specifications through hearing aid manufacturer websites. One participant reported:

“I think it may be helpful to have a blog about them, like here’s the newest technology from this person and how it compares to everything...is there a central place that you can look at hearing aids at? ...You would have to go to each manufacturer’s website to find out kind of what’s out there so to have a place where you can just kind of, um, get the information from all of them at once so at least what’s newest and what’s best form all of the brands in one place.”

The participants also agreed that similar information about connectivity and assistive listening device (ALD) options needed to be presented. It was also requested that availability of manufacturers for local audiologists be reported on the website. As explained by one participant:

“...you could also add what’s available from which audiologist...[some audiologists] only work with like a few different manufacturers, but there are more manufacturers out there. So, um, I guess what technology is available, where too, and in what ways.”

4.2.2 Social Media Network

At the time of the focus group, each participant reported that they currently did not access a social media group designed to offer support or mentoring for adolescents and young adults with hearing loss.

Participants reported that they liked how there were different areas of the website, such as blogs, dedicated to different topics related to hearing loss. One participant noted:

“I kind of like the idea of a blog where you can post links to different websites, for pretty much any type of topic that relates to hearing loss, like devices and...how to relate to other people about it.”

When asked that they disliked about the website, participants reported that they viewed the design as “plain”, “boring”, and “not interesting”. Furthermore, comments were made regarding “visual contrast”, specifically that the color options were not visually appealing. To simplify the website, it was requested that a navigation bar be incorporated, and that buttons for the blogs and discussion posts include all available topics to increase ease of access. To further enhance the website design, participants recommended that more color be incorporated, along with more pictures and better graphic designs. Recommendations for pictures included photos of hearing aid models, or photos of individuals with hearing impairment interacting in daily activities.

Participants reported that navigating the website was fairly straightforward, and easy to use. To make the website more appealing to this population, one participant suggested the incorporation of local events. To make the website more memorable to participants, it was indicated that the moderator should give members more to talk about and discuss with one another. When discussing how to make the website more memorable, another participant remarked:

“It was so like unique by itself, nothing’s ever been out there like it I guess.”

When asked about the “best part” about the website, participants commented that it was the concept of the website in itself. One participant shared:

“I think just the idea in general that there’s a place that we can kind of share our experiences and talk to other people and get information.”

The participants' reaction to using this mode of communication with other adolescents and young adults with hearing loss was overall positive. One participant commented:

"I'm around people who are all hearing, so...I've never been around a lot of people with hearing loss. So it would be nice to have a group of people who, like, to hang out with or doing things with."

A second participant followed up by adding:

"I've never been able to interact with people, um, who share the same kind of problems, so it would be nice to have that."

When asked about whether a website designed for adolescents and young adults with hearing loss would be beneficial for an individual who is newly diagnosed, participants commented about how they could see where this website would be a strong resource for informational and emotional support. For example, one participant stated:

"I think if there would have been something like this last year when I was diagnosed that it might have helped me better instead of learning everything on my own."

A second participant continued:

"...it's just kind of a shock so it's nice to know that there are other people who are going through the same thing. So it can be helpful in that way, like an emotional back-up too."

It was discussed that this type of website can help a newly identified individual see what experiences other people have had. Another participant followed-up by saying:

"...when I was first diagnosed I felt kind of alienated because it just seemed like something no one else had."

Participants also liked the idea behind blogs being available throughout the website. One participant noted:

“I think the blogs...or the way that it’s people can share website or information about what people with hearing loss can do about different obstacles and challenges.”

The participants agreed that there should be separate discussion and blog posts for adolescents and young adults in different situations such as high school, college, and the workforce. When discussing relevant topics for those adolescents with hearing loss who are in high school, it was recommended that posts related to background noise in classroom and lunchroom settings, as well as strategies to better communicate in those environments, be included. Furthermore, participants recommended that there be information for how to communicate effectively outside of a school-based environment. One participant noted:

“...all of the crowded places, um, even like at school or not at school, I sometimes have trouble with hearing, but then there’s a lot of noise in the background.”

When discussing posts that could be directed at college students, participants recommended that posts related to some classroom situations; however, both college-aged participants reported that students were more respectful in a college-courses, and that the main situation where communication comprehension can become difficult is in someone is talking from behind. For example, one participant commented:

“But sometimes it’s hard like when they are behind you to just like hear them because you always have to turn your body, and then the teacher will start talking right away.”

When asked about independent living, both young adults reported that they currently live with their parents. Because only one viewpoint could be expressed relating to this issue, a future focus group may want to incorporate further questions related to living with roommates, assistive listening devices, and information that participants feel would be relevant to an emerging adult with hearing loss who is living on their own.

The participants commented that the links were a “good start” however the website needs “more detail.” One participant shared:

“I thought everything up there was pretty good...there were things I didn’t even think of that were on there.”

Participants stated that it would be beneficial to have information about strategies regarding how to explain hearing loss to friends, as one participant noted that some people get “nervous” because they do not understand hearing loss.

However, the participant also noted that friends do ask some questions related to the cause of her hearing loss, demonstrating an attempt to understand her hearing loss.

An important issue that participants stressed that should be included was information about living independently, and what strategies and assistive devices assist for people with hearing loss. For example, one participant said:

“I know that sometimes I’m like, ‘Oh, what would it be like if I was alone, and didn’t have anybody there?’ Because I know for me, when I’m sleeping...the hardest part is getting up, and if I forget, or my alarm goes off and I don’t hear it, then nobody’s there. If my parents are there, they turn on the lights and that helps.”

The participants discussed whether users should remain anonymous, or share their identity on the social media network website. One conclusion that was

made was although website users may want each person to have an identity (e.g. name, geographic location, etc.) when building friendships, it should be up to the website user because some will only be comfortable accessing the social media network if they have the option to remain anonymous. However, it was commented that information shared would be deemed as more “credible” and more “personable” if people shared their personal identities. It was also recommended that there should be an option to allow users to remain anonymous when commenting on personal experiences.

When discussing if family members should be included on the website, participants all agreed that the website should be limited to adolescents and young adults with hearing loss. One participant remarked:

“I’m in favor of my family not being on it because, I don’t know, it kind of affects how I talk about things. It’s like I’m a whole different person when I’m away from my family, and then I feel like I can’t talk about certain things in front of them.”

Participants commented that information retrieved from the website could be shared with family members if and when appropriate or relevant. If information was to be provided for family members, it was suggested that information be included that relates to the difficulties of living with a hearing loss. One participant noted:

“[I would want my parents to know] maybe how difficult it is to go through what we’re going through so maybe they’d understand it better. I don’t know, my dad, he gets really frustrated like when you don’t hear him, and I just feel like if he had information like that then maybe he wouldn’t be so quick to be angry.”

Participants were also in agreement that friends should not be allowed on the website.

Participants were in agreement that it would be beneficial to have an audiologist available on the website to answer questions related to hearing loss. One recommendation included that there could be a question and answer section. One participant also suggested that this might be a better line of communication between the audiologist and younger patients. For example:

“...if they don't want to call an audiologist or try anything else, so they'll just Google it and find like Yahoo! Answers or something. So, um, I think it would be a lot better to kind of have the same idea as something like Yahoo! Answers, but from a credible source because it's kind of like provided by the website.”

It was also requested that information regarding local audiologists should be added to the social media website.

Participants reported that the concept of mentoring seemed inherently available in the design of the website. However, they would not want an individual mentor assigned to them through the website. They also liked the idea of mentoring opportunities coming from multiple online community members. Thus, instead of only getting advice and information from one person, and one point of view, by asking questions and having discussions with members throughout the website it allowed for people posting in the discussion areas to receive a range of opinions and viewpoints.

Participants preferred that the website be designed for adolescents and young adults in a specific geographic location to aid in the fostering of relationships not only within the website, but also in the real world. However, participants also saw benefit in having a national website. One participant commented:

“It would be more fun to talk to people and, um, like hear experiences from across the country, but it would probably be better off just locally.”

4.2.3 Psychosocial Development

When asked what they wished they had known about living with hearing loss when they were younger compared to now (e.g., what do they know now as a college student that they wished they had known in high school), one participant responded with being forthright in discussing her hearing loss. She continued by saying:

“I mean, I do that with my friends like if I’m having trouble I will tell them, and if it’s somebody new sometimes I even tell them right away, ‘I’m sorry I can’t hear you.’ And then I’ll like explain what’s going on and then they kind of understand from then on...So I think just be upfront and don’t be shy about telling people because it is really helpful to be upfront.”

When asked about advice they would give to others in the beginning of transition periods, one participant responded as to how to still get the services needed to be successful in the classroom when in college. For example:

“...before you decide where to go make sure you go and talk to the disability department at the schools you’re considering so you know what services they give because some schools give less services than others.”

It was also suggested that the website should incorporate information about rights for people with hearing loss under Individuals with Disabilities in Education Act and/or Americans with Disabilities Act. Participants were also interested in understanding issues related to technical standards for specific jobs or careers and how to handle disclosure of hearing loss in this situation. Furthermore, all of the participants reported that when they need information for services related to their hearing loss, they relied on their personal audiologist as their primary source of information.

Participants were asked about communicating with their teachers or professors about their hearing loss and accommodations in the classroom. One participant reported that their case manager discussed information related to their hearing impairment and educational accommodations needed with their teachers. However, another college-aged participant reported that she talks with each of her professors on the first day of class, and then follows up with her professors through e-mail to determine what accommodations are necessary. Another participant reported that in elementary school and high school, her hearing loss was listed in her records, but at this point if she has difficulty she discusses accommodations with her professors after a class.

4.3 Second Electronic Survey

The second electronic survey contained a five-point Likert response scale with five answer options: strongly agree, agree, neutral, disagree, strongly disagree. Modifications were made to the social media network following the first electronic survey and the focus group for adolescents and young adults with hearing loss. All participants ranked agree or strongly agree for the following areas: the social media website is easy to use, appropriate information is available for adolescents and young adults with hearing loss, the website is beneficial for adolescents and young adults with hearing loss, the website design and content is age appropriate, the website could be used as a means of support by interacting with others with hearing loss, users could provide support to others with hearing loss, reliable information to answer personal questions about hearing loss, reliable

information sources that could be used to educate family and friends, and the website would be beneficial for users with hearing loss in rural areas.

One user responded as “neutral” as to whether the design was appealing and whether they “could use this website to empower myself” while others responded with “agree” or “strongly agree.” One person disagreed with the statement “I could use this website to empower others” whereas the other three participants “agreed” or “strongly agreed.” Furthermore, when asked if this was a website they would use, one participant “disagreed” while the other three participants “agreed” or “strongly agreed.” When asked for additional comments, one participant reported that the website “...looks great!” and another reported that they “...really like the new layout.”

Results of the Supplemental Study

4.4 Comparison of Hearing Impaired and Normal Hearing Focus Group

Responses

4.4.1 Information About Hearing Aids

Responses related to information that should be included about hearing aids on a social media network were compared between groups. There was an interesting discrepancy between each population, and what information they thought to be valuable about hearing aids. Results are outlined in Table 2.

Results indicate that adolescents and young adults with hearing loss are interested in technology available, and which manufacturers local audiologists work with in relation to fitting, maintenance, etc. Young adults with normal hearing are interested in cleaning, maintenance, and general information related to hearing aid use.

Table 2: Important Hearing Aid Information to be Included on a Social Media Network

Population	Response
Adolescents/Young Adults with Hearing Loss	<ul style="list-style-type: none">• Blog to compare technology options between manufacturers• Local audiologists, and manufacturers that each fit to patients
Young Adults with Normal Hearing	<ul style="list-style-type: none">• Limitations of hearing aids• Cleaning/maintenance of hearing aids• Audibility range of each hearing aid• Price and quality of hearing aids• How often hearing aids need to be replaced• How easily hearing aids need repaired• Cosmetics of hearing aid styles

4.4.2 Social Media Network

Responses related to social media network design were compared between adolescents and young adults with hearing loss, and young adults with normal hearing. Results are outlined in Table 3. Results revealed discrepancies between groups, including topics for blog and discussion posts, who should have access to the social media network (e.g., family and friends), and if geographic location should be considered. However, there were also similarities such as including an audiologist as a moderator, the desire for blog posts related to classroom listening situations and how to explain hearing loss to others, and anonymity on the social media network.

Focus Group Topic	Young Adults with Normal Hearing	Adolescents/Young Adults with Hearing Loss
Likes	<ul style="list-style-type: none"> • Similarity to Facebook • Personalized profile pages • Did not feel “medical” 	<ul style="list-style-type: none"> • Various blog posts for issues related to hearing loss • Social media network for those with hearing loss is a unique concept in itself
Dislikes	<ul style="list-style-type: none"> • Social network format on smart phone 	<ul style="list-style-type: none"> • The design is plain, boring, and not interesting • Need to incorporate a navigation bar, more colors and pictures • Incorporate local events (e.g. 5K for hearing loss)
Blogs/Discussion Posts	<ul style="list-style-type: none"> • Incorporate “story sharing” for each member • Allow for sharing of personal experiences throughout the website • Liked that blog posts had outside links • Include blogs with “tips” for how to use hearing aid devices • Discussion posts allow 	<ul style="list-style-type: none"> • Separate posts for high school users, college users, and young adults • Reviews on hearing aids and performance in compromising environments • Posts related to hearing loss in the classroom • Posts related to explaining hearing loss to others

	<p>opportunities for mentoring and networking relationship formation</p> <ul style="list-style-type: none"> • Incorporate a Yahoo! Answers format for discussion posts • Posts related to hearing loss in the classroom • Posts related to explaining hearing loss to others 	<ul style="list-style-type: none"> • Discussions based on difficult listening environments • Communication strategies that can be used with others • Allows for the opportunity to communicate with others with hearing loss
Anonymity of Users	<ul style="list-style-type: none"> • Users should include their identity through the majority of the social media network • Possibility of users staying anonymous when commenting on blogs and discussion posts 	<ul style="list-style-type: none"> • Should be the decision of the user • Information will be deemed more “credible” and “personable” if an identity is included • Possibility of users staying anonymous when commenting on blogs and discussion posts
Family/Friend Network Access	<ul style="list-style-type: none"> • Participants were split on whether family should have access • If access is available for family, it should be limited to certain areas of the website • May be a source of support for family members • Friends should have access to social media network 	<ul style="list-style-type: none"> • Only members should have access to the social media network • If relevant information is listed on the website, it can be shared with others
Audiologist as the Moderator	<ul style="list-style-type: none"> • Should be a question and answer format (e.g. Yahoo! Answers format) 	<ul style="list-style-type: none"> • Beneficial • Should be a question and answer format (e.g. Yahoo! Answers format)
Geographic Location	<ul style="list-style-type: none"> • Does not matter if social media network is for a specific region or if it is national 	<ul style="list-style-type: none"> • Recommended that the social media network is designed for one geographic location • If localized to one region, offers the opportunity for relationships to form outside of the social media network

4.4.3 Psychosocial Development

Responses related psychosocial issues were compared between adolescents and young adults with hearing loss, and young adults with normal hearing. Results are outlined in Table 4. Adolescents and young adults with hearing loss overall had a more positive response to questions addressing psychosocial needs, and their answers revealed greater interest in self-advocacy. The participants with normal hearing expressed greater issues with anxiety and negative outcomes associated with hearing loss.

Table 4: Comparison of Psychosocial Issues

Population	Response
Adolescents/Young Adults with Hearing Loss	<ul style="list-style-type: none">• “If there was one thing I know now that I wish I had knew back then” – be upfront with your hearing loss• Transition periods – know how to get necessary services to increase academic success• Know your rights as an adolescent/young adult with hearing loss• In a university setting, participants communicate needs with professors
Young Adults with Normal Hearing	<ul style="list-style-type: none">• Felt that they would be embarrassed to have hearing loss around their peers, and they would not want to feel that they were “different”• Would feel additional “worry” as a college student with hearing loss (e.g. in the classroom and in social settings such as parties)• Would foster negative emotions related to their hearing impairment because of accommodations being made by others• Concerned about performance in the classroom, and the need for additional tutoring and assistance to be successful academically• In-person support would be beneficial, but

Chapter 5

Discussion

The present study focused on exploring the development of an online social media network for adolescents and young adults with hearing loss using a participatory research design. Through means of an electronic survey and an in-person focus group, participants were able to provide valuable feedback to further enhance the overall social network content and design. Key information collected from participants included that the website should be representative of one geographic location, it should only include adolescents and young adults with hearing loss, and there should be areas of the website designed specifically for transition periods (e.g., high school to college, college, and workforce).

Furthermore, participants noted that the “idea”, or concept, of the social media network for adolescents and young adults with hearing loss in itself is unique.

A secondary purpose was to compare the responses to the social media network design of young adults with normal hearing acuity, and adolescents and young adults with hearing loss. Some key information that was reported by participants with normal hearing included that they wanted additional information related to “basics” of hearing aids and maintenance such as cleaning and care, cosmetic information (e.g., visibility of device), and information about the quality and price hearing devices. Furthermore, they did not have a preference towards geographic location, and were not in agreement as to whether family and friends should be included on the social media network.

5.1 Social Media Networks

The social media phenomenon is already being implemented in the healthcare sector. For example, physicians are beginning to consult with patients, and individuals are able to compare symptoms and intervention outcomes with other patients over social media platforms (Hawn, 2009). In addition, social media networks are growing and evolving into tools that can be used for healthcare intervention purposes that have not yet been considered by practicing professionals. Coiera (2013) suggested that clinicians should consider using social media networks to shape “social diseases,” or conditions that are affected by social ties and influences (e.g., obesity). Knowing that hearing loss in young adults has an effect on mental health (Tambis, 2004), social media may become beneficial in the treatment of “social diseases” (e.g., depression/anxiety) related to hearing loss. Also, social media has the potential to have an impact in multiple areas of healthcare: professional-to-professional interactions, professional-to-patient interactions, patient-to-patient interactions, means to provide health information to the public, and to implement interventions. Social media networking has the ability to, and most likely will, redefine the healthcare delivery model around the globe.

From a patient perspective, social media networks provide the opportunity for increased communication and interaction with others. There is growing evidence that emerging adults with lower self-esteem are more likely to access social media networks (e.g., Facebook) at a higher rate than emerging adults with

a higher self-esteem (Steinfeld et al., 2008). Furthermore, in studies related to chronic disease management, there have not been any negative effects of social media reported; however, multiple studies have reported improvements in psychosocial well-being through peer-to-peer interaction (Merolli et al., 2013). This suggests that access to social media networks may improve psychosocial well-being through increased opportunities of interaction and support with peers.

Social media platforms have already been utilized in audiology for purposes of general public education related to the hazards of long-term noise exposure (Fonseca & Paul, 2012) and to provide updates and information related to committees working towards improving access to hearing healthcare (Clark & Saunders, 2012). Up to this point, however, social media network development by audiologists with the goal to improve patient outcomes has not been studied or discussed in the current literature. Social media may lead to greater patient engagement, and improve healthcare delivery by incorporating new technology (Hawn, 2009), which is why audiology needs to embrace this growing phenomenon and incorporate it to improve patient outcomes.

The social media network should be designed with the target population in mind. That being said, McNab (2009) recommended that practitioners “focus efforts on the specific social media tools relevant to the audience...and social media should add value to the conversation (p. 566)” between practitioners and patients. Although the results should be interpreted with caution due to the small sample size, the recommendations of participants with hearing loss can be used as

a guide for what to include when designing a social media network for adolescents and young adults with hearing loss.

5.2 Comparison of Responses Between Participant Groups

When comparing the participants with hearing loss and the participants with normal hearing acuity, several areas of contrast become apparent. When reviewing the perceptions of the young adults with normal hearing, the perceptions and views expressed could be used as an indication of what young adults would want out of a social media network if newly diagnosed with hearing loss. Because the young adults with normal hearing acuity are not as familiar with hearing loss and hearing devices, their opinions express what needs to be implemented to better serve this population. For example, participants with normal hearing do not have a preference related to geographic location. One explanation may be that they feel support is needed for young adults regardless of location, and that having a website available can serve those with hearing loss from multiple geographic locations.

Participants with normal hearing acuity expressed a desire for greater information about when people with hearing loss might not wear hearing aids or assistive technology, price and quality of hearing aids, cosmetic information, cleaning, care and maintenance. In a clinical setting, this type of information is conveyed during hearing aid fittings and follow-up appointments for new hearing aid users. However, social media networks may provide an opportunity for audiologists to convey this information to new users following the initial fitting, so that hearing aid follow-up appointments can be more efficient with less time

needed to review information presented in the first appointment. In addition, it may give those with hearing loss insight into the type of information that their peers, families, and friends are “curious” about and may open a dialogue related to hearing loss and hearing technology. Lastly, participants with normal hearing were also concerned about performance in the classroom and during social events with friends, whereas adolescents and young adults who were diagnosed with hearing loss since childhood have already learned coping strategies to compensate in adverse environments. This gives further support that an area of the social media network can be designed for newly identified adolescents and young adults with hearing loss using the information obtained from the young adults with normal hearing acuity.

The suggestions and information obtained from the participants with hearing loss may provide greater insight into what information they may find valuable when in transition phases from adolescence to emerging adulthood, and even into young adulthood. One example is the request for greater information about moving into an apartment, and resources that may make this transition easier (e.g., assistive devices). Furthermore, members of a social media network designed for this population allows for communication between members regarding advice and suggestions for making transitions. For example, an adolescent preparing for the transition to college may be able to communicate with other members in college about topics that are relevant to living with hearing loss (e.g., explaining hearing loss to a college roommate).

Young adults with normal hearing had varying opinions as to whether friends and family should be included on the social media network. This may suggest that those with normal hearing are curious about hearing loss, and that they may find a social media network designed for family and friends to be useful in providing greater information and resources. By obtaining access to a social media network, friends of those with hearing loss may have a better idea of the impairment associated with hearing loss, especially in difficult listening conditions, and how to implement strategies to improve communication with friends with hearing loss. Furthermore, allowing access to a website with this design may address questions for those who are not familiar with hearing loss, and those who may be embarrassed to ask questions related to the condition (e.g., cosmetics of wearing a device). For example, a new college roommate of a person with hearing loss may benefit from a social media network due to the resources that are provided.

5.3 Limitations

Limitations of the study include that there were only five participants in the experimental group, with four participating in the focus group, and four participants in the control group. The number of participants in the control group was based on the number of participants in the experimental group. A larger sample and progressive focus groups, or additional focus groups with other participants with hearing loss who could continue to offer suggestions to improve website design, may have further improved the design of the social media network. Furthermore, all participants were from the central Ohio geographic

area, as this was part of the design. For future studies, participation of individuals with hearing loss from other geographic areas may lead to improvements in the design. For example, inviting participants from rural areas may have an impact on responses due to the fact that there may be fewer resources for those with hearing loss. Additionally, available services related to hearing loss may not be as adequate compared to a larger geographic location, and individuals may not know others with a hearing loss, which is where a social media network for adolescents and young adults with hearing loss may prove to be a valuable asset. Although this information may not be generalizable for all adolescent and young adults hearing loss, it provides valuable insight to what elements of a social media network should be considered when designing a website for this population.

5.4 Additional Comment

Since this study was initiated, a social media network has been designed for young adults with hearing loss. Constructed through the Hearing Loss Association of America (HLAA), the “Hearing Loss Nation” (<http://www.hearinglossnation.org>) is a social media network designed to be “the social network for the young and hard of hearing.” It is designed for individuals from 18 to 35 years of age with hearing loss. Based on Erikson’s psychosocial stages and Arnett’s “emerging adult” stage, this social media network does not include adolescents and it consists of both emerging adults and adults who may be more established in their lives. The social media network developed for this study may be more likely to better serve adolescents and “emerging adults” because the age range that the designed social media network encompasses is not as broad as

Hearing Loss Nation. Furthermore, another discrepancy noted is that Hearing Loss Nation is a national social media network, whereas participants with hearing loss in the present study preferred to be involved in a social media network for a specific geographic location. Although, an advantage of the inception of the HLAA's Hearing Loss Nation may be an indication that patients with hearing loss are ready to move in a new direction related to their psychosocial hearing needs, thus suggesting that audiology professionals should begin to accommodate patient needs through social media networks and alternative communication platforms.

Chapter 6

Conclusions

The aim of this study was to develop a social media network for adolescents and young adults with hearing loss. The results of this study can be used to design social media networks for this population. Audiologists should incorporate the elements that this population wants to be available and accessible in a social media network. Audiologists have a unique opportunity, and a powerful tool that is only going to grow within our profession. By incorporating social media networks, we are responding to a need in this patient population. If this population is on social media networks, then we need to be a part of that as well. Audiologists have already used social media networks for marketing and to provide mass communication about ongoing projects and messages related to hearing loss; however, now is the time to use it to improve the quality of life for our patient populations. As one participant noted, “I think just the idea in general that there’s a place that we can kind of share our experiences and talk to other people and get information.” If this is what our patients want, and potentially what they need, it is our responsibility to start shifting the field towards a patient-driven model of care. Social media networks are an entirely new concept in audiology healthcare; however, they are also an excellent opportunity to begin this shift into new technologies that can benefit our patients outside of the clinic.

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APPENDIX A

Dr./Mr./Ms. X
Address To Be Determined
Columbus, Ohio XXXXX

Dr./Mr./Ms. X,

My name is Jessica Middaugh, and I am a third year audiology student at The Ohio State University. For my third year capstone project, I am conducting a study titled, "Utilizing Social Media to Connect Adolescents and Young Adults with Hearing Loss." The purpose of this study is to develop a social media website aimed at providing education and support for adolescents and young adults with hearing loss.

In the proposed study, a social media website will be developed based on results from a focus group that was conducted by Oticon Pediatrics at Ohio State. Following the website construction, a survey will be conducted with adolescents and young adults to acquire feedback, which will allow us to make adjustments to improve the design of the website. Following these changes, two focus groups will be conducted to elaborate on the improvements and continue to expand on adjustments that could be made. At the conclusion of the study, a survey will be distributed to allow participants to rank the final outcome of the website design. The study will begin mid-November and will conclude in mid-January.

The purpose of contacting you is to ask that if you know adolescents or young adults with hearing loss (15-24 years of age) who would be interested in this type of study, that you please have them contact me. My e-mail address is jessica.middaugh.1@gmail.com. Thank you, and please feel free to contact me for further information.

Sincerely,

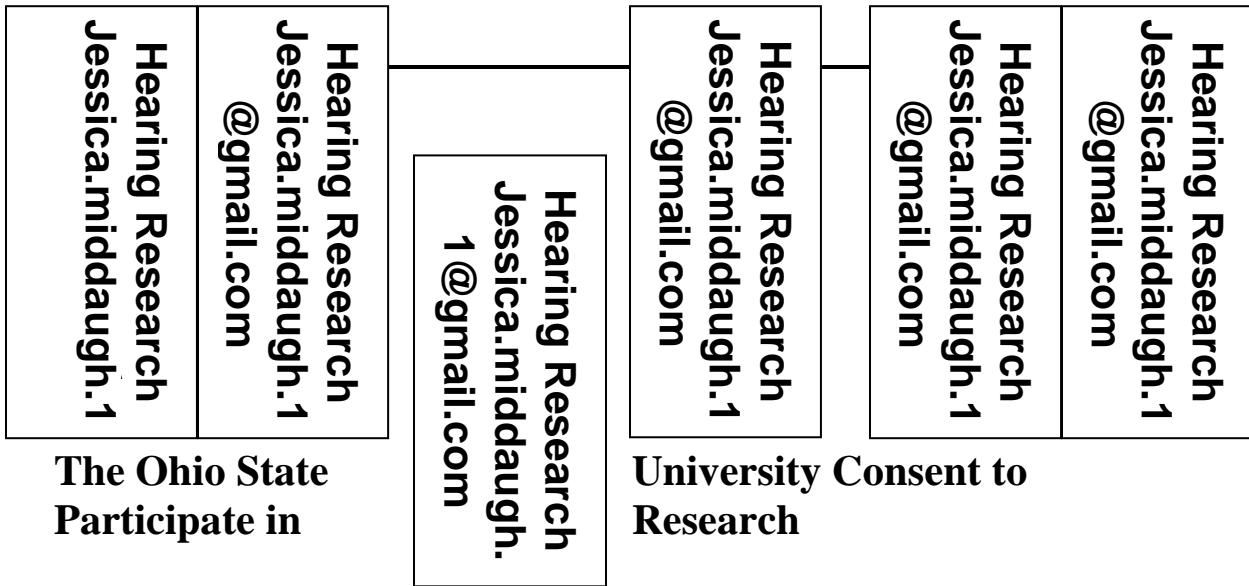
Jessica Middaugh, B.S.

RESEARCH OPPORTUNITY AT THE OHIO STATE UNIVERSITY

- **Are you between the ages of 15 and 24?**
 - **Do you have a hearing loss?**
 - **Are you interested in social media websites?**
-

If so, **email**

jessica.middaugh.1@gmail.com to receive more information for a research study aimed at developing a social media website for adolescents and young adults with hearing loss.



Study Title:

Utilizing Social Media to Connect Adolescents and Young Adults with Hearing Loss

Researcher:

Gail M. Whitelaw, Ph.D.

Sponsor:

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate.

\$10/hour
Listeners Needed
614-247-8614

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Listeners Needed
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Listeners Needed
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The purpose of this study is to develop a social media website aimed at providing education and support for adolescents and young adults with hearing loss.

Procedures/Tasks:

Following the completion of the social media website design, you will be sent a survey via an online survey tool, SurveyMonkey. Once you receive the link to the online survey, you will have access to the social media network and have 4 weeks to complete the survey. Throughout the survey time-window, you will have access to the site and will have the ability to navigate through the content on the site. Following survey completion, modifications will be made to the social media website based on responses. You will then be contacted to participate in a focus group. Prior to the focus group, you will once again have access to the updated social media website. Following the focus group, modifications will be made the social media website based on responses. A second electronic survey will be sent to you by means of SurveyMonkey to rank the outcome of the website design. You will have access to the social media network, and will have the ability to navigate through the website. Following access to the revised website, the survey will be sent out with a two-week time window for completion. The social media website will not become active following the conclusion of the study.

Duration:

You may leave the study at any time. If you decide to stop participating in the study, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

Risks and Benefits:

There are no potential risks involved in participating in this study. Participants will not be receiving any benefits for participation.

Confidentiality:

Efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law. Also, your records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;

Incentives:

There are no inherent incentives for participating in this study.

Participant Rights:

You may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you are a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights you may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study you may contact Jessica Middaugh (jessica.middaugh.1@gmail.com) or Dr. Gail Whitelaw (whitelaw.1@osu.edu).

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

If you are injured as a result of participating in this study or for questions about a study-related injury, you may contact *Jessica Middaugh* or *Dr. Gail Whitelaw*.

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

_____	_____
Printed name of subject	Signature of subject
	_____ AM/PM
	Date and time
_____	_____
Printed name of person authorized to consent for subject (when applicable)	Signature of person authorized to consent for subject (when applicable)
_____	_____ AM/PM
Relationship to the subject	Date and time

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

_____	_____
Printed name of person obtaining consent	Signature of person obtaining consent
	_____ AM/PM
	Date and time

The Ohio State University Parental Permission For Child's Participation in Research

Study Title: Utilizing Social Media to Connect Adolescents and Young Adults with Hearing Loss

Researcher: Gail M. Whitelaw, Ph.D.

Sponsor:

This is a parental permission form for research participation. It contains important information about this study and what to expect if you permit your child to participate.

Your child's participation is voluntary.

Please consider the information carefully. Feel free to discuss the study with your friends and family and to ask questions before making your decision whether or not to permit your child to participate. If you permit your child to participate, you will be asked to sign this form and will receive a copy of the form.

Purpose:

The purpose of this study is to develop a social media website aimed at providing education and support for adolescents and young adults with hearing loss.

Procedures/Tasks:

Following the completion of the social media website design, your child will be sent a survey via an online survey tool, SurveyMonkey. Once your child has received the link to the online survey, they will have access to the social media network and have 4 weeks to complete the survey. Throughout the survey time-window, your child will have access to the site and will have the ability to navigate through the content on the site. Following survey completion, modifications will be made to the social media website based on responses. Your child will then be contacted to participate in a focus group. Prior to the focus group, your child will once again have access to the updated social media website. Following the focus group, modifications will be made the social media website based on responses. A second electronic survey will be sent to your child by means of SurveyMonkey to rank the outcome of the website design. Your child will have access to the social media network, and will have the ability to navigate through the website. Following access to the revised website, the survey will be sent to your child with a two-week time window for completion. The social media website will not become active following the conclusion of the study.

Duration:

The first electronic survey that will be sent to your child will require approximately 30 minutes for completion. The focus group that your child will participate in will be approximately one hour and 30 minutes in duration. The second electronic survey that will be sent to your child will require approximately 30 minutes for completion.

Your child may leave the study at any time. If you or your child decides to stop participation in the study, there will be no penalty and neither you nor your child will lose any benefits to which you are otherwise entitled. Your decision will not affect your future relationship with The Ohio State University.

Risks and Benefits:

There are no potential risks involved in participating in this study. Participants will not be receiving any benefits for participation.

Confidentiality:

We will work to make sure that no one sees your child's survey responses without approval. But, because we are using the Internet, there is a chance that someone could access your child's online responses without permission. In some cases, this information could be used to identify your child. In addition, while participants will be asked not to share what is discussed in the group outside of the group, due to the nature of a focus group setting, confidentiality for this portion of the research cannot be guaranteed.

Efforts will be made to keep your child's study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your child's participation in this study may be disclosed if required by state law. Also, your child's records may be reviewed by the following groups (as applicable to the research):

- Office for Human Research Protections or other federal, state, or international regulatory agencies;
- The Ohio State University Institutional Review Board or Office of Responsible Research Practices;
- The sponsor, if any, or agency (including the Food and Drug Administration for FDA-regulated research) supporting the study.

Incentives:

There are no inherent incentives for participating in this study.

Participant Rights:

You or your child may refuse to participate in this study without penalty or loss of benefits to which you are otherwise entitled. If you or your child is a student or employee at Ohio State, your decision will not affect your grades or employment status.

If you and your child choose to participate in the study, you may discontinue participation at any time without penalty or loss of benefits. By signing this form, you do not give up any personal legal rights your child may have as a participant in this study.

An Institutional Review Board responsible for human subjects research at The Ohio State University reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

Contacts and Questions:

For questions, concerns, or complaints about the study you may contact Jessica Middaugh (jessica.middaugh.1@gmail.com) or Dr. Gail Whitelaw (whitelaw.1@osu.edu).

For questions about your child's rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

If your child is injured as a result of participating in this study or for questions about a study-related injury, you may contact **Jessica Middaugh** or **Dr. Gail Whitelaw**.

Signing the parental permission form

I have read (or someone has read to me) this form and I am aware that I am being asked to provide permission for my child to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to permit my child to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

<hr/>	
Printed name of subject	
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Printed name of person authorized to provide permission for subject	Signature of person authorized to provide permission for subject
<hr/>	<hr/>
Relationship to the subject	Date and time AM/PM

Investigator/Research Staff

I have explained the research to the participant or his/her representative before requesting the signature(s) above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

<hr/>	
Printed name of person obtaining consent	Signature of person obtaining consent
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	Date and time AM/PM

APPENDIX C

The Ohio State University Assent to Participate in Research

Study Title: Utilizing Social Media to Connect Adolescents and Young Adults with Hearing Loss

Researcher: Gail M. Whitelaw, Ph.D.

Sponsor:

- **You are being asked to be in a research study. Studies are done to find better ways to treat people or to understand things better.**
- **This form will tell you about the study to help you decide whether or not you want to participate.**
- **You should ask any questions you have before making up your mind. You can think about it and discuss it with your family or friends before you decide.**
- **It is okay to say “No” if you don’t want to be in the study. If you say “Yes” you can change your mind and quit being in the study at any time without getting in trouble.**
- **If you decide you want to be in the study, an adult (usually a parent) will also need to give permission for you to be in the study.**

1. What is this study about?

The purpose of this study is to develop a social media website aimed at providing education and support for adolescents and young adults with hearing loss.

2. What will I need to do if I am in this study?

Following the completion of the social media website design, you will be sent a survey via an online survey tool, SurveyMonkey. Once you receive the link to the online survey, you will have access to the social media network and have 4 weeks to complete the survey. Throughout the survey time-window, you will have access to the site and will have the ability to navigate through the content on the site. Following survey completion, modifications will be made to the social media website based on responses. You will then be contacted to participate in a focus group. Prior to the focus group, you will once again have access to the

updated social media website. Following the focus group, modifications will be made the social media website based on responses. A second electronic survey will be sent to you by means of SurveyMonkey to rank the outcome of the website design. You will have access to the social media network, and will have the ability to navigate through the website. Following access to the revised website, the survey will be sent out with a two-week time window for completion. The social media website will not become active following the conclusion of the study.

3. How long will I be in the study?

The first electronic survey that will be sent to you will require approximately 30 minutes for completion. The focus group that you will participate in will be approximately one hour and 30 minutes in duration. The second electronic survey that will be sent to you will require approximately 30 minutes for completion.

The study will last over two months. As a participant, you will have four weeks to complete the first online survey. You will then be a participant in a focus group to continue supplying feedback about the design, content, and layout of the social media website. Following the focus groups, you will have two weeks to complete an online survey.

4. Can I stop being in the study?

You may stop being in the study at any time.

5. *What bad things might happen to me if I am in the study?*

We will work to make sure that no one sees your survey responses without approval. But, because we are using the Internet, there is a chance that someone could access your online responses without permission. In some cases, this information could be used to identify you. Also, while we will ask you not to share what is discussed in the group outside of the group, we cannot guarantee others in the group will not share what is discussed with others.

There are no potential risks involved in participating in this study.

6. What good things might happen to me if I am in the study?

Participants will not be receiving any benefits for participation.

7. *Will I be given anything for being in this study?*

There are no inherent incentives for participating in this study.

8. Who can I talk to about the study?

For questions, concerns, or complaints about the study you may contact Jessica Middaugh (jessica.middaugh.1@gmail.com) or Dr. Gail Whitelaw (whitelaw.1@osu.edu).

To discuss other study-related questions with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251.

Signing the assent form

I have read (or someone has read to me) this form. I have had a chance to ask questions before making up my mind. I want to be in this research study.

Signature or printed name of subject _____ **Date and time** **AM/PM**

Investigator/Research Staff

I have explained the research to the participant before requesting the signature above. There are no blanks in this document. A copy of this form has been given to the participant or his/her representative.

Printed name of person obtaining assent _____ **Signature of person obtaining assent**

Date and time **AM/PM**

This form must be accompanied by an IRB approved parental permission form signed by a parent/guardian.

APPENDIX D
Questions Designed for Electronic Survey #1

- 1) What do you like about the website? What do you not like? Why?*
 - 2) What is your reaction to the content (e.g. information) provided on the website?
 - a. What outside links would you like to be provided where a person with hearing loss could find accurate information (e.g. manufacturer websites)?
 - b. What kind of information about hearing loss would be the most useful to put on this website?*
 - c. What additional information would you include?*
 - 3) What is your reaction to the website layout?
 - a. What would make the website easier to use?
 - b. What would make the website more attractive/appealing?
 - c. If you were to design a table of contents for this website, what would you include?*
 - d. What would make this website enjoyable? Easy to use? Memorable?*
 - 4) What is your reaction to your ability to interact with other users with hearing loss?
 - a. What would make your ability to interact easier?
 - b. What topics could be introduced to aid in information exchange?
 - 5) Would this website be beneficial for a person newly identified with hearing loss?
 - a. What additional information should be included for a person who is newly identified with a hearing loss?
 - 6) Should website users remain anonymous? Why or why not?
 - 7) Would you like to use the website alone, or with family? Do you think your parents or family would find a website helpful? How might they use it differently from you?*
- a. Would you be less likely to discuss certain topics if family members were able to access the website?
- 8) Would it be beneficial to have an audiologist available as a moderator to answer questions? Why or why not?
 - a. Would you be less likely to discuss certain topics if family members were able to access the website?
- 9) What is the best part about the website? Why?
- 10) What is the greatest improvement that could be made? Why?
- 11) Are there any additional comments/suggestions you would like to make? Please include them here.

* Sterling, L., Nyhof-Young, J., Blanchette, S., & Breakey, V. R. (2012). Exploring Internet needs and use among adolescents with haemophilia: A website development project. *Haemophilia*, 18, 216-221. doi:10.1111/j.1365-2516.2011.02613.x

APPENDIX E
Focus Group Interview Questions

Hearing Loss/Hearing Aids

- 1) What information would you like to be available about your hearing aids? Connectivity options? Assistive listening devices?
 - a. Should that information be available on the website?
- 2) Do you currently access a social media group or self-advocacy or mentoring/empowerment resource that is your go-to for information and support regarding succeeding in high school/college/the work world? Can you share any experience/advice?
- 3) What primary challenges/personal concerns would you like to address with your peers?
 - a. Where do you currently find support?
 - b. Do you feel you could support others/offer advice for others who are facing these challenges?
- 4) Would you find other users personal experiences to be helpful?
 - a. Would you be willing to share your experiences for others to learn from?
- 5) What information would you share with younger/newer users with hearing loss that you wish you would have known at their age? (Mainly, if you are in college and speaking with someone in high school—is there anything you would tell them that you wish you had known?)
- 6) Is there any information that you would want to provide to those transitioning from high school to college/work?
 - a. Is there any information that you would want to be included on the website regarding this transition period?
 - b. Advice?
 - c. Information about support services that can be used? Key contacts?

Website

- 7) What do you like about the website? What do you not like? Why?*
- 8) What is your reaction to the content (e.g. information) provided on the website?
 - a. What outside links would you like to be provided where a person with hearing loss could find accurate information (e.g. manufacturer websites)?
 - b. What kind of information about hearing loss would be the most useful to put on this website?*
 - c. What additional information would you include?*

- 9) What is your reaction to the website layout?
 - a. What would make the website easier to use?
 - b. What would make the website more attractive/appealing?
 - c. If you were to design a table of contents for this website, what would you include?*
 - d. What would make this website enjoyable? Easy to use? Memorable?*

 - 10) What is your reaction to your ability to interact with other users with hearing loss?
 - a. What would make your ability to interact easier?
 - b. What topics could be introduced to aid in information exchange?

 - 11) Would this website be beneficial for a person newly identified with hearing loss?
 - a. What additional information should be included for a person who is newly identified with a hearing loss?

 - 12) Should website users remain anonymous? Why or why not?

 - 13) What support issues would you like to be addressed in the discussion forum?
 - a. Empowerment? Self-advocacy? Communicating needs at school/work?

 - 14) Would you like to use the website alone, or with family? Do you think your parents or family would find a website helpful? How might they use it differently from you?*
- a. Would you be less likely to discuss certain topics if family members were able to access the website?
-
- 15) Would it be beneficial to have an audiologist available as a moderator to answer questions? Why or why not?
 - a. Would you be less likely to discuss certain topics if family members were able to access the website?
-
- 16) What is the best part about the website? Why?
-
- 17) What is the greatest improvement that could be made? Why?
-
- 18) Are there any additional comments/suggestions you would like to make? Please include them here.

- * Sterling, L., Nyhof-Young, J., Blanchette, S., & Breakey, V. R. (2012).
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doi:10.1111/j.1365-2516.2011.02613.x

APPENDIX F
Questions Designed for Electronic Survey #2

On a scale from 1 to 5 please indicate the following:

- 1=Strongly Disagree
 - 2=Disagree
 - 3=Neutral
 - 4=Agree
 - 5=Strongly Agree
-
- 1) The social media website is easy to use.
 - 2) I feel that the appropriate information is available for adolescents and young adults with hearing loss.
 - 3) I find the design (e.g. color, layout, etc.) to be appealing.
 - 4) This website would be beneficial for adolescents and young adults who were recently identified with a hearing loss.
 - 5) I think that the website design and content is age appropriate.
 - 6) I could use this website as a means of support by interacting with other users who have hearing loss.
 - 7) I could use this website to provide support to other users with hearing loss.
 - 8) There are reliable sources of information available that I could use to answer my own personal questions about hearing loss.
 - 9) There are reliable sources of information available that I could use to educate my family and friends about hearing loss.
 - 10) I can use this website to empower myself.
 - 11) I can use this website to help empower others.
 - 12) This website would be beneficial for users with hearing loss who live in rural areas.
 - 13) This is a website that I would use.