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Identity, Sexuality, and Relationships among Emerging Adults in the Digital Age

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Chapter 4

Use of Social Networking Sites by People with Health Issues

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ABSTRACT

Previous studies have found that the use of social networking sites (SNSs) is associated with the user's positive outcomes such as perceived social support and psychological well-being (Ellison, Steinfield, & Lampe, 2007; Nabi, Prestin, & So, 2012). To seek those positive influences, those with health issues such as physical illness or mental illness actively use SNSs (e.g., Shpigelman & Gill, 2014a; Gowen, Deschaine, Gruttadara, & Markey, 2012). The first aim of this chapter is to describe previous studies on the use of SNSs by those with health issues such as mental illnesses, HIV/AIDS, cancer, intellectual disabilities, and diabetes. The second aim is to propose a new direction of research on the use of SNSs by those with health issues: the impact of stigma on communication on SNSs.

INTRODUCTION

Today, it is difficult to find people who do not use any social networking sites (SNSs). In 2015, 90% of American young adults (18 to 29 years) used at least one SNS, compared with 12% in 2005 (Perrin, 2015). The time spent on SNSs among emerging adults is high, around 52 minutes every day (Coyne, Padilla-Walker, & Howard, 2013; Jacobsen & Forste, 2011). Emerging adults use SNSs for various purposes, such as maintaining friendships (Barker, 2009) and developing romantic relationships (Fox, Warber, & Makstaller, 2013). Thus, the use of SNSs is associated with various positive outcomes for the users. In particular, the number of Facebook friends is related to perceived social support, reduced stress, and less physical illness (Nabi, Prestin, & So, 2013). The use of Facebook is also related to psychological well-being, especially for those with low self-esteem and low life satisfaction (Ellison, Steinfield, & Lampe, 2007).

Consequently, it is not surprising that people with health issues use SNSs with the intent to improve their quality of life (e.g., Gowen, Deschaine, Gruttadaro, & Markey, 2012; Horvath et al., 2012; Shpigelman & Gill, 2014a). Shpigelman and Gill (2014a) surveyed individuals suffering from disabilities, such
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as physical disability, Autism, hearing disability, and mental illness, to examine these individuals’ use of Facebook. Results showed that 69% of the participants visited Facebook at least once a day and 48% of them reported having up to 200 Facebook friends. In addition, 10.1% of them reported that they did not have Facebook friends with disabilities, while 89.9% of them indicated that they had Facebook friends with disabilities. Furthermore, findings from this study also revealed that the participants mainly used Facebook to connect with nondisabled friends rather than to connect with disabled friends. Qualitative analyses of responses to the open-ended questions suggested that people with disabilities use Facebook to seek support and advice from other users. These findings revealed that SNSs play an important role for those with health issues in maintaining and developing interpersonal relationships.

However, when using SNSs, those with health issues might experience stigma associated with their health issues, similar to the stigma they might experience offline (e.g., Goffman, 1963; Imai & Dailey, 2015; Schneider, 2005). The stigma those with health issues experience may threaten their identity (Newman, Lauterbach, Munson, Resnick, & Morris, 2011; Schabert, Browne, Mosely, & Speight, 2013). For example, some individuals struggling with diabetes may want to share their health condition on SNSs to seek emotional support (Newman et al., 2011). However, they are concerned about the possibility that disclosing their health issue threatens their socially desired identity. This might be particularly concerning for emerging adults, whose main task is to establish a sense of identity (Schwartz, Donnellan, Ravert, Luyckx, & Zamboanga, 2013).

Despite the significant effect of stigma associated with health issues on SNSs, little research has been conducted on this topic. Thus, this chapter describes the current state of the literature on SNSs use by those with health issues and the stigma associated with various health issues. This chapter first introduces past studies investigating how those individuals with various health issues use SNSs for different purposes. Next, the effects of stigma on SNS users with health issues are considered. Finally, this chapter describes future research directions on stigmatizing effects of SNSs on emerging adults with health issues.

USE OF SOCIAL NETWORKING SITES BY THOSE WITH HEALTH ISSUES

Past studies have investigated the use of SNSs by people with health issues utilizing both quantitative and qualitative approaches. These studies have focused on the use of SNSs by those with a mental illness, HIV/AIDS, cancer, an intellectual disability, and diabetes.

Mental Illness

Five features of mental illnesses are described by Stein et al. (2010). First, a mentally ill individual demonstrates a clinically significant behavioral or psychological syndrome or pattern. Second, the syndrome or pattern is related to present distress or disability or to a considerably increased risk of suffering death, pain, disability, or an important loss of freedom. Third, the syndrome or pattern is not an expectable and culturally sanctioned response to a specific event (e.g., the death of a loved one). Fourth, the individual shows a behavioral, psychological, or biological dysfunction. Finally, neither deviant behaviors nor conflicts between the individual and society can be classified as mental illness, unless the deviance or conflict is a symptom of dysfunction in the individual. Fitting these criteria, there are a variety of types of mental illnesses, such as schizophrenia, substance-related disorders, mood disorders, anxiety disor-
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...orders, and eating disorders as described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V; American Psychiatric Association, 2013). Based on the results of a meta-analysis of mental health surveys conducted worldwide from 1980 through 2013, one in five adults (17.6%) has suffered from mental disorders within the past 12 months and 29.2% across their lifetime (Steel et al., 2014).

Past studies delineate how and why those with mental illness use SNSs, such as Facebook and MySpace. Gowen et al. (2012) surveyed 207 emerging adults (18 to 24 years) comprised of 128 individuals with a mental illness and 79 individuals without a mental illness. Results showed that 94% of those with mental illness used SNSs for a variety of purposes. Compared with those without a mental illness, mentally ill people tended to use SNSs more often to make new friends, share interests, and blog. The main communication methods they use on SNSs were sending private messages, posting public messages, sharing information and links, and commenting on blogs. Through SNSs, those with mental illness desire to find information on independent living skills, strategies to overcome social isolation, and ways to develop interpersonal relationships. This research illustrates mentally ill emerging adults’ active use of SNSs to gain various support that would not be available in face-to-face (FtF) interactions.

Specifically, MySpace has played a significant role in providing such support through health-related online communities. For instance, the most popular health-related communities on MySpace were ones focusing on depression and the second most popular communities were ones focusing on bipolar disorders (Seeman, 2008). Another study showed that a quarter of Facebook users who are juniors and seniors in a college posted comments that meet the criteria as symptoms of depression received social support from Facebook friends (Moreno et al., 2011). Taken together, many mentally ill emerging adults actively use SNSs for various purposes.

HIV/AIDS

There were approximately 34 million people living with HIV/AIDS in 2014 (WHO, 2015). The WHO (2015) reports that in 2014 about 1.2 million people died from HIV-related causes and approximately 2 million people became newly infected with HIV globally. There is no cure for the HIV infection, but effective treatments with antiretroviral drugs are available to control the virus, leading to healthy and productive lives of those with HIV.

Specifically, about 57,200 emerging adults (18 to 24 years) were living with HIV in the United States at the end of 2012 (Centers for Disease Control & Prevention, 2016). Among them, 25,300 were living with undiagnosed HIV, that was the highest rate of undiagnosed HIV in any age group. Also, 21% of them were prescribed HIV medicines and 16% had a suppressed viral load, that is the lowest rates of any age group.

Some research illustrates the use of SNSs by those individuals living with HIV/AIDS. Horvath et al. (2012) surveyed individuals living with HIV regarding their use of SNSs and found that 76% of these individuals used SNSs at least once a week. The most widely used SNS was Facebook, which was used by 62% of individuals living with HIV in this study. In addition, 22% of the participants reported that they participated in at least one of two online groups focusing on HIV. Several themes emerged from the open-ended questions assessing their ideal SNS. Forty-five percent of the participants reported that their ideal SNS would be one in which they could connect with other people, whether the people live with HIV or not. On the other hand, another 14% of them reported that they would not like to participate in a SNS focusing on HIV. An additional 26% of them were concerned about the privacy issues related...
to their participating in HIV-focused SNSs. For example, some users living with HIV were worried that others would find out they were HIV positive by participating in online groups focusing on HIV. Overall, people living with HIV use SNSs to develop interpersonal relationships and participate in online communities focusing on HIV, although privacy is a barrier to using SNSs.

In order to closely investigate online interaction of individuals living with HIV/AIDS, Mo and Coulson (2008) analyzed the contents of 1,138 messages exchanged in an online HIV/AIDS support group. Of these messages, there were 171 unique message sender names identified in the selected threads and the HIV status of 145 members could be identified as HIV-positive on their profiles. Among all the messages, 986 messages contained at least one type of social support and the supportive messages were categorized into five social support message types: information support (44.5%), emotional support (35.2%), esteem support (12.4%), network support (6.9%), and tangible assistance (1.0%). Information support is advice messages providing suggestions or guidance for coping with HIV/AIDS symptoms. Emotional support is offered by messages to express care and concern to other members. Esteem support is provided through compliment messages, which convey positive assessments of the recipient and his or her abilities. Network support involves messages that broaden the recipients’ social network by developing access to new members. Tangible support involves messages in which senders are offering to perform a direct task related to a request.

In short, SNSs and online support communities for those living with HIV/AIDS could help them seek various types of information and support. Even though these studies did not focus on emerging adults, the information of HIV/AIDS provided in online communities are helpful for emerging adults living with HIV who tend to lack enough accurate information of the disease (Centers for Disease Control & Prevention, 2016).

Cancer

Cancer represents around 12% of all-cause mortality worldwide (International Agency for Research on Cancer, 2008). In 2012, there were 14.1 million new cancer cases, 8.2 million cancer deaths, and 32.6 million people living with cancer (WHO, 2012). In the world, the most common causes of cancer death are cancers of the lungs (1.59 million deaths), liver (745,000 deaths), stomach (723,000 deaths), colorectal (694,000 deaths), breast (521,000 deaths), and oesophageal cancer (400,000 deaths).

SNSs play an important role in providing a variety of support for people having cancer. The third most popular types of health-related communities on MySpace are ones focusing on cancer (Seeman, 2008). Furthermore, Bender, Jimenez-Marroquin, and Jadad (2011) examined 620 breast cancer groups on Facebook to identify the purposes, use, and creators of the groups. They analyzed the contents of the groups and found four main types of breast cancer groups: fundraising groups, awareness-raising groups, support groups, and “promote-a-site” groups. The fundraising groups are created to attract financial resources for breast cancer through events, products, or services. The awareness-raising groups aim to bring attention to the significance of breast cancer in general. Support groups attempt to meet the information and emotional needs or breast cancer survivors or affected family members or friends. The “promote-a-site” groups are formed to increase the prominence of external websites raising funds. Participating in support groups regarding cancer was associated with increased social support, leading to reduced stress and depression (Beaudoin & Tao, 2007).
The population of these studies was not emerging adults. However, one study interviewing emerging adults (20 to 25 years) with cancer revealed that their needs such as necessary information and interpersonal support were not met (Patterson, Millar, Desille, & McDonald, 2012). Thus, if emerging adults with cancer participate in the support groups on SNSs, their needs could be met through interaction with other SNS users.

**Intellectual Disability**

According to the American Association of Intellectual and Developmental Disabilities (AAIDD; 2013), an intellectual disability (ID) is defined as significant limitations on both intellectual functions and in adaptive behavior, which includes everyday conceptual, social, and practical skills, and this disability originates before the age of 18. The adaptive behavior specifically includes language, literacy, interpersonal skills, self-esteem, occupational skills, and transportation. Approximately 200 million people in the world have an intellectual disability (Special Olympics, 2015).

There has been little research on the use of SNSs by those with an intellectual disability. Shpigelman and Gill (2014b) examined the use of Facebook by 58 people with a learning disability and/or ADD/ADHD. The participants visited Facebook at least once a week (67.2%) and they used it mainly for connecting with people they meet in face-to-face settings, such as friends, family members, and caregivers. The results also revealed that 68% of the participants reported that making new friends is easier on Facebook than in person. Also, 82% of them said that they felt more comfortable talking with people on Facebook than face to face. Some responses to open-ended questions referred to the emotional effect of communication on Facebook. For instance, Facebook helped the participants feel connected with others when they felt lonely.

Research found that young adults with ID reported that their interpersonal networks were composed of only a few people who tended to be support professionals, leading to feelings of being isolated from others (Starke, 2013). To help emerging adults with ID develop relationships with other youth, SNS may be useful as shown in the results of the study by Shpigelman and Gill (2014b).

**Diabetes**

Diabetes is the eighth leading cause of death in the world (WHO, 2014a). In 2014, the global prevalence of diabetes was estimated to be 9% among adults (WHO, 2014b). Common symptoms of diabetes are urinating often, feeling very thirsty, extreme fatigue, and blurry vision (American Diabetes Association, 2015).

Previous studies have examined individuals with diabetes’ use of SNSs. Greene, Choudhry, Kilabuk, and Shrank (2010) qualitatively examined the 15 most recent wall posts and the 15 most recent discussion topics from the 10 largest Facebook groups focusing on diabetes management. The study sample included 690 individual posts on wall pages and discussion board posts written by 480 users. The main themes identified included posts about information-sharing, patient-centered management, and community-building. As for the main function of the Facebook groups, 62% of the posts involved sharing of personal experiences with diabetes management. Furthermore, 24% of posts contained sensitive aspects of patient-centered diabetes management. For instance, posts described how to count carbohydrates to enable extended alcoholic drinking sessions among individuals with Type I Diabetes. Some posts also
functioned to form a supportive community to seek interpersonal support from group members. These findings imply that Facebook groups specifically focusing on diabetes allow diabetes patients to share and seek information related to their illness.

To understand further why and how people with diabetes share their health information on SNSs and online support communities, Newman et al. (2011) interviewed 14 individuals struggling with diabetes and weight loss management. By analyzing the contents of transcripts of the interviews, Newman and colleagues found that the main goal of the individuals using SNSs and online support communities was to receive emotional support. Through online support communities, it was easier to find people who have similar struggles, so the participants could obtain positive and encouraging messages from other users. The researchers also revealed that SNS users with diabetes had concerns regarding their identity management on SNSs. Although they would emphasize their identity as healthy people, they wanted to obtain support by being open about their struggles.

One study focusing on young adults with diabetes found that they believed that talking about their diabetes-related distress with others and joining peer support groups moderate their distress caused by diabetes (Balfe, Doyle, Smith, Sreenan, Brugha, Hevey, & Conroy, 2013). Considering findings of past studies (Green et al., 2010; Newman et al., 2011), SNSs might help emerging adults with diabetes join online support groups where they can talk about their distress with other users to moderate the distress.

In summary, the studies introduced in this section suggest that SNSs could help users with health issues improve their quality of life by sharing and seeking important information on their conditions through SNS and developing online interpersonal relationships. However, if the users with health issues feel stigmatized while using SNSs as they do in a real life (e.g., Goffman, 1963; Schneider, 2005), they might be discouraged from using SNSs. Such a stigmatizing effect on SNSs has not been fully examined. The next section introduces the definition and characteristics of stigma followed by previous studies focusing on various influences of illness or disability stigma on communication.

**STIGMA**

Stigma is defined as an attribute or characteristic that conveys a social identity that is discredited and devalued in a particular context (Goffman, 1963; Schneider, 2005). Link and Phelan (2001) argue that a set of events need to take place in order for stigma to manifest. First, people distinguish and label targets based on the differences they have from others. Second, the differences are associated with negative stereotypes. Third, the labels are given for specific categories that separate “us” from “them.” Fourth, people who receive stigmatizing labels experience status loss and discrimination, leading to unequal outcomes. Finally, the stigmatization the targets experience is related to social, economic, and political power that may identify their differences, construct stereotypes, and separate them into distinct categories.

Additionally, stigma has six dimensions (Jones et al., 1984). The essential dimension is concealability. For example, facial disfigurement and physical disabilities are harder to conceal than a history of mental illness, a prison record, or homosexuality. The second dimension is called time course. Some conditions, such as AIDS, may worsen over time whereas other conditions, such as diabetes, may improve. On the other hand, some types of physical disabilities, such as blindness and paralysis, may not change. The third dimension is aesthetic value. For instance, obesity, facial scars, and body disfigurement are related to physical attractiveness whereas AIDS may not be associated with attractiveness. How stigmatized conditions are generated is another crucial dimension called stigma origins. This dimension is related
to whether a stigmatized individual is seen as responsible for the stigma. For example, some conditions, including obesity, a criminal record, and homosexuality, may be seen as matters of choice. However, other conditions, such as cancer and physical disability, are perceived to be outside of the control of the stigmatized individuals. People often blame or devalue individuals with conditions that are seen to be caused by their choice or to be in their control. The fifth dimension is whether the stigmatizing condition is perceived to put other people in danger. For example, people might see those with criminal records to be dangerous. People with HIV may make others more afraid of contamination than those diagnosed with cancer. The final dimension is disruptiveness—the degree to which the stigma interrupts social interactions. For example, interactions with schizophrenic individuals might be disruptive because they often have symptoms of speech dysfunctions.

**STIGMA ASSOCIATED WITH SPECIFIC HEALTH ISSUES**

Previous studies suggest that different illnesses and disabilities carry different stigmas.

**Mental Illness**

Stigma associated with a general label of “mental illness” (i.e., not a specific mental illness) impacts interpersonal communication in various ways. First, Modified Labeling Theory explains how a mental illness label influences those labeled in various situations, such as interpersonal interactions, job opportunities, and quality of life (Link, 1982). According to this theory, if people believe a mentally ill individual is devalued and rejected, they worry that they would also be rejected if they have a mental illness. When they realize that they have a mental illness, the belief (e.g., people with mental illness are rejected) will bring them negative consequences, such as demoralization, income loss, and unemployment. Furthermore, Link, Cullen, Struening, Shrout, and Dohrenwend (1989) found several possible consequences associated with the fear of being labeled with a mental illness, including secrecy, withdrawal, and education. Secrecy involves concealing a history of treatment, such as being hospitalized and being prescribed medications. Labeled individuals may also withdraw from potentially threatening situations, such as a party with people who stigmatize mentally ill individuals. Education includes the active attempt at educating others in hopes of enlightening them to ward off negative attitudes. Among these strategies, the withdrawing behaviors may lead to poorer social support from others.

Second, mental illness stigma also affects others’ interpersonal behaviors toward those with mental illness. Sibicky and Dovidio (1986) found that people who believed that an individual is mentally ill leads to negative perceptions and behaviors toward that individual. In their study, participants were told that their interactant was a regular undergraduate student or a student seeking psychotherapy. After they interacted, the audio of the interaction was coded. Results revealed that the participants in the experimental condition had a more negative impression of their interactant and the coded speech of the participants toward their interactant was less open and secure compared with the control condition. In short, when individuals believe that someone is mentally ill, their perceptions and behaviors toward the person tend to be negative. Mental illness stigma may impact mentally ill individuals as well as others around them.
Depression

Depressed individuals are perceived as more violent than those without any mental illness (Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999). People also believe that depressed individuals tend to be angry, afraid, alone, tired, sad, unhappy (Horowitz, French, Lapid, & Wecker, 1982), and dependent (Rippere, 1977). These negative ideas of depression make people reject those with depression (Link et al., 1999).

Several theoretical accounts explain how the stigma of depression impacts others’ perceptions toward depressed individuals. Cane and Gotlib (1985) argued that stereotypes of depression function as a cognitive framework influencing people’s interpretations of depressed individuals’ characteristics and behaviors. Thus, people are likely to perceive behaviors engaged in by depressed individuals consistent with depression stereotypes, such as being alone and sad. In addition, Sacco and Vaughan (2006) developed the Social-Cognitive Interpersonal Process Model with an emphasis on interpersonal factors influencing depression. Similar to the ideas of Cane and Gotlib (1985), this model argues that people explain behaviors of depressed individuals in negative ways because of a negative schema associated with depressed individuals.

These theoretical frameworks are consistent with findings of empirical studies on the stigma of depression. Individuals who interacted with a confederate who they believed to be depressed evaluated the confederate more negatively on both depression-related traits and depression-unrelated traits as compared to a control condition (Nicholson & Sacco, 1999). In another study conducted by Yarkin, Harvey, and Bloxom (1981), participants were told before interacting with a confederate that the confederate was distressed or not distressed (the distressing behaviors were similar to symptoms of depression), but the confederate behaved neutrally in both conditions. The confederate in the distressed condition was evaluated more negatively than that in the control condition.

These negative evaluations of depressed individuals might lead people to reject those with depression. In the study by Yarkin et al. (1981), participants who believed that a confederate was distressed maintained a larger distance from the confederate, displayed shorter durations of eye contact, engaged in a more negatively-valenced conversation, and spoke for shorter periods of time than those who were not told that the confederate was distressed. In addition, Nicholson and Sacco (1999) revealed that participants who interacted with a confederate who they believed to be depressed showed that they were less willing to interact with the confederate again than a nondepressed confederate. Furthermore, participants who only imagined interactions with depressed individuals indicated more rejecting attitudes than did participants in a control group (Gotlib & Beatty, 1985). Taken together, depression stereotypes negatively affect others’ perceptions of depressed individuals’ behaviors, leading to rejection of these individuals.

Schizophrenia

Individuals suffering from schizophrenia are more seriously stigmatized than those with depression. Compared with depressed individuals, schizophrenic individuals tend to be seen as more dangerous and unpredictable and consequently, they are more often rejected (Angermeyer & Matschinger, 1997, 2003; Link et al., 1999). A depressed individual could elicit more positive emotions in others, such as a desire to help and empathy, whereas a schizophrenic individual elicits more fear, uneasiness, and insecurity in others (Angermeyer & Matschinger, 2003). People may have such negative feelings toward a schizophrenic individual because they believe schizophrenia is difficult to cure. For example, people believe schizophrenia is caused by biological factors, such as a chemical imbalance in the brain, more
than depression and alcohol dependence (Link et al., 1999). Angermeyer and Matschinger (2003) also found that depression is believed to be caused by social factors, such as stress at work, and life events, whereas schizophrenia is perceived to be caused by more biological and genetic factors, such as brain disease and heredity; consequently, schizophrenia is believed to be more likely to deteriorate and be harder to cure than depression.

Previous studies further reveal a strong negative effect of the stigma attached to schizophrenia on interpersonal communication. Jenkins and Carpenter-Song (2009) interviewed those diagnosed with schizophrenia and 96% of them reported experiencing stigmatization across a variety of social settings, including interactions with strangers, in work places, and within close relationships. Schizophrenic individuals reported that verbal and nonverbal communication by strangers was expressed in a way to signal that a schizophrenic individual is strange, frightening, and has less intellectual/social capacity (Jenkins & Carpenter-Song, 2009). The experience of being stigmatized was associated with low quality interpersonal relationships and with low frequency of contact with friends and acquaintances (Lysaker, Roe, & Yanos, 2007). Norman et al. (2010) assessed others’ perception of schizophrenic individuals in an experiment and found people possessing stigmatizing attitudes toward schizophrenic individuals did not desire to be physically close to them. In sum, research has revealed that schizophrenic individuals are more seriously stigmatized than those with depression, and consequently these individuals often treated more negatively.

**HIV/AIDS**

Although the perception of HIV/AIDS has improved over the past 20 years (Herek, 2014), among those without correct knowledge about HIV transmission, 34% of them reported that they would be uncomfortable working with people with HIV and 65% of them reported that they would be uncomfortable about having food prepared by people with HIV (Washington Post & Kaiser Family Foundation, 2012). Because individuals with HIV are aware of the stigma associated with HIV, they may hesitate to disclose their diagnosis even to people they feel close to (Greene, 2009). In fact, after disclosing their HIV-positive status, they receive negative emotional reactions and perceive being treated differently (Greene & Faulkner, 2002). Consequently, those with HIV perceive that they receive social rejection and social isolation (File & Wright, 2000). Furthermore, people often associate HIV/AIDS with homosexuality and IV drug use, and they believe that the patient is responsible for having HIV/AIDS because they engaged in such deviant behaviors.

**Cancer**

The stigma attached to cancer is caused primarily by fear of the illness itself (File & Wright, 2000). For instance, people tend to associate cancer with death (Chapple, Ziebland, & McPherson, 2004). Results of a survey conducted in India, Italy, Japan, Mexico, and South Africa to examine people’s perceptions of cancer showed that 30% of these individuals believed that people with cancer cannot survive (Neal et al., 2010). Sixteen percent of them believed that cancer is contagious and 25% of them believed that people with cancer bring it on themselves. These negative images associated with cancer make people reject those with cancer (File & Wright, 2000). People with cancer have difficulties obtaining social resources and their social activities are restricted (Bloom & Kessler, 1994).
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Intellectual Disability

Past research suggests that there are negative stereotypes attached to people with ID. Some people believe that those with ID are aggressive (Slevin & Sines, 1996) and threatening (van Alphen, Dijker, Bos, van Den Borne, & Curfs, 2012), so people are sometimes fearful of those with ID (Jahoda, Wilson, Stalker, & Cairney, 2010). These stereotypes make those with ID experience stigmatization in various social contexts. In school, some individuals with ID are ridiculed and called names by other students and teachers sometimes refuse to help them (Cooney, Jahoda, Gumley, & Knott, 2006). Parents are willing to include children with mild and moderate ID in school, but they oppose the inclusion of children with severe ID (Rafferty, Boettcher, & Griffin, 2001). The teacher-student relationship of children with ID are of poorer quality than that of typically developing students (McIntyre, Blacher, & Baker, 2006). Stigma associated with ID also plays a role in employment. Only 21% of working-age people with ID are employed, according to U.S. Bureau of Labor Statistics (2010). Even when they get a job, they tend to be bullied and ignored in the workplace (Johoda et al., 2010). In fact, some individuals would like to avoid working with those with ID (Bickley, 1990).

Diabetes

Studies have shown that people who do not have diabetes are likely to perceive diabetes as a non-stigmatized condition (e.g., Schabert, Brown, Mosely, & Speight, 2013), but those with diabetes experience being stigmatized (e.g., Brod, Kongso, Lessard, & Christensen, 2009). To treat diabetes, patients may have to use syringes, but using them in public may make them feel embarrassed and afraid of being rejected (Brod et al., 2009). Those with diabetes might have to be careful about what they eat, so they sometimes need to refuse unhealthy food at social events, leading to embarrassment (Wellard, Rennie, & King, 2008). Patients also feel that few people around them understand diabetes correctly, so they are afraid of disclosing their health status even to their fiancés and parents (Sato et al., 2003). Some patients reported that they were afraid to lose their job if they disclosed their health status to people they work with (Shiu, Kwan, & Wong, 2003). Patients who worry about stigmatization described above are likely to suffer from depression and psychological distress (Schabert, Brown, Mosely, & Speight, 2013).

Taken together, past studies indicate that different illnesses and disabilities are associated with various stigmas. As mentioned in the previous section, the stigma associated with health issues on SNSs has not been fully researched. However, some research implies that people with health issues experience stigma while using SNSs. For example, some Facebook users with diabetes avoid showing their concerns and distress about their health issue because of the stigma associated with diabetes even though they desire support from others on SNSs by disclosing their inner state (Newman et al., 2011). Bender et al. (2011) also suggest that features of SNSs such as the visibility of user profiles and personal networks reduce the anonymity, so users who are concerned about stigma associated with their health issue might hesitate sharing their experience on SNSs. Thus, stigma of health issues may prevent SNS users with health issues from seeking information and support on SNSs. Especially for emerging adults, most of whom are struggling to manage their identity (Schwartz et al., 2013), the negative effect of stigma on SNSs might be significant. In fact, on Facebook, emerging adults try to engage in identity management by presenting multiple facets of the self such as the real self, the ideal self, and the false self (Michikyan, Dennis, & Subrahmanyam, 2015).
FUTURE DIRECTIONS: STIGMA OF HEALTH ISSUES ON SNS

The previous sections introduce research on the use of SNSs by individuals with health issues and the stigma associated with specific health issues. Considering the frequency of SNSs use by individual with health issues and their negative experiences related to the stigma, it is necessary to investigate how stigma impacts SNSs use. People evaluate others based on the social categories that they belong to (e.g., a group of mentally ill patients, Asians, females), according to Social Identification Model of Deindividuation Effects (Postmes, Spears, & Lea, 2000). This effect is no different through computer-mediated communication. Therefore, on SNSs, people might have negative perceptions of an individual with health issues due to the effects of the stigma associated with the health issues.

On SNSs, health issues can be revealed in various ways. For example, SNS users with a health issue may disclose their health issues on a wall that other users can see. People could also disclose their health issue by sending a message only to someone they want to disclose their illness to. People may realize others’ illness by seeing interactions on SNSs that are open to other users or by seeing that others belong to an organization to which only people with a specific health issue are allowed to belong.

There are various situations in which people with a health issue communicate with others on SNSs, but little research has examined stigma effects of a specific health issue on online communication. Thus, the following sections discuss how stigma of a specific health issue influences communication on SNSs with Facebook as a particular focus, since this SNS has the highest number of users (Pew Research Center, 2014) and 82% of emerging adults who use the Internet use Facebook; the percentage is the highest of any age group (Pew Research Center, 2015). Also, Facebook has been used as the main SNS by many people with a health issue (e.g., Bender et al., 2011; Shpigelman & Gill, 2014a). Possible research questions are also proposed to drive research in these areas.

Sending and Receiving Messages

On most SNSs, users can send and receive private online messages to each other. If people realize that their interactant has a health issue, they may change their message to the interactant. For instance, people may see someone’s wall in which the person’s friends discuss a health issue the person has. After realizing the person has the issue, messages sent to the person may be negatively altered. To address the possibility that mental illness stigma influences online messages to a mentally ill individual, Imai and Dailey (2015) examined mental illness stigma effects on a request for a favor from a mentally ill individual on Facebook. Participants (97% of them were emerging adults: 18 to 29 years) interacted with a hypothetical target on Facebook, who was believed to have schizophrenia, depression, or a cavity (i.e., the control group). Participants were asked to rate the favor request in terms of face threat in addition to writing a response which was then coded by researchers. Results indicated that a request by a schizophrenic target threatened participants’ positive face more significantly than that of a target with depression or without any mental illness. Also, participants’ responses to the schizophrenic target were more likely to be polite, but less warm, whereas responses to the depressed target were more likely to be accepting messages. The results indicate that emerging adults who realize that their interactant on SNSs has a health issue, their message to the interactant may be negatively altered.

Stigma may also influence messages those with health issues send to others. Disclosing health issues to someone may be effective in obtaining social support from others (e.g., Chesney & Smith, 1999). Thus, it is possible for those with health issues to disclose their illness or disability by using online messages
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because these exchanged messages are not seen by others except for the specific recipient. However, people may decide not to disclose their illness because of the stigma associated with the illness (Greene, 2009). Research shows that people living with HIV hesitate to disclose their HIV positive status because of expected negative reactions caused by the stigma of HIV (Miller & Rubin, 2007).

Especially for emerging adults, it is difficult to talk about their health issues through online messages. Research interviewing youth living with HIV (17 to 21 years) revealed that most participants had great difficulty disclosing their diagnosis (Hosek, Harper, & Domanico, 2000). One participant told that he or she could not disclose the diagnosis even to his or her parents because of the stigma attached to HIV. Another study specifically examining diagnosis disclosure of adolescents living with HIV found that one third of the participants disclosed their diagnosis only to immediate family members and a few close friends (Wiener & Battles, 2006). Taken together, as the previous studies show possible stigma effects of messages exchanged on SNSs, future research should examine the effects by exploring the following research questions:

RQ1: If people know their Facebook friend has a health issue, will their online message to the friend be negatively influenced?

RQ2: If people with a health issue expect to be stigmatized after disclosing their issue, will they be unwilling to disclose their issue through the use of online messages?

Communication on Walls

Facebook users can write comments on their own and their friend’s walls. For example, they can post an update status on their wall that allows them to show other Facebook friends what they are doing and how they are feeling. In turn, their Facebook friends can write comments on the updated status. Also, Facebook users can use a Like button to let other users know they like other’s postings such as a status updates, pictures, and shared websites. These functions play important roles in communication on Facebook.

If people know their Facebook friend has health issues, their communication on walls involving the friend might negatively affected. For example, some individuals struggling with weight loss management reported that when they mentioned they worried about their weight on a Facebook wall, they received sarcastic and negative comments from others (Newman et al., 2011). To avoid the negative feedback from others, people with health issues often hesitate to reveal their health condition on their SNS wall. Thus, stigma of health issues could influence interaction on walls by those with and without the health issues.

To research the stigma effect on interaction on SNSs, Modified Labeling Theory (Link, 1982) is useful. This theory specifically focuses on mental illness stigma, but some concepts in this theory are applicable to other health issues. One of the ideas of the theory is that mentally ill individuals would try to educate other Facebook friends to obviate the negative effects of mental illness stigma. They may share websites that show the facts of mental illnesses to combat the myths of mental illnesses. They may also write comments on friends’ walls if the friends write incorrect information about mental illnesses. Modified Labeling Theory also suggests stigmatized individuals may avoid interaction on walls where they would be rejected by Facebook friends. For instance, if those with health issues are afraid of being rejected or ignored by other Facebook friends, they may not participate in conversations taking place on walls.
The stigma impact on interaction using the wall may be significant particularly for emerging adults. Schwartz et al. (2013) suggest that emerging adults undertake experimentation to explore who they are through interpersonal interaction. For example, to establish their identity, emerging adults may show their different facets of the self to others to see if they get feedback that is consistent with who they think they are. In fact, emerging adults present the real self, the ideal self, and even the false self on Facebook to explore their identity (Michikyan et al., 2015). Thus, if they are aware that their health issues are stigmatized, they would not reveal the information about the issues on walls of SNSs. Based on these theoretical ideas, future research should examine the following research questions:

RQ3: If people know their Facebook friend has a health issue, will their comments on the friend’s wall be negatively influenced?
RQ4: If an individual with a health issue believes their health status is known by Facebook friends, will the individual try to educate the friends by providing information related to the health issue?
RQ5: If an individual with a health issue believes their health status is known by Facebook friends, will the individual decline to participate in conversations taking place on walls?

Mixed-Mode Relationships

Past research argues that some online relationships migrate to FtF settings (Anthenunis, Valkenburg, & Peter, 2012). Such relationships are called mixed-mode relationships (MMRs), in which people meet online and migrate offline (Walther & Parks, 2002). Those with health issues actively seek new relationships on SNSs (e.g., Gowen et al., 2012), so it is possible for them to try to meet people they met on SNSs in a FtF setting.

However, stigma associated with health issues might influence the decision for SNS users with or without health issues to meet in FtF settings. For instance, people tried to avoid physically meeting a schizophrenic individual they know only on Facebook because of the stigma associated with the illness (Imai, in press). Stigma may also impact people with health issues’ decision to meet others offline. Modified Labeling Theory (Link 1982) suggests that people with health issues try to avoid potentially threatening situations, such as social gatherings where they may be rejected and isolated. Thus, people may avoid physically meeting someone they know only on SNSs because they are afraid to lose the social ties they developed online.

Research showed that the main motive to use SNSs for emerging adults is to stay in touch with friends they know offline, but one third of them use SNSs to meet and make friends with new people (Subrahmanyam, Reich, Waechter, & Espinoza 2008). The stigma associated with their health issues may prevent emerging adults with health issues from developing new relationships online. According to these accounts, the following research questions are posed:

RQ6: If people know their Facebook friend has a health issue, will they avoid meeting the friend in FtF settings?
RQ7: If individuals with health issues believe their health status is known by their Facebook friends, will the friend decline to meet in FtF settings?
CONCLUSION

Previous research revealed that some emerging adults with health issues have a hard time developing close relationships with others and obtaining interpersonal support (Patterson et al., 2012; Starke, 2013). SNSs could provide valuable opportunities for them to achieve such relationships and support (e.g., Barker, 2009; Nabi, Prestin, & So, 2013). However, those with health issues are at risk of experiencing stigma while using SNSs (Imai & Dailey, 2015; Newman et al., 2011) and this experience may have a negative impact on emerging adults’ identity management (Schwartz et al., 2013). Despite the predicted risk, there has been little research investigating the stigma effect on SNS users with health issues. To facilitate research on this issue, this chapter described the current literature on the use of SNSs by individuals with health issues. Previous research has revealed that people with health issues actively use SNSs to obtain various types of support. However, these studies are also concerned with how individuals with health issues manage their identity by sharing or withholding their health information on SNSs. To help researchers examine this topic, this chapter poses research questions that future studies should explore. Addressing these questions will make SNSs better places for emerging adults with health issues to develop interpersonal relationships and improve their quality of life.

REFERENCES


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KEY TERMS AND DEFINITIONS

AIDS: The final stage of HIV infection in which the body is vulnerable to diseases and those with AIDS may develop various serious health conditions.

Cancer: A group of different and distinctive diseases caused by an uncontrolled abnormal cell growth.

Diabetes: A group of metabolic diseases in which the body cannot control the amount of sugar in blood.

HIV: HIV interferes with the function of the immune system that fights off diseases.

Intellectual Disability: A disability characterized by impaired intellectual abilities and a lack of skills necessary for day-to-day life.

Mental Illness: A mental health condition that interferes with an individual’s cognitive, emotional, or behavioral functioning.

Social Networking Sites: A web-based services that enable users to create a public profile and develop relationships with other users online.

Stigma: A negative stereotype associated with a specific group of people, leading to the unequal treatment for them.