

THESIS

SHARING HEALTH-RELATED STIGMA THROUGH SELFIES AND ITS PERCEIVED  
POTENTIAL FOR DE-STIGMATIZATION

Submitted by

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## ABSTRACT

### SHARING HEALTH-RELATED STIGMA THROUGH SELFIES AND ITS PERCEIVED POTENTIAL FOR DE-STIGMATIZATION

This study explores the impact of posting selfies on perceptions of stigma surrounding health conditions. Using Goffman's stigma theory, it examines the communicative role of posting selfies that explicitly portray signs and symptoms of health conditions. The study uses eight one-on-one interviews with creators of what this thesis calls *stigma signaling selfies* (SSS) posted on the social media platform Instagram. It focused on people with cancer who posted SSS in order to understand motivations for and perceived consequences of posting. Interviews revealed that posting SSS provided a low-pressure way to disclose their cancer diagnoses and treatments, helped creators build closer relationships with others who have cancer, and promoted conversation about and normalization of cancer in public communication on the social media platform. In these ways, selfies fulfill each role of what stigma theory proposes revealing stigma plays for stigmatized individuals: disclosure, identity construction, and de-stigmatization. As one of the first formal research projects to study SSS, this study aims to create a starting point for future work at the intersection of selfies and stigma.

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## TABLE OF CONTENTS

ABSTRACT .....	ii
LIST OF FIGURES .....	vi
CHAPTER 1. INTRODUCTION .....	1
Research Questions .....	3
Organization of Thesis .....	4
CHAPTER 2. LITERATURE REVIEW .....	5
Stigma Theory .....	5
Disclosure .....	7
Identity Construction .....	9
De-stigmatization .....	11
Photo Sharing on Social Media .....	13
Selfies .....	14
Selfies as Media .....	16
Stigma Sharing Outcomes .....	21
Selfies and Disclosure .....	21
Selfies and Identity Construction .....	23
Selfies and De-Stigmatization .....	25
Selfies as Autopathography .....	28
Research Questions .....	29
CHAPTER 3. METHODS .....	31
Theoretical Framework of the Method .....	31
Research Design .....	34
Sample and Recruitment .....	34
Participants .....	39
Data Collection Procedures .....	45
Instruments .....	46
Pilot Study .....	46
Data Analysis .....	46
CHAPTER 4. RESULTS AND DISCUSSION .....	48
Social Media Use and Selfies .....	49
Social Media Use .....	49
Selfies .....	51
Disclosure .....	53
Advantages .....	54
Disadvantages .....	58
Identity Construction .....	61
Building relationships .....	62
Self-Acceptance .....	66

Journaling .....	68
Stigma .....	70
Education .....	71
Increasing Contact .....	72
Protest .....	75
Summary .....	76
CHAPTER 5.    CONCLUSIONS .....	77
Limitations .....	80
Data Sampling and Analysis Limitations .....	81
Implications for Research .....	82
Future Research .....	83
Final Summary .....	84
REFERENCES .....	85
APPENDICES .....	89
Appendix A: Initial Recruitment Messaging .....	89
Appendix B: Follow-Up Recruitment Request .....	90
Appendix C: Participant Online Consent Form .....	91
Appendix D: E-mail Follow-Up .....	94
Appendix E: Interview Guide .....	96
Appendix F: Post-Interview Direct Messaging .....	99

## LIST OF FIGURES

Figure 1.	A cancer patient selfie showing her head bald from treatments.....	2
Figure 2.	Typical selfie taken from an upward angle with pursed lips.....	16
Figure 3.	Twitter user in a gym selfie .....	17
Figure 4.	Subway ad encouraging customers to take and post selfies with its products .....	17
Figure 5.	Turkish woman in a #kahkana selfie .....	18
Figure 6.	Katie Perry posing for a goofy fan selfie on the American Music Awards red carpet in 2013 (Getty / Christopher Polk/AMA2013).....	19
Figure 7.	A cautionary or treatment impact selfie posted on Facebook .....	20
Figure 8.	A selfie with a visible colostomy bag that went viral. ....	22
Figure 9.	Ilana Kruger posting SSS .....	25
Figure 10.	Erin Jones' selfie with anti-anxiety medicine prescription went viral. ....	27
Figure 11.	Frieda Kahlo (1907 – 1954) 'The Broken Column', 1944 (oil on board). ....	29
Figure 12.	Instagram image of @cancer_inareddress.....	40
Figure 13.	Instagram image of @girlsonchemo .....	41
Figure 14.	Instagram image of @kimberlyannkd .....	41
Figure 15.	Instagram image of @lacyholly .....	42
Figure 16.	Instagram image of @melisse.tan .....	43
Figure 17.	Instagram image of @sharschmidt.....	43
Figure 18.	Instagram image of @therightstrong.....	44
Figure 19.	Instagram image of @tameratammytam .....	44

## CHAPTER 1. INTRODUCTION

The ease of taking photos on mobile devices and sharing them instantly has contributed to the proliferation of online photo sharing. One type of photo that has emerged as a major form of communication is the self-portrait photograph, or *selfie*. Often taken at arm's length, or in the reflection of a mirror, selfies are generally a photograph a user takes of him- or herself and posts on social media. Critics call selfies tools of the narcissistic and vapid, while proponents tout selfies as a valid form of identity construction and self-expression (Murray, 2015; Peek, 2014). Whether they are ultimately beneficial or harmful, it is clear that the role of selfies is an important part of current communicative practices. The present study explores a specific potential role of the selfie: that of a tool for social change and psychological healing.

Selfies are often assumed to be created to emulate cultural ideals for beauty, but sometimes the opposite is true. Selfies have been used to show pride in personal characteristics that have traditionally been stigmatized such as sexual orientation, race, and as is the focus of this research, health status. What this research has termed *stigma signaling selfies*, or SSS, are selfies that deliberately reveal and highlight stigmatized visual characteristics that run counter to socially determined ideals of beauty. When used by those with certain medical conditions, they have been used to show public identification with and even pride in living with those conditions.

Conditions that may have often been hidden from public view are now becoming part of some people's online identity through the use of SSS. For example, an SSS photographer may proudly post a selfie with a hairless head resulting from cancer treatment (see Figure 1), or may make no effort to hide a prosthetic limb. There is evidence that suggests that posting selfies that are not in line with cultural ideals for the physical form are meant to normalize every body type



and reduce the pressures of conforming to that ideal (Rutledge, 2013). The current research examines why some people share images of themselves that portray a less “ideal” self because of health-related conditions that have traditionally carried stigmas.



**Figure 1. A cancer patient selfie showing her head bald from treatments.**

Grounded in Erving Goffman’s stigma theory (1963) this research explores the motivations and intended outcomes of revealing personal information about their health through selfies in the public or semi-public realm of social media. This research seeks to determine if sharing health-related information may help stigmatized people bypass some of the disadvantages and uncomfortable circumstances related to revealing stigma face-to-face that stigma theory suggests. Some disadvantages noted by Goffman during face-to-face sharing of stigmas include causing the stigmatized individual to search for the ideal moment to share the existence of their conditions when developing relationships with new people, or diminishing the lack of trust that Goffman says occurs when that moment of sharing causes the people involved

to re-evaluate their impressions of one another. It also looks at other possible disadvantages noted by Goffman that can occur when revealing stigma, such as being perceived as too familiar with acquaintances by sharing personal information too soon.

Additionally, this research explores the effects that sharing SSS has on health-related stigmas for those who possess those stigmas. It seeks to determine if people who post SSS seek results such as improving public perception of illnesses, sharing the struggles associated with living with those conditions and thus conveying their own personal strength, or building community and camaraderie with others who live with similar conditions. To do so, it uses one-on-one interviews with SSS posters. The data gathered from this research will add to the knowledge about motivations for using this particular type of medium. Additionally, it could contribute to using SSS as a tool in helping people accept diagnoses of health conditions and contribute to overall well-being.

### **Research Questions**

To examine how selfies depicting illness are used and affect stigma, the current study analyzes eight one-on-one interviews with people who have created and publicly shared selfies showing health conditions. Using phenomenological interview analysis, it identifies themes in the motivations, perceived benefits, and drawbacks to posting SSS via first-hand accounts of selfie creators' discussions and explanations of sharing this type of selfie. This project aims to shed light on why people share images of themselves that do not reflect social norms for the ideal physical self and what they hope to gain from doing so. It also contributes to literature on stigma, and how representations of the self in current media contexts influence perceptions of stigmatized factors such as illness by the self and those with whom the media creators interact.

This research serves as a first step along the path to building knowledge at the intersection of selfies as a form of communication and stigma surrounding health conditions. It seeks to contribute to the understanding of how new media such as selfies can affect long-lived social psychological tendencies surrounding stigma toward the self and toward others. To that end, this project asks the following research questions:

- **RQ1: What motivates users to share selfies that portray their own chronic health conditions?**
- **RQ2: What effects do sharing selfies have on self-stigma for users?**
- **RQ3: What effects do the user perceive sharing selfies have on public stigma?**
  - **RQ3a: Are users posting SSS in order to *disclose* their stigma, construct their *identity*, and *de-stigmatize* their condition?**

### **Organization of Thesis**

Chapter 2 of this thesis discusses Goffman's stigma theory (1963) and why stigmas, especially those related to health conditions emerge. It discusses the relationships between stigma and identity formation in the literature, and applies these notions to photo sharing on social media, especially via selfies. It discusses the history of, and current research on the autopathographic function of selfies by those with medical conditions to determine how selfies might be used for self-expression and identity acceptance. Chapter 3, Methods, describes the procedures used to conduct in-depth, qualitative interviews that address the research questions and objectives for this study. Chapter 4, Results and Discussion, presents the findings of the study and discusses their relationship with the literature and theories used. In Chapter 5, Conclusions, key limitations of the study are presented, as well as suggestions for practical application of the findings of the interviews and future projects based on the results of this study.

## CHAPTER 2. LITERATURE REVIEW

### **Stigma Theory**

The term *stigma* originated in Greece and referred to bodily signs punitively burned into individuals, signifying something unusual or undesirable about their moral standings, and indicating that they should be avoided (Goffman, 1963). Today, the term is used to refer to any feature of a person that departs from the social identity that is expected of them. Put more simply, a stigma is a feature that would make someone unusual in a given situation (Goffman, 1963). In America, people who could be considered stigmatized could be anyone who is not a young, white, protestant, healthy male who is a father and married to a female (Goffman, 1963). So, in this way, it is possible for a trait or characteristic to be stigmatizing in one context but not another. This is apparent when one considers environments such as support groups where the shared experience of a typically stigmatized trait is what bring participants together. The concept of stigma in this research is important because aside from a stigmatized feature being unexpected of a given individual, the feature also causes the individual to be thought of as undesirable, or less than, someone without that feature. Stigma are entirely socially constructed and the result of the perceptions of individuals by others or by themselves. For a person to be stigmatized by others, they have to communicate that stigma, and SSS are one way of doing so.

The current research focuses specifically on health-related stigmas. Health conditions can be a source of stigma among people who live with them (Goffman, 1963). This means that people who live with health conditions are thought of by society as different, and in a sense, less than, those who are healthy. Goffman cites conditions such as deafness, blindness and paralysis

as stigmatized conditions but any health condition could be stigmatized, whether it is visible to others or not.

Some health conditions carry greater stigmas than others. In general, the more a condition is thought to be the fault of those afflicted or due to weakness in character, the more likely it is to be stigmatized (Campbell & Gibbs, 2009). Some examples of highly stigmatized conditions include lung cancer, HIV, Type II diabetes, and especially mental illnesses. No matter whether signs of a condition are immediately apparent or not, having a chronic or reoccurring health condition can affect the perception of an individual through the eyes of both others and the self (Goffman, 1963; Campbell & Gibbs, 2009). The result of all stigmatized health conditions, whether highly visible or hidden, is the same: individuals must choose whether to divulge or acknowledge their conditions in order to build close relationships.

Goffman's stigma theory and subsequent research provide a basis for explaining why people with health conditions share information about their own stigmas, including the expected effect sharing would have on others with that stigma and on people who do not have those conditions. The literature highlights three main outcomes of sharing information about personal health-related stigma: *disclosure*, *identity construction* and *de-stigmatization*. Disclosure is the process of making a stigma known, and may give stigmatized individuals control of social interactions, allowing them to choose when to share their stigmatized characteristics rather than waiting for people with whom they interact to discover them. Identity construction involves accepting a stigma as part of the self, and channeling stigmatized conditions into self-expression, as well as seeking out and creating goodwill and camaraderie with other people with similar conditions. De-stigmatization is the process of reducing the social and personal power of a stigma by normalizing stigmatized conditions.

These three outcomes work hand-in-hand, and build upon one another. For example, people with stigmas may be empowered by hearing the stories of others, spurring those people to share their own stigma and continue the cascade of normalization, in effect reducing the power of the stigma and leading to de-stigmatization. Thus, the lines between each outcome may blur. Disclosure, de-stigmatization and identity construction are discussed further in the following sections.

According to Goffman, sharing information about one's stigma can come in many forms, and though Goffman describes in-person conversations as the primary means for divulging stigma, modern forms of communication including social media may serve this purpose and allow individuals to share stigmas on their own terms. With the ubiquity of selfies and their growing acceptance as expressive communication in mind, this study investigates whether sharing SSS serves the role of revealing stigma in a similar way to in-person conversations, both in terms of empowering the stigmatized individual and reducing the power of the stigma. First, what follows is a look at each expected outcome of revealing stigmas and how each might be expressed through sharing SSS.

## **Disclosure**

A defining characteristic of a stigma is the tension caused by choosing if, how, when and to whom it should be revealed. The longer stigmas remain secret, the more impact revealing those stigmas will have on both strangers and intimate friends (Goffman, 1963). Fear of being disowned by family members and close friends is cited as a main reason people avoid revealing their stigmas (Campbell & Gibbs, 2009). When stigmas are health-related, not revealing stigmas can have detrimental effects, including avoiding seeking treatment for diseases such as HIV and cancer (Campbell & Gibbs, 2009). The act of sharing, however, can shift the balance of control

for the stigmatized individual from a position of potentially being “found out,” to one of having the power to divulge personal information when and how is deemed most appropriate to the stigmatized individual.

People with stigmas have techniques for managing revealing their stigmas. Some people whose stigmas are not physically apparent can choose whether to reveal or not to reveal their conditions, and indeed, many choose to keep their stigmas secret from everyone. If it is decided for stigmas to be revealed to some, one common method of handling information about a stigma is for the stigmatized individuals to divide the world into groups of people who know about their stigma and groups who do not (Goffman, 1963), thus creating two different environments in which stigmatized individuals lives; one where they are free to act as they please, and one where they are guarded as to not unintentionally reveal their stigmas.

When stigmatized individuals choose to reveal their stigmas they may reveal it in an intimate, intentional “confessional-type” discussion, allowing those they tell to either accept or reject them. The closer relationships become, the more it will be inevitable that stigmas must be revealed or else stigmatized people risk increasing the perception that they have been dishonest by presenting images that disregard their stigmas. Because of this, stigmatized individuals often keep others distant to avoid having to tell them about their stigmas.

Alternatively, stigmatized individuals can immediately and voluntarily disclose stigmas. This eliminates the possibility of being discredited and helps to manage social relationships. Also, if health-related stigmas are immediately revealed, stigmatized individuals can immediately engage in any actions related to a stigma, such as wearing hearing aids by the deaf, frequent bathroom breaks for someone with ostomy appliances, or exposing a hairless head by

people in chemotherapy without the fear of that moment of judgement that occurs upon reveal. It allows for more freedom (Goffman, 1963).

Taking and posting SSS may provide stigmatized individuals a route to immediately reveal stigma to those they do not know personally, thus decreasing the need to find an ideal moment to divulge information about their stigmas as relationships progress. Additionally, revealing stigmas immediately through SSS on social media can provide the freedom to practice habits necessary with some stigmas if in-person communication occurs.

Methods for revealing stigmas cited before the information age include visibly wearing the tools of the stigma, such as a cane for blind, hearing aid for deaf, etc. and the in-person “confessional-style” conversation. However, if stigmas are revealed too early in a new relationship, there may be negative consequences. Immediately revealing stigmas in new relationships can cause the impression of overfamiliarity among new acquaintances (Goffman, 1963). Nonetheless, revealing stigmas can prove empowering no matter what the method. In autobiographies by stigmatized individuals, the moment they no longer feel the need to conceal their stigma is often described as the final stage of feeling as though they have accepted and adjusted to their circumstances (Goffman, 1963).

### **Identity Construction**

According to Goffman (1963), people who suffer from health conditions, whether congenital, or acquired later in life often must assess their identities, weaving the lifestyle modifications of the condition into how they see themselves and how they are seen by others. Upon realizing that their conditions carry stigmas, stigmatized people may respond to their situations in various ways; they may try to correct their situations, as is the case when someone with a physical deformity undergoes plastic surgery. People with health-related stigmas may try



to learn or re-learn the activities that are limited by their stigmatized conditions. However, they are often unable to perform them as well as before or as well as someone without a condition would be able to, causing the stigma to remain. People with health conditions might come to accept their stigmas but blame any shortcoming on the stigmas, or conversely, accept the stigmas and come to see it as an eye-opening experience providing them with special insight about life. (Goffman, 1963).

Rogers & Buffalo (1974) identify other reactions to being stigmatized. Stigmatized individuals may acquiesce to their circumstances, repudiate them, evade the fact that they are stigmatized, or magnify the characteristics of their stigmas, making them immediately apparent, which would relieve the discomfort that would eventually come from having to reveal their stigmas naturally (Rogers & Buffalo, 1974). However, the reaction classified by Rogers and Buffalo (1974) of particular interest in this research is that of *channeling* stigmas. Once people have accepted their conditions as stigmas, they often reach a point where they not only accept their identities as stigmatized, but channel stigmas into a form of self-expression, self-identity and social effectiveness. They convert what is seen as a negative to positive, using it to form group cohesion among others with their same stigma. Through channeling, stigmatized people may agree that there are some bad aspects of belonging to their group, but having the stigma does not make them bad (Rogers & Buffalo, 1974).

The ability to share information about stigmas such as health conditions can empower individuals to accept their circumstances, and has even been seen as a sign that someone has “adjusted” to a situation that may be thought of as less than ideal (Goffman, 1963).

By using SSS to share information about personal stigmas, stigmatized individuals may seek the opportunity to express their own identities as people living with health conditions. Additionally, they may use SSS as a quick and expressive means of reaching others with similar conditions.

### **De-stigmatization**

Some theorists believe that stigmatization exists because stigmatizing some physical or mental features that fall outside of what is typical may play a role in providing a sense of security in the stability of a society (Campbell & Gibbs, 2009). A society may perceive that in the stigmatization of those who do not maintain the status-quo, it might be able to better maintain its structure. This is achieved by keeping those in power where they “belong,” and those who are different out of positions of high status (Campbell & Gibbs, 2009). If fears are projected, and problems blamed on those who are different, then everyone who does not succumb to being stigmatized can be comforted by a sense of invulnerability (Campbell & Gibbs, 2009). This can be related to health by, for example, considering the stigmatizing and false notions that mental illness only afflicts those who are weak-minded, or HIV is disease of homosexuals. Campbell and Gibbs (2009) may assert that, in these examples, someone may believe that if they are not weak-minded, or homosexual, they can avoid mental illness and HIV, respectively.

The power of a stigma can be reduced, then, by proving that those with stigmas are not limited by, or to blame for their differences, nor are they a threat to those who do not carry stigmas. De-stigmatization occurs through the act of removing the negative perceptions of a certain characteristic. De-stigmatization could help normalize health conditions and what it means to live with them, reducing the sense that people with health conditions are different, and thus less deserving of respect than those who live without health conditions. It could also provide a route to self-acceptance for those who have health conditions, by reducing the fear that might

arise upon diagnosis. Sharing information about lifestyles with health-related stigmas can serve to normalize those stigmas, and reduce their power, changing the perception of a given stigma (by both the stigmatized and non-stigmatized) from one of pity or disdain to acceptance, if not understanding (Goffman, 1963).

Displaying illness and other stigmas in selfies may have an impact on society's notions surrounding living with a health condition. Revealing stigmas can be beneficial. Upon deciding to reveal stigmas, stigmatized individuals may find there are people who will accept them regardless of their conditions (Goffman, 1963). Goffman cites examples of some people who are especially accepting of people with stigmas such as others with the same stigmas, or people who are familiar with the stigmas, either through vocation or relation to others who have similar conditions (Goffman, 1963). When people reveal stigmas, they may find, through reciprocal sharing, that there are more people understanding of their circumstances than they were aware of. However, Goffman also notes that some people may be less accepting of others when they are found to be stigmatized. This group largely consists of people who are not personally familiar with people with a given stigma (Goffman, 1963). The major difference between this group and those who are more readily accepting is the degree to which they believe they are different from the stigmatized (Smith, 2012). The greater the perceived difference between oneself and those with given stigmas, the less likely one is to accept those stigmatized individuals (Campbell & Gibbs, 2009). Therefore, by sharing stigmas through selfies with strangers and acquaintances, people who share SSS may bridge that gap between themselves and people who perceive themselves to be different from those who are stigmatized, thus removing the divide.

In line with stigma theory, this research sheds light on specific motivations, benefits, and drawbacks to posting SSS as perceived by the posters. Each of the three anticipated desired

outcomes of revealing stigmas is explored through the lens of the selfie; disclosure, identity construction and de-stigmatization. The following sections discuss motivations and outcomes for using social media, focusing specifically on selfies.

### **Photo Sharing on Social Media**

The use of social media for sharing information and communicating with friends or strangers has increased since the term ‘social media’ first appeared over 10 years ago (Sears et al, 2008). According to 2017 research by the Pew Research Center, 81 percent of all adults online use social media sites. Social media provides the opportunity for people to consume and create media in one place, lending to its role as a powerful form of modern communication (Betton et al., 2015). By sharing information either created by themselves or by conventional media, users can influence the media environment (Betton et al, 2015).

As social media’s presence in the lives of internet users has grown, it has also become more mobile. Comscore, a media measurement and analytics company, reports that over half of all media consumption on the internet now takes place on mobile devices (Lella, 2014). This includes 92 percent of all time spent taking, viewing and sharing photos. In fact, more photos and greater use of mobile devices seem to go hand-in-hand. In 2017, The internet statistics site, Statista reported that the 85 percent of all photos are taken with smartphones, and an estimated 1.2 trillion photos were uploaded to the internet over the year (Richter, 2017).

Social media platforms such as Facebook, Twitter, Instagram and SnapChat all have photo sharing features. Instagram and Snapchat, two platforms that are specifically intended for photo modification and sharing, grew at faster rates in 2014 than other popular platforms. Instagram now has more followers than Twitter (Ogilvy Social, reported by Our Social Times, 2014). The Pew Research Center reports that 52 percent of adult internet users post personal

photos online that they themselves have created. As for the demographics of photo posters, Ogilvy Social found that people who post photos they have created are largely those between the ages of 18 and 29, with 79 percent of those polled reporting they post new photos. Women post photos they've created slightly more often than men, though roughly half of each sex reporting they post photos they have created.

This increase in prevalence in smartphone use and digital photo taking and sharing has led not only consumer analytics researchers but social scientists to wonder why and how people choose to use social media. Research shows that motivations for using social media include creating relationships and information sharing, as well as keeping contact with friends and consuming news media. Studies have cited social surveillance, passing time and gaining emotional support from peers as other reasons why people use social networking sites (Cheng et al., 2016; Joinson, 2008; Leung, 2013; Papacharissi & Mendelson, 2010; Quan-Haase & Young, 2010). Many of these motivations are related to the desired outcomes of sharing personal information about stigmas: disclosure, identity construction and de-stigmatization. Social media may be an ideal vehicle for sharing the existence of one's stigmas and portraying life living with those stigmas.

## **Selfies**

The rise of social media and ease of instantly capturing and sharing information and images on hand-held devices has created ideal conditions for the advent of the selfie phenomenon. As discussed, selfies posted online have become a major form of communication in recent years. Selfies, in their simplest definition are photos taken of oneself, by oneself, and as Katz and Crocker (2015) define, are specifically for the purpose of sharing online in public or semi-public realm of social media. Though the definition of selfies is evolving as quickly as the

role of selfies is expanding, it is the selfie's ability to be shared as part of a social media identity that is most important in the present research. The fact that photos are self-selected and shared on posters' social media profiles indicates that they serve as a representation of posters' selves or lifestyles. This is more important than the fact that the selfie is taken strictly by the poster. For this research, a photo taken by someone else, or by a camera on timer would also be considered a selfie as long as it is posted in representation of the poster.

Selfies have become one of the most common forms of communication capital for those who participate in social media, and evidence supports the idea that they serve the purpose as a medium for online visual conversation (Katz & Crocker, 2015). In 2014, Merriam-Webster officially added the term to the dictionary, as of July 2018, there are over 350 million tagged selfies on Instagram.

Selfies have a mixed reputation, and on the surface may appear to be a tool of the shallow and self-absorbed (Wickel, 2015; Murray, 2015), but innovative research in online communication shows that selfies are not as skin-deep as they may appear. The current research explores the role of selfies as tools to reduce self-stigma of health conditions. It explores if people who post selfies that display their health-related stigmas seek the same outcomes as sharing stigmas through face-to-face or written communications: disclosure, identity construction and de-stigmatization. Figure 2 portrays a stereotypical selfie.



**Figure 2. Typical selfie taken from an upward angle with pursed lips.**

Before delving into the possible roles of SSS, this review will begin with a background of selfies, how they have come to be used, generally, and their potential value as tools of communication and identity construction. The rest of this review will build a foundation for exploring SSS, and the role they may have in each of the three desired outcomes for sharing health-related stigma: disclosure, identity construction, and de-stigmatization.

### **Selfies as Media**

People take and post selfies in many situations. They post them while on vacation, in the gym (see Figure 3), at the movies, and controversially, even at somber historic monuments, such as the teen girl who faced criticism after posting a smiling selfie at the Auschwitz Concentration Camp site in Germany (Booth, Phil. 2014). Companies such as American Apparel, Subway, and Lancôme encourage consumers to post selfies with their products, and selfies are even being used to take a political stand (see Figure 4). For example, Turkish women used selfies to rebel against the Turkish deputy prime minister's assertion that women shouldn't laugh in public by

posting images of themselves in the act under the hashtag #kahkana which translates to laughter in Turkish (see Figure 5; 4News. 2014)



Figure 3. Twitter user in a gym selfie



Figure 4. Subway ad encouraging customers to take and post selfies with its products





**Figure 5. Turkish woman in a #kahkana selfie**

Selfies have become infamous in their style. The idea of the stereotypical outstretched arm holding the camera and puckered lips, however, may minimize the value of the selfie, reducing it to a tool of narcissism. Selfie critics blame selfies for perpetuating and encouraging narcissism (Murray, 2015) and sexism (Tiidenberg & Cruz, 2015), arguing that they make women (as the slight majority of selfie posters) feel that it is acceptable to be judged by their looks, and seek out the validation by others in their social networks in the form of comments and “likes” (indicators of approval available as hearts or thumbs-up buttons on most social media platforms). Much discussion of selfies in mass media focuses on narcissism, self-loathing, or loneliness. Murray (2015) says that the selfie “personifies what is trivial about being human.” Additionally, posting selfies has been seen as a “cry for help” from those with mental illness, and

indeed, some research supports the idea that people who frequently post selfies may be more likely to suffer from mental illness (Fox & Rooney, 2015).

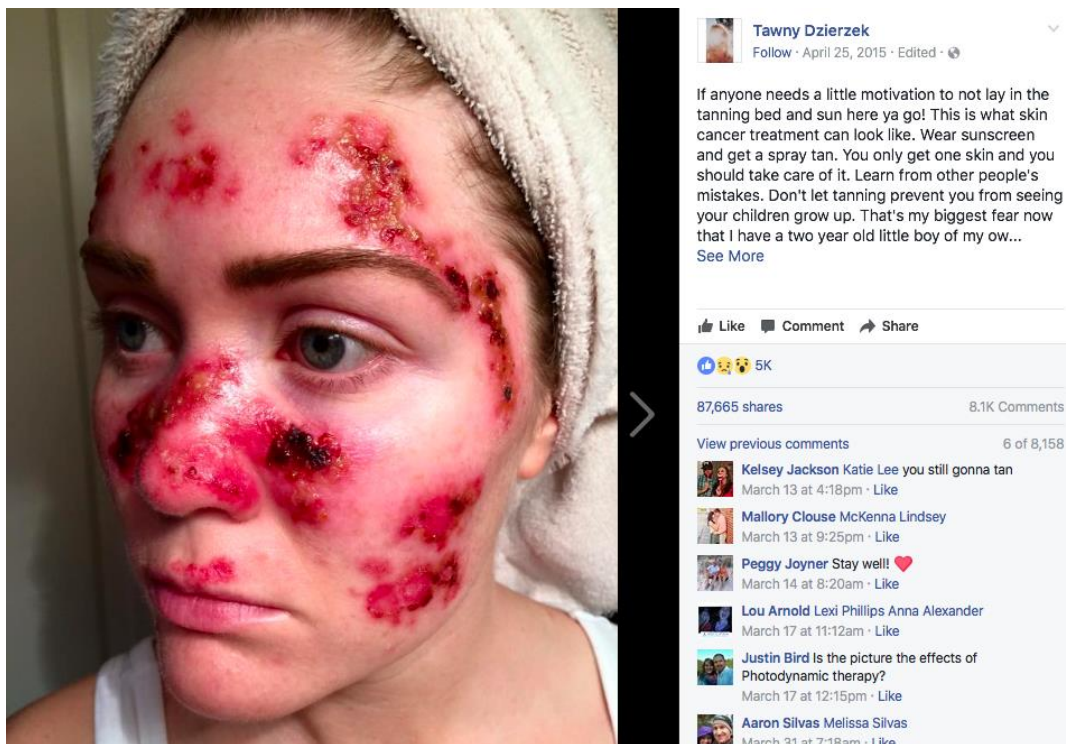
However, recent research suggests that selfies play an important role in identity construction and memory keeping, allowing their creators to keep a record of who they want to be perceived as at any point in time. In effect, selfies work as an online journal where the viewer can recall how they looked and felt at any moment in time. Furthermore, Burns (2015) claims the negative public perception of selfies is, in itself, supporting of patriarchal authority by legitimizing the discipline of women's behaviors and identities. This view is reinforced by a recent trend of selfies that are deliberately silly or unattractive, especially popular among teens and even celebrities (see Figure 6).



**Figure 6. Katie Perry posing for a goofy fan selfie on the American Music Awards red carpet in 2013 (Getty / Christopher Polk/AMA2013).**

There is some research that touches on the idea of SSS. Tembeck (2016) identifies “selfies of ill health” as the occurrence in which an individual takes a photo of him- or herself experiencing illness or hospitalization. Tembeck (2016) discusses this phenomenon as a genre of

selfie that she divides into three types: *diagnostic selfies* which are used to help a health care provider diagnose an illness or condition that may be visible in the image, *cautionary* selfies that serve the purpose of informing the viewer of the symptoms of a disease, and thus encourage them to be aware and seek help to treat or prevent similar symptoms, and *treatment impact selfies* that show “the impact of illness or treatment on a subject,” (Tembeck, 2016). This final version of selfies, according to Tembeck, provides an autopathographic function allowing the photographer to create his or her identity as a person living with a disease or condition (see Figure 7).



**Figure 7. A cautionary or treatment impact selfie posted on Facebook**

Though Tembek touches on the role of identity construction through the use of selfies of ill health (or as they are called here, SSS) in this final version of the selfies she describes, the current research will look at identity construction as one of three desired outcomes of sharing information about health-related stigmas along with de-stigmatization and disclosure. Thus

rather than being detrimental to communication and self-esteem, selfies may have the unique ability to portray an individual in a way that is intentional, empowering and authentic. The following sections will address each of these expected outcomes specifically.

## **Stigma Sharing Outcomes**

### **Selfies and Disclosure**

An important characteristic of selfies is that they are self-taken and self-selected to be shared. This means that they not only show who the selfie creators are, but how they want to be perceived by viewers with whom they are shared. Selfies do not necessarily show people at their physical best, but because they must be actively selected and shared, it can be assumed that they always show people in a way they intend to be perceived. Rutledge (2013) suggests that selfies play several different roles, including normalization of seeing what ‘real’ people look like compared to the constant exposure to unattainable ideals for beauty. Rutledge emphasizes the selfie’s tendency to show people as they are in the moment, instead of as the culturally accepted ideal for physical appearance. She deems these raw, natural selfies as “ugly” selfies. “There are many more photos of ‘real’ people compared to idealized images by thousands,” said Rutledge. “One artist commented that the ugly selfie challenges her own vanity and puts her personality back into the self-documentation,” (2013).

Selfies show people as they want to be represented, but they are not always beautiful or conventionally attractive. The SSS falls parallel to Rutledge’s ugly selfie. The SSS is not necessarily ugly, but simply shows people straying from the cultural ideal for beauty. SSSs unabashedly feature creators’ manifestations of physical and mental health conditions. SSS can come in many forms. For example, photos showing sufferers of Crohn’s Disease and Colitis

went viral after one sufferer, Bethany Townsend, posted a picture to Facebook (see Figure 8) that featured her colostomy bag (Lytton, 2014).

This prompted other people with ostomy treatments to post their own self-portraits in solidarity with Townsend. In another example of selfies showing the effects of a health condition, blogger Dena Julia ([www.denajulia.com](http://www.denajulia.com)) said that selfies chronicling her fight with cancer caused a commotion among her readership because they showed the shocking effects of cancer treatment on the blogger's body. Other photographers have taken selfies to both portray psychological disorders, and as a means to treat them (Kirkova, 2014).



**Figure 8. A selfie with a visible colostomy bag that went viral.**

These examples may be seen as achieving the role of disclosure. The fact that ostomy treatments and loss of hair are often hidden allow the posters to show parts of themselves that, if communications were face-to-face, would be likely to eventually be disclosed. The online sharing of these features allows posters to skip that step and show personal aspects of their lives immediately. They do not have to risk discredibility because anyone familiar with their social media will already know about these aspects of their lives. Additionally, they may feel freer to live lifestyles that cater to their treatments without feeling the need to hide the routines and equipment involved.

## **Selfies and Identity Construction**

The ability to take and delete a selfie in an instant allows selfie photographers to constantly create and re-create their online identities and share information about who they feel they are at any one moment. Taking selfie after selfie, as is the habit of many posters, can allow posters to embody every aspect of the selves they want to present (Rettberg, 2014). As a result, sharing selfies creates something akin to a public journal of who a person is at each moment in time, then cumulating into a serial of online identity.

With the wide availability of cameras in hand-held devices, research shows that photography, including taking and sharing selfies, is taking on more of a role in identity construction (Van Dijck, 2008). In fact, selfies have been found to play a part in online identity construction (Katz & Crocker, 2015; Elmadagli, 2016; Rutledge, 2013), acting as an online serial, literally drawing a picture of how individuals choose to portray themselves at a given point in time. The fact that selfies are self-taken and self-selected to be shared suggests that they demonstrate how individuals want to be seen and how they want their identity to be understood (Katz & Crocker, 2015). Furthermore, Katz and Crocker (2015) found that selfie creators considered how viewers might consume selfies that they post online and use those images to craft an identity presented to the public.

With this in mind, selfies can be seen as a form of spontaneous self-portrait. Women who post selfies often describe them as empowering (Murray, 2015). Selfies have been used for political engagement and radical forms of community building (Murray, 2015). Sharing selfies and blogging has created powerful social networks between individuals that could be living far from one another. Complete strangers form communities and inspire collaboration. In this way, SSS may provide a route for building group cohesion among people living with the same or

similar health conditions. Facebook groups and blogs are common among any wide range of conditions from hormonal diseases to cancer diagnoses to amputee support groups, and often, profiles for these groups or conversations among members involve posting and sharing SSS. For example, an online support group for people with a certain adrenal condition started a thread of “before and after” diagnosis photos, prompting members to comment and acknowledge physical changes. Group comments offered overwhelming support and affirmations. In this way, SSS built camaraderie and relationships between members. Selfies have the unique ability to make the viewer feel close, both physically and emotionally to the creator. Because of the selfie’s frequent perspective from arm’s length, viewers may innately feel more intimate with the subject than with traditional photography (Frosh, 2015). This familiarity could lend itself to increased empathy and understanding through the SSS.

Posting SSS may allow people with a given condition to acknowledge their own identity as someone with the condition by seeing how they have similar physical transformations as people with the same condition. In this way, selfies not only help convey a self for their creators that is presented and posted online as an outward facing identity, but they can help their creators gain a better understanding of their own identities. As Rettburg (2014) states, “Sometimes we use the mediation of technology to help see ourselves better.” People with stigmas who choose to post SSS highlighting their stigmatized features are creating an identity that includes these aspects of themselves, adding to their online serial about how they see themselves at any point in time. They may be showing that they accept their stigmas, or at the very least that they choose to reduce the power of it by sharing it and reducing their ability to be discredited.



Blogger, Ilana Kruger, published an article specifically citing reasons why she posts selfies while in the hospital receiving treatment for her own chronic illness (see Figure 9). Her reasons fall within the role of creating and affirming identity:

I think that part of the reason why I take them is somehow in defiance. I might be in this place I really don't like, but I'm still me...The photos also serve as a kind of picture diary for myself when I look back at them. They help me see that while my experiences with illness don't define me, they are still a big part of my life and my history.

If Kruger's experience is any indication of the typical reasons that people post SSS, then it is obvious that SSS should be explored as a form of identity construction and conveyance. In fact, Nemer and Freeman (2015) found in their ethnographic study that selfies were specifically cited by creators as a method for self-examination and reflection on who the creator felt they were at the time of posting (Nemer & Freeman, 2015).



**Figure 9. Ilana Kruger posting SSS**

### **Selfies and De-Stigmatization**

De-stigmatization is a complex process. Stigma exists at the societal level, and thus must be dealt with as a society. Methods cited for reducing stigmatization include education, contact, and protest (Betton et al, 2015), all of which could be applied to the role of selfies. Education about stigmas replaces stereotypes with accurate information, contact increases the time spent interacting between stigmatized and non-stigmatized individuals, and protest involves active

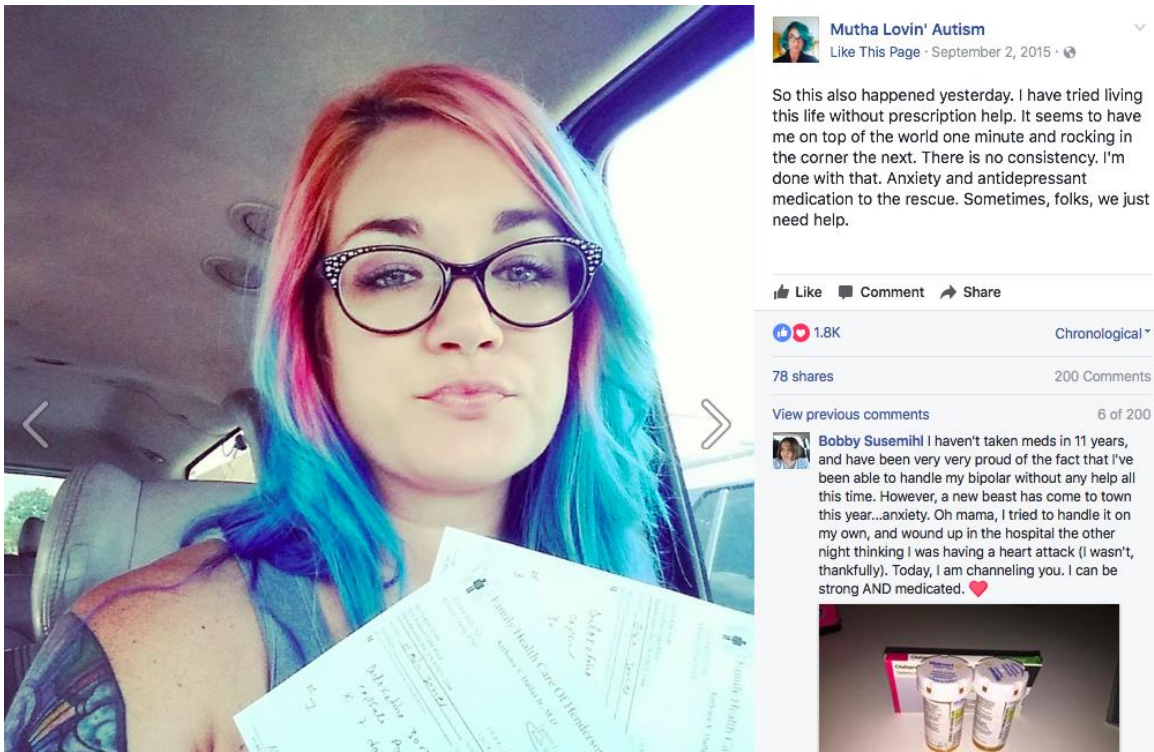


refutation of stereotypes and misinformation. Though all of these may be possible through selfies, the medium may work best to increase contact between different types of individuals, and to actively protest misinformation. One example of using selfies to protest misinformation occurred in 2016 and began as a method for Irish rugby player to fight societal stereotypes for masculinity that may limit the ability for someone with mental illness to seek help for fear of being seen as sensitive or weak.

Rugby player Luke Ambler began his campaign to encourage men to talk about mental illness and suicide with the hashtag #Itsoktotalk posted alongside selfies of himself flashing the “OK” hand gesture. Ambler started the movement in support of his brother who died by suicide, and his posts prompted many people with mental illness to post similar selfies with the accompanying hashtag, expressing their support of and identification with suicide prevention. The campaign cascaded into a worldwide phenomenon with many celebrities joining in the effort and sharing their own stories (Dupare, 2016).

In another example of using selfies to combat stigma against mental illness, blogger Erin Jones posted pictures of herself displaying her anti-anxiety medication prescriptions (see Figure 10). Jones’ selfie was “liked” over 1000 times on social media and it prompted others to follow suit under the hashtag #medicatedandmighty when she teamed with the website, The Mighty, which publishes stories and news, and creates an online community for people living with “disability, disease and mental illness” (themighty.com; Dickson, 2015). Especially as is the case with mental illness, viewers of Jones’ and other posters’ selfies may not realize that these individuals live with a health-related stigma. By sharing stigma through selfies, Jones increased contact between different types of people, or at least made viewers aware of the fact that they

were, in fact, already in contact with someone living with mental illness. Overall, the research on selfies suggests that they may indeed de-stigmatize certain features of their posters.



**Figure 10. Erin Jones' selfie with anti-anxiety medicine prescription went viral.**

Aside from reducing public stigma, there is the possibility that posting selfies may have an equally powerful effect on the negative feelings that stigmatized people often feel against themselves and their possession of those stigmatized features. Self-stigma occurs when stigmatized individuals internalize negative stereotypes and direct disdain toward themselves (Corrigan & Rao, 2012). Understanding the impact that posting SSS has on their posters is critical to any examination of this phenomenon.

Corrigan and Rao (2012) attest to the role of personal empowerment for reducing self-stigma. Empowerment in this case can come from disclosing information about living with stigmas (Corrigan and Rao, 2012; Leon Tan, 2008). Not only is disclosure effective in reducing self-stigma, but using selfies as a method for disclosure would provide what Corrigan and Rao

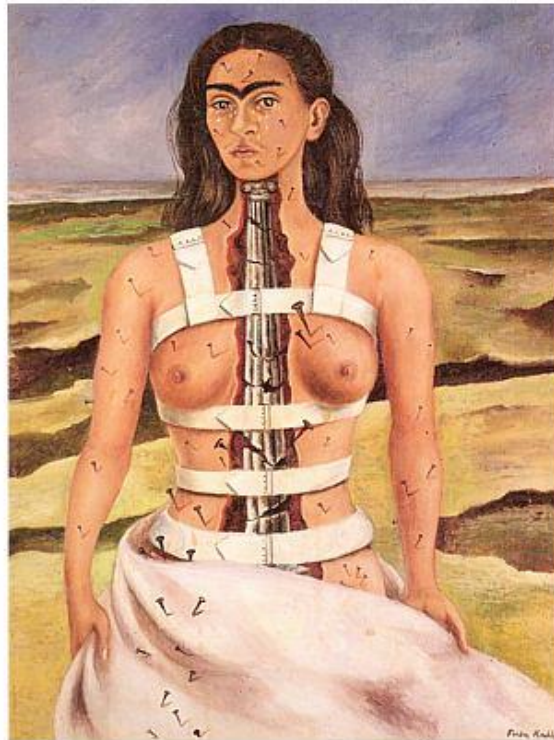
argue as the most effective form of disclosure, “broadcasting.” That is, sharing information about stigma widely and indiscriminately, providing a sense of power of and eliminating fear of being “found out,” (Corrigan & Rao, 2012).

In research by Kennedy et al. (2016), women with HIV who participated in a project by the non-profit, Photovoice, created self-portraits of their experiences living with HIV. Upon questioning by researchers, participants cited the potential for de-stigmatization as their chief reason for participating (Kennedy et al., 2016). The current research explores whether selfie photographers seek similar results when they share SSS as part of their online identities.

### **Selfies as Autopathography**

When considering the selfie as a method for sharing stigma and its potential to achieve disclosure, identity construction, and de-stigmatization, it may be appropriate to assign selfies to the category of autopathography. Autopathographies are autobiographies that deal specifically with the influence that a health condition has on the creator’s life. They are traditionally literary, but have appeared in art such as painting and photography. Autopathographies are primarily considered to provide an expressive outlet for people with health conditions that contributes to identity construction. They can also serve to provide others living with the same conditions with a guide for navigating their own illness experiences. They may even considered a form of therapy that allows their creators to accept who they are as a person living with an illness (Tembeck, 2016). They fulfil the role of disclosure by allowing artists to share parts of themselves with audiences while maintaining the power to reveal only what they choose about their story (Hall-Clifford; Pray, 2016). Autopathographies help create visibility for an illness outside medical contexts and affirm the experiences of those living with illness (Tembeck, 2016).

Finally, autopathographies often aim to reduce stigma surrounding a disease or condition. Autopathography creators often express the importance of remaining open about personal experiences to reduce shame and secrecy (Hall-Clifford). These are not a new phenomenon, and have been used in art from the self-portraits of Frieda Kahlo (see Figure 11) to film, comics, and literature (Derby, 2013). Considering SSS posted in social media such as Instagram or Facebook as part of this tradition of autopathographies highlights the ways in which they function as a form of communication (Tembek, 2016).



**Figure 11. Frieda Kahlo (1907 – 1954) 'The Broken Column', 1944 (oil on board).**

### **Research Questions**

Based on Goffman's (1963) stigma theory, this research seeks to determine the role of SSS in reaching the three desired outcomes of sharing personal stigma: disclosure, identity construction, and de-stigmatization. It explores how sharing stigma through selfies can serve to expedite the disclosure of that stigma. As a form of autopathography, SSS may both empower

the stigmatized individual and bring attention to different health conditions, thus normalizing them (Pray, 2016; Tembeck, 2016). In determining whether SSS function similarly to autopathography, this research seeks to contribute to theories about why and with what impact people share their stigma on social media, including the potential for self-expression, identity acceptance, and reduction of self-stigma. It will contribute to the understanding of how new media, such as selfies, can affect long-lived social psychological tendencies surrounding stigma toward the self and toward others. It aims to understand how stigmatized individuals use selfies to communicate about their stigmas, and what their intentions are for doing so. To that end, this project asks the following research questions:

- RQ1: What motivates users to share selfies that portray their own chronic health conditions?
- RQ2: What effects do sharing selfies have on self-stigma for users?
- RQ3: What effects do the user perceive sharing selfies have on public stigma?
  - RQ3a: Are users posting SSS in order to *disclose* their stigma, construct their *identity*, and *de-stigmatize* their condition?

Each of these three questions serves to determine the role in reaching the desired outcomes of sharing selfies. RQ1 will determine the role of selfies in disclosure and identity construction; RQ2 and RQ3 will both seek to determine the effects of selfies on de-stigmatization. Questions in the survey will ask participants to discuss the three theorized outcomes of sharing stigma: disclosure, identity construction, and de-stigmatization.

## CHAPTER 3. METHODS

To examine the motivations and desired outcomes of posting *stigma signaling selfies* (SSS), eight phone interviews with individuals who created and posted SSS to social media were conducted. Using the lens of Goffman's stigma theory and supporting research in the area of stigma, the interviews explored the creators' perceptions and intentions of posting SSS in the semi-public space of the social network Instagram. Interview questions focused on three theorized outcomes of sharing information about one's own stigmas: 1) disclosure; 2) identity construction; and 3) de-stigmatization.

### **Theoretical Framework of the Method**

As this is one of the first formal research projects to study SSS, examining the role of the medium from the perspective of the creator is essential to help build a foundation for future scientific discovery. By interviewing SSS creators, this research examines the perceived motivations and potential outcomes from the perspectives of the selfie creators themselves to get a first-hand account of the phenomenon. For this study, interviews were determined to be an effective method to identify themes in the motivations, desired outcomes, and perceived benefits and drawbacks to posting SSS. Through semi-structured interviews, data was gathered via first-hand accounts of selfie creators' discussions and explanations of sharing this type of selfie. By analyzing the themes and concepts discussed by these participants during the interview process, this project may shed light on why stigmatized individuals share images of themselves that stray from the social norm for the ideal lifestyle and what they hope to gain from doing so.

Research pertaining to the perception of stigmas and methods for reducing stigmas has been fairly extensive, especially surrounding mental illness (Livingston et al, 2012; Green-

Shortbridge, 2007), with studies showing that stigma does have a profound effect on the lifestyles of those who have them, and the perception they have of themselves (Betton et al, 2015; Campbell & Gibbs, 2009), Research has shown that there are potential methods for reducing stigma, and people with stigma feel that they can have an impact on stigma in society (Campbell & Gibbs, 2009; Livingston et al, 2012). Despite this, there is little formal research on the use of selfies to reduce stigma. However, the research that exists shows the medium's potential (Betton et al, 2015; Kennedy et al, 2016; Elmadagli, 2016), showing that people who see selfies showing stigmas are generally supportive of those who post them. Similarly, research that seeks to determine if selfies serve the other roles of sharing stigma, namely, stigma disclosure and identity construction is on the rise. Because of this, the current study involves in-depth, exploratory, qualitative examination of participants' perspectives on the SSS phenomenon through one-on-one interviews.

Qualitative research is especially well-suited to this project because it lends itself well to exploration of themes that may emerge through the interview process. Though the perceptions of the desired outcomes of disclosure, identity construction and de-stigmatization were the focus of the research questions, in-depth, semi-structured interviews were chosen for this study because they allowed for the flexibility to elaborate on any unexpected themes that might have emerged.

As an exploratory study, this research focused on individual perceptions and the unique identities of SSS creators. Interviews were selected as a method because they reflect posters' own words and ideas and are less reliant on the researcher's pre-conceived ideas (Hesse-Biber & Leavy, 2010).

When considering interviews as a potential research method for selfies, in particular, it should be noted that much of the most prominent selfie research evaluates different types of

selfies. Much of that research examines different phenomena through the lens of the observer and scientist, building validity for this young field of research and recognizing that selfies are form of communication worthy of study. Because of this, methods used in previous research largely consist of case studies (Boone & Pentney, 2015; Deller & Tilton, 2015) and discourse analyses (Burns, 2015).

More recent work has used interviews to identify motivations for posting selfies from the perspective of their creators (Kennedy et al, 2016; Elmadagli, 2016). Interviews have been used to identify people's knowledge of selfies, frequency of creation, and attitudes toward the medium (Katz & Crocker, 2015), as well as motivations and expected outcomes (Kennedy et al, 2016; Elmadagli, 2016; Nemer & Freeman, 2015). For example, interviews were used to explore the role of selfies in the empowerment of poverty-stricken selfie creators in Brazil (Nemer & Freeman, 2015).

Qualitative research has proven to be effective in the study of stigmas and their effects on individuals who have them. In stigma research, interviews have been used to explore stigmatized individuals' reactions to being diagnosed with stigmatizing conditions (Scambler, 1982; Taub, McLorg, & Fanflik, 2004; Smart & Wegner, 1999; Wahl, 1999). This research, too, sought to determine if selfies were used as a method to cope with the diagnosis of cancer, a stigmatizing condition, further supporting the idea that interviews have been effective in this type of research.

The current project's purpose was not only to determine how selfies are used in reaction to stigma-causing conditions, but also to delve into why people may choose to share such personal aspects of their identities through *stigma signaling selfies* (SSS), and what they hope to achieve by doing so. This study specifically seeks to determine whether selfie photographers intend to influence perceptions of stigma surrounding their disease. Interviews with people who



routinely post selfies showing visual manifestations of stigmatized sickness provide significant insight into their thought processes and these findings contribute to the field's understanding of computer-mediated visual communication more generally.

### **Research Design**

For this study, semi-structured phone interviews were conducted with eight adult women who had recently posted SSS to the social media platform Instagram, selected using a hashtag search. After a small pilot study to finalize procedures and questions, an interview guide focusing on the perception of the role of SSS in disclosure of stigma, identity construction around stigma, and disempowerment of that stigma was developed. Interviews were loosely constructed to allow for interviewees to add their own ideas and bring up themes that the researcher may not have considered. Interviews were recorded and transcribed professionally, and analyzed using phenomenological analysis. The following sections describe the specific processes used for recruitment, instrument design and data collection.

### **Sample and Recruitment**

Instagram is a social media platform that is semi-public, meaning that users have the option to set their accounts to “public,” and make them visible by any visitor to the site. On the platform, hashtags (#) are used to tag photos and add them to public conversation. For example, photos taken at the Grand Canyon might be tagged #grandcanyon, allowing anyone who searches for that phrase to see them. The current research used hashtags to identify and recruit participants.

As of June, 2018, Instagram had reached 1 billion active accounts per month. Because of this astounding figure, a few parameters were placed on the selection of study participants in

hopes of ensuring that interviews could be homogenous enough to draw conclusions as far as possible in this small exploratory sample. Selection of participants involved several criteria.

First, in order to create a reasonable sample size, cancer was chosen as the health-related condition. This was for several reasons. Cancer in its various forms is a prominent condition which carries complicated social stigmas. In general, people fear cancer because of its potential to threaten life and because treatment has a profound impact on an individual's lifestyle and appearance. There is a general lack of understanding of cancer, with studies showing that it is more feared than heart disease, despite the latter being a bigger risk to public health (cdc.gov, 2017). Additionally, the general public has the impression that people who get cancer could have done something to prevent their diagnoses, meaning that they can be blamed for their cancer. (Chapple, Ziebland, & McPherson, 2004). As a result, cancer is a highly stigmatized health condition. As Campbell and Gibbs (2009) suggests, the more a health condition can be considered the fault of the diagnosee, the more stigma the condition carries. Cancer's impact on a person's appearance was especially relevant to diagnosees of the condition who post and share selfies to social media.

Second, for this study, it was determined that interviewees should be limited to people who identify as women. Selfies are a highly gendered phenomenon with distinct social, cultural, and personal pressures for women compared to men (Murray, 2015); women are more likely to post selfies and women bear the brunt of negativity in news coverage of selfies (Drexler, 2013). Women also receive more societal pressure than men to look attractive and hide negative aspects of their appearance and feel pressure to live up to higher expectations than men to follow social norms for appearance (Tiidenberg & Gómez Cruz, 2015). Therefore, it is assumed that female participants would have significantly different experiences than men. Because this is a small

qualitative study (N = 8), women were chosen to be able to examine this phenomenon more thoroughly among this population. Future research on the role that SSS play in the communicative practices of men is needed to further explore this phenomenon.

Finally, adults were chosen for this study because living with a chronic or life-threatening illness would likely have a different impact on the identity construction of an adult than that of a minor. An adult usually has an established sense of self prior to the diagnosis of a life-threatening, transforming illness and may have a more difficult time accepting the changes that occur through stigmatization, both physically and socially. A minor's adjustment to an illness would likely be different than an adult's because the minor is already in a period of identity establishment (Erikson, 1972).

In order to identify specific participants, hashtags related specifically to cancer treatment were chosen based on their popularity and most common uses. Hashtags searched in Instagram included: #fuckcancer, #cancerselfie, #cancersucks, #chemohair, #stageIV, #ovariancancer and #breastcancer. Results of these hashtag searches yielded millions of images, with the most popular (as defined by “likes” from other users) listed first, then the most recent. Hashtags were ideal for the search of people who posted SSS because the presence of a medical condition-related hashtag identified that the selfie is indeed meant to highlight, or at least acknowledge, cancer. As it is possible for anyone to see publicly posted Instagram posts, the SSS posters should not have been surprised or concerned by being contacted by a stranger regarding their images.

For this study, a selfie is defined as any photo meant to represent the individual who posts it, whether it was clearly taken by that creator or not. After scanning for SSS in the results of these hashtag searches, participants were chosen to be contacted using the following criteria:

1. Participants must be recent (within one month) posters about their own cancer-related conditions or challenges. This was important given the nature of cancer, because it suggested that the poster's health was good enough to allow them to interact with social media.
2. The selection process attempted to create a diverse pool of potential participants regarding age, location and ethnicity. As the potential pool of participants was gathered, the researcher tried to create a balance among these characteristics.
3. Individuals must have posted in English and appeared to be at least 18 years old, a fact that was confirmed with an online consent form.

One limitation of using hashtags to identify potential participants was that potential participants who actively post about cancer using hashtags may have already had advocacy for their health condition in mind, making it more likely that they would believe that posting SSS would have an impact on stigma than someone with cancer who does not specifically call attention to health conditions using hashtags. As a result, these eight women may be particularly oriented around the types of outcomes theorized by this study. Further research on those who are less inclined to connect with others using hashtags is needed.

Over 50 potential interviewees were identified through this process. Five women at a time were sent direct messages (DMs) from the private account of the researcher via the Instagram direct messaging feature. Then, as the confirmed pool of participants grew, women were contacted one at a time until eight interviews had been arranged. The initial contact message, which can be seen in context in Appendix A, informed the women about the study and asked for their participation. A message coming from the private account of the researcher was deemed to be most effective in building trust and rapport with the potential subject. If a potential

interviewee did not respond to the initial message within 3 days of receipt, a follow up message was sent, providing more information about the study in the form of a link to an online consent form (Appendix B). In the end, 38 potential interviewees were sent direct messages requesting their participation in this study.

As an incentive to participate, a \$25 donation was made in the interviewee's name to one of two charities. The interviewees were able to choose either the Cancer Research Institute, which seeks to discover and develop immunotherapies for all types of cancers, or the Ulman Cancer Fund for Young Adults, an organization that provides support for young adults with cancer through education, scholarship programs, and a network of human and health care resources. The donations were made after the interviews occurred and were attributed to the interviewees Instagram handle.

Of the 38 women who were sent direct messages, 17 responded, two of whom declined, seven expressed interest but were unable to schedule interviews, and eight set up and completed interviews. Three interviewees responded to the initial contact, but requested more information about the type of questions that would be asked during the interview. Two of these were particularly adamant that they did not want to be involved in a study or article that painted cancer-related selfies in a negative light, which, in itself speaks to the importance of the medium to these women, further validating this study and the therapeutic potential of its findings.

Another interesting and unfortunate finding that might guide future research is that one respondent reported that she was hesitant to reply because she had already been "scammed" several times by people contacting her through DM about her cancer hoping to gain her involvement in research studies that offered cancer treatment.

The ages of the selected interviewees roughly reflected the demographics of Instagram users, with ages ranging from 26-54, skewing slightly older than the average Instagram user, but definitely younger than the average cancer diagnosee. In general, all the women were active on social media, accessing Instagram and/or posting new content daily. Most women had additional social media accounts on other platforms, and some even had multiple Instagram accounts featuring different content; some of the women with multiple Instagram accounts used one account for personal posts and another for when they would post specifically about their cancer journeys, a phenomenon that will be analyzed in the following chapter.

With 80% of Instagram users living outside of the United States, it is no surprise that the women interviewed hailed from all over the world. Two were located in England, one from Malaysia, one from Israel, one was located on the East Coast of the United States, two were on the West Coast and one from the Midwest (Omnicores, 2018).

In correspondence with these women, a link to an online consent form was provided which included a specific request to refer to the women by their Instagram handles in the write-up for this research. The consent form was distributed through the online survey creation website, SurveyMonkey.com. Full text of the consent form can be found in Appendix C. Participants were also asked to send their email address through Instagram DM so that they could receive a copy of the consent form for their records, as well as have easy access to Colorado State University's IRB contact information should they need it (Appendix D).

## **Participants**

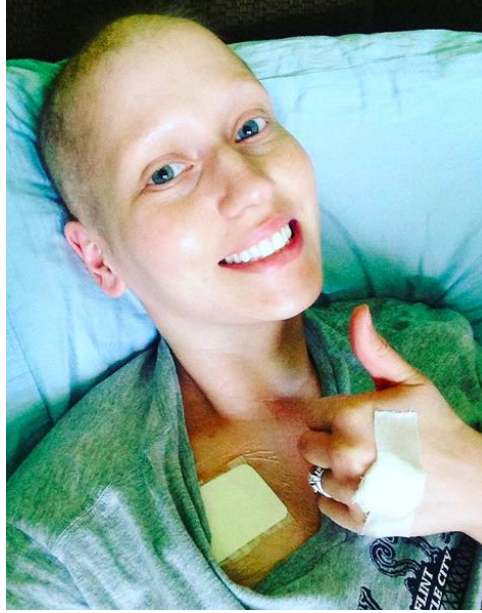
As was agreed upon in consent for participation in this research, all participants are referred to by their Instagram handles in this thesis. The following is a brief description of each interviewee and an SSS that she posted publicly to her Instagram account.

Participant @cancer\_inareddress is 48 years old and was diagnosed with stage II breast cancer (see Figure 12). She is the sales and marketing director at a firm in England. She is a frequent social media user with two Instagram accounts, one specifically for posting about her journey through cancer. As a professional in the marketing industry, she explained that selfies were part of how she presented herself - her “personal brand” - and she is known as the “Selfie Queen” among her coworkers.



**Figure 12. Instagram image of @cancer\_inareddress**

This participant, @girlsonchemo, is a 34-year-old mother of one child who is in remission with Hodgkin’s lymphoma (see Figure 13). She created a separate Instagram to share about her experience with cancer and she was active in creating a local support group for young women with cancer. She is from the East coast of the United States.



**Figure 13. Instagram image of @girlsonchemo**

Interviewee @kimberlyannkd is fighting a second bout of cutaneous lymphoma in England (see Figure 14). She is a 34-year-old mother of two children, and with the current recurrence of her cancer, her prognosis is not optimistic. She came to some internet “fame” with the publication of an article she wrote describing her experience with cancer.



**Figure 14. Instagram image of @kimberlyannkd**



Interviewee @lacyholly is from the Midwestern United States, and is a 35-year-old mother with stage III breast cancer (see Figure 15). She is active on Instagram, posting frequently. She expressed that her cancer diagnosis affects her life more than she might have predicted it would. She was going through treatment at the time of our interview.



**Figure 15. Instagram image of @lacyholly**

Next, @maliesse.tan is an entrepreneur who has finished treatment for stage II Hodgkin's lymphoma (see Figure 16). She lives in Malaysia and is the 32-year-old mother to a baby girl. She has used her cancer experience to develop a business creating products that empower cancer fighters through fashion.



**Figure 16. Instagram image of @melisse.tan**

Participant @sharschmidt is a 35-year-old mother of one son from southern California (see Figure 17). She was diagnosed with stage II breast cancer and found that she was positive for a BRCA gene that increases the likelihood of breast cancer returning. She decided to have a double mastectomy and removal of her ovaries and uterus to stem the likelihood of recurrence and was immediately post-operation at the time of the interview.



**Figure 17. Instagram image of @sharschmidt**

Participant @therightstrong is a 26-year-old South African living in Israel (see Figure 18). She was diagnosed with breast cancer while working in public relations. She is at the

beginning of her cancer journey, having been recently diagnosed and has created a separate Instagram account describing how she has incorporated veganism into her own treatment plan.



**Figure 18. Instagram image of @therightstrong**

@Tameratammytam is a 54-year-old mother of five from California (see Figure 19). She is fighting stage IV metastatic ovarian cancer and has decided to stop medical interventions, opting for “natural” treatment options. She has linked her Instagram account with a GoFundMe page that has helped support her during her cancer journey.



**Figure 19. Instagram image of @tameratammytam**

## **Data Collection Procedures**

Phone interviews were conducted in a private space and recorded. International calls were conducted using the WhatsApp application and calls within the U.S were conducted with Google Voice. All interviewees were given the contact information of the researcher and requested to call at an agreed upon time.

Interviews began with demographic questions and personal history questions to build rapport. Questions sought to be sensitive to the nature of the interview, recognizing that the research is asking participants to share personal information about themselves, their medical histories, and how they came to be part of a stigmatized group. After the initial questioning, the rest of the interview focused on how, or if, posting SSS addresses each of the three desired outcomes of sharing stigma. During the interview, conversation was allowed to deviate from the script of questions to build rapport and to explore any unexpected themes that arose.

The researcher used a printed copy of the interview questions with space to take notes during the interview. The interviews were audio recorded for transcription and analysis using the audio recording feature of Google Voice, or in the case of international calls, interviews were conducted via speakerphone, and recorded with the researcher's laptop computer's audio recording function. Prior to confirmed interviews, the participants' Instagram accounts were reviewed further, and relevant images were saved as jpeg files and accessible during interviews for potential discussion.

After the submission of this thesis, a follow-up email message will be sent thanking participants for their time once again, sharing this thesis with them, and letting them know how to contact the researcher again in the future if they need to. This message will also confirm that a

donation was made in their name to the charity they chose. Appendix F shows the anticipated content of this message.

### **Instruments**

The interview used for this study was an open guide, focused on the three outcomes theorized to be desired in the revealing of stigma by stigmatized individuals: disclosure, identity construction and de-stigmatization. It was developed based on the theories underlying this study and on a pilot study of three participants, described below. Questions in the guide addressed each of these concepts, but were open-ended enough to discover any other perceived or desired outcomes and motivations. Questions focused on the selfie creator's personal experience to draw conclusions about the motivations and perceived benefits and drawbacks of sharing SSS on social media. Full text of the interview guide can be found in Appendix E.

### **Pilot Study**

The first three interviews conducted were considered pilot interviews to ensure that the recruitment method and interview questions were effective in answering the research questions. For these pilot interviews, questions at the end of the interview process asked for feedback on the participant's experience to determine if changes were needed to the questions or procedures. Participants all reported that they were comfortable during the interview process, and that they felt able to share information with the researcher freely. Pilot interviews are included in the final data analysis because no interviewee reported that adjustments were required.

### **Data Analysis**

Data were analyzed using a thematic method of phenomenological analysis. After interviews took place, notes and initial interpretations were developed for later inclusion in analysis. The interviews were professionally transcribed and assessed by the researcher while

listening to the recordings of the interviews to ensure that any inflection or significant non-verbal information such as pauses or laughter were noted. The interviews were then read thoroughly and repeatedly.

Once the researcher was thoroughly acquainted with the content of the interviews, they were analyzed and coded using research questions to guide a color-coding system, identifying text that addressed each question, focusing on whether information reflected the expected outcomes for sharing stigma. These color-coded data were looked at as individual sets, and themes were gleaned from the content. Braun and Clarke (2006) assert that for information to be considered part of a theme, it must appear in two or more interviews, however, it is appropriate to include information that is unique in discussion of the analysis if it is regarded by the researcher to be important to the research, though it should be noted as such.

Using phenomenological thematic analysis was ideal for identifying what was similar and what was different between each interview, allowing for the creation of a cohesive analysis (King & Horrocks, 2010). Using phenomenology allows for consideration of the unique perspective and context of each interviewee, considering that her diagnosis, prognosis, and the point in which she was in treatment may color her perception of how or why she posts SSS (King & Horrocks, 2010). This method of broad thematic analysis prevents limiting the data by language and word choice in favor of considering the intentions of the text which might not be fully possible in a more rigid discourse analysis (Taylor, 2001). Phenomenology allows for interviewees to think about the way they think. This is especially relevant in a study that asks participants to examine their own motivations for communicating in the way they do (Giorgi & Giorgi, 2008).

## CHAPTER 4. RESULTS AND DISCUSSION

Selfies taken and shared by people with cancer play a fundamentally different role than the stereotype of the selfie might propose. In support of research that shows that selfies play a profound communicative role for their creators (Best, 2015; Rutledge, 2013), this research has found that, for the women interviewed, selfies that show health stigma largely serve the purpose that stigma theory suggests as the outcomes that stigmatized people may seek when they choose to announce their stigmas to others at all. (Betton et al., 2015; Campbell & Gibbs, 2009; Corrigan & Rao, 2012; Smart & Wegner, 1999; Smith, 2012).

Evidence gathered in eight semi-structured, open-ended interviews with women who post selfies showing the effects of their cancer, or *stigma signaling selfies* (SSS), reveals that SSS play a role in stigma disclosure, identity construction surrounding the stigma, and refutation and disempowerment of the stigma surrounding cancer.

In this chapter, I follow the lead of the women whom I interviewed, and use the term “cancer fighter” to refer to any person who is diagnosed with cancer, rather than “cancer sufferer,” or “cancer patient,” which may imply weakness or victimization. The chapter begins with general findings and discussion, then discusses individual responses regarding stigma disclosure, identity construction and de-stigmatization and perceptions of the role of SSS in each of these, reflecting each of the three research questions. The chapter also includes unexpected themes that emerged from the interviews such as how SSS can reduce the stigma around *selfies* per se, and how these women wanted to “look their best” even when posting SSS.

## Social Media Use and Selfies

### Social Media Use

The use of social media was an important part of these participants' lives and they were all very active on social media. They all reported using social media at least once per day, and specifically, Instagram with as much frequency. When asked about their use of social media and Instagram in specific, several themes emerged: posting images on social media helped them tell others about their diagnoses and treatments; the role of selfies shifted from a casual self-expression to an intentional message; and new techniques were needed to navigate audience expectations.

Interviewees, especially those with only one Instagram account, explained that the audience for their SSS were mostly friends and family, although they also noted that other people with cancer or who have loved ones with cancer see their SSS. They generally saw Instagram as somewhere to post images of interesting and attractive objects, places, and people. For example, @sharschmidt described Instagram as a place for "beautiful things," but in sharing about her cancer and posting SSS, she uses it more as a "way to bring people together." Since Instagram is about lovely things, to @sharschmidt it is a way to create love for whatever the subject matter is. This in itself suggests that posters of SSS may have de-stigmatization in mind when they post their images. If Instagram is meant to create love, posting about cancer may help extend that love to people who are traditionally stigmatized. As @therightstrong explains,

We all have our narcissistic moments where, you know, you're feeling pretty and you take a selfie in the mirror and you get a lot of likes and comments, and you feel lovely, and you're just putting it out for funzies, but that's never really been for support, you know. It's nice for people to comment, "Wow. Beautiful," or "You look so stunning," or whatever it is. That's really – that's so different from [these selfies].

About half of the women interviewed created separate accounts to post images specifically about their experiences with cancer. They did this because they found they gathered



new followers who were particularly interested in their cancer journeys, but they did not necessarily want to share openly about other aspects of their lives. The women indicated that they expected, and found, the followers of their personal accounts to also follow their cancer accounts. Interviewee @therightstrong created a separate page because she decided to become vegan when she was diagnosed with cancer and wanted to share information with the public about this experience, and wanted a place where the followers of her private page could go to specifically get updates on her treatments and condition. Similarly, @girlsonchemo created a separate page to communicate specifically with other cancer patients and their loved ones, and @cancer\_inareddress wanted to have a separate account so that she could create a public “brand” around her identity as a cancer fighter.

All these women mentioned not wanting to overwhelm friends and family who followed their private accounts with information about cancer that these followers might not want to hear. This may indicate that though SSS are used to disclose information about cancer, cancer fighters still hold the idea that there might be a limit to the amount of cancer-related information that followers of their personal pages want to gain. @girlsonchemo discussed how she wanted to use her cancer page to talk to other people with cancer, and discuss things that people without cancer might not understand. She said, “I need a place where I can say these things to people who will understand where I’m coming from; that I’m not being mean.” This may be part of the broader social norms of Instagram, where it is not always beneficial to post too many photos of any one specific topic; food, pets or children, for example, unless their account is specifically designated for that purpose. Indeed, by creating an account for SSS, these women were signaling to their audiences that their posts would focus on their diagnosis, thereby allowing them to use their other account(s) for more expected – or “normal” – types of posts.

Conversely, instead of wanting to protect close relations such as friends and family from SSS, the women who created separate pages might actually want to protect private information about their children and location from new people who might follow them on their public cancer pages, as illustrated by @cancer\_inareaddress, “I know that on my personal social media I obviously talk about my children and my family. I wasn't sure if I wanted to cross the boundaries between that.”

This is fascinating because it suggests that, when it comes to sharing information about their diagnoses with new people, that they are more willing to share something that is potentially stigmatizing than “normal” information about their lives.

### **Selfies**

Although the women interviewed regularly posted selfies, they made a distinction between their motivations and the “typical” reasons they believed people post selfies online. For some, this was a change in the way they used selfies as part of their communication. Most of the women mentioned that, before cancer, they were not the “type” who would regularly post selfies, one woman saying that she wasn't into “getting the right angle,” and “pouty lips.” This may point to the negative stereotypes of typical selfies and of people who post them. However, after cancer, the role of the selfie changed for interviewees. They went from a way to show off their looks, to a way to show off their strengths. @therightstrong said that before cancer, she posted selfies to get “likes” and compliments from her followers, but after she posted her first selfie with her head shaved, she drew strength from posting SSS. In referring to her first SSS, she said, “I don't care if I get one like on this picture but I did this. And I was so proud of myself. And I guess I used that selfie, you know, to put on my Instagram page for, just to – it was like my gift

to me, you know. And after that, I had so much more strength to post selfies of me at my worst moments.”

At least in their post-diagnosis lives, selfies play an important role for these women. @sharschmidt, agreed to be interviewed only after assurance that this thesis project was not meant to denigrate selfies as a form of communication. Interviewees were almost protective of selfies as a tool for cancer fighters to connect to one another, learn about their illnesses, and educate both the public and other cancer fighters about life with cancer. All of the women said that their frequency of posting selfies increased after they were diagnosed with cancer.

Though evidence collected in this research largely suggests that SSS serve to fight the stereotypes of selfies by showing women in situations where they are not at their best, an interesting phenomenon did arise. One SSS creator talked about how even with SSS, she used filters to “improve” the lighting and look of her skin to minimize the effects that chemotherapy can have on it. This is particularly thought-provoking, perhaps indicating that though SSS might show a condition that is stigmatized, the people who post these images want to be seen as “normal” otherwise, leaning toward the more traditional role of the selfie (Murray, 2015).

Another interviewee mentioned that she posted selfies that show the effects of her cancer, specifically to decrease the stigma surrounding *selfies* and fight society’s perceptions of what beauty should be. She said that she knows that many selfies are posted when people particularly like their hair or makeup in a given instant. @sharschmidt posts selfies to show that people can be going through cancer treatment and still like things about the way they look despite what is socially ideal.

I didn’t post selfies of myself hardly ever before I had cancer, but now I find myself posting them more because when you’re on Instagram, what do you see? You see people with their selfies and their makeup, and they’ve got their hair done and everything’s nice. I still do my makeup even though I have cancer. I still do my makeup some days, and I

still feel like I look pretty even though I don't have hair or eyelashes. I'm still me, just because I have cancer doesn't mean that I'm not pretty or beautiful. I want to show people that you don't have to have hair or makeup on to be able to post a picture of yourself, and have it be acceptable to other people. What should be deemed acceptable should change.

### **Disclosure**

Disclosure is proposed by stigma theory as an important outcome of revealing stigma, and participants in this study agreed. Research suggests that the act of revealing one's stigma creates more honest, intimate relationships and prevents discomfort for both stigmatized people and the people they are interacting with (Goffman, 1963). Indeed, this was a major theme among interviewees. Other major themes that arose regarding disclosure include how SSS reduce stress around telling others about their cancer and how SSS were used as a way to keep friends and family informed about their health status. More generally, disclosing their cancer experiences on Instagram provided these women with control over the process of revealing their cancer experiences, control over the images and ideas that they used to communicate those experiences, and control over others' responses to their diagnoses.

One interviewee, @melisse.tan, felt that she needed to share cancer as a part of her life on social media through selfies because if she did not, she would feel as though she were hiding the fact that she had cancer. She said she would use selfies and share pictures in any other situation, so, being a natural extrovert, if she did not share about her cancer, she would, essentially, feel dishonest. This aligns with what Goffman (1963) offers as a reason for sharing stigma. He states that sharing information about one's stigma prevents an individual with a stigma from appearing deceptive when the time comes that she does decide to share it. "I didn't want to hide behind this because I knew it would make me feel worse, and I'm just naturally someone that's quite an extrovert and I have quite an active social life, so I knew that if I were to, you know, cut off ties to the outside world then it would be obvious," @melisse.tan said.

The women interviewed all reported a similar pattern of disclosing their cancer to the people in their lives. All mentioned that they personally talked to their closest friends and family first, revealing their diagnoses in person or by call or text. They also recognized that there were ways in which using SSS increased disclosure stress, namely that some people may be insulted by not being told in person, and that using SSS as a method of disclosure may make some people feel that they were too open with private information. Some women stated that they hoped the news would travel naturally by word of mouth after sharing it in person. Then, after a time, they made a post to social media. One participant, @cancer\_inareaddress, specifically used a selfie to announce her diagnosis and plans for treatment publicly. In several other instances, posts included selfies with cancer-related hashtags.

### **Advantages**

Interviewees were asked about the perceived advantages and disadvantages that might occur if SSS viewers find out about their cancer through SSS. Similar to their remarks about selfies in general, they explained that the advantages to posting SSS outweighed the disadvantages. Overall, these women felt empowered by sharing their SSS, explaining that it gave them a sense of control over who found out about their cancer and prevented it from becoming “table talk.” That is, gossip among family and friends, the message of which is out of their control, causing them to lose power over their own cancer stories. Posting SSS appears to diminish the stress caused by sharing stigma face-to-face, as suggested by stigma theory. For example, because of a family situation, @girlsonchemo was forced to share her cancer diagnosis before she felt she was ready. She explained that sharing SSS and creating her cancer Instagram page allowed her to control what was known about her after that. She said, “I wasn’t quite prepared for all of the awkward comments, or invasive comments that would come my way. And

we also had to let, people at my son's school know, and so I was kind of forcefully publicly outed.” In contrast, her use of SSS on Instagram allowed her to disclose her cancer in her own way on her own time.

Some interviewees mentioned that they were particularly comfortable communicating online, so it felt natural to them to post about their cancer there. For example, @therightstrong said she felt people would find out about it anyway, and since she was very comfortable on social media and selfies, she used SSS as a way to take control of the narrative about who found out what information. Sharing SSS prevented her from having to wonder “who knows what, and what people are saying.” This is what Corrigan and Rao (2012) might call “broadcasting,” or publicly announcing a stigma to help remove its power, placing the stigmatized individual in control of who knows about it, by ensuring everyone knows about it.

Although less common, posting SSS may provide more practical benefits to users. One woman talked about the financial support she received from her followers, and gifts that she received from friends. She did not mention specifically seeking these gifts when posting SSS, but she did allude to her sharing her story as a way to thank those who have supported her, and as a way to keep them informed about her cancer journey. Many cancer patients do have links to charity donation pages where followers can donate to them, as many people are unable to work as they go through treatment.

Participants' perceptions of reactions of people who viewed their selfies fell within one of two themes: either they thought viewers of their selfies saw them as brave for fighting their cancer and for sharing their experiences, or they suspected that people who saw their photos felt sorry for them. It has been found by prior research, however, that the most common responses to SSS were encouragement and support rather than sympathy, both by people with and without

that stigma (Radmacher, 2018; Frolich & Zmyslinski-Seelig, 2016). Although they did at times mention that they received sympathy and admiration when they posted SSS, most of these women were adamant that neither admiration nor sympathy was their intention when posting SSS. This difference between their motivation and the responses they received may be because they were trying to distance themselves from the stereotypes of posting selfies as narcissistic or self-absorbed. Indeed, all of these women said that they posted SSS in part to educate or connect with others rather than simply to display their current appearance.

These cancer fighters also believed that having SSS permanently posted to their newsfeeds provided a place for their followers to see exactly how they were doing and understand their cancer journeys. Several noted that it was beneficial to not have to explain their condition or course of treatment over and over to different people, again, thereby diminishing the discomfort caused by frequent face-to-face conversations.

The desire to be able to share their stories with everyone simultaneously was reiterated by several women. For example, @lacyholly said that SSS were a way to update friends and family without having to repeat herself. Stigma theory describes this as a way to avoid the feeling of living in two separate worlds simultaneously: one that is aware of her cancer, and one that is not (Goffman, 1963). By sharing their cancer diagnoses in the form of selfies on public social media platforms, these women may have felt it is safe to merge their worlds and assume that everyone knows about their diagnoses. This prevented the discomfort caused by trying to remember who they have and have not shared their stigmas with, and allow freedom to talk about this aspect of their lives openly.

Aside from only having to tell their stories once through social media, several women also appreciated the ability to keep people they were telling at arm's length. @sharschmidt said

that it gave those in her life whom she was not close to an “out” when it came to having to respond to hearing about her diagnosis. As Goffman (1963) argued, there is social pressure created by hearing about and needing to respond to another person’s stigma; anticipating this pressure is one reason why stigmatized people may delay sharing information about their stigmas. For example, @sharschmidt used SSS to relieve herself from having to hear insincere responses or wait for phone calls from people whom she might expect to call, but did not. Perhaps for her, SSS are a way to insulate herself from feeling as though people should be reaching out to her who are not.

Similarly, some women mentioned that they used SSS so they did not have to hear the same “trite” responses to their disclosure over and over. For example, @sharschmidt mentioned that she felt people did not know what to say when they were told about her cancer. She explained that she did not want people to have to say “I’m so sorry,” or “How can I help,” etc. and stumble for condolences. This function was so important, in fact, that some women used SSS to instruct those without cancer on how to respond to disclosures about the diagnosis. For example, @girlsonchemo explained that she wanted to use SSS and her cancer account to educate people about exactly what to say when people with cancer share their diagnoses. She said that when she told people in person, she frequently got a response about how the person they were telling knew someone with cancer who had died. “That’s not what anyone with cancer wants to hear,” she said. These reactions show ways that SSS can be a tool to help ease discomfort that might occur when revealing stigma and suggest that SSS have communicative value for both the creator and viewer. For the women interviewed, posting SSS on social media provided a greater sense of control over others’ responses than they felt they had when telling people face-to-face.



## **Disadvantages**

One disadvantage to sharing information about stigma that stigma theory identifies was the possibility that in disclosing health related information stigmatized people may be perceived as being too open or familiar to the people they are disclosing their stigmas to. Several interviewees mentioned that they considered this possibility (@lacyholly and @kimberlyannkd), but did not let it hinder their posting. This may indicate that the filter of social media prevents creators from feeling overly self-conscious about what they post (Best, 2015), or perhaps that the subject that they are posting about, their lives with cancer, is important for them to share about, and the risk of being too familiar is worth the social price. Interviewees also noted that some friends or family members who found out about their cancer diagnoses through SSS might be insulted that they were not told in person suggesting that creators believe that SSS are less intimate than in-person conversation.

Most women talked about how they wanted to share every aspect of their treatment so that they could provide a realistic picture of what cancer treatment and life with cancer are like. However, some women said that despite their use of posting SSS to openly show their experiences, there were still things that they would not disclose. Some experiences or images were too personal for this public forum. For example, one woman talked about how she was not comfortable sharing the process she went through to preserve her fertility through cancer treatment. Others talked about not wanting to share especially graphic or “gory” images. This process of filtering content even in a context where openness and self-disclosure is a primary goal suggests that there are specific types of messages these women seek to communicate. Importantly, this results in a curation of images of the self that parallels the use of typical selfies and allows the users to maintain control over the image their posts portray.

To the extent that the SSS these women post are intended to counter the stigma of cancer itself more than the details of diagnosis and treatment, holding back some images of their cancer experiences does not reduce the influence of their disclosure. It is possible that broader considerations of personal modesty or offense from over-explicit images motivates these participants to select the images they share carefully. This also reinforces the notion that SSS are not simply a free-for-all display of every moment in their fight against cancer but instead an intentional set of messages aimed at communicating specific challenges or ideas to their followers. They may have considered some images to distract from their messages about how cancer is part of their lives. Alternatively, it is possible that these women still felt the pressure typically associated with selfies and social media to present a “best” version of themselves, even of their ill selves. They may have held back the most unpleasant images of themselves to avoid evoking unwanted responses.

This tension between sharing enough information to feel that they are being honest in their representation of what life with cancer is like and the desire to keep some information private was reported throughout the interviews. However, this tension was not noted by participants; they spoke comfortably about the desire to share the social stigma of cancer while holding back some of the details. This finding suggests that although SSS depart in many ways from the use and function of selfies in social media, there are some ways that these types of selfies follow social norms around self-disclosure online more generally.

Another disadvantage to sharing information about cancer through selfies noted by @melisse.tan is that when she shared her diagnosis, she was bombarded with ideas for treatment from others who had heard of ways to fight cancer. She and @girlsonchemo were both sent information from people who “meant well” that detailed treatments and miracle cures. These

interviewees said that not only was this distracting, it made choosing their own courses of treatment more confusing. Also, as @girlsonchemo mentioned, hearing about miracle ways to fight or prevent cancer only compounded the stigma that she felt that getting cancer was her own fault, and if she had only “eaten more blueberries or avoided lotion with parabens,” she might not have cancer at all. In our information age, this is an outcome that stigma theory might not have anticipated. As people have access to more health information and mis-information (especially related to miracle cancer preventatives and treatments), disclosing cancer stigma through SSS may often result in many un-educated suggestions for addressing the stigma. Indeed, in research about how viewers of SSS react, Rademacher (2018) found that various negative audience responses included unsolicited treatment advice. The platform of Instagram made these advice responses particularly easy because articles and memes can be quickly located and shared. Compared to face-to-face disclosure, it is possible that sharing SSS on Instagram increased the amount of unwanted advice these women received.

The concept of autopathography proposes that people with cancer-related stigma may channel that stigma into a form of self-expression (Tembeck, 2016). However, none of the interviewees described disclosing their cancer as a way of expressing themselves per se as Rogers and Buffalo (1974) might have expected. However, posting SSS did function as a form of journaling with themselves as the audience. This function was generally combined with a desire to use SSS to educate people and for some, made them feel that they were being “productive” by describing their experiences for the broader public. For example, @lacyholly and @kimberlyannkd both talked about how there was not much physically that they were able to do, so creativity in posting SSS and through other social media such as blogging, was one way to feel that they were contributing to society. This suggests that artistic uses of SSS as self-

expression as autopathography traditionally has done were less common or important than using SSS as a form of information, tying these women's use of SSS more to mass media and news functions than to artistic ones. This finding may help explain why these women curated their SSS through selecting only some images and/or creating a separate account for posting them.

The medium of social media is used by these women for stigma disclosure, and posting SSS offers both benefits and drawbacks, especially in ways that SSS creators can control the flow of information about and responses to their disease. As stigma theory suggests, avoiding discomfort is an important benefit, but posting SSS runs the risk of over-sharing for some participants. Resolving this tension is difficult, especially because SSS may be more associated with norms around news and mass media content than artistic content for these women. Similarly, sharing publicly versus privately to close friends and family creates a tension in how and when to share to different audiences. Although SSS help address many of the challenges in disclosing stigmatized health information, it does not resolve all the struggles of this process for these participants.

### **Identity Construction**

By far, the most prevalent theme that interviewees reported when asked about why they post SSS was the opportunity it afforded them to build relationships within the cancer community. As part of constructing and maintaining an identity, these relationships were part of giving and receiving support from other cancer fighters and their loved ones, as well as accepting themselves as people with cancer. Sharing selfies about cancer and seeing the selfies of other people with cancer made interviewees feel less alone and reinforced their sense of taking on a new identity. To the women interviewed, SSS helped them establish and share their identities as cancer fighters, especially through displaying physical characteristics that marked them as cancer

fighters such as losing their hair. These interviews revealed several themes expected by stigma theory: building relationships, self-acceptance, and journaling. These uses of SSS aid in identity construction by providing a series of events and means by which to reflect (Katz & Crocker, 2015) within a broader context of a community of people who share that identity.

### **Building relationships**

Using SSS allowed the cancer fighters who were interviewed to build relationships with other people in the cancer community by introducing themselves to others on similar paths and to help them feel supported in their cancer journeys. SSS were a mode of introduction that provided a way for them to have questions answered. The participant @melisse.tan said that when she posted a selfie showing her cancer and tagged it with cancer-related hashtags, other people active in the cancer community shared her posts and encouraged other cancer fighters to welcome her and “lift her up” as she began her cancer journey. This is an interesting departure from what research suggests is the main reason why people post regular selfies, which is attention seeking (Sung et al, 2016; Kearney, 2018), but is in line with stigma theory which argues that disclosing a stigma provides connections with others who have that stigma, contributing to the construction of a new identity. This could indicate that the particular genre of the SSS holds a different purpose for the people who post them compared to typical selfies which are reported by posters to be used for attention seeking first, posted in hopes to get approval from followers in the form of “likes” (Sung et al, 2016; Kearney, 2018).

The cancer fighter interviewees reiterated frequently how they used selfies to give support and get support from others. According to @therightstrong, when other cancer fighters saw her posts, they responded enthusiastically. She explained, “Other cancer fighters would say, ‘Come on! Let’s help this girl. She’s new to this. She’s a sister.’ It’s a sisterhood. It’s a little

sisterhood of these breast cancer survivors and breast cancer warriors and I feel like I'm part of a family." In this way, SSS reinforced a new identity for these women. Building relationships contributes to identity construction around stigma because it allows them to engage with a community of cancer fighters, which in turn identifies the poster as a person with cancer who may follow a path similar to others with the disease (Sandstrom, 1990).

Becoming part of that community is important because, as explained by @therightstrong, there are some things that only other people with cancer can understand. Even well-intentioned people without cancer can say hurtful things, and having the opportunity to share stories and talk about how the things that people without cancer cannot understand is an important result spurred by sharing SSS. The participant @sharschmidt said,

Posting selfies is kind of like, this is the true account of what cancer is like. This is an honest look into somebody's life who has cancer. Maybe they wouldn't have posted a selfie before, but now they want you to have a share of the journey with them. It makes them feel like they're not by themselves.

This suggests that SSS may serve as a form of therapeutic communication, reinforcing the power of selfies as an important form of interaction. Women also reported that they share SSS in order to receive advice from other people with cancer and as a way to help cope with the treatment process, as suggested by research on photo sharing in online support groups which demonstrates that responses within these communities are nearly all positive and supportive (Frolich & Zmyslinski-Seelig, 2016; Rademacher, 2018). This sharing and receiving of advice may serve as a method to create closeness within the online cancer community. Additionally the use of selfies to gain as much information as possible about cancer and courses of treatment through other cancer fighters may be a coping method for creators in dealing with their own cancer.

The women also posted SSS as a way to become closer to family and friends who do not have cancer. Several interviewees reported that in response to SSS, friends reached out to get in touch with them who they had not heard from in a long time. For example, @lacyholly said that she learned about the cancer of friends that she had not heard about before.

It's brought more people to, like, reach out to me, which is very nice because, actually a girl I graduated with was diagnosed two months before me. I hadn't quite reached out to her, but, then, when I got diagnosed, now her and I have talked a lot more because I knew about her diagnosis via social media because she had shared it on Facebook and that was how I found out, ya know. And so, otherwise I would've never have known.

This support from family and friends aligns with stigma theory, and is identified as an advantage to sharing stigma.

Aside from gaining support, all of the women interviewed said it was just as important to be able to offer support through social media and reach other women who had cancer. They want to help other cancer fighters not feel alone because that is what they were looking for when they were first diagnosed with cancer. @malisse.tan said "I had people reach out to me, you know, cancer fighters that are going through certain things or are about to go through certain things and I give them as much information as possible based on just my own experience." The participant @therightstrong echoed this sentiment, saying "I wanted to open up this journey to other people and to be of support to other people, to receive support from, from breast cancer warriors and breast cancer survivors alike."

Building relationships though social media could be done without the use of selfies, but for @girlsonchemo, it would not be as effective. She used SSS specifically because she knew that they were the posts that got the most "likes" and "shares." She felt if she wanted people to read her messages, a selfie was the best way for it to reach the most people. She said that the selfies are part of her message, but that her full message was in the comments she added to the image. In a sense, then, the selfie was a way to draw attention to the text she used to

communicate her ideas. She said, “It was a huge education on what it is that people look at, or what it is that they want to see. And so I knew that the best way for them to hear the message, sometimes, was through a fancy picture of my face, unfortunately.” One reason for this may be an increased sense of authenticity for viewers, as suggested by by Kedzior & Schroeder (2016), who found that when bloggers post selfies, it increases viewers’ perception of their authenticity.

One unexpected finding around identity construction and relationship building was how SSS are used by *young* women with cancer. All of the women interviewed were less than the median age to get cancer, 66, according to the National Cancer Institute (2015), and most of them expressed that they did not have anyone in their “real” (outside Instagram) lives to talk to who had experienced the same things they had. They used selfies and Instagram to reach out to others like themselves, finding more people like themselves through a medium favored by millennials and younger. In fact, @girlsonchemo searched out support groups in her geographic area, but found the youngest person to be in her 50s. Interviewees were looking for a way to connect to younger people with cancer which evolved into, for some, advocacy and awareness of cancer for young people. “I wanted to join a, you know, a support group for therapeutic purposes. I couldn’t find one. This filled that void for sure,” said @girlsonchemo about her search for support from cancer fighters her own age. As selfie creators are also generally young (Bruno et al, 2018), this emphasizes the ways in which SSS are especially important for young people with cancer in building relationships and connecting to other young people with similar conditions whom might not be present in the cancer fighters’ real lives (Statista, 2018).

Though evidence presented by the cancer fighters interviewed suggests the importance of being able to interact with others with cancer through SSS, this may bring into question what an



SSS really is when it is used to communicate with others who carry the same stigma. That is, if a stigma is defined as something that sets one apart from the norm, does that stigma exist when communicating with others who experience it? If everyone in a given group experiences the same stigma, perhaps, among cancer fighters, these SSS provide a route for inclusion in a community where SSS creators can feel “normal.”

### **Self-Acceptance**

According to stigma theory, acceptance of stigma as part of identity is an important part of reducing the power a stigma has over stigmatized individuals. It helps reduce fear of the condition and fear of losing connection to society. For the women in this study, accepting cancer as a part of their lives that changes their appearance was supported by posting SSS (Tembeck, 2016). The cancer fighters largely indicated that posting SSS was a way to take control of the fact that their appearances had changed with their cancer diagnoses, specifically that they would be likely to lose their hair in the course of chemotherapy or radiation treatment.

According to @therightstrong, every single SSS she posts is thought-out, and each is different from selfies she would have posted before she had cancer. She said, “I can post photos that I never in a million years would have ever thought of posting in a Instagram.” To her, the SSS she posts now portray “a cancer warrior.” She stated that sometimes, when she is in denial about having cancer she posts SSS, suggesting she uses the act of posting itself to help her accept her condition. Several interviewees expressed that, in sharing SSS, they were able to portray themselves as people who were fighting cancer, despite the potential reactions of others. This portrayal served as a way to establish an identity that integrated cancer more fully and in a positive way for some of these women.

The act of posting itself was transformative for some participants. Although @therightstrong thought that major events such as losing her hair would be the ways that she would internalize her condition, she found this was not the case. Instead, it was posting SSS about her journey that helped her accept her experiences more fully and overcome feelings of denial about her condition. She explained,

I really feel like I'm in denial about the fact that I have cancer. It's something that happens to other people, ya know? And it's always stories you hear, and you feel so bad for that person, and you pray for that person, and now I'm that person. And, it's really a very big transitional phase in my life in so many ways. And, I thought that getting chemo would be the wakeup call, you know. "Oh you've got cancer," and it wasn't. And then I thought, ok, you know, cutting my hair short would be a wakeup call and it wasn't. And losing my hair would be – or shaving it off would be a wakeup call because it hasn't all fallen out yet, and even that hasn't. It's really hard for me to say to you, "I've got breast cancer," and I haven't internalized that in a lot of ways yet. And I don't know what or when my wakeup call will be. You know, that day, that moment, that click, of, of acceptance. But my selfies and my posts on my Instagram page are definitely this, this journal of and documentation of my journey.

Similarly, @melisse.tan said that she thought her hair was a big part of her identity, and had worried about losing it from her treatments. She posted SSS that showed the process of her shaving her head in anticipation of losing her hair to chemotherapy in a way to publicly announce that cancer was going to change her, at least temporarily. Several of the women interviewed said that shaving their heads was like a rite of passage that all cancer fighters go through. They expressed feelings of vulnerability at this time, and posting SSS was a way for them to "own" the experience and the effect it would have on their appearances. Posting their first shaved-head selfie was a theme seen throughout the Instagram accounts of many cancer fighters. This action suggests that posting SSS of this process served an important function of constructing a new identity that incorporates cancer for these women.

@melisse.tan discussed how she described herself on her profile and what her Instagram account was about before she was diagnosed with cancer. Prior to diagnosis, she included things

such as location, children, occupation and now, as a cancer fighter, she explained that she had to add an extra dimension to her profile about her condition. This use of her profile to show her condition suggests posting to social media, including SSS, was one way she sought to accept cancer as part of her life. Cancer fighters mentioned that SSS were posted intentionally, especially those with separate cancer accounts, perhaps indicating that the cancer fighters feel that SSS are different than more traditional types of selfies in their role first to communicate instead of just “seeking attention,” as suggested by research on the uses of selfies (Sung et al., 2016; Kearney, 2018).

In mentioning the fact that her whole Instagram account changes with her cancer diagnosis, defining herself in her headline as a person with cancer, @malisse.tan suggests that cancer has become part of her online identity more generally. For those women who created separate accounts for posting about their cancer journeys, SSS may play a less important role in identity construction. This suggests that some people may use SSS to construct an identity as a cancer fighter that is distinct from their overall identity, whereas for others, SSS allow them to integrate this new identity into their prior notions of self. Future research should examine the impact of posting SSS on different identities in different contexts.

### **Journaling**

As research in stigma theory suggests, it is important for people with stigmas to examine their stigma as part of their identity (Rogers & Buffalo, 1974; Corrigan & Rao, 2012). Posting SSS was an important way the women interviewed for this study kept track of their experiences and reflected upon them. Creating SSS was described as a form of online journaling, which has been proposed as one of the communicative function of posting any kind of selfie (Rettburg, 2014; Kearney, 2018; Rutledge, 2013). In this way, SSS align with traditional selfie use. These

participants used posting SSS as part of an online journal that allowed them to examine themselves from the outside, and in a way, recognize themselves as cancer fighters in their similarities between themselves and other cancer fighters who post SSS.

For example, @sharschmidt said that posting SSS was a way for her to prove to herself that she is strong. She said that in the future she will look back at SSS as evidence of a time when she was brave. She talked about how she plans to look back at her SSS, see what she has gone through, and inspire herself. She explained,

I spent the majority of the time just being bald and just being with no hair on my face or eyelashes or eyebrows and things like that, but I think that in posting the selfies, it's like this is me today, right now. And next week it will be different. Next week I might look better. I might feel better. It might be a different selfie. It might be a different me next week, but this is me today.

Another, more pragmatic function of SSS was offered by several interviewees who talked about the convenience and reduced effort required to post a selfie compared to other types of online journaling such as blogging. For example, @tameratammytam said that she used SSS and her Instagram account as a way to be productive when her cancer treatment limits her daily activity. She uses SSS to be “useful” and share positivity and encourage others, allowing her to avoid feelings of hopelessness. In fact, people who spend great amounts of time in medical treatments may be able to participate in a limited number of activities in general. Future research may focus on how social media use and selfie content change for people who are in different phases of their cancer journeys. Perhaps there is significance in the different motivations for posting during different parts of the treatment process. Additionally, it might be valuable to understand how the role of selfies changes for people with cancer throughout their treatment process. As noted in this study, the frequency of posting selfies increased for the women interviewed after diagnosis. Future research could determine if selfie posting decreases again after treatment is complete.

The SSS role of helping to create an online serial also provided a cathartic function for several of the cancer fighters. For example, @cancer\_inareddress talked about posting SSS as a way to release stress and worry so it would not “sit inside and fester.” She said, “It’s a cathartic process. Sometimes those photographs are a way for me to express a moment or emotion and give me an opportunity to talk about it. Sometimes in the process of taking the picture and talking through it, I’m able to straighten my thoughts up.” The women said they use posts and comments on those posts to sort through feelings and manage emotions. Similarly, @therightstrong said that it was part of her character to be forthright about her life experiences, and using selfies was a coping mechanism. When she would talk about things that were bothering her through social media in conjunction with her selfies, it would make her feel better. In referring to how she felt about coping with her feelings around losing her hair and posting an SSS showing her bald head, she said “I guess I used that selfie, you know, to put on my Instagram page for, just to – it was like my gift to me, you know. And after that, I had so much more strength to post selfies of me at my worst moments.” These findings suggest that posting and viewing SSS may play a therapeutic role for those with cancer.

Overall, posting selfies provided a way for the women interviewed to construct an identity that integrated cancer into their previous selves. Although some may have separated this identity from their previous selves more than others by using a separate account for their SSS, most interviewees expressed beneficial ways that SSS helped them identify their experiences, reflect on their process, connect with others, and accept their diagnoses and treatments better.

### **Stigma**

An important part of determining how these women perceived their SSS to affect stigma on a broader level is identifying how they thought the viewers of their selfies reacted to their

posts. Most of the participants in this study were motivated to post SSS, in part, as a way to educate audiences, provide greater visibility for the disease, and counteract negative perceptions in the hopes that this would help reduce the stigma of cancer, as suggested by Betton et al. (2015). Several themes around using SSS for de-stigmatization emerged in these interviews. These include educating those without cancer, normalizing cancer for those who aren't regularly exposed to it, protesting the stigma of cancer by showing their strengths, and encouraging others with cancer.

### **Education**

Several cancer fighters explained that sharing knowledge was the main reason that they share SSS on social media. They used images and accompanying text to show people that receiving cancer diagnoses is not a cancer fighters' fault. Blame for a condition is, in fact, one of the ways something becomes stigmatized according to stigma theory; the more a disease can be attributed to the diagnosee, the greater the stigma surrounding that disease. If SSS can help viewers see the disease is not the fault of the person herself, the stigma around that disease may be diminished (Campbell & Gibbs, 2009).

Interviewees explained how they used selfies to educate others who do not have cancer. They talked about using SSS to communicate what life is like with cancer, to help people understand ways that they can support the loved ones in their lives with cancer, and to serve as a voice for those who might not be as open about cancer as these SSS posters are. For example, @girlsonchemo said, "if somehow it reached someone who didn't have cancer, my hope is that they would, first of all have more compassion for someone who has cancer, and second of all, try to understand how they can support that person, because I think that we don't know really until we're told. And educating somebody is the best way to stop them from the bad behavior." She

explained that she posted information about what her friends were doing that she found helpful so that people who are trying to support a loved one with cancer could learn how to do so in the most effective ways. There is reason to believe these participants' desires to change perceptions may be successful: Rademacher (2018) found viewers of ostomy SSS posts who did not themselves have ostomies, became more aware and understanding of people with ostomies.

In addition, @girlsonchemo used SSS as a way to inform the world about the prevalence of cancer and its growing impact on people who have been traditionally considered too young to be susceptible to it. To her, cancer is different than how it is portrayed in popular media, and posting SSS and her comments about her experiences helps combat those misleading portrayals, specifically that cancer is just a disease of the old. She explained, "There's still the belief of, 'Well you're not over 50. You don't have to worry about that,' and it's, 'People are getting cancer because people are living longer.' Well that would be true if I was over the age of 80, you know. But all these lies that we're hearing, I just think that, you know, it's just kind of hush-hush as this moment." This sentiment was reiterated by @sharschmidt, "This is not what it shows you on tv or in movies, you know, always in bed or always too weak to move or always one foot in the grave, because I'm not... It's not like how its portrayed in movies."

Overall, educating others about cancer was common among these participants, and was part of what they saw as both a personal and public struggle to change how people see the disease. SSS were used to make those messages more powerful and provide legitimacy to them for these participants.

### **Increasing Contact**

By posting SSS, the women interviewed sought to give people without cancer the opportunity to look into the lives of people who are living with the disease. The presence of these

photos in one's newsfeed and subsequent increased exposure to cancer may provide a method for normalization of the disease (Betton et al, 2015). SSS are seen to serve to help make cancer fighters more common, reducing any sense of spectacle that may occur in the presence of a cancer fighter either online, or in real life (Rademacher, 2018). According to the women interviewed, this is valuable because it will give cancer fighters more freedom to exist without feeling the need to blend in. They hoped that others would not feel the need to wear a wig or scarf all the time and would not fear that somebody would talk behind their backs. They expressed that posting SSS reduced this need for themselves, and they hoped that in posting SSS it would help others with cancer. Some women mentioned they wanted to eliminate the need for anyone to feel ashamed of having cancer. As @sharschmidt explains, "When I post a selfie, it's kind of like, I don't want to be ashamed or afraid of what I look like now because this is my life now."

Though these women want people to know that they are still themselves, and that fighting cancer is a common occurrence, most of them were of two minds when it came to exactly how they feel about their own stigma of cancer. The women interviewed talked about how they use SSS both to let people know that their lives are normal in the way that they still want to be with friends, want to enjoy good meals and want to nurture their children (all of which are the popular themes for Instagram posts, not just by people with stigma), and to let others know that things are, at the same time, far from normal and that cancer has a big impact on a person's life.

For example, @kimberlyannkd summed it up well when she said she wants to paint a picture of the impact that cancer has on a person's life. She wants people she shares SSS with to know how cancer fits in with her life before her diagnosis. She said,

I share to let other people know what it's like and also to give advice to other people suffering the same sort of thing as me, and also to show that life doesn't stop when you



have cancer. When you have cancer, you don't just shut off from everyone. You continue to go on and live your life and do normal things, and a lot of people, I think are so scared of cancer, and think that it changes everything, and actually, in reality, it doesn't change everything; like, you are still who you are.

She wants people to know that she is a "normal" person, except right now she is battling cancer. According to Campbell and Gibbs (2009), this might just be key to reducing stigma around health conditions such as cancer, showing that people with cancer are not that different from themselves in the fact that they have good days and bad, that they enjoy good food and time with family, and that they just want to share beautiful things on Instagram, including their own selfies.

Not all participants felt that SSS would reduce fear and stigma around cancer, however. One interviewee explained that she thought showing pictures of herself in treatment would make people feel that having cancer is scary and traumatizing. She still wanted to educate people without cancer and inspire those with cancer, but she explained that she hoped her SSS helped people without cancer realize that "however bad their day was going, at least they did not have cancer." This notion positions cancer as a kind of ultimate bad experience that is worse than anything else people face. It is possible that although SSS may help those with cancer feel less stigmatized, they may still increase the fear and dread those without cancer feel about the disease. This suggests that there may be a difference in the power of SSS to reduce stigma for those inside and outside cancer fighter communities. It is possible that SSS are beneficial to those with cancer but reinforce negative associations for those without it. Additional research with social media users without cancer who regularly see such posts is needed to explore this possibility further.

## **Protest**

Posting SSS was a way that interviewees actively sought to protest the power of the cancer stigma as has been found elsewhere (Betton, 2015; Corrigan and Rao, 2012; Leon Tan, 2008). Interviewees reported that SSS were a source from which they draw strength. Several participants posted SSS without care for what others would think, purely for their own personal empowerment. @therightstrong explained, “It just gave me so much strength to put [the selfie] on there and say, ‘Look at what I did.’ I was so proud of myself. I cut my hair and I don't care if anyone else likes it.” Research by Corrigan and Rao (2012) supports the idea that sharing SSS provides a form of “broadcasting” of stigma, and as these women attest, can be a source of empowerment. Broadcasting gives women control over their own stigma through mass sharing. It prevents them from fearing being “found out.”

When asked how they thought their photos made other people feel about what it must be like to live with cancer, many of the women used comments on their photos as evidence that they thought viewers must think that they were brave, or fighters, or “wonder woman.” These comments can be seen as helping to fight stigma in two ways. First, it may help the woman with cancer eliminate her own self-stigma toward cancer, and how she feels about herself by transforming her from a victim to be pitied into a strong person who is doing battle. The use of the phrase “cancer fighter” that was the preferred way to call those with cancer by these women serves the same function. This terminology can also help reduce stigma by publicly congratulating and admiring those who fight cancer (Rademacher, 2018). When these interactions occur, it can improve the cycle of how people with cancer are thought about, showing that they deserve respect. However, it is important to note that no woman mentioned actively seeking out these types of stigma-busting responses, as discussed above.

The women also mentioned that they want to reduce stigma for others with cancer and empower them to feel confident in posting images exactly as they want to without need for feeling embarrassed or ashamed. For example, @lacyholly mentioned that she posts SSS to make others with cancer feel confident in posting their own selfies or being part of society even with the visible effects of cancer treatment. She explains, “I have a couple of followers who have sent me direct messages that said thank you for sharing your posts, because now I can post a picture of myself or not feel bad.”

Though de-stigmatization was on the minds of the interviewees, there were some ways that posting SSS did not necessarily reduce stigma for these women. One participant, @lacyholly, stated that when people saw her photos, their first reaction probably was one of pity. “I have a feeling most people probably feel bad for me, which was not my intent. But I imagine that their first thought – is that they think, ‘Oh. Oh this poor person going through this,’ ya know?” This sentiment was echoed by others. It may indicate that though their intent in posting SSS is normalization, they recognize that that may not be the actual effect their photos have on viewers. This suggests that although they themselves may have felt less stigmatized when they posted SSS, they were unsure if their followers were affected in the same way. The protests they aimed to communicate may not have been read by audiences as such. Thus SSS may not have the broader de-stigmatizing effect postulated by stigma theory.

### **Summary**

These interviews demonstrated the ways in which posting SSS may function for women with cancer. Overall, the ways in which the women interviewed used SSS largely corresponded with stigma theory’s prediction that posting SSS helps these women disclose their cancer and treatments, construct identities that integrate cancer, and reduce stigma around the disease.

## CHAPTER 5. CONCLUSIONS

The purpose of this research project was to determine the motivations, perceived benefits and drawbacks, and impact of posting selfies that convey health-related stigma. To determine why selfie creators would post *stigma signaling selfies*, or SSS, eight phone interviews were conducted with frequent users of Instagram who used hashtags associated with having cancer. The interviews loosely followed an interview guide that addressed the three main reasons that people share information about personal stigmas: disclosure, identity construction and de-stigmatization. The study hypothesized that sharing SSS results in similar outcomes.

The results suggest that among the reasons people post SSS, disclosing their condition to others, participating in communities of other cancer fighters as part of their identity, and educating their followers to help reduce stigma around the disease were indicated. This study found that, for the women interviewed, SSS were created for the same reasons that people use social media in general: to build relationships, to share information, and to gain and give support (Cheng et al., 2016; Joinson, 2008; Leung, 2013; Papacharissi & Mendelson, 2010; Quan-Haase & Young, 2010). However, motivations for posting this particular type of selfie departed in important ways from the reasons people post traditional selfies: SSS were not intended to show an idealized self that would gain attention and approval (Sung et al, 2016; Kearney, 2018). Instead, SSS serve communicative and relationship-building functions that are important parts of generating self-acceptance and social support.

The interviews also revealed some important tensions around posting SSS. First, although SSS are a clear departure from the typical selfie posted to show a user's idealized or best self and to gain attention (Sung et al, 2016; Kearney, 2018), interviewees still curated and edited their

SSS and wanted followers to attend them closely. This suggests that although SSS may not show attractive versions of their posters, they often follow a set of social norms around what is expected in Instagram posts, such as avoiding overly-graphic or intimate images. In addition, although the attention they sought was often for educating followers or connecting with and related to communities of other cancer fighters, SSS were used as important ways to call attention to the user and the disease.

Second, SSS were used by all participants to disclose details about their diagnoses and treatments, but some created separate accounts to do so. This may have resulted in less widespread disclosure than posting to their regular account would have achieved, and demonstrates ways that people differentiate audiences for that disclosure. This created a tension in the effective use of SSS for disclosure: the disclosure provided by posting SSS was largely for a particular audience, not for everyone. This may have resulted in creating distance between users “normal” lives and their experiences with cancer rather than the intended function of disclosure which is integration.

Finally, although posting SSS clearly helped users feel less stigmatized and were actively used to combat misleading or erroneous portrayals of cancer fighters prevalent in mass media, most felt that audiences did not always understand those messages. The SSS may have instead reinforced pity or fear in viewers that could add to the stigma of cancer. Interviewees hoped that in exposing viewers to images of cancer fighters, they would normalize the disease and establish those with cancer as brave and strong. Though stigma research supports this as an effective technique for de-stigmatization (Betton et al. 2015), some interviewees admitted that it would be hard to escape pity caused by sharing their images.

For the women interviewed, sharing SSS achieves a similar result as sharing information about stigmas in person, but without some of the disadvantages (Goffman, 1963). Sharing SSS can be seen as reducing stress caused by having to divulge unpleasant information repeatedly and having to choose when to tell new acquaintances about a stigma. It allows for broadcasting of a stigma and may free the stigmatized individuals from the fear of being “found out” by the people in their lives (Goffman, 1963; Corrigan and Rao, 2012). However, disadvantages that were noted were the possibility of appearing too forward with acquaintances that are often followers of social media, and receiving unwanted health advice.

SSS served to aid in identity construction of participants by initiating and deepening relationships with other people with cancer and with friends and family, both providing and receiving support from their social circles. SSS allowed creators to increase acceptance of their conditions as part of their identity by providing catharsis, allowing them to release and examine feelings around their conditions as well as journaling function that lead to reflection and self-examination.

Interview evidence suggests that SSS play a perceived role in de-stigmatization of cancer. Interviewees use SSS to provide education about what life is like with cancer, increase contact with people who do not have cancer to provide a normalizing function, and increasing the understanding of the lives of people with cancer (Betton et al., 2015). SSS creators gain a sense of empowerment to perform the lifestyle that goes along with being a cancer fighter. However, though de-stigmatization is the goal for interviewees, some recognize that viewers of their SSS may feel pity for them, or even fear of cancer, which would go against cancer de-stigmatization.

## **Limitations**

Though interviews are a good choice for this research, the method does have its limitations. By relying on the personal perspective of selfie posters, this research must accept participants' interpretations and reports of their motivations. This means that less socially desirable motivations participants might have had, such as seeking sympathy through posting health-related SSS, might not have been reported. It is possible that participants in this study intentionally or unintentionally falsely reported their motivations. For example, participants may believe they are posting SSS as a means to normalize the presence of their health condition among their social media followers, when in fact their motivations may lean more toward sympathy seeking. They may say that they use SSS as a means to show personal strength when what they actually do is use SSS to publicly present their health conditions so the conditions can be blamed for any personal shortcomings (Goffman, 1963). To address this response bias limitation, interview questions were worded in the most neutral language possible, and interviewees were allowed to remain as anonymous as they desired throughout the interview process. This would allow the freedom to answer questions without fear of social consequences (Paulhus, 1991).

The fact that interviews occurred by phone or video call may also limit the results of the study. Because interviews were not conducted face-to-face, there may have been some opportunity for rapport lost, and answers to interview questions may be less detailed and exposing. Body language and facial expressions are also lost. To address this limitation, special care was taken in analysis to consider other non-verbal cues such as tone of voice, pauses, and language choice. By paying attention to these non-verbal forms of communication and noting them in the transcripts for the interviews, the true intent of interviewees responses can be

analyzed as well as the words they chose to describe their experiences. In addition, the pilot interviews found that interviewees perceived phone calls to be efficient in allowing them to convey their thoughts and feelings adequately.

### **Data Sampling and Analysis Limitations**

Though efforts were taken to purposively choose a variety of individuals from different demographics with varying types of health conditions, the nature of selfie posters and Instagram users, and people who are likely to participate in a study when contacted by a stranger may tend slightly toward one demographic or another. It was anticipated that fairly affluent white women under the age of 40 would respond, and this was largely the case. And indeed, these appeared to be the women that were most active in posting cancer-related SSS in general during the hashtag searches. (Though, of course, it is difficult to precisely determine age and socioeconomic status in a single image.) Similarly, with a small sample typical of qualitative research, these findings are not representative and may miss important themes, trends, and outcomes. For example, differences by age, race, gender, religion, and geographic location may be important factors in the motivations and perceived outcomes of posting SSS. Additionally, considering the very personality types of SSS posters may be important. It may be that people who are more outgoing are more likely to post selfies, and therefore may have shown up more commonly in a hashtag search. More introverted people may have different motivations for posting the SSS they do choose to post. Also, socioeconomic status may be an important factor in why someone may post SSS. As noted, some people use SSS to encourage or thank people who donate to them during their cancer journeys. This may not be so for people with plentiful means. Future research with a broader sample is needed to further explore how different people use SSS to communicate about their health and stigmatized conditions.



One problem with online communication in general is that identity is hard to prove and fraud is very common. Because of this, it is possible that many of the women contacted ignored requests for participation simply because they did not trust that the research was legitimate. Every effort was taken to appear both sincere and credible in recruitment communications with potential participants. With a response rate of about 50%, there did not seem to be a hindrance to communication. However, one potential participant did question the legitimacy of the study, explaining that she had been contacted frequently about “research studies” regarding her cancer which turned out to be expensive treatment methods with unsubstantiated efficacy. This participant did not ultimately participate in the current study.

### **Implications for Research**

This study expands the knowledge the field of communication has about the functions of selfies as a visual medium. The results expand stigma theory, developed before social media were invented, by suggesting that the affordances of digital communication provide new forms of control and influence when disclosing and combating stigma in social contexts. In particular, disclosure can be adapted more strategically to specific audiences in online contexts, and the images used to reveal stigma can be curated to communicate specific ideas about the stigmatized condition. This study is a first step in illuminating how people with stigma may create and share their identities, and how (or whether) they seek to actively reduce the stigma surrounding their conditions in digital contexts. Additionally, it has been observed in this study that using selfies serves to reduce self-stigma of the SSS creator, so this research may open the door to further study on how creating and posting selfies might be used as a therapeutic tool for those who are diagnosed with stigmatizing health conditions.

This study also adds to the growing literature on selfies by highlighting ways that selfies are used strategically to communicate specific experiences and participate in specific communities. Far more than a narcissistic cry for attention, selfies as revealed in this study are a vital tool for connecting users and processing their life experiences. Research on other types of selfies is still needed to fully understand this important medium of self-expression.

### **Future Research**

As is common, this introductory study brings up more questions than it was able to answer. There is no doubt that the data collected here was limited and there are many avenues for future research. Some of the most important future studies would broaden the participant pool to consider the possible motivations by different groups. Future research could specifically examine the role that SSS plays for groups such as men, people of varying socioeconomic status, races, age, health stigma, or even personality types.

Additionally, future research should examine the role of posting SSS in personal social media accounts versus in accounts specifically created for sharing about one's stigma. The impact on identity construction and de-stigmatization may vary when an individual is less personally enmeshed in the presentation of information. In this same vein, Instagram is different than other social media platforms where SSS are shared. It is common for people on Instagram to have several accounts for different purposes, but on Facebook, for example, users are supposed to represent themselves in one account. Future research may focus on how SSS are used in these different web environments.

It may also be valuable to look at the role of selfies before and after a person is diagnosed with a health-related stigma. As noted, the participants interviewed mentioned that the frequency of posting selfies increased after they were diagnosed with cancer. It would be interesting to

follow cancer fighters throughout their journeys to see if their frequency of posting decreases again after their treatments have finished. Questions about how selfie posting habits change before and after diagnosis of cancer might be explored, and what the content of the selfies consist of, and the intentions of the creators in posting in each time period. The impact of SSS should also be studied among those who do not have the stigmatized condition.

Finally, special mention should be given to the use of hashtags in conjunction with posting selfies. Though selfies can speak volumes about the mind frame and mood of the SSS creator (Rutledge, 2013), it is the use of hashtags that really adds SSS to public conversation. If SSS are posted without a hashtag, they are likely to be viewed by creators' friends and family, that is, people who already follow the creators, so are already connected them on some level. If SSS use hashtags, anyone who follows that hashtag will see the SSS. This feature may give SSS more power for public de-stigmatization. Additional research on the use of hashtags in conjunction with SSS would be a fascinating opportunity for future examination.

### **Final Summary**

The present study aimed to uncover some of the ways in which social media provide a communicative outlet for those with stigmatized conditions such as cancer. It revealed that those who post selfies about their experiences both departed from and adhered to norms and expectations around selfies and around social media use more generally, but that posting such images had a powerful set of benefits for users. Although posting selfies had been maligned as damaging, insensitive, and objectifying, this study demonstrates that they can serve an important function in helping people understand themselves and those around them.

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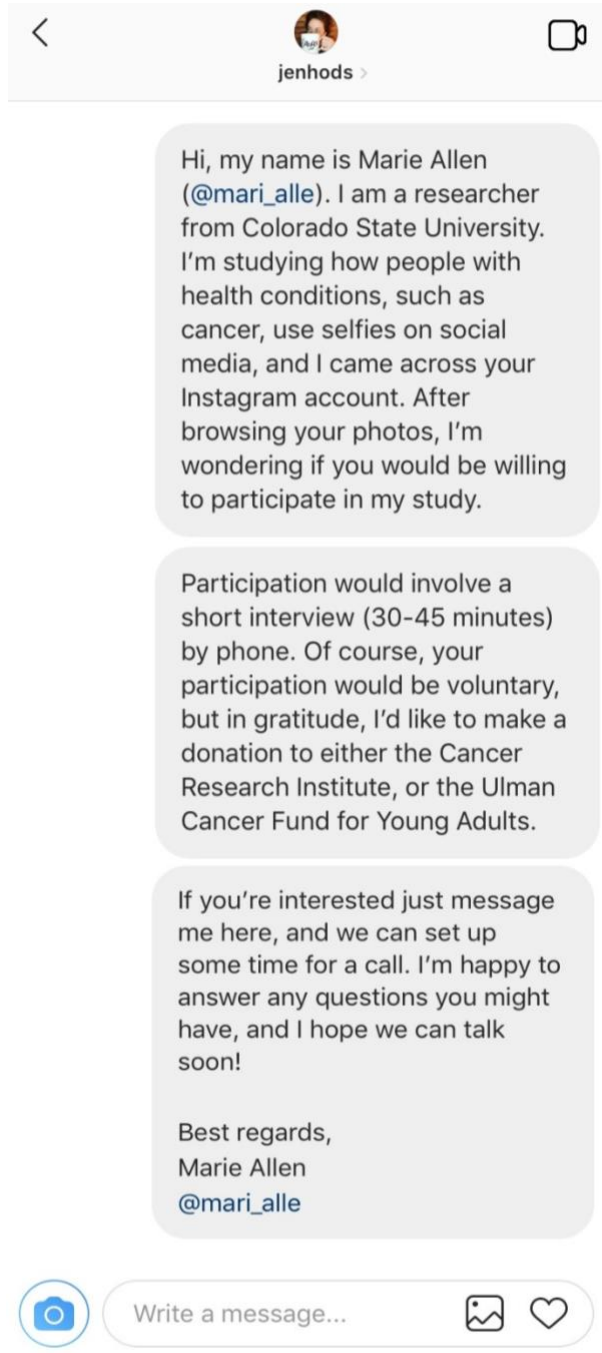
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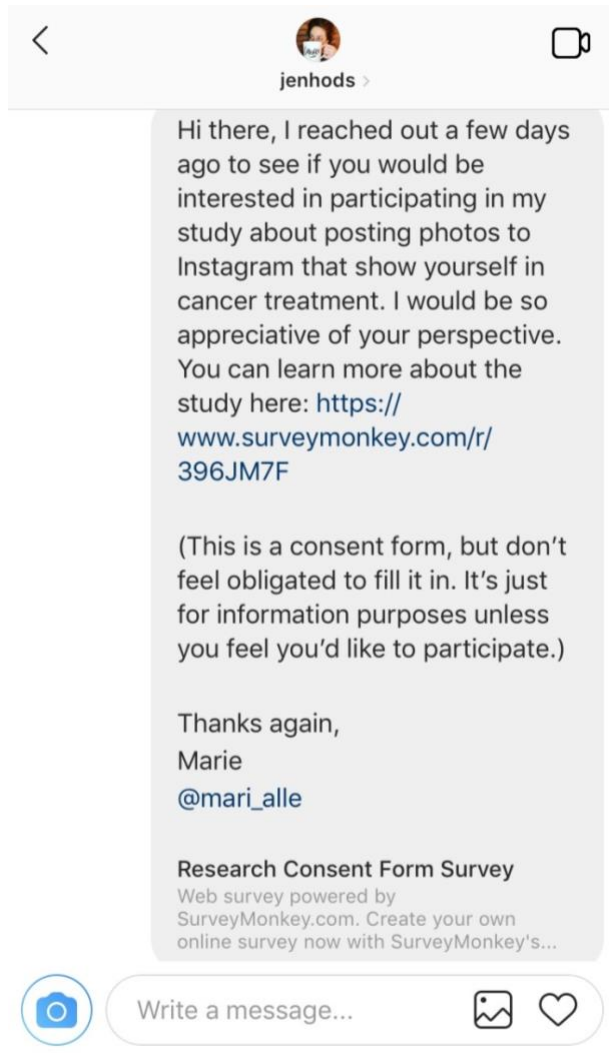
## APPENDICES

### Appendix A: Initial Recruitment Messaging





## Appendix B: Follow-Up Recruitment Request



## **Appendix C: Participant Online Consent Form**

**TITLE OF STUDY:** Sharing Health-Related Stigma Through Selfies and Perceived Potential For De-stigmatization

**PRINCIPAL INVESTIGATOR:** Rosa Martey, Ph.D., Associate Professor in the Journalism Department at Colorado State University, and Marie Allen, Master's of Science Student in Public Communication and Technology, Department of Journalism and Media Communication at Colorado State University.

### **WHY AM I BEING INVITED TO TAKE PART IN THIS RESEARCH?**

You were selected to participate in this study because you have posted selfies on Instagram about your health.

### **WHAT IS THE PURPOSE OF THIS STUDY?**

This study seeks to learn about people's use of Instagram, especially around health topics. We want to learn more about how posting images on Instagram is related to communicating about your health.

### **WHERE IS THE STUDY GOING TO TAKE PLACE AND HOW LONG WILL IT LAST?**

The study will take place by phone interviews. We will schedule a time for a phone call using Instagram messenger, where we will exchange phone numbers. The interview will last approximately 30-45 minutes.

### **WHAT WILL I BE ASKED TO DO?**

We will ask you to participate in a voice interview with the researcher using Google Voice or a cellphone. You'll be asked some questions about your perceptions of Instagram, what you post, and why. We'll also ask about how you use Instagram to communicate about your health. If you wish, you may also email the researcher at the email below to add additional thoughts and comments that you have after the interview.

### **ARE THERE REASONS WHY I SHOULD NOT TAKE PART IN THIS STUDY?**

During the interview, we will be discussing your health, specifically your experience with cancer, and how you post about it to Instagram. You will be sharing information about your health that many consider private. Additionally, talking about your feelings about your cancer may impact you emotionally.

### **WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?**

The interviews for this study will ask about your experience with cancer. Because this disease, no doubt, has impacted your life, you may feel exposed and vulnerable after we speak. If you feel emotionally distressed during or after our interview, you can call the American Cancer Society's National Cancer Information Center at 800-227-2345 or visit their website at <https://www.cancer.org/about-us/what-we-do/providing-support.html> for emotional support. Due to the personal nature of these questions, you may not feel comfortable answering the questions. If so, you may stop the interview at any time or decline to answer specific questions. It is not possible to identify all potential risks in research procedures, but the researcher(s) have

taken reasonable safeguards to minimize any known and potential, but unknown, risks.

#### ARE THERE ANY BENEFITS FROM TAKING PART IN THIS STUDY?

There may be no direct benefit to you from participating in this research, but by participating in this study you will have a chance to examine your own motivations and habits in posting about your health. This may provide emotional clarity and mindfulness about your own actions. Your participation may also help us understand the role that posting about health potentially plays in the mental health of others with similar health conditions, allowing for the development of therapies to cope with chronic illness and reduce the stigma surrounding those illnesses.

#### DO I HAVE TO TAKE PART IN THE STUDY?

Your participation in this research is voluntary. If you decide to participate in the study, you may withdraw your consent and stop participating at any time without penalty or loss of benefits to which you are otherwise entitled.

#### WHO WILL SEE THE INFORMATION THAT I GIVE?

We will keep private all research records that identify you, to the extent allowed by law. For this study, we will assign a code to your information so that the only place your name will appear in our records is on the consent and in our data spreadsheet which links you to your code. Only the research team will have access to the link between you, your code, and your data. The only exceptions to this are if we are asked to share the research files for audit purposes with the CSU Institutional Review Board ethics committee, if necessary. When we write about the study to share with other researchers, we will write about the combined information we have gathered. You will be identified by a pseudonym and a fictional Instagram handle that you select. We may publish the results of this study; however, we will keep your name and other identifying information private.

#### WILL I RECEIVE ANY COMPENSATION FOR TAKING PART IN THIS STUDY?

In gratitude for your participation in this study, a donation will be made in your name to either the Cancer Research Institute, which seeks to discover and develop immunotherapies for all types of cancers ([www.cancerresearch.org](http://www.cancerresearch.org)), or the Ulman Cancer Fund for Young Adults, an organization that provides support for young adults with cancer through education, scholarship programs, and a network of resources (<http://ulmanfund.org>).

#### WHAT IF I HAVE QUESTIONS?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now through Instagram messenger. Later, if you have questions about the study, you can contact the Co-Investigator, Marie Allen at (970) 430-6184 or at [msallen@rams.colostate.edu](mailto:msallen@rams.colostate.edu). If you have any questions about your rights as a volunteer in this research, contact the CSU IRB at: [RICRO\\_IRB@mail.colostate.edu](mailto:RICRO_IRB@mail.colostate.edu); 970-491-1553. We will message you a copy of this consent form for your records through Instagram.

By choosing "yes" below, you agree that you have read the information stated and willingly sign this consent form. Choosing "yes" also acknowledges that you have received an electronic version of this document via email.

Marie Allen  
Rosa Mikeal Martey  
Department of Journalism and Media Communication  
(970) 430-6184  
msallen@rams.colostate.edu

Do you consent to participating in this study? (Please choose one.)

Yes

No

What is your Instagram handle?

[TEXT BOX]

If you would like your Instagram handle to be kept private, what alternative name would you like to use? (Or type "choose one for me" if you don't have a preference, or "use my handle" if you don't mind your real handle used.)

[TEXT BOX]

## Appendix D: E-mail Follow-Up

Hi [Participant],

Thanks again for your willingness to participate in my research study.

Before we set up an interview, I have a few important things to tell you. This study has been approved by Colorado State University's Institutional Review Board, and you should know:

If you decide to participate in the study you may withdraw your consent and stop participation at any time without penalty. Through the interview, I will be asking for your name, age, location, and Instagram handle. I may also use one or more of the selfies you've posted to Instagram as examples in my report. When I write my report, I will only use your Instagram handle as an identifier, or a pseudonym that you choose. Everything else will be kept separately in password protected files, and remain confidential, accessible only to the research team.

While there are no direct benefits to you, we hope to gain more knowledge on how posting selfies about your health condition makes you feel, and what you think others might feel about seeing them. I will also make a \$25 donation in your honor to either the Cancer Research Institute, which seeks to discover and develop immunotherapies for all types of cancers ([www.cancerresearch.org](http://www.cancerresearch.org)), or the Ulman Cancer Fund for Young Adults, an organization that provides support for young adults with cancer through education, scholarship programs, and a network of resources (<http://ulmanfund.org>).

There may be some risks associated with this study. Because we'll be talking about a health condition that, no doubt, has impacted your life, you may feel exposed or vulnerable after we speak. If you feel emotionally distressed during or after our interview, you can call the American Cancer Society's National Cancer Information Center at 800-227-2345 or visit their website at <https://www.cancer.org/about-us/what-we-do/providing-support.html>. This help center provides resources that can help you cope with your feelings. It is not possible to identify all potential risks in research procedures, but I've taken reasonable safeguards to minimize any known and potential (but unknown) risks.

If you have any questions about my research project, please contact me through Instagram, email, or call 970-430-6184. I'd be happy to explain more. If you have any questions about your rights as a volunteer in this research, contact the Colorado State University Institutional Review Board at: [RICRO\\_IRB@mail.colostate.edu](mailto:RICRO_IRB@mail.colostate.edu); 970-491-1553.

By setting up an interview call, you agree to be part of this research project. You are also acknowledging that you are at least 18 years old.

I've attached a copy of the consent form you accessed through the SurveyMonkey link I sent on Instagram (<https://www.surveymonkey.com/r/396JM7F>)

Thanks again for your interest in participating. I sincerely look forward to talking with you!

Best,  
Marie  
@mari\_alle

[Electronic Consent Form Attached]

## Appendix E: Interview Guide

The interview will consist of approximately 15 questions, plus demographic questions.

**Researcher:** First I'm going to ask you some questions about yourself and how you use social media.

### Demographic/Background/ Social Media Usage

1. Please tell me your name, age, and where you are from.
2. How often do you use social media like Facebook, Twitter, Instagram, or Snapchat?
3. For this interview, we'll be talking specifically about Instagram. What is your handle? Do you have more than one account?
4. As I'm sure you know, a selfie is a photo that you take of yourself. How often do you post selfies on your Instagram account(s)?

I asked you to be part of this study because I noticed that you post selfies that show or even highlight a chronic health condition you experience. Would you share with me about your condition? What have you been diagnosed with?

1. How long have you been living with it?
2. How does it affect your daily life?

### Disclosure

1. Do you use selfies as a way to let people know that you have [condition]? Do you think people ever find out about it through your selfies before you tell them in person? What do you think would be the benefits or disadvantages of people finding out this way?
  - a. Seeking to answer specifically: if disadvantages include whether people might consider the participants too forward and familiar, and if advantages include that they don't have to find a time to tell new acquaintances in person.

2. What do you think people think when they see a selfie showing how you live with [condition] What do you want them to think?
3. Who do you think views these selfies?
4. Do you think that posting selfies showing [condition] helps you build closer relationships either in real life or online?

#### Identity Construction

1. Do you have a separate Instagram account for when you post about your health condition than the one you use for your personal identity?
2. The way we represent ourselves in selfies often reflects the way we feel about ourselves in any one moment. How do your [condition] selfies represent who you are?
3. How do you think other people with [condition] feel when /if they see your selfies?

#### Stigma

1. When you post [condition] selfies, how do you think it makes people feel about [condition]?
2. How does posting selfies make you feel about your [condition], and you, as a person, living with it?

#### Final

1. If you had to give one reason why you post selfies that show you [condition], what would you say?

### **Pilot Interview Questions**

Thank you so much for participating in my study. Now I'd like to ask you a couple questions about the interview process itself, to help me ask better questions in the future.



1. Is there anything you felt you would like to say in this interview that didn't come up?
2. Were you comfortable with the interview process?
3. Were any of the questions unclear, confusing, or insensitive?
4. Do you think that talking by phone allowed you to express everything you wanted to?

## **Appendix F: Post-Interview Direct Messaging**

Hi [Participant]

I hope the last few months have treated you well. I just wanted to reach out one final time to thank you for your participation in my study. I have finalized and submitted my thesis, and if you are interested, you can read it here: [Link to Google document]. I also wanted to confirm that I have donated to your chosen charity. Thanks again for your time. If you have any questions, you can always contact me here.

Best,

Marie