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The Lived Experience of Young Adult Burn Survivors' Use of Social Media

Marie S. Giordano
Graduate Center, City University of New York

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THE LIVED EXPERIENCE OF YOUNG ADULT BURN SURVIVORS'

USE OF SOCIAL MEDIA

by

MARIE S. GIORDANO, RN, MS

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Margaret Lunney

Date_____   _____

                                       Chair of Examining Committee

Donna Nickitas

Date _____   _____

                                       Executive Officer

Vidette Todaro-Franceschi_____

Keville Frederickson_____

Barbara Montero_____

Judith Cukor_____

Supervisory Committee

THE CITY UNIVERSITY OF NEW YORK

Abstract

THE LIVED EXPERIENCE OF YOUNG ADULT BURN SURVIVORS'

USE OF SOCIAL MEDIA

by

Marie S. Giordano, RN, MS

Advisor, Professor Margaret Lunney

The purpose of this phenomenological study was to illuminate the meaning of social media use by young adult burn survivors. Five females and four males, aged 20-25, who sustained burns > 25%, were interviewed. Van Manen's (1999) phenomenological methodology provided the framework for this study. The meaning of the context of the lived experience is described in the five essential themes of *identity, connectivity, social support, making meaning, and privacy.* These young adult burn survivors, having experienced the traumatic effects of a burn during adolescence, use social media as a way of expressing their identity, while being cautious about privacy. Part of that process involves connecting others to enable a flow of social support and information, which is motivating and encouraging. Social media facilitates an accessible exchange of information that helps young adult burn survivors make meaning out of the traumatic event. The Neuman Systems Model was found to support the findings of this study.

Keywords: Young Adults; Burn Survivor; Social Media; Phenomenology; Qualitative; Neuman,

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And, finally, to the participants of this study, thank you for sharing your story.

Dedication

I dedicate my dissertation to the memory of three wonderful men who left this earth too soon.

To my father, Donald Scotto: Dad, although you passed when I was only six,
I know there is so much of you in me. I cherish that.

To my stepfather, Nick Calvoni: Nick, you are the most gracious, caring, and giving man
I have ever known. My life's work with people who are burned is to honor you and
remember all you endured.

To my husband, Jeff Giordano: Jeff, you are the most brave, loving, and amazing person
in the world. My heart aches every day I'm without you. You are the love of my life, my
soul mate.

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Chapter I

There are approximately 2.4 million people who sustain and suffer from burn injuries each year in the United States with about 450,000 people requiring medical treatment in hospitals (American Burn Association, 2010). Burn injuries are characterized according to cause, type, total body surface area, depth, distribution, and inhalation injury (American Burn Association, 2010). The greater the severity of the injury, the greater the risk of associated physical, psychological, and social problems after discharge from the hospital (American Burn Association, 2010).

For burns covering greater than 30% of the total body surface area (TBSA), severe stress responses are initiated along with responses such as pain and fear. Systemic responses are generated by the release of inflammatory mediators and every organ system is affected and compromised. This results in cardiovascular, respiratory, metabolic, and immunological problems (Hettiaratchy & Dziewulski, 2004; Kramer, Lund, & Beckum, 2007). Further problems occur as compromised organ systems affect other systems creating a "domino effect". With massive insults to the integrity of skin and immune systems, people with burn injuries are often isolated from other people for extended periods to minimize the risk of infection (Hodle, Richter, & Thompson, 2006). Staff and visitors must wear barriers to prevent direct contact such as gowns, masks and gloves when providing care or visiting, which magnifies the patient's stress, pain, and fear, as well as feelings of social isolation, depression, and anxiety (Travado, Ventura, Martins, & Veloso, 2001). Comprehensive nursing and interdisciplinary care that focuses on the multidimensional aspects of the burn victims lived experiences is important to achieve positive patient outcomes during all phases of healing while hospitalized and post discharge (Badger & Boyse, 2010; Zengerie-Levy, 2004).

After leaving the hospital, young adults who suffered burn injuries reenter the world they knew, but not as the persons they were. They often experience serious losses such as living conditions, jobs, personal belongings, relationships, and sometimes other family members (Sproul, Malloy, & Abrism-Yago, 2009). Physical changes such as scaring, disfigurement, and loss of body parts may contribute to a variety of stress responses and lower self esteem, which can limit interactions with other people (Badger & Royse, 2010; Rivlin & Faragher, 2007). Fear of social rejection may hinder burn survivors' motivations and hope for reintegration into society (Badger & Royse, 2010).

Young adults burned as adolescents are a group particularly at risk for loneliness related to loss of, change in, or inability to connect with peer social supports because most of the post burn programs are aimed at reentry back to school or support groups for other age groups (Badger & Royse, 2010; Christiansen, Carrougher, Engrav, et al, 2007; Edwards, 2001; Smith, Doctor, & Boulter, 2004; Travado, et al., 2001; Van Loey & Van Son, 2003). The Phoenix Society (2012) recognizes the need to consider this population as a unique group with special developmental issues and social needs. There are approximately 120 young adult burn survivors who are registered with the Phoenix Society. Online chat groups are one way the Phoenix Society addresses the social support needs of this population; however, the purpose is peer support of other burn survivors as opposed to peer support from relationships outside the burn community. Developing and maintaining social networks may provide hope and a sense of belonging that can decrease loneliness and help in the psychological healing of burn victims (Badger & Royse, 2010; Cacioppo, Fowler, & Christakis, 2009). For young adult burn survivors, online social networks may be a method of connectivity to social situations that otherwise would not be possible.

The use of social media across the lifespan is growing at a rapid pace and it has become an important topic for research. Social media websites provide access to computer-mediated communication. A Pew internet study found that, as of September 2009, 93% of teens and young adults used the internet with 73% belonging to and using social networks (Lenhart, Purcell, Smith, & Zickuhr, 2010). This statistic has steadily increased from 55% in 2006 and 65% in 2008. There are many studies about social media, its use by adolescents and young adults, and online relationships (Dowdell , Burgess, & Flores, 2011; Kim, LaRose, & Peng, 2008; Morahan-Martin & Schumacher, 2003). Researchers studying use of social media and psychological well being report conflicting results (Huang, 2010). Some studies report the internet provides social support and a chance to develop friendships that allow for social development (Morahan-Martin & Schumacher, 2003). Others describe detrimental effects including increased loneliness and predatory dangers (Dowdell , Burgess, & Flores, 2011; Kim, LaRose, & Peng, 2008). With use of social media, burn survivors can gain access to social situations and social support when psychological and physical limitations create barriers to face-to-face communications (Inmon Long, 2005). To advance nursing science so that nurses can help young adult burn survivors to heal, this study is needed to understand and describe young adult burn survivors' perceptions of their experiences with social media use. To date, this phenomenon has not been studied.

Aim of the Study & Research Question

The trauma of being burned carries significant adjustments in lifestyle for young adults. These adjustments are related to losses associated with the incident. These losses include changes in physical, psychological and social experiences of young adult burn survivors (Badger & Royse, 2010; Rivlin & Faragher, 2007). Young adults, in general, are continuing to develop a

sense of self in relation to others as they seek loving relationships (Erikson, 1980). Young adult

burn survivors are faced with fulfilling these needs while coping with associated losses, which

present barriers to socialization and further isolate them (Pellard, 2004; Travado, Ventura,

Martins, & Veloso, 2001; Ullrich, Wiechman-Askay, & Patterson, 2009).

Since social media is widely used by this population as a means of communication and

socialization, it may be a way for young adult burn survivors to gain access to relationships and

cope with some of the losses associated with being burned (Lenhart, Purcell, Smith, & Zickuhr,

2010). The purpose of this study was to explore and describe the lived experiences of young

adult burn survivors' use of social media after being discharged from the hospital. This study

addressed the research question: What are the lived experiences of young adult burn survivors

who use various forms of social media?

Phenomenon of Interest

The phenomenon of interest is the young adult burn survivor using various forms of

social media. Social media is participative internet or online communications that allow

individuals to share information through social software. Participation in online support groups,

blogs, or social networking sites is available through the technology of Web 2.0 (Chou, Hunt,

Beckjord, Moser & Hesse, 2009). Online social networks, e.g., *Facebook, MySpace,* and

LinkedIn, may provide interaction, information sharing, and support through electronic means

(Christakis & Fowler, 2009). It is estimated that 93% of teens and young adults use social media

as a form of communication (Lenhart, Purcell, Smith, & Zickuhr, 2010). Many studies have

been conducted exploring the impact of social media on relationships in teens and adults

(Dowdell , Burgess, & Flores, 2011; Fogel & Nehmad, 2008; Huang, 2010; Mazur & Koazrian,

2010). Most of these studies are quantitative and report both positive and negative relations

between use of social media and social relationships within specific cultures or groups. There have been no qualitative studies designed to understand and describe the use of social media by young adult burn survivors. Studying the use of social media by young adults through phenomenological induction as a methodology illuminated the essences of their experiences.

Perceived Justification of the Study

Young adults, ages 18 to 25, have specific developmental needs that involve an understanding of self in relation to others (Erikson, 1980). Young adult burn survivors are faced with developmental challenges related to developing a sense of self in relation to others with the complication of physical and psychological scars (Erickson, 1980; Lawrence, Fauerbach, & Thombs, 2006). Self esteem, body image, and acceptance of appearance all affect their ability to master this stage of development so that they can adapt and move to the next stage (Lawrence, Rosenberg, & Fauerbach, 2007). The ability to develop relationships as opposed to social isolation builds upon their mastery of identity developed in the previous stage (Erikson, 1980).

As adulthood approaches, young adults experience hormonal shifts resulting in physical, emotional and psychological changes (Santrock, 2008, p.391). Physical changes and feelings of sexuality affect perception of self esteem and body image. Fear of being rejected by peers and issues related to belonging or conformity peak during late adolescence and young adulthood (Santrock, 2008). The need for relationships and the desire to regain freedom was identified as a priority for late adolescent and young adult burn survivors (Moi & Gjengedal, 2008; Smith, et al., 2004). Burn survivor organizations, recognizing the need for relationship building have developed online support groups and "chats" for this age group (see, for example, Phoenix Society, 2010). These peer support groups, however, may not help burn victims to reintegrate

back into their social networks and/or develop new networks that are not focused on the burn experience.

Social media enables development of online social networks without face-to-face communication. Some of these networks are mainly organized to establish friendships and others have a special focus on various things such as hobbies, professions, or businesses (Web trends, 2011). Young adults who participate in social networks can reach the masses in an instant and develop "friendships" at a rapid rate (Christakis & Fowler, 2009).

Relevance to Nursing

This study is relevant for knowledge development to advance nursing science of the lived experience of young adults after burn injury, and to further understand their use of social media as a mechanism for re-entering society. The knowledge gained from this study will facilitate development of nursing interventions to prepare young adult burn survivors for reentry into society. Nurses are poised to assist young adult burn victims to achieve optimal healing because nurses are the largest number of professionals on burn teams. Total care and management of burn victims begins at the time of admission and extends past discharge to rehabilitative phases of burn health (Gordon & Marvin, 2007). Burn teams can help young adult burn survivors to face the many physical and psychological issues affecting the development of a sense of self in relation to peers. Evidence based interventions developed from studies such as this one may contribute to the post burn recovery of young adult burn victims.

Assumptions and Biases

My assumption was that the participants of this study will be open and honest in their description of their experiences of social media use as young adult burn survivors because of my shared background with them. As a family member of a burn victim, I witnessed the agonizing

experience of my stepdad while hospitalized. I dedicated my life to understanding and caring for burn victims and survivors as a nurse and fund raiser for the burn center. And, I experienced the use of social media by family after a traumatic event that resulted in loss. With this connection, I felt the participants may have been able to connect with and trust me.

My belief was that young adult burn survivors seek out social experiences through social media. These experiences may lead to perceived social support that will reflect positively on their ability to cope with their losses and changes. I believed they would also reflect on the use of social media to help them attain knowledge about their recovery, which supports their ability to cope as young adult burn survivors.

Summary

Chapter I outlined the framework for this study in which burn survivors described their lived experience of using social media after discharge. A phenomenological method was used to understand the experiences of the study participants. Interview questions were guided by the aim of this study and the research question.

Within the context of nursing, I addressed the specific developmental needs and challenges of young adult burn survivors. Viewing this culture within a holistic perspective encompasses understanding the physiological, psychological, sociocultural, developmental, and spiritual components in meeting their needs. Understanding their perception of social media use as a young adult burn survivor can further illuminate needs and interventions so that optimal care can be delivered. Review of the literature does not provide this information; indicating a need to pursue this study. In Chapter 2, I will describe the evolution of this study, which includes the historical background of social media and young adult burn survivors. My experiences with this phenomenon will also be described.

Chapter II

Evolution of the Study

This chapter describes evolution of the conceptual aspects of this study. It includes a review of the relevant literature on physical and psychological aspects of care of burn victims from a historical context and from the theoretical perspective of Betty Neuman. My experiences with burn care and trauma will also be addressed.

Historical Context

Understanding the effects that trauma, scarring, disfigurement and isolation have on burn survivors' ability to connect and engage in social relationships is important for nurses in developing plans of care (Goyata & Rossi, 2009). In this section, burn care, isolation, and connectivity to social situations will be explored.

Burn Care. During the 15 the century, Fabricius Hildanus, a German physician, developed a classification system of burns identifying three degrees of depth that serve as the basic classification used today (Barrow & Herndon, 2007). Up until World War II, when there were various theories and methods used to treat burns; consensus was eventually reached and skin grafts were a treatment of choice. In the early 1950's, there was an increase in burns among soldiers fighting in the Korean War, which prompted the establishment of a center at Brooke Army Hospital in San Antonio Texas dedicated exclusively for the study and treatment of burns (Barrow & Herndon, 2007). Calculation of degree and depth of burns, formulas for adequate fluid to replace losses from the burn, and various topical wound treatments were studied and developed. Eventually the burn center at Brooke Army Hospital became a model that was nationally adopted (Barrow & Herndon, 2007) and dedicated burn centers opened throughout the country.

The American Burn Association (ABA) was established in 1967 with the purpose of "stimulating and supporting burn-related research, education, care, rehabilitation, and prevention" (ABA, 2011). While advances in care led to better patient outcomes including survival of people who sustained larger burns (Herndon & Blakeney, 2007), it was noted that complex psychological and social issues were associated with extensive burns and scarring (Barrow & Herndon, 2006). The focus of care and research shifted from survival to preparing the burn survivor for discharge and reentry into society (Thomas, Meyer, Blakeney, 2007). Studies on psychological and social issues, developmental needs, and the effect these have on recovery and health began appearing in the literature.

Currently, it is recognized that care of people with burns begins with emergency treatment at the scene and extends far past discharge (Mlcak & Buffalo, 2007). The initial physiological consequences related to the effects of burn trauma can be death. Therefore, stabilization of physiological status is the main focus at the time of admission to a burn center (Mlcak & Buffalo, 2007).

Throughout the hospitalization, one of the major focuses is on care of the burn wound and prevention of infection using isolation (Gallagher, Williams-Bouyer, Villarreal, & Herndon, 2007). With a major burn, i.e., greater than 30%, this period of isolation can last for greater than three weeks, even months for some (Hettiaratchy & Dziewulski, 2004; Kramer, Lund, & Beckum, 2007)..

Isolation during the time of hospitalization is further compounded by many other physical, psychological and social complications of a burn injury (Thomas, Meyer, Blakeney, 2007). These complications continue for burn survivors after discharge. Scarring, contractures, or disfigurement can decrease mobility of burn survivors making it difficult to perform activities

of daily living and engage in face to face contact. Historically, society has placed high value on physical appearance. People with visible scars or physical deformities have been stigmatized and isolated (Pruzinsky & Doctor, 1994). Travado, et al, (2001) identified feelings of anxiety related to uncertainty about how burn survivors would be able to function and care for their families as well as fear of social situations and facing people. Another theme that emerged was sadness related to perceived loss, namely physical, social, or professional.

Pre-burn relationships may be affected by death of a family member as a result of the burn incident, loss of home and personal belongings, or disfigurement. Moi and Gjengedal (2009) described the "meanings of the experience of life after burn injury" (p. 1621) through themes of disrupted life and relationships, desire to independently achieve personal goals, and difficulty regaining freedom. In addition, acceptance and learning to cope with intense grief and sadness related to losses were also identified. Fear of rejection and stigmatization limit the ability of burn survivors to enter into social situations after they are discharged

Isolation. In health care, isolation separates patients from others for the purpose of protecting them from infection or from infecting others (Centers for Disease Control [CDC], 2010). The practice of isolation for this purpose can be traced to the 14th century when, during the Middle Ages in Venice, the plague was an epidemic (CDC, 2010). Ships were quarantined for 40 days before unloading.

During the beginning days of the establishment of the United States, imported infectious diseases posed serious health threats. In the late 1800's, Congress passed legislation addressing the problem at a federal level. The Public Health Service Act of 1944 gave the federal government the authority and responsibility for the oversight of communicable diseases. In

1967, the CDC became the official federal agency charged with studying, preventing, and controlling communicable diseases.

Isolation can also refer to a state of being alone, without social relationships (Peplau and Perlman, 1982). Social relationships promote a sense of belonging that contributes to developing a sense of identity. Current burn practice to prevent spreading of infectious pathogens includes isolation rooms, hand washing, and barriers in the form of gowns, gloves, and masks (Gallagher, et. al, 2007). These practices are strictly enforced in the care of patients who are severely burned. Therefore, in addition to being isolated in rooms, burn patients are experiencing a state of aloneness.

According to Peplau and Perlman (1982), aloneness or social isolation results from relational deficits that are antecedents of loneliness. Relational deficits are changes in both the quality and quantity of social situations that decrease one's ability to cope with stressors. Relational deficits result from external factors such as changes in appearance or health, living conditions or social support. Internal factors that increase susceptibility to becoming and remaining lonely are personality, self esteem, situational factors, and social skills (Peplau & Perlman, 1982).

Loneliness has been associated with increased risk for physical and mental health problems, decreased cognition, and poor health behaviors (Caspi, Harrington, Moffitt, et al, 2006; Hawkley, Masi, Berry, & Cacioppo, 2006: Thurston & Kubzansky, 2009). The negative impact of loneliness on mental health, health behaviors, and cognition was identified in many studies (Akerlind & Hornquist, 1992; Cacioppo & Hawkley, 2009; Cacioppo, Hughes, Waite, Hawkley, & Thisted, 2009; Man-Ching, 2002). Mental health issues such as depression, low self

esteem, and heavy use of alcohol and drugs were reported as consequences of loneliness in young adults (Man-Ching, 2002).

Physical, psychological and social changes, as well as developmental needs put young adult burn survivors at a disadvantage when trying to reenter society. Access to social situations is compromised and there is a need to reconnect.

Connectivity to Social Situations. The importance of social connectivity can be linked to ancient history. From the beginning of the development of civilization, connectivity played a major role in the success of communities (Ellis & Esler, 1999). Social and familial relationships contributed to the smooth operations of communities. In order for communities to be self sustaining, farming, hunting and trade with other communities were paramount issues. Societies were developed around rivers that provided connectivity to other societies (Ellis & Esler, 1999). Since then, human beings have sought to be socially connected.

Social connectivity is a challenge for burn survivors because of physical, psychological and social complications resulting from trauma (Pellard, 2004; Travado, Ventura, Martins, & Veloso, 2001; Ullrich, Wiechman-Askay, & Patterson, 2009). Recognizing this, burn care teams and burn survivors sought to identify and support connectivity for burn survivors (Blakeney, Rosenberg, Rosenberg, & Fauerbach, 2007). Informal face to face or telephone meetings with other burn survivors were arranged to offer support in recovery. Formal burn support advocacy groups, such as The Phoenix Society formed, which provided a forum for connectivity. In addition face to face and telephone support, meetings and publications connected burn survivors and their families with other burn survivors and members of the health care team (Sproul, Malloy, & Abriam-Yago, 2009). Burn support groups were formed to share feelings, solutions and hope.

Computers and social media have been identified as the next generation of providing connectivity to social situations (Lenhart, Purcell, Smith, & Zickuhr, 2010). On line chat rooms and peer support groups, set up by the Phoenix Society provide opportunities for connectivity without visual, audio, or physical contact. The use of social media by young adults is widespread (Lenhart, Purcell, Smith, & Zickuhr, 2010). Face book, Twitter, blogs, and texting are some examples of how this generation connects to social relations. In fact, they are always connected. Online gaming is another way of entering into social relations without face to face communication (Griffiths, Davies, & Chappell, 2003). Online gaming not only provides connectivity but it enables participants to choose an identity in the form of a character that exists and interacts in a fantasy society.

Social media is the focus of many psychological, developmental, and sociological studies, the results of which vary and encompass the full range of conclusions (Dowdell , Burgess, & Flores, 2011; Fogel & Nehmad, 2008; Huang, 2010; Kim, LaRose, Peng, 2009; Mazur & Koazrian, 2010). A qualitative study that explores the lived experiences of social media use by young adult burn survivors will illuminate meanings as identified by the first person.

Theoretical Context

Neuman's Systems Model identifies individuals as open systems comprised of parts that are dynamic and unified within and around the system (Neuman & Fawcett, 2011). Concentric circles represent various levels of defenses that may or may not be available to individuals for coping with environmental and internal stressors. Neuman's Systems Model supports the proposition that environmental stressors, such as experiencing major burns, contribute to changes in quality and quantity of social situations for young adult burn survivors.

Individual systems are comprised of interacting variables of physiological, psychological, sociocultural, developmental, and spiritual aspects (Neuman & Fawcett, 2011). These variables are continuously cycled as input, process, output, and feedback to maintain balance. An outermost circle represents the flexible line of defense. This protective boundary consists of various resource levels available to the system to prevent invasion of the normal line of defense. Individual resources are acquired based on life experiences, developmental stages, social networks, cognitive function, physical condition, and spiritual connectedness. When the flexible line of defense is compromised, the normal line of defense is susceptible to stressors. The normal line of defense is the current state of health and is depicted by a solid line representing "system variables, coping patterns, lifestyle factors, developmental and spiritual influences, and cultural considerations" (Neuman & Fawcett, 2011, p.18).

The current state of health results from prior actions affecting the balance of the system and ability to cope with stressors. When the normal line of defense is compromised, the lines of resistance are activated in attempts to support and re-stabilize individual systems. Internal and external resources are used to cope with stressors. When the system fails to provide support, the current state of health is compromised, which affects the core or basic structure.

Availability of socialization within the lines of resistance can contribute to achieving a dynamic homeostasis and affect core responses. Understanding the lived experience of the young adult burn survivor using social media may illuminate core responses and contribute to nursing knowledge development.

Experiential Context

The choice to dedicate my professional life to the care of burn victims was profoundly influenced by my stepfather, Nick, who entered my life a few years after my dad died of cancer.

He was a loving, respectful and caring man. He was very proud when I decided to become a nurse. As a new nursing student, I remember sharing with him my first copy of the American Journal of Nursing. The feature article was about the care of burn victims and, being a retired New York City firefighter, Nick was very interested in this topic. We did not know that shortly thereafter, he would suffer fatal burn injuries which led to his death six weeks later.

Nick sustained 50% second and third degree burns mainly on his legs, arms, hands and back. My family and I kept vigil at the burn center for the six agonizing weeks of his hospitalization. Multiple grafts, raw donor sites and painful dressing changes dominated the next few weeks. We watched as infection set in and his brave battle was coming to an end. Before he died, he made me promise that I would work with people who had been burned after I graduated. That was the last time I spoke with him.

The following year, I fulfilled my promise and began my professional mission dedicated to the care of burn victims. Being a young adult at the time, I often thought of the psychosocial issues involving people my age who were burned and how they would deal with their new lives after discharge. I knew how to give them excellent care while they were in the hospital unit, but I wondered how they would face the world after the losses they had sustained, not only in appearance, but also social networks, and living quarters. These were traumatic issues to address and I knew I wanted to learn more from the perspective of young adults who had been burned.

In another turn of tragic events, my husband Jeff was killed in the September 11th terrorist attacks while in the line of duty as a member of the New York City Fire Department. This time, my children had to deal with the loss of their father. I watched them try to cope with fear, anxiety, and depression as we struggled to deal with our losses. Being in the company of others was unbearable because of the discussion of painful reminders of that day and of "whole"

families. I watched as they turned to interactive video games and social media as a way to develop relationships. This was their way of coping with their new lives. At that time, I wasn't sure how this made them feel but in retrospect, I recognize now that it gave them the confidence to realize they had the strength inside of them to continue on despite their losses.

My experiences at the burn center, as family member and caregiver, have provided me with a comprehensive body of knowledge regarding the hospitalization of burn victims. In addition, the losses my family experienced from Jeff's death provided me with a new perspective on social media as a way young people communicate. Through this experience, I became sensitive to the unique needs of adolescents and young adults who experience loss and how they may cope. I've watched them deal with pain, fear, worry and anxiety as they progress through the healing process. From my perspective, I have felt the pain of Nick, Jeff, and every single patient for whom I provided care; both those who have lived and died.

Summary

In this chapter, I presented an overview of the historical context of isolation of young adult burn survivors and their need for socialization. In addition, the role of social media in society and its implications for connectivity were explored. A brief mention of Neuman's Systems Model was presented as a theoretical framework that views humans as interacting systems seeking balance. The experiential context of the researcher illuminated the interest of this phenomenon.

Chapter III

Methodology

A phenomenological approach was used to explore the lived experiences of young adult burn survivors' use of social media after they are discharged from the hospital. In phenomenology, the goal is to discover the meaning of a lived experience. The evolution of the scientific methodology of hermeneutic phenomenology can be traced to the works of Husserl, Heidegger, Merleau-Ponty, and van Manen.

Phenomenology

Phenomenology began as a philosophical movement with Edmund Husserl, a 19th Century mathematician. His intent was to identify and describe phenomena as they exist, free from preconceptions and theories (Polifroni & Welsch, 1999). He believed that knowledge is derived from experience. His epistemological approach to knowledge is based on understanding what is in the consciousness (Moustakas, 1994).

The three concepts inherent in Husserl's method are intentionality, epoch, and intersubjectivity. Intentionality describes the meaning and intention of phenomena as they are experienced (Polifroni & Welsh, 1999). The goal is to preserve the essences of the experience as natural or intentional. He proposed a method for the researcher to bracket any preconceptions by identifying/acknowledging that they exist and clearly describing them. In this way, phenomenological reduction can occur. This reduces the experience to pure phenomena, without the clutter of influences (Dowling, 2007; Munhall, 2007).

Husserl used the concept of *essence* to describe the commonality or universality of an experience (Creswell, 2007). This is accomplished by identifying common themes that appear in the description of the lived experience of subjects. Intersubjectivity establishes these essences as

that which is (van Manen, 1990). Husserl believed his method of inquiry and analysis would give philosophy the rigor it needed to be considered a science.

Husserl felt that it was imperative that there be unbiased and rigorous methods to uncover essences as they exist in life (Dowling, 2007). He believed that the essential features of a phenomenon can only be understood in their natural form; as thoughts coming into consciousness before interpretation or reflection (van Manen, 1990). They can then be viewed as a new event, or *epoch.* This would require restraint from using any preconceived concept, theory, or relation in order to see the event in its "natural" form. These experiences are then analyzed to search for shared meanings or essences, which establishes intersubjectivity.

Heidegger expanded on Husserl's work to refocus the philosophy of phenomenology on the meaning of being (Polifroni & Welsch, 1999). Martin Heidegger (1889-1976) derived his approach to phenomenological research from a hermeneutic perspective. While agreeing with Husserl's importance of the lived experience, he differed in that he believed that knowledge development occurs with both understanding and describing. His ontological view supports an exploration of the lived experience through interpretation (Dowling, 2007).

In the early 20th century, Merleau-Ponty built on both Husserl's and Heidegger's work; however, his focus was on understanding the experience as it exists in its context (Polifroni & Welsch, 1999). Merleau-Ponty proposed that the goal of phenomenology was rediscovery of the original experience, to see the world as if it were new. This process gives clarity to the experience as it is seen in a new light (Dowling, 2007). Although he agreed with existential philosophers, he focused on the existence of the human form in terms of embodiment. He described this embodiment as an *intertwining* of the subject and the world in which he lives.

Because they are inseparable, the lived experienced is therefore a perception, which is influenced by this embodiment within the life-world (Munhall, 2007).

Merleau-Ponty's concepts focus on human existence with the structure of the life-world: spatiality, corporeality, temporality, and relationality. He describes phenomenology in terms of these concepts in that the lived experience of a phenomenon includes the lived space, body, time, and human relationships (Dowling, 2007). His philosophy seeks to not just describe, but to understand the experience of humans within the world they live. This way of thinking is embraced by nurses and health care as a method of knowledge development as we seek to understand phenomena as lived by a person with in the world they perceive to live within.

Max van Manen (1990) a Canadian phenomenologist, embraced the philosophy of Merleau-Ponty and believed that the lived experience incorporates person, time, space and relationships. His method of hermeneutic phenomenological research is a non-linear process that includes inter-subjectivity, bracketing and reflectivity.

 The foundation of hermeneutic phenomenology supports the belief that both the researcher and participants, through communication and interpretation, describe and understand the meaning of a phenomenon (van Manen, 1990): "It is aimed at gaining a deeper understanding of the meaning of our everyday experiences…it attempts to gain insightful descriptions of the way we experience the world pre-reflectively, without taxonomizing, classifying, or abstracting it" (van Manen, 1990, p.9).

van Manen (1990) described hermeneutic phenomenology as a science that cannot be fully understood without actively "doing it" (p. 8). The concepts or theories of the science can be identified however, participating in the interaction and interpretation of the lived experience

gives meaning to the methodology. Illuminating existential meanings, describing, and interpreting provide the methodology used in understanding the phenomenon.

Description of the Method

van Manen's (1999) method includes a dynamic interplay of six nonlinear steps to guide the research process:

1. Identifying a phenomenon that interests the researcher.

2. Investigating the lived experience as it is, not as it is conceptualized.

3. Reflecting on illuminated themes that characterize the phenomenon.

4. The act of writing and rewriting to describe the phenomenon.

5. Maintaining a strong relation to the phenomenon in terms of pedagogy.

6. Balancing the context by considering the parts in addition to the whole. (p. 30-31)

The first step is to identify the phenomenon of interest. The beginning or starting point of phenomenological research is identifying a lived experience that is of strong interest to the researcher. Hence, passion for discovery becomes the beginning and end point of phenomenological research (van Manen, 1997).

In the second step, van Manen (1998) speaks to the importance of seeking the wisdom of "being experienced" (p.32). This requires that the researcher be in the "world of living relations and shared situations…while exploring all its modalities and aspects" (p. 32). In other words, the researcher must be fully aware of and open to the world of the participants to allow an understanding of the experience from their perspective.

According to van Manen (1997), the third step is to understand that the lived experience does not occur without reflectivity. The process of reflectivity allows for thoughtful understanding of the significance of the experience. From this reflection, essential themes are

identified which give meaning to the experience of the participant. The fourth step involves applying language and thoughtfulness to the phenomenon through the process of writing (van Manen, 1997).

The fifth step involves a continued commitment to the phenomenological research process and phenomenon. Maintaining focus and orientation is imperative to the rigor and strength of the research. The inquiry must be meaningful and guided. The researcher must be strongly committed to this process in describing and understanding the lived experience. The aim is to perceive the experience, write about it and use relevant information from the literature to learn and understand it.

The sixth step, balancing the research context by considering both the parts and the whole, involves careful analysis of each step and relating to them as a whole (van Manen, 1997). These steps, as described by van Manen (1999), provided the methodological structure for this study.

Summary

Chapter III identified the design chosen for the scientific investigation of this study. Phenomenology was described and explained through an evolution of its development. The philosophical explanations of phenomenology by Husserl, Heidegger, and Merleau-Ponty were discussed. Hermeneutic phenomenology, as described by van Manen, was introduced as the methodology for this study.

Chapter IV

Methodology Applied

Phenomenology was used to explore the phenomenon of young adult burn survivors' use of social media. With phenomenology, the meaning of a phenomenon is studied as experienced by a person and is devoid of predetermined "data' from the literature (Creswell, 2007). I chose a phenomenological research method to "empower individuals to share their stories, hear their voices" which provided an understanding of their experiences (p.40). In phenomenology, we seek to discover what is true as it emerges and reveals itself (Munhall, 2007).

Research Activities

According to van Manen (1999), the lived experience is transformed into text that is reflexive by nature of being re-lived. Therefore, the lived experience is both the starting and ending point in phenomenological research. van Manen's method uses in depth one-to-one interviews that provide participants with an opportunity to describe the meaning of a phenomenon from their perspective (Creswell, 2007; van Manen, 1997). The interplay of dialogue, between the researcher and the participant, attempts to reveal and understand meanings. Therefore, in phenomenological methodology, the researcher is both participant and instrument (Munhall, 2007). The application of van Manen's methodology to this study was be described as it relates to understanding the phenomenon of interest through rigorous data collection and analysis. Through this process, I sought to uncover and understand the lived experiences of young adult burn survivors' use of social media.

Protection of Human Subjects

After CUNY Institutional Review Board (IRB) protocol application was submitted and approved, consent was obtained from each participant prior to being interviewed (Appendix A).

Each participant was also asked to complete a demographic data sheet (Appendix B) after the interview. All aspects of the study were explained along with my role as researcher. Participants were reminded that they could withdraw from the study at any time without penalty. Confidentiality was maintained and identities masked by assigning a code to each participant. No identifying information will be published and anonymity will be preserved at all times. All material was and will be kept in a locked cabinet and held on an encrypted secure server at the CUNY Graduate Center and the University of Pittsburgh.

I conducted computer interviews, using *Skype*, a social media platform. Each interviewee chose a time and place that he or she selected as safe, private, and comfortable. Interviews were conducted in a manner that was professional and respectful to both participants and researcher. Recognizing that the participants experienced a traumatic event and were continuing to heal, I provided participants with appropriate resources if they or I felt they needed mental health counseling (Appendix C). All participants said they did not need to use the resources. As a burn nurse, family member of a burn victim, and victim of major trauma and loss, it was acknowledged that I might have strong personal responses to the stories and experiences of the participants. Therefore, I kept a reflective journal of my personal responses to the interviews.

Sample Selection

A purposive sample was obtained for this study. Purposive sampling is used in phenomenology because it enables the researcher to select participants and sites that "inform an understanding of the problem and the phenomenon" (Creswell, 2007, p. 125). In phenomenological studies, purposeful sampling must also include criterion sampling, meaning, that all participants must have experienced the same phenomenon (Creswell, 2007). In phenomenology, sample size is determined when there is richness in depth of data and when

saturation occurs (Burnes & Grove, 2005). Saturation is noted to occur when no new information comes from additional sampling and there is redundancy in collected data.

Participants in this study were young adults between the ages of 20 to 25 who sustained burns covering greater than or equal to 25% of their total body surface area (TBSA). In addition, all participants were burn survivors during their adolescence and are currently using social media. After obtaining approval from the CUNY IRB, flyers were posted in the waiting rooms of burn center outpatient clinics describing the study and asking for voluntary participation (Appendix D). The investigator also distributed these flyers to burn center directors in New York, NY, Livingston, NJ, Cincinnati, Ohio, Washington DC, and Galveston, Texas who distributed flyers to potential participants. In addition, national headquarters of burn survivors' organizations contacted potential participants from their organizations who met these criteria and sent them the same flyer. Individuals who were interested in participating in this study contacted me by email. I contacted interested participants in an email consisting of a description of the study, a consent form (Appendix A), and a request for a time to meet on *Skype*. Written and verbal consent was obtained prior to the interviews. In addition, participants were offered appropriate resource contact information (Appendix C). I conducted the interviews from July, 2012 through March 2013.

Data Collection

Phenomenological data collection involves gathering and collecting information from conversational interviewing and close observation (van Manen, 1997). Interviews were conducted with each participant that enabled each participant to tell his or her story. In this study, young adult burn survivors told their stories about their experiences with social media after the traumatic experience of being burned. Throughout the interview, I considered

nonverbal responses, such as body language, gestures, facial expressions, etc… and took notes accordingly, which were incorporated in the transcript

A date and time was arranged with each participant. All participants were geographically located across the country and therefore, all the interviews were conducted using *Skype*, a social media platform. *Skype* enables face to face interviews to be conducted through the internet. Each audiotape file was assigned a pseudonym title and individually downloaded to a secure server at the Qualitative Data Analysis Program (QDAP) at the University Center for Social and Urban Research affiliated with the University Of Pittsburg. All the interviews were transcribed verbatim by a transcriptionist who is familiar with phenomenological studies. In addition, the transcriptionist completed a CUNY approved course on the protection of human subjects. Certificates are stored at the Assistant Director's Office of QDAP. The audiotapes were reviewed along with the transcribed data for accuracy and completeness. Any names used were removed and replaced with a pseudonym to ensure anonymity.

Interview Process and Research Questions

In the interview process, the first research question was: *'What are your experiences using social media as a young adult burn survivor?"* Additional questions were used during the interview to reflect, clarify, or seek additional information. For example, *"Can you tell me more about that?"; "What did you mean by....?"; "How did you feel when…?"; "What was it like for you when you were discharged from the burn unit?"; "What does that mean to you?"* I also used silence to enable participants to reflect on emerging experiences.

Data Analysis

Qualitative data analysis consists of preparing and organizing the data, reducing and coding the data into themes, and presenting the data in discussion (Creswell, 2007). In this

study, I had considered using a computer-assisted qualitative data analysis program such as

ATLAS. However, I chose to personally analyze the text myself as I felt the richness of the data

would be compromised by using software.

Analyzing the text began with a description of my experiences with the phenomenon

being studied. This was done in order to attempt to bracket or set any personal beliefs aside in

order for the experiences to be perceived as original awareness. It represents the "pre-reflective"

experiences of the phenomenon. This process of phenomenological reduction adds rigor to the

study (Burns & Grove, 2005). Transcribed data was analyzed for significant statements that

were then grouped in to larger meaning units or themes. A textural description of what the

participants experienced, as well as a structural description of how the participants experienced

the phenomenon was described in the narrative description of the study.

Reliability and Validity: Rigor

In qualitative research, rigor is achieved when there is methodological congruence (Burns

& Grove, 2005). Methodological congruence or "rigor has four dimensions: rigor in

documentation, procedural rigor, ethical rigor, and auditability" (p. 628). Rigor in

documentation was achieved by a clear representation of the elements of a phenomenological

research design, namely van Manen's (1999).

Procedural rigor was achieved by the researcher's adherence to the methodology and

procedural steps described. In addition, phenomenological reduction is a strategy used to bracket

reflection or interpretation of experiences and give rigor to the methodology. In this study, data

collection and analysis is free from researcher bias and any assumptions.

Ethical rigor was achieved by adhering to procedures as described in the Protection of

Human Subjects section including, but not limited to CUNY IRB approval, informed consent,

anonymity and confidentiality of all materials and safety and comfort during the interview. Audit-ability occurs when there is an information trail. This was achieved through meticulous documentation of all steps, procedures, and data obtained throughout the research process.

Summary

This chapter described the applied methodology of van Manen. The rationale for using a phenomenological method for this study was described. The protection of human subjects, sample selection, data collection, interview process, and data analysis were reviewed. Attention to rigor in qualitative research was addressed.

Chapter V

Findings of the Study

This study explored the meaning of young adult burn survivors' experiences with use of social media. Six females and three males, who use social media, participated in the study; all had been hospitalized for at least three weeks during adolescence or before with burns greater than 25%. Data saturation indicated that additional participants were not needed. The interpretative phenomenological method of van Manen was used to analyze and interpret the data. This chapter describes recruitment and setting, study sample, data analysis, and synthesis of the experience.

Recruitment and Setting

After IRB approval, paper and electronic recruitment flyers were distributed to burn centers as well as organizations for burn survivors (see Appendix D). Paper flyers were posted in waiting rooms of outpatient burn clinics. Burn survivor organizations distributed electronic flyers to members who were young adults. The flyers instructed those interested in participating to contact me by email. After initial contact from participants, I conducted a brief screen based on participation criteria included in the flyer, and then we agreed on interview dates. The consent form was emailed for review by each potential participant. All interviews were conducted using *Skype*, a social media platform that enables visual and audio communication. Audio informed consent was obtained for participation in the study, which included audio recording. Hard copies of the signed consent were either mailed or scanned and emailed back to me. Privacy and quiet were assured in each of the interviews. All of the interviews took place in participants' homes or dormitories. Each interview was 25 to 45 minutes. Digital audio recordings were electronically sent to a professional transcription service and electronically returned for my review. To

maintain confidentiality of participants, I assigned a pseudonym for each participant.

Study Sample

The study sample was nine participants, ages 20 to 25 years old. The total burn surface area (TBSA) sustained by participants ranged from 25% to 85% (mean = 56.7%). The length of time spent in a hospital burn unit ranged from 3 weeks to 44 weeks (mean = 15 weeks). Body areas that were burned were face, head, neck, chest, back, genitalia, arms, and legs. Seven participants sustained burns to the face and had visible scars on their bodies. Two participants could hide their scars under clothing (back, genitalia, and legs).

All participants had transitioned to young adulthood. Participants were from several states, including Arizona, Arkansas, California, Colorado, Connecticut, New Jersey, North Carolina, Pennsylvania, and Washington State. Self-reported ethnicity or culture included white (n=4), Hispanic (n=1), African American (n=1), Germanic American (n=1), Southern American (n=1), and Scottish/Mexican (n=1). Geographically, seven reported currently living in suburbs, one in a city, and one in a rural area. Six were college students, one was a mother of three children, and two were employed full time. Four participants were Christian/Catholic, one was a 7th day Adventist, and four others did not identify with any religious group.

All participants reported using social media from 5 to 20 hours per week (mean= 10.4 hours). *Facebook* and *Twitter* platforms were used by most participants. They also used the social media platforms of *Google Plus, Instagram, Pinterest, Skype, YouTube, Redit, LinkedIn, Four Square,* and *MYSpace.* Some reported using private social media platforms accessed by membership in organizations.

Description of Participants

The description of participants contributes to painting a complete picture of the experienced phenomenon. According to van Manen (1999), this supports the dynamic and non-linear research process. During the interview process, the interplay of dialogue between the researcher and participants enabled the researcher to become both participant and instrument. This facilitated immersion in the investigation of the lived experience. After listening to tapes and reading the transcripts multiple times, an overall picture capturing the experience as a whole came through, as described in the following descriptions.

Nicole

I met Nicole on a spring afternoon. She was alone in a family room and was able to give me her undivided attention. Nicole's voice was soft yet strong. She started speaking about using social media before her injury and the issue of confidentiality came up immediately.

> I am very sensitive and confidential about it. I went for 2 ½ years without using my real name. Now, it still doesn't (use my real name), but it has my first and my middle, which is better than a made up name.

Nicole was articulate throughout the interview. Her description of social media use was focused on key issues that were important to her. The primary one was related to connecting with people. She described her inability to go outside because of recovery from the injury. Social media helped her connect with her friends.

> It's been good 'cause the first year and a half after the hospital, I couldn't go in the sun. So, it was my way to connect with my friends and to reestablish relationships and feel involved in people's lives when I couldn't actually go out.

Nicole spoke about her injury which was a result of an autoimmune response to a medication she was taking. Stevens Johnson's Syndrome, (SJS) or toxic epidermal necrolysis, caused her to lose most of her skin. As she described her experience of dressing changes, pain, and physical scarring, her voice remained calm and purposeful. I felt my eyes welling up with tears. And, although we were not sitting in the same room, I felt an exchange of energy. She described using social media to connect with others who had suffered from SJS.

> When I first got home, when I first started to go back on social media, I used it to connect with people and I found this girl who had SJS…We grew in our recovery together, watched our hair grow. That was so encouraging to me.

Nicole spoke about the recovery and how social media helped her. She felt it was important to chronicle her journey through recovery by posting pictures of herself at various stages. She identified reasons as being helpful to others who were going through similar ordeals. In addition, it was very important for her to educate others about SJS. She felt this helped people understand what she was going through. Posting pictures on *Facebook* reached many people and she didn't have to repeatedly explain about the illness and the recovery. It also enabled friends to react to her physical scarring before they came face to face with her again.

> Trying to explain to 400 people what just happened to my life, like," if you missed it, here's what happened"… I adjusted quickly with my friends accepting me and not looking at me funny… I went out …not hiding my face.

Nicole spoke about her church group and her affiliation with them. She gained much support from connecting with them on *Facebook*. She said she kept abreast of events this way. She identified the immediacy of the connection to support by using social media. She spoke of crisis intervention: being there for others and vice versa.

> I can do it from the comfort of my bed or from the comfort of my home and once I do
> that, it initiates the ball rolling to initiate connection and get involved again. When I
> posted the first three pictures…I got a flurry of responses from my non-Christian and
> Christian friends saying that what I went through was a miracle.

I was inspired by her strength and tenacity. Her desire to help others recovering from SJS by using social media, was admirable. I was pleased when she invited me to "friend" her on *Facebook*.

Andrew

Meeting Andrew was overwhelming. Having sustained burns to 85% of his body, his physical appearance reflected facial deformity, loss of limbs, and hair loss. He is currently living with his father, over a thousand miles from the accident, while he attends college. We met on *Skype* in mid afternoon on a hot summer day. He was visibly hot, wiping perspiration from his face. However, there were areas where he could not perspire because of damage from the burn. He said he just came in from mowing the lawn, but wanted to talk. He was using his laptop in his room which seemed dark. There were no visible pictures on the walls. I immediately felt compelled to listen to his story, because he had experiences he wanted to tell.

Of the nine participants, Andrew was, by far, the most severely affected by his injury. He was hospitalized after a "car wreck" for 11 months; the first three in a medically induced coma. He didn't reveal the details of the accident but spoke about his recovery and his experience using social media.

> I like re-sharing funny pictures I find. I was given a laptop…towards the very end of
> my stay… the first thing I did was to download music…when words fail, music speaks. I
> use music to just kind of transport me to a different place.

Much of his experience was related to me in obscure statements that required explanation.

> Hmmmm. Well with social media, you can kind of be whoever you want to be or be no
>
> one at all.

I kept asking him to tell me more or to explain how he felt. At times, I felt like he was holding back but, his experiences were deep and required thought. I felt like he was testing me, to see how I would react to the things he was saying, to see if I was interested enough to pursue his explanation. For instance, he spoke of the "wreck" and when I asked him if he wanted to talk about it he responded, "It's not really related to what we are talking about ...I don't know how relevant it would be to your study. It would be for personal information between the two of us."

It seemed almost like he was trying to gain control over a situation that, he had no control over for a long time. I felt like he was, slowly, gaining trust in me. By the end of the interview, he invited me to "friend" him on *Facebook*. He thought he might go to the annual meeting of burn survivors and asked if I would be there. I felt obligated, but didn't give false hope.

Lauren

I met Lauren while she was in her dorm room. Her room was neat, organized, and bright with light. She is a 23 year old graduate student at a university where she studies mathematics. She also works as a resident assistant. She spoke with a slight southern drawl, in a confident, upbeat manner. I immediately felt the light shining from her as she virtually accepted me into her dorm room. She began by telling her story about how she was burned at the age of four. She described how a fun family gathering turned into a disaster for her. She remembered the excitement she felt prior to the burn and vividly described it.

> My family was at a fish fry and we were at a family reunion. I was so excited about
>
> having this book that had all these pictures in it and everything. And I was like, 'I'm

gonna go tell my mom. This is totally awesome." And, so I ran up the steps and was

looking at the book. I wasn't really watching out where I was going and I tripped over a

dish cooker and the dish cooker had about four hundred degrees of hot grease in it.

I not only heard words, but felt the experience. Her description brought me to that day and I had

a flood of emotions as I listened to her continue to describe the hospitalization and healing that

continues to this day. She was unwavering in her description of her experiences. It seemed very

important to her that I know the history of how she got to where she is and how her use of social

media evolved.

I grew up in a small town…my family didn't have the Internet. In high school, I thought

it was a bunch of nonsense. I went through a lot of turmoil and people making fun of my

face, especially 'cause I am burned on my face. I went through so much of that, that if I

were to post something like that on social media site that could come back…I didn't want

to experience that pain and agony and stuff that I've already experienced face to

face…where they laughed, growing up through middle school and elementary school. In

college, I went to events and a lot of meetings and they were like, "add me on *Facebook*"

…I ended up getting *Facebook*.

Lauren continued to describe how, through social media, she is able to get and give

support to other burn survivors, as well as other young girls who are facially disfigured. She

spoke about private social media sites of which she is a member. She considers herself a role

model in many ways. As a resident assistant, she is the "go to" person for undergraduates in her

dorm. She takes this seriously, which is evident in her words and her tone. She became very

serious when describing her role and how she needs to be careful about privacy and what she

posts. She is careful about what she posts and how she is perceived.

I try to keep it as clean as possible. After all, I am a role model. I live in a fishbowl.

Everyone sees what I am doing, especially the 300 and about 2 girls that I am over.

Lauren is an active participant in other types of burn survivor groups both online and in person.
She keeps in contact using social media and giving back is very important to her.

It makes me feel really, really great…I feel like I'm making a difference and I'm

providing some kind of help to someone who may need it through social media during

the connection of the Worldwide Web. I think it's amazing.

Lauren continued to speak about how social media is uplifting to her. She posts pictures, art,
music and other links to share with "friends." One thing she said she enjoyed was TV. She uses
Twitter, to follow the stars and producers of her favorite shows.

Twitter gives me a connection with a world that is a million miles away. I might not ever

have the opportunity to see anything like it but, it gives me that sense of, "That's cool,

that's awesome, and I'm a part of something"…I follow a lot of funny tweets. It gives

me a laugh…it gives me an outlet. When I'm sittin' on waiting for a meeting to start or

sittin' waitin' on class to start, I have that …connection right there.

She summed up the interview by talking about the most important way that social media
impacted her life. She spoke about how certain sites helped her connect and accept who she
really is.

Before I became involved with social media, I was scared to put things out there…would

I really be the person that I could be, could I really see past my physical difference and

see me as a person when all they see is a picture?... All the invites gave me the courage to

join…I have outlets and I'm able to connect…One of my favorite fruits is a pineapple…a

symbol of hospitality and acceptance. And, I wear a pineapple everyday to remind me

that I accept my body and I accept who I am and being out there on *Facebook* is

something of a great accomplishment.

Jessica

I met Jessica in her dorm room at the beginning of the autumn semester in her junior year

of college. Her room was bright with light and there were many pictures on the walls; pictures

of herself and her family both before and after the injury. Her scars were visible on her face,

upper body, and hands. She was sitting comfortably on her bed with her laptop. Her upbeat and

friendly attitude was engaging. When I asked her about her use of social media, she began by

describing herself.

> Well usually, you know, I'm always open. I have, ever since it happened. I've never hid
>
> my scars. When I *Skype*, it's with someone that I usually know or…can potentially
>
> have as a friend. So, you know, just the way I'm speaking with you, I'm being
>
> open…that's the way I am all the time.

She went on to describe explosion that caused her burn. She felt it was important for me to know

what she and her family had been through. When she was a teenager, she lost interest in school

and in caring about how it affected her parents. She described the violent and intentional

incidents that led up to the explosion that burned her. She spoke, without interruption for about

eight minutes sharing the details of the months that led up to the incident. She described that she

was thankful that her mother hadn't been hurt and talked about being given a second chance.

> "You know, when I look back at it, I'm definitely not that person…the rebel girl that
>
> everybody knew…like God gave me a second chance to reflect on my downfalls…and
>
> learn from them."

Jessica described being socially isolated while recovering from the burn. She described

using social media as a way to connect with friends she could not see face to face.

> I got burned and I wasn't able to go out, and it just, it impeded me to do so much of what
>
> I used to do before I got burned…I was prone to get infections…I wanted to go out but
>
> my doctor was telling me, you know, "it's best for you to stay indoors." And that is
>
> why…I would chat with them on *Facebook*.

Her openness was evident in her use of social media to inform friends, acquaintances, and the

World Wide Web users of her journey. She produced videos about herself, talking about what

happened to her, and how she was healing. She posted them on *YouTube,* a social media site.

Her primary focus was on who she was and how experiencing this traumatic event refocused her

priorities. She learned from her experiences to make meaning out of the situation.

> "It motivates me…and I feel as if I am a motivator …to people who aren't burn
>
> survivors, but who have, you know, people who have emotional scars."

I was impressed with her willingness to share private information and in her ability to be positive

in light of the situation. She has plans to be a broadcaster, which is another example of strength.

Valerie

Valerie virtually welcomed me into her new apartment, having just recently moved in..

She had graduated college and was working in the health care field. Valerie was neatly dressed

and poised as we began our interview. Although she had no visible scars, she began the

interview by addressing them. She spoke of how she used social media and one of the issues

concerning her that she was careful about was posting pictures in which her scars were visible.

> But, I think that the most affected by my burns would be the pictures. The burns are on
>
> the back of my legs and lower back. So, they are not evident everywhere. I like going to

the beach and having that skin exposed makes me think twice about taking certain

pictures and putting them up on line.

She did, however, participate in an art show on her college campus where black and white photos

of her scars were displayed. She felt that she was able to tell her story in this way and felt a

sense of relief to openly discuss this; but she did say that she felt vulnerable. She said she might

consider an artistic expression through pictures of her burns in an online forum.

I enjoy telling the story. It's about healing and overcoming an obstacle…Every time I

tell it; it's a little bit healing for me.

Getting support through social media was one of the key issues Valerie spoke about. Part of her

healing was supported by being motivated to follow the "tweets" on *Twitter* of J.R. Martinez.

He is an actor who served in the Middle East Wars and became severely burned and facially

disfigured. He became a contestant on Dancing with the Stars, and eventually won. Throughout

his experience, "he tweeted" inspirational experiences.

I did follow J.R. Martinez for a while (*Twitter*). Some really good positive "tweets"…It

was really cool…He would just say some positive little one liners that were kind of cool

to pop up during my day.

She identified how social media helped her connect to the burn community. It was important for

her to feel as if she was part of a community where others were going through the same thing.

She was able to use social media as a resource for information about scholarships, listing to

stories and sharing stories.

I think it's definitely helpful, um, as a resource just to see other people who have, you

know, really cool stories and how they have overcome their burns. I don't run into a lot

of burn survivors in my everyday life. So, it's good seeing that there are other people out

there that have dealt with what I have dealt with. And stories that are worse than mine, or similar to mine that I can get encouragement from.

In addition to connecting to the burn community, Valerie spoke about sharing stories, through social media, as a way to increase awareness about what she and others went through. She spoke about healing again in relation to sharing experiences and making meaning about what happened. She was focused and intent in her tone. She wanted her message to be heard.

I wanna increase awareness for burn survivors and say, "Hey, this is out there." J.R. Martinez came out with these incredible stories and say, "Hey, my friends might be interested in this," and then they will also get to see that I was part of this. It makes me feel like I can help burn survivors by showing it to other people that might not necessarily see burn survivors. …It's not just my story, it's everyone's story.

Toward the end of our time together, she began speaking of using social media as a way to connect with others in relation to decorating ideas, entertainment, and sports information. Her tone became lighter and she was proud to show off her new apartment.

I share pictures and music that I like…I recently got into *Pinterest*. Oh, the second you do that, that's fun cause I've moved into my own apartment and do fun stuff. It's not very decorated yet.

Christy

I met Christy, a single mother of three, while she was preparing dinner. She was visibly scarred having sustained an 85% burn as a child. The atmosphere seemed hectic but she acted oblivious to what was going on around her. I suggested that we meet at another time. However, she wanted to talk and share her story. Although I felt we should not continue, she wanted to

continue. Her voice became almost monotone and steady as she described her physical

appearance and the impact it had on her relationships.

> The majority of people, you know, they've known me for a while, and this is all I know.
>
> I've been burned since I was two. So, I find it OK. I've never had any problems, and I,
>
> you know, I'm a very outspoken person, and once people get to know me, they, uh, no
>
> longer look at the scars.

I noticed that she referred to herself as being burned since she was two, and that she didn't refer

to herself as healing or being a survivor. After she completed sharing her thoughts, I refocused

the interview and asked her to describe her experiences using social media. Her tone changed

and she became more upbeat with positive inflections when she spoke of connecting with her

family and sharing pictures of her children on *Facebook.*

> I use it to keep, uh, communication with family who live farther from me and I can't see
>
> them on a daily basis. I like to take pictures so they can see pictures of uh, my children,
>
> and I just try to stay in contact with them that way. It feels good. I sometimes don't like a
>
> lot of pictures of me.

She continued sharing her experiences using social media by identifying online burn support

groups with which she connected. She spoke of how important it was to her to be able to relate

to someone who went through the same thing she did. However, as she clarified, I realized that

she did not actually engage in active discussion but spoke of a desire to connect, identifying what

it might mean to her if she did.

> I know they're not judging me based on my scars because they have scars, too. Maybe, I
>
> actually wanted to try to talk in their support group. I was going to try, so I can talk to
>
> them to let, you know how, like what I went through and how I'm coping with situation

still to this day. And um, you know, listen to their stories, because that might help inspire

me.

Christy frequently returned to her experiences with people in relation to her scars. It was

important for her that they get to know her so they can see who she was on the inside. She

shared how social media helped her get this message across.

I post pictures of them (children)…if I've taken them to the park or something and I hear

people always say, um, "You're such a great mom, and you're doing so well with three

children." And that makes me feel good, too, that they know that I'm doing something.

At this time, her mom came in to watch the children and Christy was able to continue the

interview in a quiet room. She continued to share feelings about how she was teased when she

was younger and how it hurt. She also said that by using social media, people find out first who

she is on the inside. She joined an online dating service and relayed positive experiences from it.

I have a picture up with me…with make up on, so you can't see the burns as much. But

then I have other pictures showing the scars. And, I've gotten a lot of messages from

people, like who, they see that I have kids and they don't want to deal with me. But some

people .message me just that they say, "I just want to let you know that you're beautiful."

And, I like to hear that.

As a mother, I connected with her feeling of recognition and pride, which defined her beauty.

Peter

I met Peter in his off campus housing apartment. He had severe burns on his arms and

legs; his face was not scarred. He showed me his hands and described them as "those of an 80

year old." He just finished his junior year college finals and was preparing for the MCAT exam.

He was engaging in his manner and confident in sharing his experiences. He chose to begin by

telling his story of how he was burned and how social media played a role in information dissemination and connectivity during his hospitalization.

> I was 17 when everything happened. I guess the short version is I was playing in my backyard and I, um put gasoline on the fire and the fire exploded…So throughout the actual experience, my mom posted something for me on *Facebook.* And then, uh, my girlfriend also was kind of sending updates to everybody. It was easier for them not to have to make individual phone calls.

Peter struck me as an active, caring and involved person. He spoke about attending burn camp and making friends that he was able to keep in touch with using social media. He was proud that he was asked back to be a counselor and that he was able to give back.

> I still keep in touch with people I met through a couple of different things…I was asked to come back as a counselor this summer because I am finally 21. And, then there is the World Burn Conference. I keep in touch with people that went.

Peter is focused on his studies. He described using social media as "keeping it relevant" and goes on to clarify how making connections and networking using social media, has helped him with scholarships and many other opportunities.

> I've gotten a couple of different burn survivor scholarships and you go to receptions for those. *Facebook* is the only way that I've kept in touch. That's how I found some of the scholarships, is through that kind of networking.

He also identified social media as a way to give back. He is part of a group that gives outreach talks to young people to increase awareness about burn prevention and how being burned affected his life. He tells his story using social media. "Um, I mean, part of it is an outlet to share my story." He also donates money using social media sites, toward burn rehabilitation.

I was impressed by Peter's maturity and focus. He spoke confidently about his use of technology in helping his mom with her master's thesis preparation by using *Dropbox*; and, how he frequently visits his grandparents using *Skype*. Peter explained how he communicated with his research group in the Bahamas by using *Skype*.

> I Skype with my research group… the head of my research group is in the Bahamas right now at an institute but he's able to check in during our meeting…Its easier to Skype and be able to send them a picture and talk through it and explain it…it's instant feedback.

I learned a great deal from listening to how he conducts his life using social media both as a burn survivor and as a young man.

Stephanie

I met Stephanie in her apartment. The room was sunny and gave a light, airy feel. She is a 20 year old woman who was a victim of Steven Johnson Syndrome (SJS) when she was 16 years old. She sustained a 75% burn to areas covering most of her body. Her scars were not visible to me. As the interview began, she immediately focused on the issue of privacy. She described being frustrated because her family members kept putting up pictures of her but then "gave in" to having them posted, as she chuckled.

> You can't keep it private. Everybody's going to know about it no matter what, whether you want them to or not. When I was in the hospital, that's how my parents and I like kept friends and family updated without having to call every single person… At first, it was kind of frustrating…they kept putting up pictures and stuff that I wasn't exactly comfortable with yet. It took some time to get used to and I didn't care anymore.

She continued describing her experience with her family chronicling her hospitalization with pictures posted on *Facebook*. She was unaware they were taking the pictures and that they were posting them on *Facebook*.

> OK, so when I was in the hospital they shaved my head for the skin grafts, and I didn't, like I was still kind of out of it when I woke up out of surgery. Like the first thing I did was check my *Facebook,* so I found out on *Facebook* that I didn't have hair. They already put a picture on it, and I hadn't like touched my head yet, so I was just like – I saw the picture and I just immediately started crying my eyes out 'cause that was not the way to tell me that I didn't have hair.

She laughed it off and made jokes about it. I was sad that she felt violated and felt as if she had to accept it. However, she continued along the lines of informing others about SJS by her story in pictures. She made meaning out of it by starting a *Facebook* page dedicated to SJS.

> I started a *Facebook* page and everything about SJS and there's a foundation, like I made sure like I joined their group, and I'm always sharing their posts and everything. And once, there was like a car rally in Oregon, so I like shared like that for, like, to my friends there in Oregon, to see if they wanted to go 'cause all of the proceeds go to Stevens-Johnson Syndrome awareness.

Stephanie spoke about the importance of using social media to connect with people who have had similar experiences and how social media connected her with someone globally with whom she could share information about recovery.

> I've met like a ton of people. It's just easier because there's not anybody to talk to about it. So when you meet people on *Facebook* that have had it, you can talk to them, and… like me and her tell each other everything. We've never even met in person.

It helps a lot, actually. Because like you actually have somebody finally that understands

what you're going through.

She further described how friends and other SJS survivors reacted, using social media, to her

being pregnant. Her face lit up and she was proud to be "expecting". She took it as a sign of

hope and recovery which she was able to share using social media.

Like it's just people can see that life does go on, like don't let whatever you went through

hold you back.

Mike

I met Mike in his apartment. He is a college graduate working in business and market

research who had just come home from spending time with his girlfriend. I could see the snow

on the trees through the window behind him. He took a breath and got settled. His first

comments about social media were directed at typical use by any young adult. But as he

reflected, his thoughts brought him to the scarring and posting of pictures. He revealed a

conscious effort to maintain privacy in relation to his scars.

I'd say my social media use is pretty normal. I wouldn't say it has been impacted a

whole lot by uh, the burn. I was burned on the lower half of my body on the legs…The

scars are mainly covered up during the day. So there's not, um, I guess a lot of you

know, what typical burn survivors have all the time…But it definitely has impacted, you

know when I was burned I was 16 and *Facebook* had just kind of come about. So within

a year and a half of my burn, I was graduating and going off to college, and Facebook

was really big at that time and we, you know, start posting pictures and stuff, and I

would always be a little self-conscious. Um, you know, like "Oh, you know, are my legs

showing?" … "Should I un-tag myself so people can't see it?"

Mike expressed the value of being able to connect with other people who had gone through what he had. Through the hospital and burn survivor organizations, he shared stories and was motivated to "get through it." Mike spoke of "supporting the cause" by donating, online, to burn survivor organizations. He used the word support and reflected on it.

> Support is very important. And um, it's kind of… maybe "double-edged sword" isn't the best phrase, but when you're going through it, you know that nobody else knows, like your friends and family, they don't know what you're going through…So like having somebody who has gone through it to support you is like the other support that you need. Your family and your friends provide love, and they, they know that they're there for you, but you don't have that "you haven't walked through my shoes" kind of support. And that's where like the Phoenix Society was really great. Just like reading people's stories and knowing that they went through this same stuff, so they added support in that regard.

Mike talked about using social media for his work, entertainment, and to connect with friends. Interactive gaming was a part of his college life. He currently shares interesting stories or events with his friends and posts information that describes his likes.

> I just like to post stuff that's on my mind or I'm thinking about it or share them with my friends to see if, if it's something that I'm laughing at, hopefully they'll get a laugh out of it, as well. If it's a – some of it, a lot of it is like sports-related, so I have friends who are fans of my team or not can post their opinions on what's going on.

He reflected on social media towards the end of the interview and expressed the "power" it can have to impact the lives of people who were burned.

There, there's just a lot of ways to – now, especially now, to really voice your opinion

and get your emotions out there. So as you're going through, like a burn victim who is

just going through the rehabilitation or getting back into society or trying to move on

with their lives, it can be a very good outlet to really voice that and really get the support

from your peers. You know, there are groups that you can join, not just through Phoenix

but all the Internet on burn survivors, different ways to cope with it and rehab stuff like

that, support groups. So it's a very powerful tool, and it can definitely be utilized in a

great way for people who are going through it now.

Data Analysis

Data analysis followed van Manen's six non-linear research steps (van Manen, 1997). In

the first step, I considered the nature of the lived experience of social media use. In the second

research step, investigating experience as it is lived, I listened to participants' descriptions of the

experience, which were gained through in-depth interviews. The interviews, which were

conducted through *Skype*, at a time and place chosen by participants, were audio-taped. Each

interview was transcribed from which a text was created.

In the third step, reflecting on illuminated essential themes, transcripts were read and

reread, while listening to audio-taped interviews. Emerging themes were identified. The

participants were asked to review the transcribed interviews and provide, if they desired,

additional clarification or comments. This represented part of the process of reflection. There

was no additional feedback.

The fourth step in van Manen's research process describes the act of writing and

rewriting to describe the phenomenon. I read the transcripts through, immersing myself in the

participants' experiences. I then selectively reread each of the transcripts with the goal of

understanding the experiences from the perspective of the burn survivors. As I read, I made notes in the margins and underlined phrases that captured the essence of meanings. I did this several times; color coding similar phrases or meanings that led me to clustering of ideas into themes that expressed the essence of the meaning.

Identification of Themes

The following themes represent transformed meaning units from participants' interviews:

- This is who I am inside, behind the scars

- You can be who you want to be

- Chronicling my story using social media, informs others of what I went through and continue to go through

- There is an immediate connection and you can reach people whenever you want

- There is global access to friends, other burn survivors, and information

- It provides connection from being socially and physically isolated

- It is encouraging and enlightening to hear other burn survivors journey

- It is important to have access to other burn survivors who understand me without judging

- Peer support from friends made me feel like I was part of the group

- Finding meaning from the burn experience that affects life choices

- Raising awareness on a large scale

- Motivating and supporting others is an important part of healing

- There is not much privacy

- I can share what I want and with whom I want

Identification of Essential Themes

Essential themes are the essences that make the phenomenon what it is and without them, it is not the same (van Manen, 1997). The process of discovery of the essential themes is supported by van Manen's fourth step of writing and rewriting. Themes were "examined, articulated, re-interpreted, omitted, added or reformulated" (van Manen, 1997, p. 100). This was done in collaboration with two expert researchers. This approach helped establish content validity and rigor.

In an effort to further establish validity and reliability, participants were further engaged in the research process when I sent them the list of themes and essential themes. I asked them for feedback on whether these themes described their experiences with social media use as a young adult burn survivor. Feedback was positive, with no changes indicated. One of the participants was anxious to read the entire study, as he felt it would "help him." The meaning of the context of the lived experience is described in the following five essential themes, which, in this study, describe the experience of young adult burn survivors' use of social media.

Essential Theme I: Identity

- This is who I am inside, behind the scars

- You can be who you want to be

- Chronicling my story using social media, informs others of what I went through and continue to go through

Essential Theme II: Connectivity

- There is an immediate connection and you can reach people whenever you want

- There is global access to friends, other burn survivors, and information

- It provides connection from being socially and physically isolated

Essential Theme III: Social Support

- It is encouraging and enlightening to hear other burn survivors journey

- It is important to have access to other burn survivors who understand me without judging

- Peer support from friends made me feel like I was part of the group

Essential Theme IV: Making Meaning

- Finding meaning from the burn experience that affects life choices

- Raising awareness on a large scale

- Motivating and supporting others is an important part of healing

Essential Theme V: Privacy

- There is not much privacy

- I can share what I want and with whom I want

Support of Essential Themes

Excerpts from participant interviews provide the narrative to support the five essential themes identified, thereby further establishing rigor. Quotes from participants enable their voices to be heard as they describe their experiences.

Essential Theme I: Identity

The following themes are contained in Essential Theme I: *This is who I am inside, behind scars; you can be who you want to be; chronicling my story using social media, informs others of what I went through and continue to go through;*

When asked to describe their experiences with using social media as young adult burn survivors, many of the participants began by telling their stories. There were stories of how they were burned, how they went through it, and what it meant to them to have scars. They identified

with the experience of being burned and expressed it using social media. Many of the participants or their family members chronicled the hospitalization and at home recovery on various social media platforms. Some chose to post pictures and some chose to write about it. One of the participants chose to make *YouTube* videos so that others could see what she had gone through. They wanted people to know what they had been through and how that defines who they are.

> Nicole: I used it a lot to transmit, share with people my journey of recovery. Um, I never posted a picture of myself till I posted pictures of me in the hospital. They were the first pictures I posted of myself online. And um it's been good. Trying to explain to 400 people what just happened to my life, like, if you missed it, here's what happened.
>
> Jessica: I started *YouTube* videos…to show the world what you've been through is immense. They look up to a person who has been through so much and yet …over passed their circumstances to be a somewhat better…I feel like I'm kind of a motivator.
>
> Peter: So throughout the, uh, the actual experience…my mom posted something for me on the Facebook. And then, uh, my girlfriend also was kind of sending updates to everybody so everybody knew how I was doing throughout the process. I mean, just communication in general. I didn't really, I mean, I have, I didn't really put pictures up or anything, obviously. Um, I mean, part of it is an outlet to share my story.
>
> Stephanie: I just got to the point where I was just like, "OK I'm going to have to accept it. Like, everybody's going to know when I go home anyways, so there's no point in like hiding it." So, eventually I kind of warmed up to the idea, like I let my parents like go on my *Facebook* and...I showed them what pictures they could put on.

They discussed the perception of their identity in terms of who they are, who they want to be, or who they don't want to be.

> Nicole: I went for the first 2 ½ years that I had *Facebook,* I didn't use my real name. Now, it still doesn't but it has my first and my middle [name], which is better than a made up name.
>
> Andrew: Hmmm, well, with the social media, you can kind of be whoever you want to be or be no one at all. I mean before the wreck I probably shared a lot more pictures of me.
>
> Lauren: So, that was one of my first concerns about social media was that , hey would I really be the person that I could be on this, could I really see past my physical difference and see me as a person when all they see is a picture.
>
> Christy: But, I have recently started using this dating website called Plenty of Fish. And, you know, I have a picture up with me with, I have like real, I have uh, makeup on, so you can't see the burns as much.

Social media provided a platform to express who they were inside without people judging them based on what they looked like. Many of the participants posted pictures, on social media sites, of art and music they like, quotes they found inspirational, stories they found funny, and other things that were important, interesting, or resonated with them.

> Andrew: I share some of my music that I found on Facebook. Uh, when words fail, music speaks. That's kind how I feel about music… (I) like re-sharing funny pictures I find. Some of them are profound in stuff and others are that just mostly posting pictures I find. I've always that been the kind of person that shares wisdom with people and that

hasn't really changed, whether they are just a good friend, or acquaintance or fellow burn survivor.

Lauren: Um, that's one of the things that I try not to put many photos of my say my scars…I like people to see me as who I am , and my personality, not necessarily worrying about the physical dynamics of my body.

Valerie: But, I think that the most affected by my burns would be the pictures. Just things like going to the beach and having that skin exposed makes me think twice about taking certain pictures and putting them up on line … I share pictures and music that I like I recently got into *Pinterest*…Yea, I put up a lot of pictures, um depending on what I'm doing or If I see something cool.

Christy: I sometimes don't like a lot of pictures of me, but I like to see pictures of the kids...So it feels good when I put pictures up of the kids because everybody's like, "Oh, they're so cute." And you know, it's like taking um, taking the distraction off of me and putting it towards them with positive, you know, So I'm doing the best I can to raise them, and people are noticing that, and that makes me feel good.

Stephanie: I'm expecting a child, and so that was kind of a huge thing because we're not really supposed to be able to have kids being SJS survivors, and so that's kind of brought up everybody's attention again, so like the trend, just follow along and see how I'm doing without me calling everybody.

Mike: So within a year and a half of my burn, I was graduating and going off to college, and *Facebook* was really big at that time and we, you know, start posting pictures and stuff, and I would always be a little self-conscious.. People ask about scars and stuff all the time…I'm sharing everything from just if I have random thoughts or if I see a good

article or something that I want to share, whether it be sports-related or …a funny picture. Pictures of what I've done.

Essential Theme II: Connectivity

The following themes are contained in Essential Theme II: *There is an immediate connection and you can reach people whenever you want; there is global access to friends, other burn survivors, and information; it provides connection from being socially and physically isolated.*

The ability to immediately "connect," whether it is to friends, family, or the World Wide Web was a very important aspect of social media for these young adult burn survivors. As a result of burns and complications of healing, these burn survivors were often isolated from activities and people with whom they would otherwise connect. They spoke of the ability to "connect" using social media how that connection to the outside world provided them with a sense of belonging. They were able to access and share information that helped them with the process of healing and getting on with everyday life.

> Nicole: So, it was my way to connect with my friends and to reestablish relationships and to feel involved in people's lives when I couldn't actually go out and meet people… Um, but then there are people that I don't see on a regular basis that I really want to connect with. And also, like all of the events from my church, college group and for other events, all the events go out through *Facebook*. You find out when the event is to actually go and see people. So, it's really important for me there…I can do it from the comfort of my bed or from the comfort of my home and um once I do that, it initiates the ball rolling to initiate connection and get involved again.

Andrew: It kind of allows instantaneous chat that you don't have to have. I feel that people feel more comfortable talking about almost anything over texts than they would in person. In person, people tend to be self conscious about how they look and how they talk and things like that... I use it for talking with my friends that back in North Carolina and sharing with a few I've made in here in Colorado... It's the primary way I communicate nowadays.

Lauren: One of the biggest things about being a burn survivor and being on *Facebook* is that I am on *Facebook*. Or that I'm on twitter. That I have these media outlets; that I'm able to connect with the world is that a lot of burn survivors like me, before I got that involved with social media, don't have…I just get a joyful feeling whenever I can connect with someone and make a difference in some one's life…So when I'm sittin' or waiting for a meeting to start or sittin' waitin' on class to start , I have that email that I can pull and read um and have that connection right there. Twitter gives me a connection with a world that is a million miles away.

Jessica: I got burned and I wasn't able to go out, and it just, it impeded me to do so much of what I used to do before I got burned…I was prone to get infections…I wanted to go out but my doctor was telling me, you know, "it's best for you to stay indoors." And, that is why…I would chat with them on *Facebook*. At the World Burn Convention that we attended, you know, it's, I love it because, you know, I found the majority of the ones who, you know, I was with those days, I found them on *Facebook.*

Valerie: The World Burn Congress is always far away…I don't run into a lot of other burn survivors in my everyday life. So, it's good seeing that there are other people out

there that have dealt with what I have dealt with… I graduated from college 2 years. So most of my friends that are not around here I keep in touch with on Facebook.

Christy: I use it to keep, uh, communication with family who live farther from me and I can't see them on a daily basis. … It means a lot because I don't really see anybody else around me who are burn survivors.

Peter: I definitely think it was more helpful than not, because otherwise people wouldn't have really known. .. So, it was easy to look up people that I've met through events like that. And, even through camp trainings, that I've been able to just kind of look up people and it's easier to find than somebody's phone. So, you can stay in touch with everybody… And also, um, they've been able to give me more opportunities, like different scholarships. So, that's how I found some of the scholarships is through that kind of networking.

Stephanie: I've connected with people that have had it [SJS] too. Like in my town there's like nobody has had it. My hospital has never even seen it. And um, I've, I actually heard about your study through somebody that I met on *Facebook* that was a Stevens-Johnson syndrome survivor,

Mike: *Facebook* is a great way to stay in contact with everybody. I use it, um, to stay in touch with friends. Sports, I get my, you know, sports updates very quickly on Twitter.

Essential Theme III: Social Support

The following themes are contained in Essential Theme III: *It is encouraging and enlightening to hear other burn survivors' journey; it is important to have access to other burn survivors who understand me without judging; peer support from friends made me feel like I was part of the group.*

Participants recognized the importance of social support in the healing process and in everyday life. They spoke about giving and receiving support through social media. It provided them with access to the stories that were posted on *Twitter, Facebook*, and other private burn social media sites. These stories gave them hope, inspiration, and motivated them. Social support from social media extended, in some cases, to the parents of burn survivors.

> Lauren: The girl that I was telling you about…She's connected with J.R., who was on Dancing with the Stars. She's really, really, close with him and just seeing her grow and just seeing the progress she's made from where she was you know, two years ago to where she is now is, you know, quite enjoyable.

> Valerie: I think it is definitely helpful, um, as a resource and just to see other people who have, you know, really cool stories and how they have overcome their burns…So, it's good seeing that there are other people out there that have dealt with what I have dealt with. And have stories, you know, worse than mine or similar to mine that I can get encouragement from or, um, things like that.

Peter described a chance meeting of parents of a young boy who was recently burned in a similar accident to his.

> Peter: I'm hanging out with (my friend's) parents and just talking to the family, and then they had friends come over that just had a son who had experienced, that basically had the exact same accident I did. They were looking for support from my friend's parents, and I just happened to be there. So, it was good that I kind of got to talk to them through the whole experience. And then, that was the one situation where they did actually give my information, they gave him my phone number and they gave him my *Facebook*, so I've been able to stay in touch with them and kind of help them through the process.

Mike: It makes me feel good. I mean, I know I had real, a lot of trouble when it first happened: angry, sad, all that stuff going through that. So, I know it's really nice to see people who are also going through it and like getting past it and moving on with their lives and living life to the fullest. You know, just basically just maintaining their lives after that…In my head at least, I was just like, "Will life actually go on? Like, is this the end? You know, can you move forward?" So, seeing people that have moved forward, as well, is really great.

Many of the participants identified with the need to share stories and gain information that would help them to progress through the healing journey. They spoke about how important it is to be in a judgment- free zone in which people who have experienced the same trauma can truly say, "I know how you feel." The participants shared the importance that social media played in finding other burn survivors with which to share the journey to survivorship.

Nicole: I used it to connect with people and I found this girl who had SJS. She's about 3 years younger than me I think and she had it a few months before me. And we kinda of grew in our recovery together, watched our hair grow.

Andrew: Before it was mostly high school friends and just like horizontal networking. Now a days, it's with other burn survivors…like uh… I use it for talking with my friends that back in North Carolina and sharing with a few I've made here in Colorado.

Lauren: I just get a joyful feeling whenever I can connect with someone and make a difference in some one's life. Whether it's just a "hey I'm really enjoying what you are doing."

Jessica: *Facebook* helped me make friendships…it's amazing to me, you know, it only, it took us only three days to build such a strong bond. And, I tell them, you know, it's

because we've experienced the same thing, we're taking the same journey, and you know

it's obvious that when you're in an environment where everyone around you looks

exactly like you, has suffered what you've been through, and has the same story to talk

about, You know, it's, it's kind of like there is a strong connection.

Valerie: Social media, yes. It definitely helps out a lot. It's definitely one of the ways I

connect with the burn community, it's out there. It's something I use to help heal and

feel better about myself and spread the word to others.

Christy: So it's pretty nice to see people who can have some type of relation—um, you

know, they can relate in some way, of a similar situation as to what I went through. I

know they're not judging me based on my scars because they have scars, too.

Peter: I've met like a ton of people. It's just easier because there's not anybody to talk to

about it. So when you meet people on *Facebook* that have had it, you can talk to them,

and… like me and her tell each other everything. We've never even met in person, so.

Stephanie: It helps a lot, actually. Because, like, you actually have somebody finally that

understands what you're going through and so other people are like, "Oh, suck it up."

And then you have them, and they're like, "No, I totally understand. Like you have a

complete, you have a reason to be upset. Like, "It's OK." And so it's just nice being

able to talk to people that fully understand. They're not just kind of get it because they

know what you went through… I've taught them things, they've taught me things. If I

discover something that like hurts or something, then I'll tell them, "I don't know if this

is for you, but I can't do this," and stuff like that.

A feeling of belonging is inherent in the need to connect with family and friends. The

participants of this study spoke about the positive feelings of "knowing" activities and events. In

addition, confirmation of understanding the effects of the trauma was also something that was conveyed from friends and family through social media. The young adult burn survivors felt caring when people commented on what they posted or when they did not post for a period of time.

Nicole: So it was my way to connect with my friends and to reestablish relationships and to feel involved in people's lives. I think I was at the three pictures that were warning signs on my album and um so I sent those um so that the first three pictures that FB posted wouldn't show my face to my or wouldn't show my injury to my peers. And, mostly right when I posted it, I got a big flurry of responses from most my non Christian and Christian friends saying what I had been through was a miracle… Having that encouragement, actually I've gone back to that several times because on *Facebook,* the comments are kept forever until you delete the picture.

Lauren: Twitter is hilarious. I follow a lot of funny, funny tweet things…they tweet different jokes, funny little sayings, and stuff like that. And it gives me a laugh; it gives me kind of an outlet...Twitter gives me a connection with a world that is a million miles away. White Collar, it films in NY actually but, I would have never known who is on set that day or what they are doing or the progress of the TV show, if I didn't follow the show's creator… I might not ever have the opportunity to see or anything like to see but it gives me that sense of, "That's cool, that's awesome, and I'm a part of something."

Essential Theme IV: Making Meaning

The following themes are contained in Essential Theme IV: *Finding meaning from the burn experience that affects life choices; Raising awareness on a large scale; motivating and supporting others is an important part of healing*;

For many of the participants, social media helped connect them to sources of information, including scholarships that were used to fulfill dreams and aspirations. Some of these life choices were a result of being burned and going through the experience that "changed their lives".

Lauren: It's kind of my link to the outside community. It's what I like to do in you know, what I like to volunteer for..I volunteer with the SOAR program at *** Hospital. So, a lot of my donations and a lot of my charity work go towards the burn survivor community…It gives me excitement and joy when I think about that.

Peter: But typing stuff out, it gears more towards what I gained from it and why I'm a better person and why I wouldn't take anything back that happened and all of that. And I feel like, as a doctor I could,… I feel like I could do something that somebody else could do. So, just that motivation and seeing the kind of pain people can be in, um, it kind of helps motivate me towards going down my career path and doing what I want to do.

Mike: I actually was awarded the scholarship for two years. So you know, I like reading, keeping up on that and just seeing what the young burn survivors who qualify for these scholarships, you know, what their story is, what they're hoping to do, stuff like that. I donate to just help support the cause. Like, I want them to be able to maintain and do what they do…and they need financial support to support it. So... after they gave support to me, I am more than happy to give my support back to them to help others that are, that are going through what I went through.

Part of the healing experience included raising awareness about burn prevention or Stevens - Johnson syndrome. It was also important for participants to share insights into their

reentry into society in the form of chronicling the healing process, including physical, psychological, and social issues. Some of the participants did this through production of *You Tube* videos, postings on *Facebook* and *Twitter,* sharing links and articles, sharing stories on burn and SJS support websites, and conducting fundraising activities to support awareness.

> Nicole: She wanted to learn about SJS and like I want to promote to everyone and actually at the bottom of my *Facebook* page, I have a URL at the bottom of my album, And, I've shared that with others. You can spread it and tell other people about it. Cause they can see my pictures with that URL, without being my *Facebook* friend.
>
> Valerie: I just wanna increase awareness for burn survivors and say, hey this is out there. I know one of the big times was when JR Martinez was on Dancing with the Stars and he came out with his incredible stories and say, "Hey, my friends might be interested in this and then they will also get to see that I was also part of this, the Phoenix Society burn groups." I don't know, it just makes me feel like I can help burn survivors by showing it to other people that might not necessarily see burn survivors.
>
> Christy: I would like to get to share my stories and how I cope with it and see how other people cope with the situation so maybe I could even learn something as to how to go about it if somebody were to approach me in the wrong way… And, I just wish, you know, I could let, you know, more people know about burn people, and you know, of course how to prevent it, but once you are burned, how to cope with it, and you know, to help others who aren't burned see the struggles that people like myself go through so they can stop teasing, and stop judging so fast without knowing the story, 'cause I don't like that.

Peter: So there's a lot of burn scholarships out there. So um, the more I tell the story like when I'm typing... which is more of like "this is what I learned, and this is what I overcame, and this is why I'm a better person because of it," and it gears more towards that, the feelings behind it instead of the actual events that happened, which is what people want to know when you're actually physically talking to them. They want to know what happened, why it happened.

Stephanie: It's just… at first I was going to try to do, like, a Relay for Life thing, but for Stevens-Johnson Syndrome …But, it was kind of hard to get everybody into that, so I just started, um, because a little boy in our town had got Stevens-Johnson Syndrome last year. And so it started it off as a page for him. It just describes in depth, like, what it is and I like openly put pictures of myself on it.

It was important for some of the participants to share their stories and be available as mentors, to others who have gone through similar experiences. They spoke about how they used social media to accomplish this and that it made them feel a sense of accomplishment. They considered themselves as motivational speakers, role models, and advocates for the "cause."

Andrew: It allows me to put myself out there in a virtual sense while I am still doing what I am doing being a student pursing a law degree and being a motivational speaker. You know out here in the real world… how many times a month a month, a day, it just flows off the tongue these days and that's kind of why I want to be a motivational speaker.

Lauren: It's AngelFacesRetreat.org and it's a non- profit organization that helps young women with facial disfigurements. Angel Faces has the, um, page which they post with

the new girls that go and so, I get to see these girls going through the program that I've been involved with.

Jessica: It motivates me (to help people), even people who aren't burn survivors, but who have, you know, people who have emotional scars, you know, that has played a major role, and that is the reason I started *YouTube* videos…to show the world what you've been through is immense…I feel like I'm kind of a motivator.

Essential Theme V: Privacy

The following themes are contained in Essential Theme V: *There is not much privacy; I can share what I want and with whom I want.*

Privacy, or the lack of it, was discussed when young adult burn survivors described their experience with social media. Some of the participants discussed the fact that there is not much privacy. They realized that what you post is out there for all to see. They discussed the consequences they perceived could occur when too much information is given. However, some of them were cautious about what they wanted to be shared and with whom, especially related to private burn-related social media sites.

Nicole: I used social media but I'm very sensitive and confidential about it. I went for the first 2 ½ the first half years that I had *Facebook*, It didn't use my real name…I don't have my profile picture on there but that has nothing to do with my injury. That's just cause my own privacy thing.

Andrew: How it's probably not a whole lot of privacy on there. It's only what you put out there so it's kinda of your own doing if you don't have any privacy.

Lauren: It's also a struggle of how much do I put out there and allow myself to go with and how do I connect with others.

Lauren: I try to keep it clean when I'm doing my tweet. If I tweet, you know, I live in a fish bowl. Like I said earlier, I'm over 302 girls, um that live in my residence hall and they see me tweet something with bad language they or that's offensive … they cannot trust me with information that they needed to come share with… On the Angel Face site, it's a private group…you have to be invited.

Jessica: I'm always open. I'm not a private person. I never hid my scars.

Valerie: I try not to make it too personal…keeping my personal life a little out of it but just letting people see a little part of my life.

Christy: I like to be truthful. Instead of trying to lie just to feel, make myself feel good, because I don't like to live a lie. I don't want them to think that I'm somebody I'm not.

Peter: I'll try to keep it relevant.

Stephanie: You can't keep it private. Everybody's going to know about It., no matter what whether you want them to or not.

Mike: First, I was hesitant to post any pictures that I had of me kind of with my scars showing. And, if people had pictures and they would tag me, you know, sometimes I'd go like, "Oh, should I un-tag myself so that others can't see?"

Synthesis of the Experience

Maintaining a strong focus on the phenomenon is the fifth step in the research process (van Manen, 1997). My commitment to the process of describing and understanding the lived experience of young adult burns survivors' use of social media added to the rigor of the study. Throughout the process, I strove to adhere to the methodology, further validating the integrity of the study.

The last step of the research process, as described by van Manen (1997), is balancing the research context by considering the parts as well as the whole. I kept the study grounded in the phenomenon by continually looking back at descriptions in relation to the lived experience of using social media. I identified significant statements of the participants' descriptions of experiences with social media. Themes were then identified from groupings of "like" descriptions. From these descriptions, the essence of the experience led to identification of essential themes, which embodied the meaning of the grouped themes. These were supported by narrative excerpts of each of the participant's interviews. I related the "parts to the whole" and formulated an interpretative statement to capture the essence of young adult burn survivors' use of social media.

Integrated Essential Essence

These young adult burn survivors, having experienced the traumatic effects of a burn during adolescence, use social media as a way of expressing their identity, while being cautious about privacy. Part of that process involves connecting with friends who are not connected to the burn experience, other burn survivors, and social networking sites that enable a flow of social support and information, which is motivating and encouraging. Social media facilitates an accessible exchange of information that helps young adult burn survivors make meaning out of the traumatic event.

Chapter VI

Reflections on the Findings

This study was conducted to illuminate the meaning of young adult burn survivors' experiences in use of social media. Participants in this study consisted of young adults who were burned prior to or during adolescence. van Manen's interpretative phenomenological approach (1997) provided methodology for this study. In-depth interviews were conducted and, through phenomenological reduction, five essential themes emerged.

This chapter describes a synthesis of the findings with previous research, and reflections of the relation to nursing care using Neuman's System's Model. Implications for nursing, study limitations, and future research are also presented.

Discussion: Synthesis of Findings with Previous Research

The structure of the experience of social media use by young adult burn survivors is illuminated and expressed in the essential themes of this study as follows: *identity, connectivity, social support, making meaning, and privacy.* Integrating essential themes with current literature contributes to a fuller understanding of the phenomenon. The following discussion represents a synthesis of the data with current literature.

Identity

The essential theme of *identity* incorporated the themes of: *this is who I am inside, behind scars; you can be who you want to be; chronicling my story using social media, informs others of what I went through and continue to go through.* These themes also appeared in recent studies of social media and identity. Davis (2013) studied the relation of digital media and identity formation in adolescents (n = 3791) ranging in age from 11-19. Online expression of identity was mediated by the quality of friendships, motivation to communicate online, and

quality relationships with their mothers. Conversely, there was a negative expression of identity that correlated with low quality of friendships. The researchers concluded that peer and parent relationships worked together to influence identity, which was expressed online.

The process of constructing online identities in adolescents was studied using a qualitative research methodology (Siibak, et. al. (2012). Adolescents, aged 13 and 14, participated in two separate workshops (n=16 and n=19), in which they constructed identities using both online and offline resources (photos, art, written characterizations, and drawings). Group discussion focused on themes that contributed to the identities they created. Researchers found that construction of a social online world was "intertwined" with participants' offline world. The benefits of creative self-expression using electronic and social media in construction of online identities empowered participants and enforced a feeling of "expert within." These processes enabled researchers to chronicle the formation of peer groups and the construction of norms within the group. This is consistent with findings of this study in which young adult burn survivors, who experienced burn trauma during adolescence, expressed their identity by sharing who they were through art, music, literature, and their roles in society. Social media became a platform for creative expression of who they are. Sharing this with peers fulfilled the developmental need of identity formation (Erickson, 1980).

Developing self-identity in relation to peer groups is a developmental task of adolescence in preparation for emergence into young adulthood (Beyers & Cok, 2008; Erickson, 1980). In a mixed methods study conducted by Pempek, Yevdokiya and Calvert (2009) undergraduate college students (n=92) kept a seven day diary chronicling how they used social networks and how much time they spent in doing so. A 52 question survey was administered after the seven days, which asked specific questions about students' use of social media. Although students

reported use of social media to *disclose* identity, their posts reflected information about themselves that contributed to *establishing* identity. These included "classic identity markers of emerging adulthood, such as religion, political ideology, and work, young adults also used media preferences to express their identity" (p 227). Within this age group, social media may have become a platform for self expression and identity formation without face-to-face contact and actual visual photographs. This is an important platform for adolescent burn survivors and others who are socially and physically isolated, to assist them in achieving the task of identity formation.

Disclosure of identity is consistent with the theme of *you can be who you want to be.* Walton and Rice (2013) studied micoblog postings on *Twitter* of self-identified social media professionals and moms/dad. In a three day period, 3751 postings were analyzed and grouped into common themes. Themes related to construction of identity and social roles were evident in relation to personal and private information. McAndrew and Jong (2012) studied social media use among 1026 *Facebook* users (mean age of 30.24). Participants completed surveys assessing profile statuses and online activities they engaged in. A factor analysis identified variables of social status, photos postings, management, and avoidances, family activity, and sharing information. They found that young women were more apt to use profile pictures and information that was geared toward self identity portrayal in relation to impression management. The findings of these studies are consistent with the theme of *you can be who you want to be*.

A correlational study of identity construction using social media and relation to depression and self-efficacy in people with cancer showed that participants' stories reflected their identities in relation to perceptions about their illnesses and survivorship (Song, et. al., 2012). Fourteen childhood cancer survivors participated in a six month intervention program, on

a customized social media network, where participants shared their stories in narratives. At the end of the intervention, participants completed a depression and a survivorship self efficacy scale. In this population, depression and low self efficacy, correlated with participants who associated with negative cancer stereotypes. Those who assumed positive identities in relation to their illnesses also demonstrated less depression and higher self efficacy.

In an ethnographic study of young women with cancer, aged 20 to 39 (n=16), it was found that participants used social media to self identify and chronicle their experiences with cancer (Keim-Malpass & Steeves, 2012). Ethnographic immersion and thematic analysis of blog postings identified a "new normal" as a means of self identity.

The essential theme of identity in young adult burn survivors' use of social media is supported by the literature as a developmental need of adolescents and young adults. In previous studies and this study, social media was identified as a platform for self expression and construction of identity in the general population of this age group and within certain illness groups.

Connectivity

The second essential theme of *connectivity* is expressed in the themes of: *an immediate connection and you can reach people whenever you want; global access to friends, other burn survivors, and information; and providing connection from being socially and physically isolated.* These themes are represented in the very nature of social media, which is virtual global connectedness to people, resources, and ideas (Ahn & Shin, 2013; Christakis & Fowler, 2009; Nelson, Joos, & Wolf, 2013).

A descriptive study of internet use conducted by the Pew Research center, identified teens and young adults as the group most likely to access social media as a form of connecting

(Lenhart, Purcell, Smith, & Zickuhr, 2010). Adolescents (n=800) and adults (n=2,253) participated in over 100 surveys of internet and social media use. Results indicated that over 73% of teens and young adults connected using social media platforms. Furthermore, young adults were identified as the group more likely to use social media to instantly connect, naming *Twitter* and *Facebook* as the popular sites.   This is consistent with the theme described by young adult burn survivors as *immediate connection and reaching people whenever you want.*

Online communities of people with similar health problems have been valuable in connecting people and disseminating information in people with burns and other specific populations (Badger & Royse, 2010; Cacioppo, Fowler, & Christakis, 2009; Keim-Malpass & Steeves, 2012; Panzera, et. al., 2013; Phoenix Society, 2012; Thielst, 2011). Zhao, et al (2013), studied the relation of trust, empathy, and social identity to knowledge sharing in a patient online community. Quantitative data analysis indicated that motivating factors of trust, empathy, and group cohesiveness contributed to knowledge sharing and support of others. They found that these types of on line communities connect people with the same illness and provide access to information about the illness.

An ethnographic analysis of data from a study of young adult women aged 20 to 39 (n=16) examined online narratives on cancer social media sites for people with cancer related symptoms. Information and emotional exchange was shared because of their abilities to connect in this specialized online community (Keim-Malpass & Steeves, 2012).

Within populations of people with specific illnesses, consequences of the illness or injury are that disabilities may result in physical and social isolation. Moi & Gjengedal (2014) illuminated the meanings of relationships to survivors of a major burn. In a phenomenological

study of 14 adults who survived a major burn, (mean age = 46), themes that emerged included inability to access social situations and barriers to regaining freedom.

In a qualitative study of social media use by 101 disabled participants, it was found that participants self identified to other people online about their disabilities including visual, hearing, physical and others (Tollefsen, et.al, 2011). Qualitative data from an open ended survey were analyzed. Consistent with the theme of connectivity, participants reported that social media helped them "feel like everyone" and "be where the others are" (p. 34).

The essence of connectivity in young adult burn survivors' use of social media is supported by the literature as an important aspect of gaining immediate access to people, support, and information for those who may be at risk for physical and social isolation. Social media facilitates regaining freedom by being connected. Social media platforms were found to be particularly useful with hard to reach populations, including those who are physically and socially isolated because of illness or disability. Young adult burn survivors identified social media as a way they connected when socially and/or physically isolated.

Social Support

Participants in this study identified *social support* from social media, as an essential theme expressed in the themes of: *it is encouraging and enlightening to hear other burn survivors' journey*; it *is important to have access to other burn survivors who understand me without judging; and peer support from friends made me feel like I was part of the group.* The need for social support for children and adolescent burn survivors has also been documented in the literature (for example, Badger & Royse, 2010; Christiansen, Carrougher, Engrav, et al, 2007; Edwards, 2001; Smith, Doctor, & Boulter, 2004; Travado, et al., 2001; Van Loey & Van Son, 2003).

In a phenomenological study of 14 adults after a major burn injury (mean age = 46), Moi & Gjengedal (2014) concluded that there is a need for social support to assist adult burn survivors to regain freedom. Participants described their experiences of relationships as having assistance from others and described the importance of sensitivity and competence of others. This is consistent with the findings of social support as described by these young adult burn survivors' use of social media, especially with regard to connecting with people who understand without judging, being able to regain freedom, and feeling like they were part of a group.

Social media has been used by burn survivor groups as a means of connecting to social support (Phoenix Society, 2012). In particular, young adult programs have brought together burn survivors in both face to face and virtual forums. Patient online forums, especially among cancer survivors, have been reported in the literature in relation to social support. In an ethnographic study by Keim-Malpass & Steeves (2012), online blogs of 14 women's stories of cancer allowed for sharing information, emotions, and social support. Participants in this study expressed a positive effect from social support, which contributed to transition through the illness and survivorship.

Participation in specialized online forums, by 14 young adult cancer survivors, was studied by McLaughlin, et. al (2012). Qualitative data analysis after of six months of participation on the site identified higher use of the site by participants who had weak offline bases of social support and used this platform to fulfill a need for social support. The need for social support and exchange of virtual support in an online infertility community was studied by Wellborne, Blanchard, & Wadsworth (2013). Participants (n=144) shared stories and information on virtual health communities focusing on infertility. They were surveyed for motivation, support exchange, connectedness, community, and stress. "**S**upport was associated

with greater sense of virtual community as well as more general feelings of connectedness, which was related to less stress" (p. 129).

In a qualitative study of hospitalized adolescents (n=20), content analysis of semi structured interviews focused on participants managing privacy on social media sites (van der Velden & El Emam, 2013). Chronically ill adolescents used social media as a way to connect to peers to gain social support and feel normal, while not disclosing information about their illnesses. Online peer support contributed to feeling like they were part of a social peer group which did not identify with their illnesses. A review of the literature by Mikal, et. al (2013) studied computer mediated social support in people undergoing a transition. Transition was associated with change and loss of social contacts and social capital. Social media facilitated reestablishing a support group after a transition or traumatic event.

Adolescent and young adult burn survivors, experience transition developmentally and in relation to the traumatic effects of being burned. Participants in this study illuminated the meaning of the experience of social media through the essence of social support. Social media provided global access to friends, information, and patient online communities. The exchange of support was motivating and comforting.

Making Meaning

The themes expressed for the essential theme of *making meaning* include: *finding meaning from the burn experience that affects life choices; raising awareness on a large scale; and motivating and supporting others is an important part of healing.* Young adults described their experiences of being burn survivors, in terms of making meaning out of the experience. Many of them described what they had been through and how they could now help others with similar experiences. Finding meaning from the burn experience put them on paths to choose

careers in the health care field, be motivational speakers, educate others about burn prevention, and raise money for burn survivor support groups. They found that this motivated them to cope with the trauma, which helped them to heal. Previous studies support better adjustment and coping in people who find meaning in the experience of a traumatic event or loss (Adler, et al, 2013; Armour, 2010; Henrickson, et al, 2013; Park & AI, 2006; Vis & Boynton, 2008). However, no studies have described social media in terms of making meaning.

The ability to find meaning in traumatic events that affect life choices is not universal (Armour, 2010). A phenomenological study of survivorship in 133 Holocaust victims who had immigrated to the United States identified "intentional engagement in behaviors designed to focus explicitly on the things that matter most" (p. 440) as contributing to their ability to make meaning and cope. A content analysis of taped interviews illuminated that their life choices reflected the meanings of survival, which included being successful, having a family, and not looking back. In addition, participants expressed making meaning as "fulfilling their obligations to those who died, and taking principled stands to fight hatred and oppression." This is consistent with the themes of (a) *raising awareness on a large scale and (b) motivating and supporting others is an important part of healing.*

The act of organ and tissue donation supports the making meaning theme of *motivating and supporting others is an important part of healing.* Making meaning of the death of a loved one was illuminated in a study by Hogan, Coolican, & Schmidt (2013). Content analysis of qualitative data identified that doing the right thing to help others helped families make meaning of the death by believing that something good came from it. In the cases described, spirituality played a major role for two girls.

Children frequently experience turning points related to developmental, social, and physical changes. In a correlational study with 418 adolescents, Tavernier and Willoughby (2012) examined the relation of ability to make meaning from a turning point event and psychological well-being in 418 adolescents. All participants completed scales measuring well-being. Quantitative analysis suggested ability to make meaning of a turning point event in adolescents was associated with higher psychological well being contributing to positive adjustment following a traumatic event.

In previous studies, investigators describe making meaning from traumatic experiences or loss in general, but do not specifically address burn survivors or social media. In this study, social media provided a platform for young adult burn survivors to make meaning out of the trauma of burn experiences through their use of technological tools, access to resources, and connecting with other burn survivors who benefitted from their online help. Because previous studies support the benefits of better coping, social media should be investigated as a viable means of helping young adult burn survivors and others who suffered trauma or loss, to make meaning of their experiences.

Privacy

The essential theme of *privacy* was expressed in the themes: *there is not much privacy; I can share what I want and with whom I want*. The meaning of privacy for young adult burn survivors is therefore, expressed as having no control and/or having total control when using social media. Privacy in social media is well referenced by other authors, especially in relation to children, adolescents, and young adults (Amanda, 2009; O'Keeffe & Clarke-Pearson, 2011; Park & Calamoar, 2103; Walton & Rice, 2013).

Social media posts by children, adolescents, and young adults are especially susceptible

to violations of privacy (O'Keeffe & Clarke-Pearson, 2011). A clinical report on the impact of

social media on children, adolescents, and families identified developmental issues related to

limited self-regulation, peer pressure and experimentation, which increases the vulnerability of

this age group to online privacy violations including bullying, sexting, and other privacy issues.

In a qualitative study (n=14) of adult burn survivors (Moi & Gjengedal, 2014) burn

survivors reported feeling insecure about revealing their altered physical appearance in public

and safeguard against public reaction. The essence of privacy and in social media use by young

adult burn survivors expressed by the theme of, *there is not much privacy,* addresses the

confidential nature of the circumstances the burn experience and their vulnerability. Private

social media sites for burn survivors and those with other physical deformities were discussed,

by young adult burn survivors, as sites that protected privacy. Private social media sites and

patient online communities are designed to connect participants and facilitate exchange of

information within specialized, protected online environments. However, confidentiality issues

related to disclosure need to be studied (Fitch, 2012; Kimball & Kim, 2013).

The theme of *I can share what I want and with whom I want* relates to disclosure.

Walton & Rice (2013) studied 3751 Twitter posts in a three day period and identified disclosure

of sensitive personal information in half of the tweets. In specialized online communities of

people with specific illnesses, disclosure influenced trust, empathy and willingness to engage in

information sharing (Keim-Malpass & Steeves, 2012; Zhao, et al., 2013). Privacy issues on

social media sites among chronically ill, hospitalized adolescents (n=20) were studied by van der

Velden & El Emam (2013). Content analysis of semi-structured interviews revealed that

disclosure about their illnesses was not discussed on open online forums. It was rather a place to

socially connect and be "regular." Having control over posting and disclosure may be difficult

for adolescent and young adult burn survivors with the culture of open and private social media

sites. Emerging technologies also make it easier to post varied content and increase the speed of

transmitting content.

The essence of privacy in social media use is addressed by many authors in relation to

implications for children, adolescents, and young adults.

Reflections Using the Neuman Systems Model Perspective

In reflecting on the synthesis of data with current literature, I referred to the Neuman

Systems Model to further illuminate the meaning of the experience (Neuman & Fawcett, 2011).

The overall meaning of young adult burn survivors' use of social media is expressed in the

integrated essential essence of: young adult burn survivors, each of whom experience the

traumatic effects of a burn during adolescence. These burn survivors used social media as a way

of expressing their identity, while being cautious about privacy. Part of that process involved

connecting with friends who were not connected to the burn experience*, other burn survivors,*

and social networking sites that enabled a flow of social support and information, which is

motivating and encouraging. Social media facilitates an accessible exchange of information that

helps these young adult burn survivors make meaning out of the traumatic event.

The Neuman Systems Model proposes that individuals are open systems made up of parts

in dynamic interplay within themselves and their environments. The degree of action and

reaction between individuals and their environments depends on the integrity of systems and

their boundaries, all of which are affected by stressors (Neuman & Fawcett, 2011). These

boundaries are indicated by concentric circles around the core as: normal lines of defense

(NLD), lines of resistance (LOR), and flexible lines of defense (FLD). The NLD represents the

current state of health achieved as having evolved over time. Neuman (2011) describes the LOR

as barriers that are activated to protect the core from stressors that break through the NLD. The

flexible line of defense (FLD) acts as a protective buffer for the NLD, or the current state of

health. Because it provides more protection, the FLD expands from the NLD, thereby protecting

and restoring health and homeostasis. Neuman's assumptions are that a person, when faced with

stressors, strives to achieve a steady state. The philosophical underpinnings of Neuman's

Systems Model are "holism, a wellness orientation, client perception and motivation, and a

dynamic systems perspective of energy and variable interaction…with the goal of optimal health

retention, restoration, and maintenance" (Neuman & Fawcett, 2011, p.12). Individuals, such as

young adults with physical scarring, strive to achieve balance when affected by stressors as

described by study participants.

The balance or steady state of participants in this study was affected by stressors related

to the burns and healing. Young adult burn survivors identified stressors in descriptions of their

stories about burn traumas and related healing processes. Study participants described their

stories in relation to their burn injuries. Detailed descriptions included events that led up to the

burn incidents. Participants spoke about where they were, what they were doing, and how they

felt when injuries occurred. Progression of their hospitalizations, discharge, and use of coping

strategies were described in the contexts of physical, psychological, and social impacts on their

lives. Physically, burns and scars were painful and contributed to limited mobility, which

affected face to face social interactions with friends and families. Psychological effects of

scarring also contribute to degree of willingness to disclose physical appearance. Many

described painful hurt feelings and withdrawing from social situations after being confronted

with negative remarks about physical appearance.

Within Neuman's model, physical, psychological and sociocultural variables are represented in all components of the model. This study illustrates the lived experience of young adult burn survivors with use of social media in terms of social interactions with families and communities such as friends, groups of burn survivors, church groups, college communities, and work environments. Participants described social media as a way to connect to gain access to social situations without face to face contact. These interactions were described by participants as social support and were identified as an important part of healing, which is expressed in the themes of: *it is encouraging and enlightening to hear other burn survivors' journeys*; it *is important to have access to other burn survivors who understand me without judging; and peer support from friends made me feel like I was part of a group.* According to Neuman, components of social variables work together with other components of individual systems in holistic exchanges of energy in attempts to achieve wellness or a steady state. Homeostasis or steady state is achieved through feedback, which aids systems in self regulation. Steady state is referred to as achieving a desired goal or state of health.

The findings of this study identified in the theme of *social support* align with tenets the Newman Systems Model (2011). Participants' descriptions of their increased need for social support to assist in healing processes may be depicted in the normal lines of defense (NLD), which represents what each person has become. In addition to increased need for social support, young adult burn survivors in this study experienced decreased face to face interactions that could have provided social support. In coping with this stressor, participants gained access to social support through social media, thereby activating the flexible line of defense. Access to social support through social media may have assisted them in healing processes and in achieving a steady state within a new normal.

Implications for Nursing

The findings of this study suggest ways in which nurses can participate in helping burn survivors tell their stories, and consider ways that assist them to self-identify and connect to others, using social media as a vehicle. Although more study is needed, use of social media with children and adolescents who are burned may be warranted to help in healing processes. Access to the Internet and social media platforms such as *Facebook, Twitter,* and *YouTube* could begin during hospitalization. Participants in this study used various forms of social media to tell their stories, connect, communicate and self identify.

Nurse-led programs could encourage self identity through writing and self expression using electronic media in addition to other tools. Practicing nurses can use forms of social media to help children and adolescents who are burned and encourage use of interactive online programs that focus on health protection and maintenance, e.g., programs that connect burn survivors with available resources.

Connectivity and global access to resources and people, while physically and socially isolated, were identified by participants in this study as ways of gaining social support. Nurses can address computer literacy and help children and adolescents with burns to improve literacy as needed (Nelson, Joos, & Wolf, 2014). Interactive programs of health promotion can be developed that facilitate long term relationships of burn survivors with nurses, which may contribute to continued knowledge development and help from nurses (Keim-Malpass & Steeves, 2012). In addition to encouraging face to face interaction, nurses can suggest ways to access interactive online programs that promote resource utilization for healing and social support (Park & Calamoar, 2103). Links to burn survivor organizations and specialized online communities can be provided to facilitate connectivity and global access to resources.

The role of nurse educators is to translate social media knowledge into educational programs (Agazio & Buckley, 2009; Nelson, Joos, & Wolf, 2014). Based on the findings of this and many other studies, nursing education programs should include a strong emphasis on social media use for health promotion, health protection, and health restoration

Social media use can connect adolescents and young adult burn survivors who may feel disconnected from society. Nurse led programs for children and adolescents who were burned can focus on prevention of problems and reestablishment of a steady state. Social media can supplement face to face connections and provide additional means for burn survivors to connect as they transition to a new normal.

Limitations

A limitation of this study is that results cannot be generalized to all young adult burn survivors because other burn survivors may not use social media. Access to social media and motivation to use it may affect the experiences of some burn survivors, which limits generalizability of the results. The experiences of young adult burn survivors who use social media may not be represented in the population of young adult burn survivors who do not use social media.

Since this study included participants from many different areas of the United States, *Skype*, a social media platform, was used to conduct the interviews. Some researchers may construe the lack of face-to-face interviews as a limitation. However, there was no evidence that the interview experiences were negatively affected by using *Skype*. In fact, at times, I was able to experience the environmental conditions being experienced by participants. Heat, fresh cool air, levels of anxiety, and comforts were all transferable from participants to the researcher, as documented in my journal.

Implications for Future Research

Additional research is needed with young adult burn survivors who do not use social media, to understand the healing process. Studies of social media use with other groups of young adults who have had traumatic injuries or chronic illnesses, and with healthy young adults could provide insight into other variables related to social media use in this age group. In addition, future research should include quantitative studies measuring the relation of the variables identified as essential themes to use of social media in young adults and longitudinal studies measuring identified themes and social media use in adult burn survivors.

Qualitative phenomenological studies of young adult burn survivors who do not use social media would provide additional information in relation to recovery experiences and healing. Comparative analyses of those who do not use social media would provide further data with regard to social media use and healing processes. It may, however, be difficult to obtain an adequate sample size of this age group who do not use social media.

Future research should include replicating the study in other groups who are socially and physically isolated and have suffered traumatic injuries or chronic illnesses. Similarities between groups of children and adolescent who were traumatized, such as physical and psychological scarring, developmental age and needs, physical and social isolation, and access to social support suggest that similar themes may be identified in each group.

Replication of this study with healthy young adults to see if the same themes are identified would provide valuable information about social media use. A comparative analysis of social media use by both young adult burn survivors and young adults in general, would provide information in relation to other variables and themes.

Longitudinal studies could be conducted to determine whether these same essential themes are considered important in the lives of burn survivors when they are middle aged or older adults. In longitudinal studies, additional themes may be identified that would guide nursing care.

Conclusion

Young adult burn survivors, having experienced the traumatic effects of a burn during adolescence, use social media as a way of expressing their identity, while being cautious about privacy. Part of that process involves connecting with friends who are not connected to the burn experience, other burn survivors, and social networking that enable a flow of social support and information, which is motivating and encouraging.

A literature review confirmed that many of the issues discussed in this study were universal in relation to age, social media, trauma, and chronic illness. However, the holistic perspective of this study described the relation of the essential themes to young adult burn survivors' use of social media. Participants discussed survivorship in relation to social media. Important issues such as identity and telling their story, connecting with others for social support, disclosure and privacy, and meaning making are paramount in the re-entry of young adults after the traumatic experience of the burn. Social media provided the platform through which participants addressed these issues, as part of the healing process.

Making meaning of a trauma or loss was discussed in the literature as a component of the healing process. Accepting the "new normal" is discussed in the burn and making meaning literature (Keim-Malpass & Steeves, 2012; Moi & Gjengedal, 2014). In this study, participants made meaning the "new normal" by using social media. Social media helped connect groups together where information was shared and support was given in a caring, nonjudgmental,

understanding way. This helped transition to the "new normal," while seeking ways to make

meaning out of the event or illness.

Appendix A
CITY UNIVERSITY OF NEW YORK
The College of Staten Island & The Graduate Center
Department of Nursing
CONSENT TO PARTICPATE IN A RESEARCH PROJECT

Project Title: <u>THE LIVED EXPERIENCE OF YOUNG ADULT BURN SURVIVORS' USE OF SOCIAL MEDIA</u>

Principal Investigator: *Marie Giordano, Graduate Student, CUNY Graduate Center,* <u>mgiordano@gc.cuny.edu</u>, (718) 982-3836

Faculty Advisor: Dr. *Margaret Lunney, Professor / Dissertation Sponsor, College of Staten Island, CUNY,* <u>margaret.lunney@csi.cuny.edu</u> , *(718) 982-3845*

<u>Introduction/Purpose</u>: Marie Giordano is a doctoral student in the Department of Nursing at the Graduate Center, City University of New York. She is conducting a study about the use of social media by young adult burn survivors. You are being asked to participate in this study because you are a young adult burn survivor who uses social media. Approximately 20 subjects are expected to participate in this study.

<u>Procedures:</u> You are being asked to participate in an interview, which will either be in person or online using SKYPE. During the interview, you will be asked questions about what is it like to be a young adult burn survivor using social media. The interview will be audiotaped. The interview will last approximately one hour and there will only be one interview.

<u>Possible Discomforts and Risks</u>: The risks from participating in this study are minimal in that they are no more than encountered in everyday life. It is however possible that discussing your experience may raise difficult issues for you. In the event that this happens, the researcher has a list of resources that you may contact for assistance should you need them. You may choose not to answer a particular question and to stop the interview process at any time. Your participation is voluntary.

<u>Benefits</u>: There are no direct benefits. However, your participation in this study may increase the knowledge about what it is like for young adults who have been burned to use social media. After participation in the interview, you will be given a $50 Visa gift card as a token of appreciation for participation in this study.

<u>Voluntary Participation</u>: Your participation in this study is voluntary, and you may decide not to participate without prejudice, penalty, or loss of benefits to which you are otherwise entitled. If

you decide to leave the study, please contact the principal investigator *Marie Giordano* to inform her of your decision.

Confidentiality: The researcher and a professional transcriber are the only ones who will listen to the tapes. All identifying information about you will be omitted or disguised in the form of codes. Tapes will be destroyed after the study is complete. All materials will be kept in a locked file cabinet in the researcher's office, accessed only by the researcher or her dissertation sponsor. It will be stored for a minimum of three years and then it will be destroyed. This information will be used to produce a doctoral dissertation. Only aggregate data will be used in any reports or publications derived from this research. The researcher is mandated to report to the authorities if you are in imminent danger or harming yourself or if there is suspected child abuse.

Contact Questions/Persons: You may discontinue participation at any time without penalty or loss of benefits. If you have any questions about the study, you can contact the researcher, Marie Giordano at mgiordano@gc.cuny.edu or at (718) 982-3836, or her dissertation sponsor Dr. Margaret Lunney at margaret.lunney@csi.cuny.edu or at (718) 982-3845. If you have questions regarding your rights as a subject or if you feel you have a research related injury, please contact Angela Cartmell at the CUNY Institutional Review Board at (718) 982-3867, angela.cartmell@csi.cuny.edu.

Statement of Consent:
"I have read the above description of this research and I understand it. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions that I may have will also be answered by the principal investigator of the research study. I voluntary agree to participate in this study.

By signing this form I have not waived any of my legal rights to which I would otherwise be entitled.
I will be given a copy of this statement."

_____ _____   _____
Printed Name of   Signature of Subject   Date Signed
Subject

_____ _____   _____
Printed Name of   Signature of Person Explaining Consent Form   Date Signed
Person Explaining
Consent Form

_____ _____   _____
Printed Name of   Signature of Investigator   Date Signed
Investigato

Appendix B
Participant Survey Questionnaire

1. How old are you now?_____

2. How old were you when you were burned?_____

3. Date of burn_____/_____/_____

4. Are you male or female?_____

5. If you have a religious affiliation, what is it?_____

6. What is your ethnicity or culture?_____

7. How would you describe where you live?

City/Urban_____   Suburb_____   Rural_____   Other _____(describe_____)

8. How long were you hospitalized for burns?_____

9. What is the percent of burn sustained?_____

10. Where were you burned? (check all that apply)

   ___face   ___neck   ___back   ___arms

   ___head   ___chest   ___genitalia   ___legs

11. Do you use social media?

   ___Yes   ___No

12. Which one(s)?

   1. _____

   2. _____

   3. _____

   4. _____

   5. _____

13. How many hours per week do you spend using social media?

   _____

Appendix C

Resources available if there is any emotional/psychological discomfort related to our discussion

- New York Presbyterian Medical Center/ Cornell
  525 East 68th Street
  NY, NY 10021
  (888) 694-5700

- New York Presbyterian Medical Center/ Cornell
  622 West 168th Street
  NY, NY 10032
  (212) 305-6001

Online or Phone

- www.abct.org

- www.phoenix-society.org

- 1-800-LIFENET

Appendix D
Invitation to Participate

ATTENTION YOUNG ADULT BURN SURVIVORS
Invitation to Participate

You are invited to participate in a research study looking at your experiences using social media as a young adult burn survivor.

My name is Marie Giordano and I am a nurse and doctoral student in Nursing. I am studying what it is like to use social media as a young adult burn survivor. I would like to hear your story about your experiences in this area.

Participants must be:

- Between the ages of 18 and 25
- Have sustained a burn before the age of 19
- Have sustained at least 30% burn (flame, scald, chemical, Stevens Johnson Syndrome)
- Been hospitalized for at least 2 weeks
- Use social media

The study consists of an interview which may last for approximately 30 to 60 minutes. I would arrange to meet you wherever it is most convenient for you. If distance prevents meeting in person, an online meeting, using *Skype*, can be arranged. Your participation is completely voluntary. All participants completing the study will be given a token of appreciation ($50.00 gift card).

Interested parties' should contact:

Marie Giordano
mgiordano@gc.cuny.edu

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