PATIENTS' AND CAREGIVERS' EXPERIENCE OF SOCIAL SUPPORT ON CARINGBRIDGE

by

Rosaleen Duggan Bloom

A dissertation submitted to the faculty of
The University of Utah
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

College of Nursing

The University of Utah

December 2017

The University of Utah Graduate School

STATEMENT OF DISSERTATION APPROVAL

The dissertation of **Rosaleen Duggan Bloom**

has been approved by the following supervisory committee members:

Lee Ellington , Chair **8/11/2017**
Date Approved

Susan L Beck , Member **8/11/2017**
Date Approved

Wen-Ying Sylvia Chou , Member
Date Approved

Maija Anne Reblin , Member
Date Approved

Andrew Ralph Wilson , Member **8/11/2017**
Date Approved

and by **Patricia G Morton** , Chair/Dean of

the Department/College/School of **Nursing**

and by David B. Kieda, Dean of The Graduate School.

ABSTRACT

Family caregivers to cancer patients face stresses and burdens that may be buffered by receiving social support, and social media may provide a forum to receive support. Little research has examined how caregivers share their experiences on social media, however, and how this disclosure affects the support they receive. Guided by the model of social support elicitation and provision, this retrospective, longitudinal, descriptive study explored cancer caregivers' experience on CaringBridge to address four aims (*N* = 20 public-access cases). Each case comprised all journal entries and all guestbook postings. A content analysis identified categories of caregivers' experiences: patient health information, cancer advocacy, social support, burden, daily living, emotions, and spirituality. The Social Support Behavior Coding system was used to code requests and offerings of support. Throughout the cases, there were journal entries (JEs) and guestbook posts that contained multiple requests for or offers of different types of social support. For example, a caregiver may have requested both emotional and tangible support in the same JE and a guest may have provided both emotional and tangible support in return. Caregiver requests consisted of emotional (27.76%), informational (0.77%), network (7.97%), and tangible (6.68%) support, but not esteem support. Guests offered emotional (97.51%), esteem (23.70%), informational (2.82%), network (18.19%), and tangible support (9.24%). The matching of request and offer of support was examined descriptively. When support was requested, 66.67% were matched with support within 24 hr and 70.24% within 7 days. Data visualization tools were used to explore directionality of support, changes in directionality at transition points, and changes in support over time, using postings from 3 cases. Data visualization demonstrated that support was directed at patients and families but not solely at caregivers; support direction shifted from the patient to the family at or near death for 2 of the cases; and there was a pattern of gradual decline in postings until the patient's death, when postings increased. Future research should explore ways (a) to ensure that caregivers are eliciting helpful support, (b) to examine the benefits to caregivers when the network responds with support, and (c) to develop ways to prevent support from fluctuating over time.

Never believe that a few caring people can’t change the world.

For, indeed, that’s all who ever have.

—Margaret Mead

There are four kinds of people in the world:

those who have been caregivers,

those who are caregivers,

those who will be caregivers,

and those who will need caregivers.

—Rosalynn Carter

This dissertation is dedicated to the many cancer patients, families, and friends I have met who showed me the important work that caregiving is and will always be.

TABLE OF CONTENTS

Chapters

Appendices

LIST OF TABLES

Tables

LIST OF FIGURES

Figures

LIST OF ACRONYMS AND ABBREVIATIONS

Acronyms/Abbreviations	
ACS	American Cancer Society
CDC	Centers for Disease Control and Prevention
FCA	Family Caregiver Alliance
GP	Guestbook posts/postings
HIPAA	Health Insurance Portability and Accountability Act
IOM	Institute of Medicine
IRB	Institutional Review Board
JE	Journal entry
NCI	National Cancer Institute
REDCap	Research Electronic Data Capture (University of Utah)
RQ	Research question
SACHRP	Secretary's Advisory Committee on Human Research Protections
SD	Standard deviation
SNA	Social network analysis
SPSS	Statistical Package for the Social Sciences
SSBC	Social Support Behavior Codes
UCLA	University of California, Los Angeles

ACKNOWLEDGEMENTS

I began this journey not knowing what to expect or the obstacles before me as I pursued a lifelong dream of earning my doctorate. Throughout this journey, so many people have helped me along the way, and I cannot even begin to describe all that my support system has provided me, but I will attempt to now.

To my mother and father, who instilled in me a love of lifelong learning and the importance of kindness and compassion. I have followed in the footsteps of my mother and her passion for oncology nursing. She gave me the gift of my first membership in the Oncology Nursing Society (ONS), and encouraged me to obtain my first oncology certification and to attend my first ONS Congress. She has always inspired me to challenge myself and to keep going even when times get tough.

To my husband Steve: Without his support, I could never have accomplished this work. For all the days he encouraged me to keep going and watched our sweet boys so that I could dig in. Even on the days I did not want to do anything, he told me to just do 15 minutes; then those 15 minutes would turn into hours, and finally this product was created.

To my two beloved boys, Desmond and Ian, who have taught me what being a family caregiver means, to a deeper level than I have ever known. Their sweet smiles, giggles, and love replenished my spirit.

To the members of my committee, who each pushed me to look harder, think longer, explore further, and grow every step of the way. As a whole, their passion for this research and their creativity and knowledge were integral to this dissertation.

To my chair, Lee Ellington, who always reminded me of the importance of my work, and whose input and feedback were integral to the final product you see before you. She kept me going with her encouragement and passion for the work I was doing. Our biweekly and weekly talks helped me to maintain my focus, and she could always help me begin again when I struggled to keep going.

To Susan Beck, who helped me when I couldn’t see the forest for the trees. She helped me refocus, regroup, and work through my struggles with how to frame and understand my work.

To Sylvia Chou, who inspired me in my social media research quest. Her knowledge of social media research and the complexities of my work aided me so much along the way.

To Maija Reblin, whose knowledge of social support and willingness to get down into the trenches with me and help me learn how to code were immeasurable.

To Andrew Wilson, for helping me to understand my data and grapple with the complexities of attempting statistics on a natural data set.

To The Sisterhood—the five women who started this doctoral journey with me. Meeting them has forever enriched my life. Hollie Devine, Hilda Haynes-Lewis, Jill Olausson, Marie Seitz, and AnnMarie Walton are my people. I could not imagine a day or moment of this program without all of them. They lifted me up at my lowest points, and taught me to always believe in myself and to have hope. To AnnMarie: Thank you for being my second coder, especially when the task was larger than we had imagined. To

Marie, for always being there for a midnight phone call or a visit. To Jill, for always bringing joy and showing the importance of work–life balance. To Hilda, my roomie for life, whose positivity and love of life always brighten my day. To Hollie, who was the first person I met when I landed in Salt Lake City, and who is an inspiration in her resolve to keep going.

Finally, to my oncology mentors and friends, who have taught me and encouraged me along the way: Dianne Brundage, Vicki Norton, Andrea O’Hern, Bryan Schuler, Kim Wedin, Millie Toth, Gwen Corrigan, Rebecca Schmid, Kimberley Konovalenko, and all of the other wonderful oncology colleagues I have met over my career.

CHAPTER 1

INTRODUCTION

Problem Statement

A cancer diagnosis is a significant life-changing event for cancer patients, which extends to their informal caregivers—including friends and family. The experiences of cancer patients and caregivers vary based on diagnosis, treatment options, goals of treatment, and the progress and setbacks each family experiences along the way (Dubenske et al., 2008; Ellis, 2012; Given, Sherwood, & Given, 2011; Shaw et al., 2013). The initial diagnosis and changes in the cancer trajectory often prompt one's social support systems to engage and provide resources for coping; however, this support may diminish as time passes (National Cancer Institute [NCI], 2017a). This decrease in support is potentially due to the chronicity of cancer and the difficulty in keeping the support network engaged (NCI, 2017a). One of the key support systems for cancer patients is their caregivers, who are crucial in providing care and support (NCI, 2017a); however, caregivers face not only many of the same obstacles as patients, but additional ones related to caregiving.

Research has shown that cancer caregivers share in cancer patients' experiences of psychological distress (Northouse, Katapodi, Schafenacker, & Weiss, 2012). Caregiver distress increases along with patient distress when significant events occur (McGuire, Grant, & Park, 2012; Northouse, Katapodi, et al, 2012; Shaw et al, 2013). These significant events range from unanticipated events, such as unexpected hospitalizations, disease progression, and cancer recurrence, to anticipated events, such as chemotherapy, radiation, and planned surgery (Blum, & Sherman, 2010; Dubenske et al., 2008; Ellis, 2012; Shaw et al., 2013). Patients and caregivers are at an even greater risk of psychological distress when multiple events occur, as stress and burden increase significantly (Meleis, 2010; Schlossberg, 2011). The cancer course often causes isolation for cancer patients and caregivers (NCI, 2017a). A lack of personal and social support increases the likelihood that a cancer caregiver will be distressed (NCI, 2017a). Cancer caregivers' distress and burden can lead to long-term adverse health effects (Northouse, Williams, Given, & McCorkle, 2012). Social support provided directly to caregivers could help relieve these psychological burdens and alleviate the physical effects of caregiving if caregivers' needs are met (Northouse, Williams, et al., 2012; Reeves et al., 2014). Few studies have examined caregivers' needs throughout the full course of the cancer trajectory, however (Given, Given, & Sherwood, 2012).

The needs of caregivers identified in the current literature include information about disease/treatment; how to carry out caregiving tasks; how to relate to the patient, to the family, or to other individuals; financial and legal assistance; assistance with coordination of care; and transitions from hospital to home (Dubenske et al., 2008; Shaw et al., 2013). Social support is crucial during stressful times, as friends and family help patients and caregivers process the subsequent ramifications of the diagnosis and decisions about treatment. A supportive, receptive, and noncritical environment helps the individual by suggesting new and positive perspectives, providing information on how to cope, and offering encouragement (Lepore, 2001).

As our society becomes more connected via the Internet, research has increasingly focused on how social support may be provided using technology and social media (Yao, Zheng, & Fan, 2015). Social media is the use of the Internet to create virtual communities in which data are shared (Duggan, Lenhart, Lampe, & Ellison, 2015). Social media sites used by cancer patients and caregivers include CaringBridge, CarePages, PatientsLikeMe, Facebook, MySpace, YouTube, LIFECommunity, online support groups, and professional and personal websites/blogs (Anderson, 2011; Bender, Jimenez-Marroquin, & Jadad, 2011; Bender et al., 2012; Chou, Hunt, Folkers, & Augustson, 2011; Clerici, Veneroni, Bisogno, Trapuzzano, & Ferrari, 2012; De la Torre-Díez, Díaz-Pernas, & Antón-Rodríguez, 2012; Farmer, Bruckner Holt, Cook, & Hearing, 2009; Frost & Massagli, 2008; Iredale, Mundy, & Hilgart, 2011; Keim-Malpass & Steeves, 2012; Kim & Chung, 2007; Lam, Roter, & Cohen, 2012; Setoyama, Yamazaki, & Namayama, 2011; Song et al., 2012; Suzuki & Beale, 2006; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008). Social media is uniquely positioned to bring social support to patients and caregivers wherever they may be throughout the cancer continuum, as it can reach them even in isolation at home or in the hospital (Yao et al., 2015).

The Centers for Disease Control and Prevention (CDC) considers caregiving a public health priority (CDC, 2016a). As the population ages, the need for family caregivers will rise across all diagnoses (CDC, 2016a); there will be a clear gap between the number of individuals needing care and the number of caregivers available (CDC, 2016a). Family caregivers report significant distress—equal to or exceeding that of patients (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007; Girgis & Lambert, 2009;

Lambert, Girgis, Lecathelinais, & Stacey, 2012). Caregiver distress can lead to declining physical health, decreasing financial stability, and diminished immune function (Northouse, Williams, et al., 2012).

Early descriptive findings of social media use indicate that patients and families benefit from the emotional and spiritual support offered by visitors to these sites, which also offer the convenience of communicating to large groups of people quickly and connecting with other individuals with similar experiences and diagnoses (Anderson, 2011; Bender et al., 2011; Bender et al., 2012; Kim & Chung, 2007; Suzuki & Beale, 2006). This research study adds to the current understanding of how caregivers' journal entries (JEs) and family and friends' guestbook postings (GPs) create a social support network in the digital age, and how this support changes throughout each patient's cancer course.

Significance

General use of the Internet, as well as social media use, crosses all racial and ethnic groups, genders, urban and rural communities, and levels of socioeconomic status (Kontos, Emmons, Puleo, & Viswanath, 2010; Perrin, 2015; Pew Research Center's Internet and American Life Project, 2011). The number of adults using social media in 2015 increased almost 10 times the 2005 numbers, with approximately 65% of adults using social networking sites (Perrin, 2015). Older adults, also, are adopting use of the Internet, with 67% of individuals age 65 and older reporting its use (Anderson & Perrin, 2017). An increasing number of older adults are also on social media, with use increasing from 11% to 35% from 2010 to 2015 (Perrin, 2015). Just as general Internet use is rapidly expanding, the use of social media for general communication, and specifically for health-related information and communication, is increasing (Prestin, Vieux, & Chou, 2015).

Caregivers are at the forefront of health-related utilization, and their use surpasses that of noncaregivers, including patients (Pew Research Center, 2013). Of late, more and more individuals own smartphones (77% of adults, per Anderson & Perrin, 2017), so that even if an individual does not own a computer he or she is able to access the Internet through a smartphone. Additionally, many hospitals provide computers for patient and caregiver use during their hospital stay or clinic visit. As social media use grows, it has in some cases supplemented or complemented face-to-face or telephone interactions between individuals, becoming the primary method of communicating about a health event. Researchers are beginning to examine similarities between social support offered by these sites and social support offered in face-to-face interactions (Yao et al, 2015).

A subset of social media sites specifically focus on supporting patients and families during a health event. CaringBridge (the focus of the current study) and CarePages are the most well-known sites designed for support. CaringBridge has an average of 300,000 visitors per day and CarePages has over a million unique visitors per month (CarePages, 2017; CaringBridge, 2016). The individual websites are centered on the patient, although, in the case of CaringBridge, caregivers comprise the majority of site owners (K. Palmstein, personal communication, April 23, 2013). As caregivers continue to use these sites in greater and greater numbers, it is important to understand how they share their experiences. What they share may impact what support is received and how visitors to the sites direct their social support. Support may be directed at the patient, the family caregiver, or the entire family. If support is primarily directed to the patient, this may potentially impact how much benefit the caregiver gets from the support received. Other available social media sites focus on meeting caregivers' tangible needs. Caregivers can create calendars of needed tasks and guests can sign up to provide support on websites such as Carezone, SignUpGenius, and Lotsa Helping Hands (Carezone, 2017; Lotsa Helping Hands, 2015; SignUpGenius, 2017). Some sites also focus on financial aspects of tangible support, such as fundraising sites like GoFundMe, which can be used to collect donations (GoFundMe, 2017).

We need to understand how caregivers use social media and how guests respond to caregivers' writings. Understanding how social support provided through social media impacts caregivers, both positively and negatively, can lead to strategies to maximize social media to reduce caregiver burden and improve coping and psychological adjustment. Research has shown that social support may help alleviate caregiver distress and burden, as well as improve quality of life and physical health (Choi et al., 2012; Ownsworth, Henderson, & Chambers, 2010). This study can guide further research as we refine and create social media tools to further support for caregivers and patients through these websites.

Summary of Pilot Study

A pilot study was conducted to examine the feasibility and pragmatic logistics for conducting research on the website, CaringBridge. During the pilot study, methods for case selection and data extraction were developed. Additionally, analytic techniques were trialed, including directed content analysis and social network analysis. A summary of the pilot study is presented in Chapter 3; the results of the pilot informed the aims, methods, and analysis of the current study.

Specific Aims and Research Questions

The following are the aims and research questions (RQs) related to this study.

Aim 1: To explore the caregiver's experience as expressed on CaringBridge

RQ 1.1: *How are the activities of caregiving described by caregivers?*

RQ 1.2: *Do caregivers write about the psychosocial impacts of the cancer diagnosis on themselves? If so, what do they write about?*

Aim 2: To describe the types of social support (informational, tangible, emotional, network, and esteem versus no request/offer of social support) patients and caregivers request in journal entries and the social support guests offer in guestbook entries

RQ 2.1: *What is the relative occurrence of the different types of social support in each posting by caregivers/patients in their journal entries and by guests in their guestbook entries?*

RQ 2.2: *What subcategories/themes are evident within each type of social support (informational, tangible, emotional, network, esteem, or no request for support)?*

Aim 3: To examine the relationship between the types of social support (informational, tangible, emotional, network, and esteem versus no request for/offer of social support) patients and caregivers request in journal entries and the social support guests offer in guestbook entries

RQ 3.1: *To what extent are requests for types of social support related to types of social support received?*

Aim 4: To explore the response (social support type and direction) of the CaringBridge social support network to the patients' and caregivers' postings using data visualization techniques as a proof of concept

RQ 4.1: *For 3 selected cases, to what extent do guests direct social support to caregivers versus patients versus families (e.g., patients and caregivers)?*

RQ 4.2: *For 3 selected cases, how does the guest network respond with social support to journal entries over time?*

RQ 4.3: *For 3 selected cases, what are the patterns of social support?*

Innovation and Contribution

By examining cancer caregivers' CaringBridge JEs, we can explore how they share their experiences on social media. Some caregivers may write openly and honestly about their distress and burden, while others may not. CaringBridge is designed to assist patients and caregivers with sharing their experiences, and to bring social support to patients and caregivers; however, no known studies have examined caregivers' writings about their experiences or the social support offered on CaringBridge or similar sites, such as CarePages.

There is also a clear gap in longitudinal research exploring the psychological distress and challenges experienced by caregivers throughout the trajectory of the cancer experience (Choi et al., 2012; Given et al., 2012; McGuire et al., 2012). CaringBridge provides a unique resource for retrospective longitudinal research into the caregiver experience through JEs and GPs. Entries can span from initial diagnosis through and even beyond treatment, or after a patient's death. While cancer caregivers' and patients' needs have been studied at specific time points, especially at diagnosis and end of life, few studies have explored needs during other time points, and none of the studies, to our knowledge, have looked at needs of caregivers in the context of social support provided by social media (DiGiacomo, Lewis, Nolan, Phillips, & Davidson, 2013; Drevdahl, & Shannon Dorcy, 2012; Dubenske et al., 2008; Edwards, Olson, Koop, & Northcott, 2012; Gofton, & Graber, 2012; Hoerger et al., 2014; Kim, Spillers, & Hall, 2012; Schaepe, 2011; Shaw et al., 2013; Sutherland, 2009; van Ryn et al., 2011).

By examining what caregivers, patients, and guests write, we can ascertain whether caregivers and patients are receiving directed support from an online social network throughout the course of the disease. While current studies show that emotional and informational support is offered through social media, in this study, we aimed to examine whether other types of support (e.g., network, esteem, and tangible) are also present in the GPs (Anderson, 2011; Bender et al., 2011; Bender et al., 2012; Kim & Chung, 2007; Suzuki & Beale, 2006). The directionality of support and patterns of support were explored using data visualization techniques, including social network, temporal (longitudinal graphs), and multidimensional analysis (histograms/barcharts/pie charts; (University of California, Los Angeles [UCLA] Institute for Digital Research and Education, 2017). This is the first known study to use exploratory data visualization to examine CaringBridge. The results of this study will inform future research as researchers create and refine social media tools to address caregiver burden and provide further support to patients and their families through these sites.

A retrospective, longitudinal, descriptive, mixed-method approach focused on CaringBridge postings from 20 cases. Chapter 2 describes the literature at the foundation of this study, including the conceptual framework. Chapter 3 details the methods utilized for this research. Chapter 4 focuses on Aim 1 and the qualitative content analysis used to examine caregivers’ experiences. Chapter 5 focuses on Aims 2 and 3, describes the results of the social support behavior coding of JEs and GPs, and describes the matching of support. Addressing Aim 4, exploratory case studies of visualization techniques provide the basis for Chapter 6; the chapter is focused on how social network support responds to patients and caregivers and explores how visualization techniques may help to better understand the caregiver journey. Finally, Chapter 7 provides a summary of the research findings as well as guidance for future clinical and research directions.

CHAPTER 2

CANCER PATIENT AND CAREGIVER SOCIAL SUPPORT USING SOCIAL MEDIA: BACKGROUND AND CONCEPTUAL FRAMEWORK

Introduction

This chapter will provide a review of the literature regarding Internet use by cancer patients and caregivers. Cancer caregivers are defined, including the roles and responsibilities they take on. Additionally, a review of the domains of social support and the potential benefits social support may provide to patients and family caregivers are examined. Lastly, the conceptual framework of this study, the model of social support elicitation and provision, is described. For information regarding search strategies, see Appendix A.

Internet Use by Cancer Patients and Caregivers

Research on the use of social media and health is a relatively new and growing field. Methods used to explore the use of social media for health purposes have included surveys of use (Anderson, 2011; Bender et al., 2012; Kim & Chung, 2007; Setoyama et al., 2011; van Uden-Kraan et al., 2008), content analysis of information on the sites, including posts by patients (Bender et al., 2011; Clerici et al., 2012; De la Torre-Díez et al., 2012; Eddens et al., 2009; Farmer et al., 2009; Frost & Massagli, 2008; Keim-

Malpass & Steeves, 2012; Kim, 2009; Lam et al., 2012; Suzuki & Beale, 2006), narrative analysis of the posts (Chou et al., 2011), and interviews of patients using social media (Anderson, 2011). Intervention studies are a growing area, with numerous studies focused on changing/promoting health behaviors (Balatsoukas, Kennedy, Buchan, Powell, & Ainsworth, 2015; Joseph, Keller, Adams, & Ainsworth, 2015; Maher et al., 2015; Merolli, Gray, Martin-Sanchez, Mantopoulos, & Hogg, 2015; Williams, Hamm, Shulhan, Vandermeer, & Hartling, 2014) and on online support-group use by patients (Lepore, Buzaglo, Lieberman, Golant, & Davey, 2011; Song et al., 2012). A small subset of the research has explored how to maximize the storytelling component of social media by utilizing surveys and feedback from a panel of patients about which components of the stories were most valuable to them (Iredale et al., 2011; Overberg, Alpay, Verhoef, & Zwetsloot-Schonk, 2007; Overberg et al., 2010). There is also research examining health information content of sites (Lam et al., 2012).

Populations under study have included individuals with chronic illnesses (Anderson, 2011; De la Torre-Díez et al., 2012; Farmer et al., 2009; Frost & Massagli, 2008; Merolli et al., 2015; Patel, Chang, Greysen, & Chopra, 2015; van Uden-Kraan et al., 2008) and cancer patients (Beaudoin & Tao, 2007; Bender et al., 2011; Bender et al., 2012; Chou et al., 2011; Clerici et al., 2012; Eddens et al., 2009; Iredale et al., 2011; Keim-Malpass & Steeves, 2012; Kim, 2009; Kim & Chung, 2007; Lam et al., 2012; Setoyama et al., 2011; Song et al., 2012; Suzuki & Beale, 2006; Wang, Kraut, & Levine, 2015). Family caregivers were grouped with patients in a small subset of the studies (Anderson, 2011; Clerici et al., 2012; Farmer et al., 2009; Kim & Chung, 2007), but for the vast majority, patients were the focus. Most studies examined the benefits of using social media health sites, and three major themes emerged: storytelling, sharing medical information, and connecting with others for support.

Patients tell their stories and describe their personal cancer journeys on social media sites (Anderson, 2011; Bender et al, 2012; Chou et al, 2011; Clerici et al, 2012; Iredale et al, 2011; Keim-Malpass et al, 2012; Kim & Chung, 2007; Suzuki & Beale, 2006). Social media often includes a profile or minibiography of the individual for whom the site was created (i.e., the patient). Many of the online pages, for example CaringBridge, CarePages, PatientsLikeMe, or personal websites/blogs, are formatted as an online diary or journal in which the patient or his or her caregivers can post day-by-day experiences. Postings may be more or less frequent depending on what is occurring in the patient's life. Information in these JEs ranges from a medical plan of care to test results or detailed descriptions of the patient's or caregiver's feelings about the cancer experience (Anderson, 2011; Bender et al., 2011; Clerici et al., 2012; Keim-Malpass et al., 2012; Kim & Chung, 2007; Kim, 2009; Suzuki & Beale, 2006). JEs may even include information about health care providers (Anderson, 2011; Kim, 2009).

Information sharing can go beyond the personal experience to disseminate complex information about cancer treatment and resources. Patients or caregivers share websites and resources with other cancer survivors, friends, and family (Anderson, 2011; Bender et al., 2011; Chou et al., 2011; Frost et al., 2008; Kim & Chung, 2007; Suzuki & Beale, 2006). The most common reason found in the literature for using social media is to connect with other people, even strangers. Users report that these sites help to communicate the ups and downs of their illness to family, friends, and acquaintances, who often provide emotional support in the form of GPs or comments (Anderson, 2011;

Beaudoin & Tao, 2007; Patel et al., 2015).

Gaps in Existing Literature

Due to the relative nascence, the broad definition, and the ever-evolving nature of social media, research specific to health-communication websites such as CaringBridge and CarePages and to cancer caregivers of adult patients is limited (Hamm et al., 2013). The term *social media* can be used to describe a wide range of Internet sites. Research is spread across several modalities ranging from general social media, which was created for and can be used for many nonhealth reasons (e.g., YouTube, Facebook, MySpace, professional and personal websites/blogs), to sites created specifically to support cancer patients and/or caregivers (e.g., CaringBridge, CarePages, PatientsLikeMe, LIFECommunity, and online support groups). CaringBridge and CarePages are used extensively by patients and families to communicate during their cancer journey. Despite the high volume of use (CarePages, 2017; CaringBridge, 2016), only one study has specifically examined CaringBridge (Anderson, 2011) and no studies have examined CarePages. As mentioned previously, social media use crosses racial/ethnic and socioeconomic boundaries, and is beginning to cross the age boundary (Internet World Stats, n. d.; Anderson & Perrin, 2017); however, most of the research that has been conducted has focused on adolescents and adults under 40 years of age (Bender et al., 2012; Clerici et al., 2012; Keim-Malpass et al., 2012; Lam et al., 2012; Song et al., 2012; Suzuki & Beale, 2006). More research is needed to assess if there are individual variations in use, needs, and benefits across different patient/family populations (Hamm et al., 2013). While we have a basic knowledge of how patients use and benefit from social media, we are lacking in knowledge of how caregivers use these sites. This study focused on addressing this gap by exploring caregiver use and social support offered to caregivers on these sites.

Cancer Caregivers

In 2016, it was estimated that over 1.6 million people will be diagnosed with cancer in the United States (National Cancer Institute [NCI], 2017b). Most of these patients will at some point require the help of an informal caregiver. Informal caregivers are frequently family members who volunteer to provide unpaid care to patients (Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, 1998). Caregivers of cancer patients are often over the age of 55 years and are more often women (Duggleby et al., 2010; Kim et al., 2012; NCI, 2017a; Schaepe, 2011; Shaw et al., 2013; van Ryn et al., 2011)

Caregiver roles and tasks vary based on the cancer patient’s diagnosis, symptoms, and comorbidities (Ellis, 2012; van Ryn et al., 2011). Caregivers may be involved in assisting the patient with activities of daily living (Duggleby et al., 2010; Gofton & Graber, 2012), financial and household activities (Dubenske et al., 2008; Given et al., 2011), helping the patient to navigate the health care system (Shaw et al., 2013), providing symptom management, and monitoring for side effects (Dubenske et al., 2008; Given et al., 2011; Shaw et al., 2013). Additionally, their work life may be altered, which may lead to financial and legal stressors (Dubenske et al., 2008). The emotional toll of caregiving can lead to depression and anxiety, making caregiving even more difficult (Lambert et al., 2012).

With the complexity of the cancer trajectory, there can be many changes to a caregiver’s role. For example, a spouse caregiver may have relied on the patient to do the housework or manage the finances, but must now take on that role while the patient is unable or is limited in ability (Dubenske et al., 2008; Given et al., 2011; Shaw et al., 2013). Along with these changing roles, caregivers' needs increase as they take on more tasks but do not have time to care for themselves (Dubenske et al., 2008; Given et al., 2012; Given et al., 2011; Shaw et al., 2013). Caregivers need support to function in their new roles and to meet their needs.

Social Support

It is important to identify how social support may help patients and caregivers during difficult times throughout the cancer experience. Social support has been linked to psychological and physical effects on individuals (Barth, Schneider, & von Kanel, 2010; Ell, Nishimoto, Medianski, Mantell, & Hamovitch, 1992; Holt-Lunstad, Smith, & Layton, 2010; Lee & Rotheram-Borus, 2001; Manne, Pape, Taylor, & Dougherty, 1999; Ozbay et al., 2007; Pinquart & Duberstein, 2010; Thompson, Rodebaugh, Perez, Shootman, & Jeffe, 2013; Uchino, Bowen, Carlisle, & Birmingham, 2012). Poor social support is linked with increased incidence of anxiety and increased comorbid depression (Manne et al., 1999; Thompson et al., 2013). Physical impacts from poor social support include higher morbidity and mortality from cardiovascular disease, cancer, and infectious diseases (Barth et al., 2010; Ell et al., 1992; Lee & Rotheram-Borus, 2001; Pinquart & Duberstein, 2010). Being socially integrated provides more opportunities for support and the outcomes can be very positive. Perceiving high social support results in a lower risk of all-cause mortality (Holt-Lunstad et al., 2010). In fact, the physical effects of social support are as significant as the physical effects of smoking, exercise, and obesity on cardiovascular and immune function (Holt- Lunstad et al., 2010; Uchino et al., 2012).

The mechanism between social support and physical and psychological outcomes includes increased heart rate, blood pressure, and neuroendocrine response to stressors (Ozbay et al., 2007). Social support is theorized to buffer these responses by the body to increase resilience to stressors and protect against psychopathology. In theory, social support likely increases resilience to stress by affecting the body's neurochemical response to stress (Ozbay et al., 2007). Social support has also been linked to greater feelings of self-efficacy, self-esteem, and control, and conversely, less depression, lower stress perception, and less exposure to stress (Uchino et al., 2012). It was theorized by Uchino et al. (2012) that these factors could further explain how social support affects physical and psychological health.

Social support helps as a buffer for patients and caregivers during stressful events, such as those experienced on the cancer trajectory (Cohen & Wills, 1985). How the buffering works is impacted by a concept called *optimal matching*. Under this concept, social support is best received when it consists of what the receiver wants or needs (Cutrona & Russell, 1990; Tian & Robinson, 2009). In other words, if a person wants information on his diagnosis, he benefits from receiving informational support; however, he may not benefit as much from receiving emotional support while what he is seeking is information. This is also true of the other types of support.

Research specifically on caregivers has shown that social support may help alleviate caregiver distress and burden, as well as improve quality of life and physical health (Bowman, Rose, Radziewicz, O'Toole, & Berila, 2009; Choi et al., 2012; Downe-Wamboldt, Butler, & Coulter, 2006; Ownsworth et al., 2010). Research findings related to caregiver distress and social support vary. One study found that the number of hours of social support received did not cause any differences between the distress experienced by men versus women (Perz, Ussher, Butow, & Wain, 2011). Another study found that although women reported using more emotional support, they had higher levels of distress than their male counterparts (Mazzotti, Sebastiani, Antonini Cappellini, & Marchetti, 2013). In other studies, low social support was linked to higher levels of distress (Butow, Price, Bell, Webb, & deFazio, 2014; Choi et al, 2012; Goldzweig et al., 2013; Götze, Brähler, Gansera, Polze, & Köhler, 2014; Lo et al., 2013). Inversely, high levels of social support were linked to lower levels of distress (Cassidy, 2013). Individuals with higher levels of distress were also more likely to be dissatisfied with their social support (Teixeira & Pereira, 2013). Caregivers in spiritual distress were less likely to engage in coping behaviors such as eliciting emotional support (Delgado-Guay et al., 2013). Social support was shown to mediate between caregiver burden and distress (Teixeira & Pereira, 2013). In one qualitative study, caregivers reported that their social support network mediated between coping and distress (Ellis, Lloyd Williams, Wagland, Bailey, & Molassiotis, 2013). Caregivers also reported that their family and friends helped them to stay positive (Ellis et al, 2013).

Family caregivers who report higher levels of perceived social support also report lower levels of loneliness or depressive symptoms (Sahin & Tan, 2012) and lower levels of caregiver burden, including impact on the caregivers' health, schedule, and finances (Shieh, Tung, & Liang, 2012). Social support functions as a moderator to alleviate/prevent depression and stress amongt caregivers (Nijboer, Tempelaar, Trienstra, van den Bos, & Sanderman, 2001; Ostwald, 2009). Additionally, caregivers who were more satisfied with the support they were receiving also reported higher psychological well-being; this was especially true for caregivers supporting patients with greater functional impairments (Ownsworth et al., 2010). Alternatively, one study found that a lack of family social support was the greatest predictor for caregivers reporting mood states of anger, depression, and total mood disturbance, and also was the greatest predictor of reporting health problems (Daly, Douglas, Lipson, & Foley, 2009).

As for social support received by caregivers on social media, in one small study examining social media preferences of cancer survivors and caregivers, caregivers reported wanting to use social media to receive social support (Badr, Carmack, & Diefenbach, 2015). Most research examining social support provided by social media has consisted of intervention studies of social support groups (Hamm et al., 2013); however, very few of these studies were focused on caregivers (Namkoong et al., 2012). Namkoong and colleagues (2012) found that a computer-mediated support-group intervention demonstrated bonding between caregivers. These bonds between caregivers in the support group in turn led to increased instrumental support. Caregivers were more comfortable seeking advice from the other caregivers in their support group (Namkoong et al., 2012).

Measuring social support can be difficult as it is a dynamic construct with varied concepts, each capturing different components of the full picture. The concepts range from the social network to concepts such as social integration, functional support, structural support, directionality of support, perceived support, received support, adequacy of support, and types of support (Gottlieb & Bergen, 2010). For the purpose of this study, we focused on the key concepts of the social network, directionality of support, and types of support. From a social-network perspective, support involves looking at the structure of support: how an individual is supported by his or her social ties to other people (Gottlieb & Bergen, 2010). In other words, it is finding all the people who provide support to or receive support from the individual in question. The network structure includes the resources available to all of the individuals involved. Network support also involves the structure of the web of the network itself and how the individuals connect (e.g., the number and pattern of ties; Gottlieb & Bergen, 2010).

Directionality of support refers to whether the support is shared between individuals (bidirectional) or is delivered but not reciprocated (Gottlieb & Bergen, 2010). Social support is an exchange process in which an individual can be on either side of the act of support—as the provider or the receiver (Mattson & Gibb Hall, 2011). Within social networks, communication (social exchange) from an individual is directed at other individuals (Hanneman & Riddle, 2005). The direction of the exchange may be to one or more individuals. If the exchange includes social support, it is directed at whomever the individual addresses. Thus, support can be directed to one individual, a pair of individuals, or a larger group.

There is a further layer to support in that, even if support is received, it may not be perceived by the individual. Most research to date has focused on the broad constructs of perceived social support and received social support (Uchino et al., 2012). Perceived support is that which an individual thinks is available to him, while received support is the actual support given to him (Gottlieb & Bergen, 2010; Uchino et al., 2012). Perceived and received social support may not align when an individual does not perceive that the support received is responsive to his needs. This misalignment may cause the receiver of support to feel threatened, and may lower his self-esteem. If the perceived and received support do align, it may lead to better adjustment. The concept of support adequacy measures how perceived and received support align (Gottlieb & Bergen, 2010).

Although the different types of support have not been studied as extensively as perceived and received support, their importance may be as significant (Uchino et al., 2012). The types of support have been categorized many different ways, but frameworks mostly overlap conceptually. Social support was divided into five major domains by Schaefer, Coyne, and Lazarus (1981): informational, emotional, esteem, network, and tangible. Informational support involves offering suggestions or advice (Cutrona & Suhr, 1992). Examples of emotional support include expressing sympathy or offering encouragement (Cutrona & Suhr, 1992). Esteem support takes place when an individual validates the feelings of or compliments the recipient of the support (Cutrona & Suhr, 1992). Network support is about connecting the caregiver to his or her community; it is about companionship and connectedness (Cutrona & Suhr, 1992). Tangible support involves offering to assist with actual tasks (Cutrona & Suhr, 1992). See Table 1 for further definitions of these five types of support, as well as other names used for each type. Thoits (2011) postulated that the type of support that works best in a given situation may be linked to the level of intimacy the receiver has with the giver. In other words, emotional support may be better received from a close friend or family member, but informational support may be better received from an acquaintance. A family member may be too close to the situation or not possess the knowledge to provide adequate informational support; an acquaintance is not as close to the receiver, and thus, his or her emotional support may not be as impactful.

Table 1

Definitions of Types of Social Support

Type of Social Support	Definition
Emotional	Expressing sympathy or offering encouragement to the caregiver
Esteem or Appraisal	Validating the feelings of or complimenting the caregiver
Informational	Offering suggestions or advice to the caregiver
Network or Companionate	Connecting the caregiver to his or her community; companionship and connectedness
Tangible or Instrumental	Offering to assist the caregiver with actual tasks (e.g., cooking, cleaning, caring for, and/or transporting the patient)

(Cutrona & Suhr, 1992; Gottlieb & Bergen, 2010; Lakey & Cohen, 2000)

While we know the benefits of social support, it may be difficult for caregivers to find. Caregivers may be isolated by their caregiving responsibilities (e.g., hospitalization, traveling for treatment, providing direct care; Given et al., 2011). Along with increased isolation, they can have difficulty maintaining social ties (Williams & Bakitas, 2012). Caregivers may focus their time and attention on the caregiving at hand and not have the time or resources to direct their attention to their social networks. These combined difficulties may decrease the amount of support they receive from their regular support network. Computer-mediated social support may be beneficial to reach individuals who are isolated from their support network (Mikal, Rice, Abeyta, & DeVilbiss, 2013).

Conceptual Framework

Model of Social Support Elicitation and Provision

A study by Wang et al. (2015) proposed and examined a conceptual model exploring how emotional and informational social support is elicited by cancer patients.

The social media site examined in the study was a large online breast-cancer support group. The types of elicitation strategies examined included self-disclosure (positive and negative emotional self-disclosure; positive and negative informational self-disclosure) and asking questions (Wang et al., 2015). The researchers identified perceived needs from patients' writings and categorized them as perceived emotional or informational needs. After the elicitation strategies and perceived needs were identified, the researchers looked at the support provided by the network—specifically, whether emotional support or informational support was provided (Wang et al., 2015). The researchers posited that self-disclosure would lead to a perception of emotional needs and the provision of emotional support. They also posited that asking questions would lead to perceived informational needs and in turn lead to the provision of informational support. The conceptual model for the study is depicted in Figure 1.

Study findings showed that self-disclosure is related to a perception of emotional needs and thus increases the likelihood of receiving emotional support. The study also found that asking questions increased the likelihood of receiving informational support but decreased the likelihood of receiving emotional support because of a perception of the patient having only informational needs. Writers who provided positive informational self-disclosure were more likely to elicit informational support. The authors found that perceptions by the network, as well as what was written by the individual patients, affected the type of social support received (Wang et al., 2015).

The current study used the model of social support elicitation and provision as its foundation. This model has application for the study of cancer patients and caregivers as it explains how what an individual writes/discloses on social media can affect the social

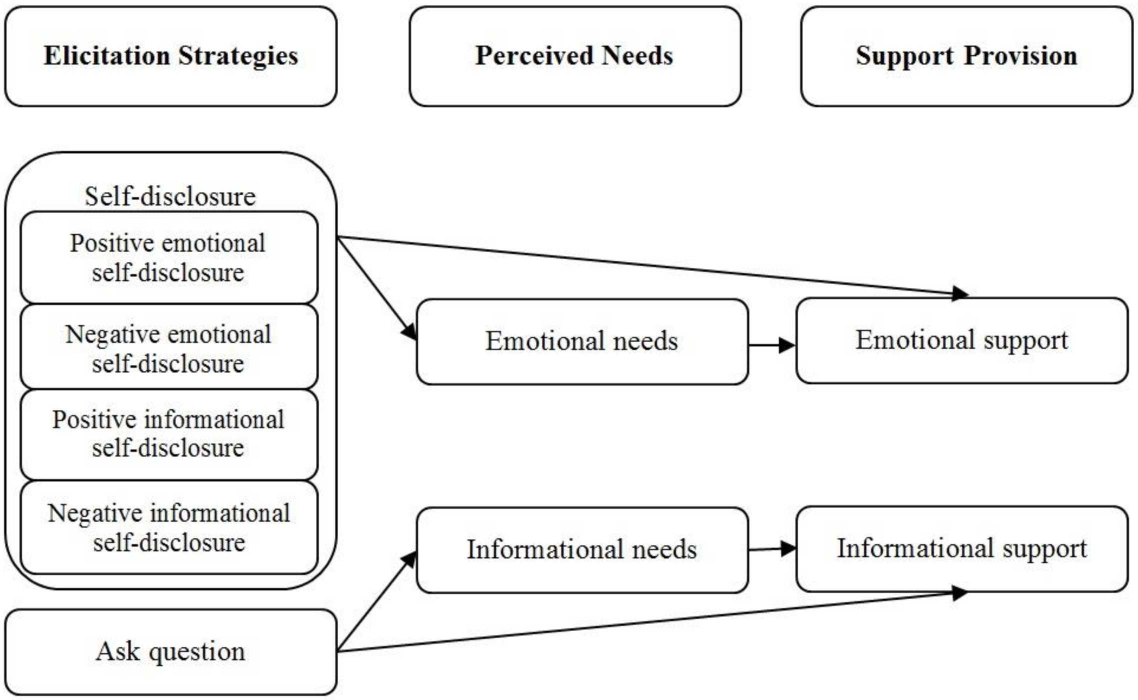


Figure 1. Conceptual model of social support elicitation and provision.

Note. Reprinted from “Eliciting and Receiving Online Support: Using Computer-Aided Content Analysis To Examine the Dynamics of Online Social Support,” by Y. C. Wang, R. E. Kraut, & J. M. Levine, 2015, *Journal of Medical Internet Research, 17*(4), p. e99; doi:10.2196/jmir.3558. Reprinted with permission.

support he or she receives. Because this study was focused on understanding how the CaringBridge social network responded to the needs of patients and caregivers, this framework helped to provide guidance on how the network provides support based on the elicitation strategies caregivers and patients use in their journals; however, the model was adapted to adjust for the focus and broader definition of social support examined in this study. While the focus of the model is on the patient, the focus of this study was primarily caregivers. Caregivers may disclose their own and the patient’s needs; however, since the social support elicitation and provision model uses the term *self-disclosure* throughout, it was revised for the purpose of this study’s model to simply *disclosure*, as what was disclosed was not always what was happening to the caregivers themselves. Additional types of social support (e.g., esteem, network, and tangible) not in the original model were crucial to the framework of this study, so they were added to the parts of the model this study utilized. The revised model is depicted in Figure 2.

For this study, the elicitation strategies were examined in Aims 1, 2, and 3. The focus of Aim 1 was to examine caregiver disclosure in its entirety, exploring what cancer caregivers disclosed about their cancer experiences (see Figure 3). Aims 2 and 3 explored more specifically the disclosure of support needs by patients and caregivers in JEs, and the provision of support in GPs (see Figures 4 and 5). Aims 2 and 3 indirectly examined perceived needs. In addition, Aim 3 examined the relationships between types of support requested through disclosures and types of support provided by guests. Aim 4 focused on the provision of support and added another layer to the model by looking at who the provided support was directed to (see Figure 6).

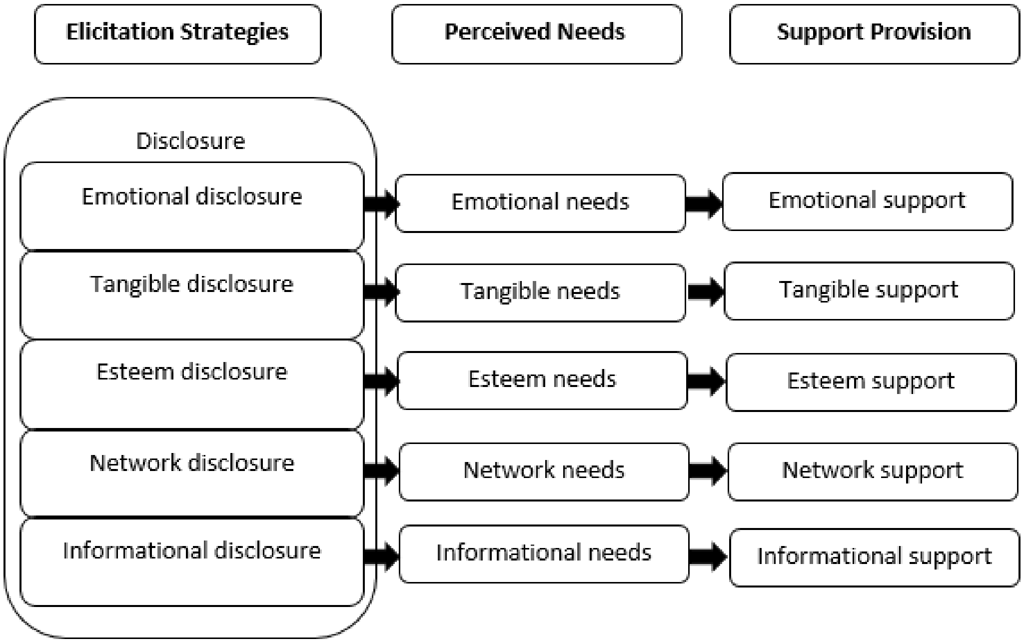
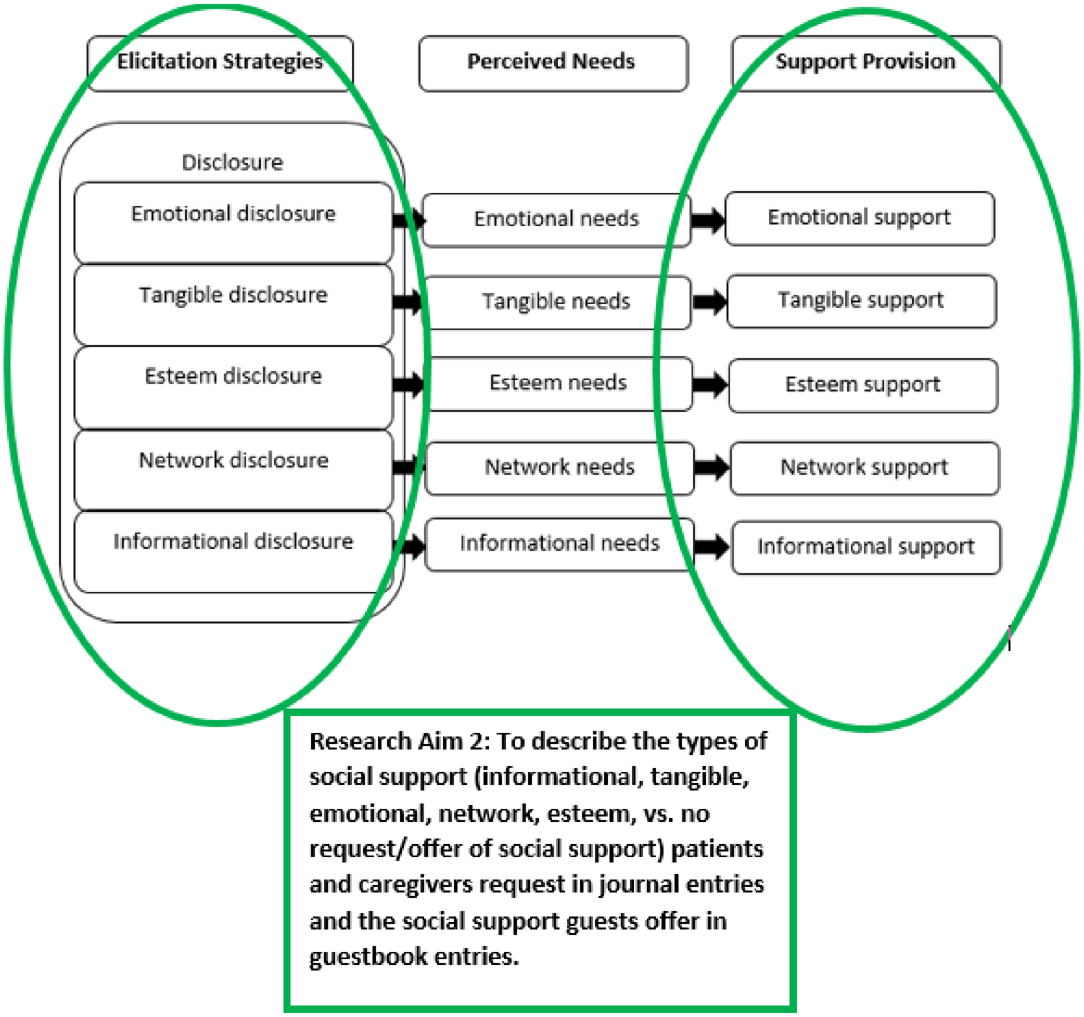


Figure 2. Conceptual framework of CaringBridge modified social support elicitation and provision.

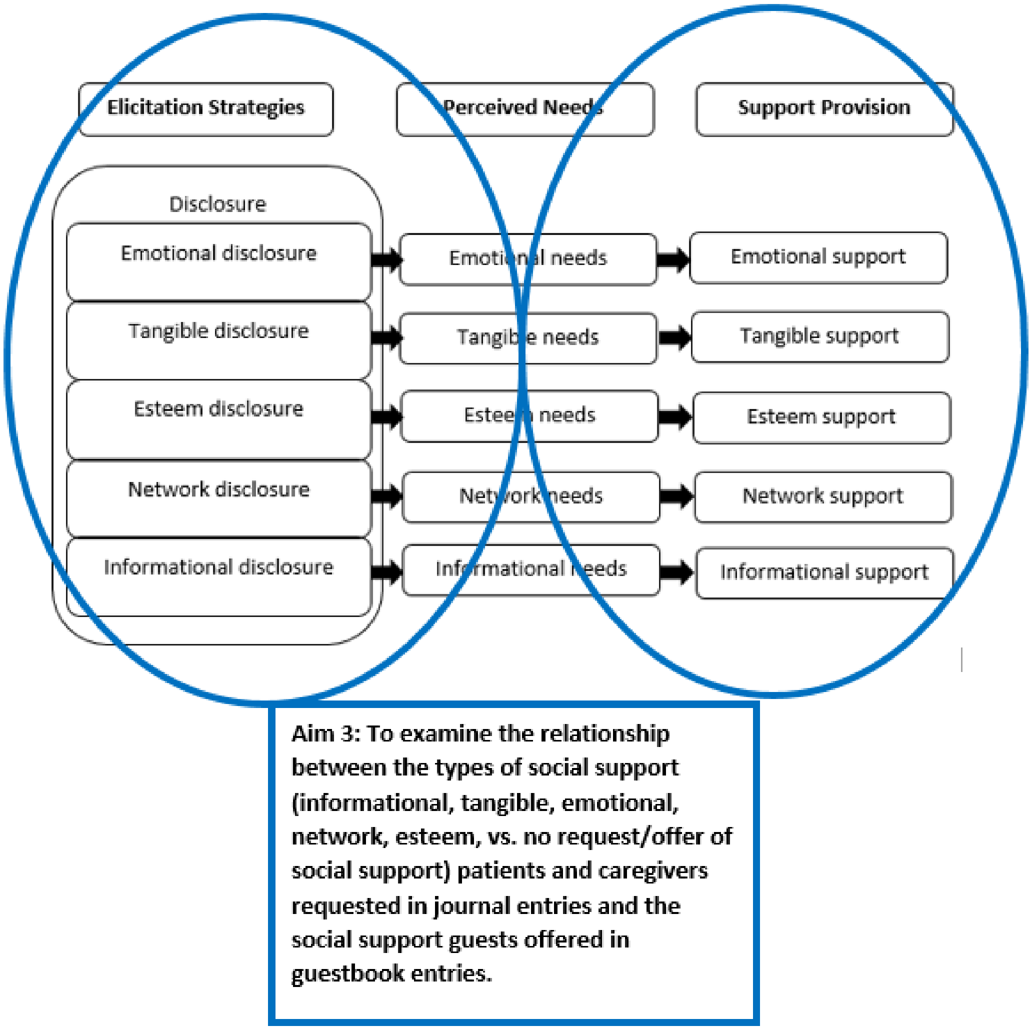
Research Aim 1: To explore the caregiver's experience as expressed on CaringBridge.

Figure 3. Conceptual framework Aim 1: Cancer caregiver experiences expressed in disclosure.



Research Aim 2: To describe the types of social support (informational, tangible, emotional, network, esteem, vs. no request/offer of social support) patients and caregivers request in journal entries and the social support guests offer in guestbook entries.

Figure 4. Conceptual framework Aim 2: Social support elicitation in patient and caregiver journal entries and support provision in guestbook postings.



Aim 3: To examine the relationship between the types of social support (informational, tangible, emotional, network, esteem, vs. no request/offer of social support) patients and caregivers requested in journal entries and the social support guests offered in guestbook entries.

Figure 5. Conceptual framework Aim 3: Relationship of social support elicitation in patient and caregiver journal entries and support provision in guestbook postings.

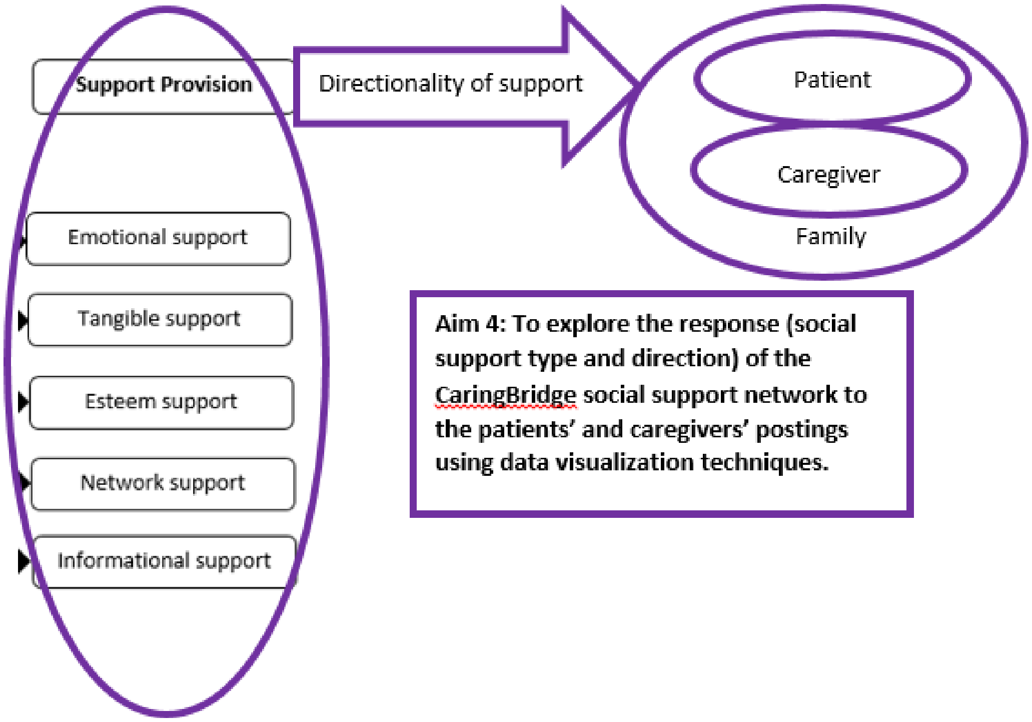


Figure 6. Conceptual framework Aim 4: Directionality of support provision in guestbook postings.

Conclusion

As cancer-patient and caregiver use of social media grows, websites that aim to help them communicate around a health event may be beneficial. As the literature shows, the benefits of this new communication methodology can reach patients and caregivers even in times of isolation. These sites allow patients and caregivers to express emotion, share information, and receive social support. Cancer caregivers experience distress and burden that may be alleviated by the social support offered on these sites; however, what cancer caregivers write on CaringBridge can affect the types of support they receive. The focus of this study was to explore the elicitation of support by patients and caregivers, and to uncover the relationships between the support requested and the support offered by guests.

CHAPTER 3

RESEARCH DESIGN AND METHODS

Introduction

A retrospective, longitudinal, descriptive, mixed-method research approach was utilized to address the aims of this study. The study design and methods were developed and informed by a pilot study described in this chapter. Pragmatic logistics were captured in the pilot study and included identifying processes through trial and error, capturing characteristics of CaringBridge writers and documenting the logistics and duration of each step in each process. The processes piloted included methods for sampling, data extraction, directed content analysis, and data visualization.

Definition of Case

The unit of focus was the open-access portion of a social media website: CaringBridge. CaringBridge sites are created by patients, families, and/or friends to communicate with others and allow others to follow the family's cancer journey. Individual sites contain multiple written entries, including a short biography (*My Story*), JEs, GPs, and a planner to coordinate care. These entries are written by a variety of individuals, including the patient, family/friend caregivers, other family members, friends, and acquaintances.

For the pilot study and the larger study, one full site per cancer patient was considered one case. Each case consisted of JEs by the caregiver(s), GPs by guests to the site, and occasionally JEs by the patient. CaringBridge also has a tool called the *Planner*, which is a separate site for coordinating care for the patient; however, per privacy guidelines outlined in this chapter, planners are considered medium to high privacy tools and were thus excluded. At the time of the study, medium privacy cases required individuals to log into the website to view the case and high privacy cases required the patient or caregiver to send individuals the case information in order to view the case (CaringBridge, 2016). For the purpose of this study, photographs and the *My Story* biography section of each case were not examined.

Pilot Study

A pilot study was conducted from December 2013 to April 2014 to inform the development of this research. The pilot study was designed (a) to help create a process for case identification; (b) to identify which demographic variables were readily accessible within the CaringBridge cases; (c) to determine the feasibility of using social-support coding tools to code the data; and (c) to pilot the application of a type of social-network analysis, a form of data visualization. Careful documentation was made to understand the logistics and feasibility of the processes for selecting cases, extracting data, and analyzing data. Characteristics related to postings were also noted (e.g., caregiver relationship to patient; frequency and length of postings).

Pilot Study Aims

Pilot Study Aim 1: Determine feasibility and pragmatic logistics of research utilizing CaringBridge site writings.

Pilot Study Aim 2: Using a directed content analytic approach, determine the feasibility of identifying the types of requests for and offerings of social support (emotional, tangible, informational, network, and esteem) that are demonstrated in patients' (journal), caregivers' (journal), and guests' (guestbook) postings on CaringBridge.

Pilot Study Aim 3: Explore the use of social network analysis to determine the directionality of support for a subset of cases.

Pilot Study Methods

Sample Inclusion and Exclusion Criteria

Eligible CaringBridge cases met the following criteria: the cancer patient/caregiver selected open settings with no restrictions (i.e., open access); postings were written in English; the patient for whom the site was created was an adult (if age could not be determined, the case was not used); the cancer was at any stage (I–IV); an oncology-patient caregiver (including family and friends of the patient) must have posted on the site in the JEs; there must have been GPs by individuals other than the patient and caregiver; and the case must have been created at least 6 months prior to the study, to ensure that there would be multiple JEs and GPs. Only low privacy (open access) cases were used for this study. Low privacy sites comprise approximately 30% of all CaringBridge sites (K. Palmstein, personal communication, April 23, 2013).

Pilot Study Phase 1: Case Selection

A first step in the pilot project was to determine the optimal approach for selecting cases for analysis. Cases needed to be searchable within the parameters of the CaringBridge search engine. Two separate processes were tested: personal surnames and geographic regions. First, a search by surname was implemented. The plan was to search for eligible cases by first searching for cases matching selected surnames and then examining the content of each case to see if it met the eligibility criteria. This attempt was designed to yield a diverse sample. The initial search used last names from U.S. Census (2000) data with the greatest likelihood of surname by race and Hispanic origin (Word, Coleman, Nunziata, & Kominski, 2000). The top two surnames most closely linked to race/ethnicity were used for the search (see Table 2). Names for American Indians/Alaskan Natives were excluded, as no names were more than 4% likely to correlate with race (Word et al., 2000).

Of the 328 cases identified, 197 were excluded because the surname searched was the patient's first name or a city name. During the screening for inclusion/exclusion criteria, another 128 cases were excluded due to having one or more of the following: medium to high privacy settings (78 cases), being a spam site (13 cases), patient ≤21 years old (29 cases), patient did not have a diagnosis of cancer (5 cases), or no caregivers posted in the journal (3 cases). Case selection using names most highly associated with

Table 2

Pilot Study Case Selection: Last Names With Greatest Likelihood of Race and Hispanic Origin

Race/Ethnicity	Name	Number of Sites Identified
White	Yoder	19
	Krueger	25
African American	Washington	98
	Jefferson	32
Asian/Pacific Islander	Zhang	5
	Huang	11
Two or more races	Ali	72
	Khan	58
Hispanic	Barajas	5
	Orozco	3
	Total	328

(Word et al., 2000)

race/ethnicity yielded poor results, with only 3 cases meeting the eligibility criteria for the pilot study. It was determined based on the search findings that it would be difficult to identify racially diverse sites.

A second search was developed based on the four regions of the United States as designated by the U.S. Census Bureau: Northeast, South, Midwest, and West (U.S. Census Bureau, n.d.). The largest city, by population, was chosen for each region in order to increase the likelihood of having more racially diverse cities included in the sample; however, the limitation of this search was that the sample did not include rural areas, and all races/ethnicities still might not have been present at the sites sampled. Cities were found to be searchable during the previous case selection using surnames (i.e., the search for the surname *Washington* gave results of surnames and locations).

Although the region/city search result showed that there were hundreds of cases for each city, only the first 100 cases for each city searched were available. After reviewing the site-search information on CaringBridge, it was difficult to determine why the search result was limited to 100 results. CaringBridge was contacted, and no further information was provided regarding the site search. The results appeared to be in the order of sites most frequently posting and most frequently visited.

Of the 597 cases identified, only 400 cases were available within the search results due to the 100-case limit. A total of 7 cases were excluded because the city name was the patient’s first or last name. During the screening for inclusion/exclusion criteria, another 298 sites were excluded due to having one or more of the following: medium to high privacy settings (180 cases), being a spam site (9 cases), patient was ≤ 21 years old (40 cases), patient did not have a diagnosis of cancer (47 cases), or no caregivers posted in the journal (22 cases). Using the largest city in each of the four census-defined geographical regions was a successful strategy and yielded 95 cases meeting the pilot study's eligibility criteria. Results of the search are presented in Table 3.

Within the sample of 95 cases, each case contained multiple JEs and GPs. JEs per case ranged from 1 to 337, with a mean of 48 and a standard deviation (*SD*) of 53.2. GPs per case ranged from 0 to 2,318, with a mean of 397 and an *SD* of 467. Descriptive statistics for the JEs and GPs are presented in Table 4. Due to the large amount of content available for each case, for reasons of practicality we made the decision to select a sample of cases. From the 95 cases, 2 cases were randomly selected (sampling from +/- 1 *SD* from the mean number of JEs) from each region/city, for a total of 8 cases.

Pilot Study Phase 2: Data Extraction

The contents of all 8 cases were downloaded into NVivo, a software package that provides for qualitative analysis of many data types. NVivo (QSR International, n.d.) was chosen specifically for its ability to capture website data for analysis. Contents

Table 3

Pilot Study Case Selection: Largest City in Each Region

Region	City	Number of Cases Identified	Number of Cases Available in Search Result (Number Meeting Criteria)
Northeast	New York, NY	112	100 (25)
South	Houston, TX	223	100 (18)
Midwest	Chicago, IL	147	100 (29)
West	Los Angeles, CA	115	100 (23)
	Totals	597	400 (95)

Table 4

Pilot Study Descriptive Statistics: Journal Entries and Guestbook Postings From 95 Cases

Statistics	Value(s)
Journal Entries	
Lowest number of JEs	1
Highest number of JEs	337
Mean number of JEs	48
Median number of JEs	30
Mode number of JEs	24
Sample *SD*	53.2
Sampling range for number of JEs (+/- 1 *SD* from mean number of JEs)	1–101
Guestbook Postings	
Lowest number of GPs	0
Highest number of GPs	2,318
Mean number of GPs	397
Median number of GPs	214
Mode number of GPs	204
Sample *SD*	467
Sampling range for number of GPs (+/- 1 *SD* from mean number of GPs)	0–864

included all JEs and GPs. Each page of the case was collected using the NCapture function of NVivo; essentially, a PDF was created of the page as it appeared on CaringBridge. This meant that multiple JEs or GPs were captured together, which allowed the data to remain in chronological order within each page of JEs or GPs. Each case's PDFs were then organized into sets within NVivo, so that all data for that case were in the set assigned to the case. These sets were named using a number-based naming system (e.g., #1Practicum, #2Practicum, #3Practicum, and so forth). Nodes were created in NVivo for each patient, caregiver, and guest for each case. These nodes were then assigned to the passages/phrases that were identified as having been written by the given individual. Nodes were named using the previously identified case-naming system for the set and using what the individual's role, and for caregivers, their role and relationship to the patient. Examples of the caregiver nodes are Case 1 Caregiver Husband, Case 1 Caregiver Son 1, Case 1 Caregiver Son 2, and Case 1 Caregiver Unknown. Examples of guest nodes are Case 1 Guest 1, Case 1 Guest 2, Case 1 Guest 3, and so forth.

Pilot Study Aim 1: Feasibility and Pragmatic Logistics

To address Aim 1 of the pilot study, we timed and documented each step of the process (case selection, downloading data, organizing data, de-identifying data, and analyzing data). We kept start and stop times throughout the pilot study to determine the practicality of analysis on a larger number of sites for the current study. A summary of the timings for each step of the process are outlined in Table 5.

We also took notes regarding methods and barriers encountered, and gathered demographic characteristics throughout the pilot study. Demographics were identifiable for the majority of the time for gender (patients [100%], caregivers [93.8%], and guests

Table 5

Timing of Processes

Steps	Mean Times
Case Selection	2 mins 10 secs per site (14 hr 30 mins/ 400 site data sets)
Downloading (8 Data Sets) & Organizing Data	47 seconds per page (200 mins /253 pages)
Analyzing data	
Collecting Demographic Characteristics, Directionality of GPs & Directed Content Analysis	17 mins per page (38 hr / 133 pages; 133 pages = 303 JEs & 426 GPs)
Preliminary Social Network Analysis	1 hr per site (2 hr / 2 sites)
leaning data	1 hr per code (however- can clean up multiple codes simultaneously when applicable)
De-identifying data	TBD

[92.9%]), the location where the patient was receiving care (100%), and the caregiver's relationship to the patient (87.5%; see Table 6); however, it was sometimes difficult to accurately determine the guest's relationship to the patient (only 11.6% were identifiable) or to other guests (only 8.6% were identifiable). For the 8 cases examined in the pilot study, there were between 1 and 4 caregivers posting on each site, with an average of 2 caregivers per case. The number of guests per case ranged from 13 to 54 guests, with an average of 33.5 guests per case.

Pilot Study Aim 2: Directed Content Analysis

Directed content analysis involves the use of predetermined codes, often derived from existing theories, to analyze data (Bernard & Ryan, 2010). The coding schema is preset and the textual data are coded using the pre-existing codes. An initial pilot study of the codes on a selected amount of text is recommended (Bernard & Ryan, 2010). In the

Table 6

Pilot Study Identification of Roles and Relationship Characteristics

Role	Characteristic	% of Writing Containing Characteristic
Patient	Gender	100 % (8 of 8 patients)
	Cancer type	100 % (8 of 8 patients)
	Where receiving care (away vs. at home)	100 % (8 of 8 patients)
Caregiver	Gender	93.8 % (15 of 16 caregivers)
	Caregiver relationship to patient	87.5 % (14 of 16 caregivers)
Guest	Gender	92.9 % (249 of 268 analyzed guests)
	Guest relationship to patient	11.6 % (31 of 268 analyzed guests)
	Guest relationship to other guests	8.6 % (23 of 268 analyzed guests)

case of this pilot study, the predefined codes were derived from social support theory, specifically the Social Support Behavior Codes (SSBC).

The analysis began with the earliest online posting and moved forward in time to the most recent post. I read each posting several times to identify passages that reflected requests for and offerings of social support. We then coded these passages using predetermined codes for the categories of social support (Hsieh & Shannon, 2005). Based on the recommendation of Maija Reblin, a committee member, the five categories of social support initially utilized for coding were *emotional*, *tangible*, *informational*, *network*, and *esteem* support (Cutrona & Suhr, 1992). We analyzed the data that did not match the codes after the initial coding to decide if the content represented a new category of social support or was a subcategory of one of the five types of support. We created nodes in NVivo for each code. These codes were then assigned to the passages/phrases that were identified as having the codes. Based on feedback from and review of the coding by a committee member, we reviewed and refined the coding schema multiple times. Once the content analysis was completed for each of the postings, the codes, and the content of the social support postings were compared to note any similarities or differences across the different CaringBridge cases. Directed content analysis evolved over the course of the pilot study as codes were refined and clarified, with the aid of a committee member, using examples found in the writings. I developed a coding manual, in collaboration with a committee member, to assist in maintaining consistency with coding (see Appendices A and B). The initial 4 cases were coded in their entirety; however, many overlapping themes emerged and the subsequent 4 cases were coded only until no new emerging themes were discovered and saturation was achieved (Morse, 2004).

The final codes for social support were based on the SSBC: *emotional*, *tangible*, *informational*, *network*, and *esteem* support (Cutrona & Suhr, 1992). Examples of emotional support include expressions of love and prayers for the patients and cancer caregivers: “Our thoughts and love are with you.” “We send you our love and healing thoughts.” “Rest in God's arms, he's got this!! Never Give Up!! And stay strong in your Faith. Much love and prayers coming your way.” “Praying this surgery will be totally successful and you will be in full recovery soon.” Tangible support themes included general offers of support: “If there is anything at all that I can do please don't hesitate to ask.” “[C]all me if you need ANYTHING!” “Let us know if there is anything we can do to help you guys.” Tangible support also included specific offers of support: “I am here for you whenever you need anything! meals, take the kids, or just a friend to talk to . . . Please don't hesitate to ask!” “[C]an help out with kids, too.” “I'll be coming down this summer once or twice, so if there's anything I can do to help out with the little ones or the house or whatever, I'd be happy to do so."

Informational support included advice on self-care: "[B]e SURE to be eating. Unfortunately, I've seen a couple people go through this and while you may not always feel up to it, eating helps your body be strong." "[G]et sublingual melatonin it will help you rest. It is a natural herb whole foods dont [sic] forget about sleepy tea."

> We both know how chemo affects the taste buds and we found that lots of Bluebell Homemade Vanilla ice cream fortified with Ensure made a great milkshake and got calories in you. XXX also loves macaroni and cheese and though it didn't taste like he thought it should, he ate a lot of it because he knew he liked it a lot and tried to remember the taste while putting in the calories. He also exercised every day dragging that pole from which hung the chemo bags with him (he walked on a treadmill that was in an exercise room for the patients)—the doctor had told him that eating and exercise were key to recovery during chemo.

Network support often involved offerings to visit with the patient and/or caregivers: "[W]e'll be in town Thanksgiving and would like to catch up." "I'm in town May 13–16 and I would love to come by." "Call me if you want some company. . . ." "Visitors? Or no?" Esteem support included compliments and validation: "You are an inspiration to all . . . you live each day to the fullest with great wit, warmth, energy and "XXX Passion." "[Y]ou are an amazing person and will certainly handle this with strength and grace." "I wish you were as well as you look—you are looking GREAT." "You have all created an amazing cocoon of love to surround Nina with." "This is a wonderful idea!"

Pilot Study Aim 3: Social Network Analysis

We conducted further exploration of the pilot study data to assess whether conducting social network analysis on the cases was possible. 2 separate cases were selected based on the notes taken during the directed content analysis. I noted that guests appeared to direct their social support differently depending on what was happening to the patient. The 2 separate cases selected reflected two different transitions being experienced by the patients. We selected one case to examine how the network responded at diagnosis, and a second case to examine how the network responded at time of death. Feasibility of social network analysis was piloted in Gephi. Gephi is a software system that allows for visualization of a social network (Gephi, 2017). During the pilot study, we created simple visualizations to document the directionality and volume of social support for the 2 cases. For the 2 cases examined, one key event/transition point in the patients' cancer trajectory was identified (death for case 1 and diagnosis for case 2). For each JE that identified the transition, all subsequent GPs were examined for data regarding the directionality of support (i.e., *Was support directed to patient or to the caregiver?*). Each patient, guest, and caregiver was entered as a node into Gephi. We entered the number of entries by each guest into Gephi as *Out-Degrees* and the number of entries directed at each patient and caregiver as *In-Degrees*.

Figures 7 and 8 illustrate the directionality and volume of support directed at the patient and caregivers. For case 2, Figure 7, at the initial transition to a diagnosis of cancer, the majority of the support is directed at the patient, with a smaller amount of support directed at the caregiver son and an even smaller amount directed at the caregiver daughter. In Figure 7, the large rose circle represents the patient, the large purple circle represents the son caregiver, and the small yellow circle represents the daughter caregiver. The size of each patient or caregiver node reflects how many GPs were directed to each individual. In this case, the patient had 12 guestbook entries directed to him or her, the son caregiver had five GPs directed to him, and the daughter caregiver had only one GP directed to her. The remaining nodes are the 13 individual guests who

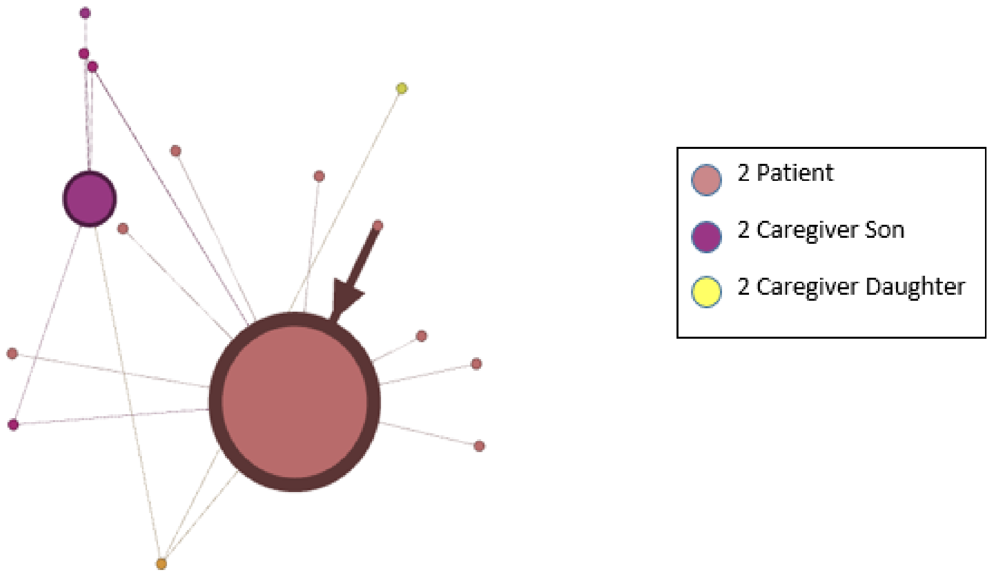


Figure 7. Transition diagnosis: Case 2 Journal Entry 1
and accompanying guestbook postings.

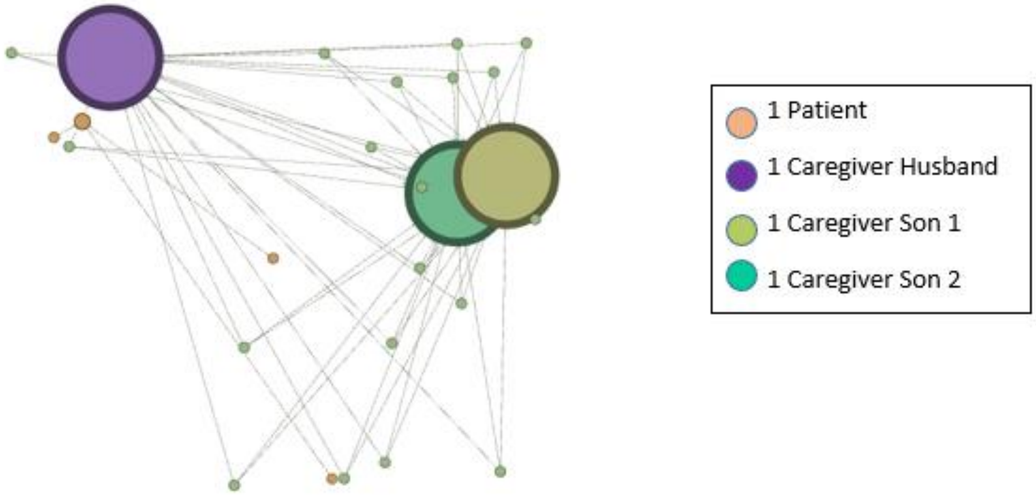


Figure 8. Transition to death: Case 1 Journal Entry 7
and accompanying guestbook postings.

directed support to the family. The thickness of the ties (the arrows connecting each node) reflects the number of GPs by each guest. The majority of guests posted only once; three guests posted twice and one guest posted three times, so the guests' arrow is thicker than the rest. The length of each line in these figures does not represent any specific relationship, and appears as assigned by the software.

In Figure 8, at the transition to the end of life, specifically after the death of the patient, the GPs are directed primarily to the caregivers. The death transition was selected to show the change in direction of support from being directed almost solely to the patient to being directed to the patient's caregivers upon her death. The patient's node is much smaller than the caregiver husband's and sons' nodes because less support was directed to the patient after she had passed away. In Figure 7, the small peach circle represents the patient, the large purple circle represents the husband caregiver, and the two large green circles represent the caregiver sons. The network members directed their support primarily to the patient's family once she passed away. Four GPs were directed to the patient and the remaining 18 postings were directed to the husband, and both sons. As seen in the figure, there were 22 guests and each guest posted just one time, so all of the ties/arrows are of the same thickness.

Summary of Pilot Study Findings

We developed an effective case-selection strategy using the largest city in each of the four defined geographical regions of the United States. Data extraction was successfully completed and assessed for feasibility. Directed content analysis evolved over the course of the pilot study. Codes were refined and clarified with examples found in the writings. A coding manual was developed to guide consistency with coding.

Feasibility of social network analysis was piloted in Gephi with some success, but further refinement in using the social network analysis tools is needed.

Design of Dissertation Project

A retrospective, longitudinal, descriptive, mixed-method approach focused on CaringBridge postings from 20 cases. To meet Aim 1, we used qualitative content analysis to examine the caregivers' experiences. For Aim 2, we conducted directed content analysis of JEs and GPs to identify social support codes. The directed content analysis provided the data used to conduct further analysis of the matching of support for Aim 3. For Aim 4, an exploratory case study of visualization techniques explored how the social network social support responds to patients and caregivers, and explored how visualization techniques may help to better understand the caregiver journey. The data used for the data visualization analysis include the social-support coding and additional data regarding the directionality and number of postings.

Sample and Setting

We used the open-access portion of a social media website, CaringBridge, and each site served as a case. CaringBridge sites/cases are created by patients and/or family members to communicate with others and allow others to follow the family's cancer journey. Individual cases contain multiple written entries, including a short biography (*My Story*), the JEs, and GPs. These entries are written by a variety of individuals, including the patient, family/friend caregivers, other family members, friends, and acquaintances.

A sample size of 20–60 people is typically used for qualitative studies to examine a domain or lived experience (Bernard & Ryan, 2010). During the pilot study, the examined CaringBridge cases had between 1 and 4 caregivers, averaging 2 caregivers per case. The number of guests per case ranged from 13 to 54 guests, with an average of 33.5 guests per case. By sampling 20 cases, the sample was likely to contain the writings of at least 20 caregivers and 260 guests. The actual sample of 20 cases contained the writings of 36 caregivers and 1,098 guests.

The number of JEs and GPs can vary, as shown in the pilot study. For the 95 cases identified during the pilot study, the number of JEs ranged from 1 to 337, with a mean of 38 entries, and the number of GPs ranged from 1 to 2,318, with a mean of 397 postings. For each JE, there can be multiple pairings with GPs (i.e., when the caregiver writes a JE, many people may reply to that one entry). With 20 cases, and given the mean number of JEs and GPs, the average number of pairings was likely to be larger than the 100 pairings needed. The data visualization techniques are exploratory in nature and are intended; thus, they did not require a specific sample size (World Health Organization, 2017). We selected 3 cases for the data visualization.

Inclusion/Exclusion Criteria

Eligible CaringBridge cases met the following criteria: the cancer patient/caregiver selected the open settings with no restrictions (i.e., open access); postings were written in English; the patient was an adult >21 years (if age could not be determined, the case was not used); the cancer was at any stage (I–IV); an oncology patient caregiver (including family and friends of the patient) must have posted the majority of the JEs (>50%); there must have been at least one GP by an individual other than the patient and caregiver; the patient had to have multiple transitions (e.g., hospitalization, discharge); the case must have been created at least 6 months prior to the study to ensure that there were sufficient data available; and the patient must have died. Only low privacy (open-access) cases were used for the study. Low privacy sites comprise approximately 30% of all CaringBridge sites (K. Palmstein, personal communication, April 23, 2013).

Exclusion Criteria

The following CaringBridge cases were excluded: cases created for patients with diseases other than cancer; cases in which the patient was the only author of the JEs; cases in which there were no GPs; and cases created less than 6 months prior to implementation of the study.

Data and Measures

We collected demographic data based on what was available in CaringBridge, as access to the patients' medical records was not possible. Pilot study data demonstrated that not all initially proposed demographic characteristics could be ascertained from the CaringBridge networks. The characteristics that were collected were consistently identifiable and included role of writer (patient, caregiver, or guest), patients' cancer type, patient gender, caregiver gender, guest gender, and caregiver relationship to the patient. When other demographic or health-characteristic data were available, they were documented.

All textual data were coded using the SSBC, which were applied to pilot study data to develop a coding manual (see Appendices A and B). These included caregiver and/or patient requests for *emotional, tangible, informational, network*, or *esteem* support. We also identified the types of social support offered by guests to the site. Table 7 outlines the various variables and measures that were obtained for the purpose of matching, data visualization, and social-network analysis. In addition to the support offered and requested, data were gathered on the person(s) to whom each writer (patient, caregiver, or guest) directed his or her posting (guest[s], patient, caregiver, or family member[s]). Additional information tracked included the number of entries by caregiver(s), patient(s), and guest(s), respectively.

Table 7

Variables and Measures

Variable	Measure	Time Point	Storage
Patient, Guest, and Caregiver Roles	Role (patient, caregiver, guest)	Initial	REDCap[a]
Patient, Guest, and Caregiver Relationship Characteristics	Caregiver relationship to patient		
Patient's Cancer Type	Cancer type as described in case	Initial	REDCap
Patient, Guest, and Caregiver Gender	Gender	Initial	REDCap
Social Support Requested and Received	SSBC Six categories of social support: • Emotional • Tangible • Informational • Network • Esteem support • Other	Ongoing	NVivo (textual data) and REDCap (content for each SSBC code)

[a] See the *Data Extraction and Management* section, below.

Procedure

After institutional review board (IRB) exemption, case selection began. Participants were not recruited. Because of the CaringBridge privacy settings, the public (including investigators) can view only the open-access cases unless invited by the site owner (CaringBridge, 2016); thus, we used only low privacy open-access cases. I received IRB approval to waive notification of individuals because the cases were publicly accessible.

Case Selection

Regional City Search

As was tested in the pilot study, case selection for this study was based on the four regions of the United States designated by the U.S. Census Bureau (n.d.). In order to have racially diverse cities included in the sample, we chose the largest city, by population, for each region: Northeast—New York, NY; South—Houston, TX; Midwest—Chicago, IL; and West—Los Angeles, CA. For the current study, case selection was rerun using the same four cities as the pilot study, but excluding the 8 cases analyzed in the pilot study.

Privacy

According to the Health Insurance Portability and Accountability Act (HIPAA), de-identified health information may be disclosed without any restrictions (U.S. Department of Health and Human Services, 2003); however, social-media research is fraught with potential violations of individuals’ privacy. The Secretary's Advisory Committee on Human Research Protections (SACHRP), which advises the Office of

Human Research Protections, created basic recommendations and considerations for Internet research to ensure that privacy is maintained. One recommendation is to review the privacy policy of the site from which data are collected, to ensure that the individual's perceived/intended privacy is met according to the website's policy (SACHRP, 2013). As stated previously, all cases included in this study of CaringBridge were obtained from open-access pages that the creators of the pages kept public, so any person could view the cases. Another consideration from the SACHRP (2013) is to understand the implications of identifiable private information. Although data may be de-identified, if direct quotes are used, an individual may potentially be able to connect the quote back to the writer and the writer's privacy would no longer be maintained (SACHRP, 2013). During the pilot study, I tested whether CaringBridge quotes are searchable using the search engines Google or Bing. The quotes did not lead to search results that included CaringBridge; thus, privacy was able to be maintained. For this study, direct quotes were used to demonstrate codes.

Data Extraction and Management

All corresponding role and relationship characteristics of the writers on the cases were de-identified (all names removed and an identification code assigned for each writer), then entered and stored in the Research Electronic Data Capture (REDCap) software on the secure servers of the University of Utah. These characteristics included gender, and role as patient, caregiver, or guest. In addition, we entered counts of social-support codes into REDCap, and all textual data (patients' and caregivers' JEs, and guests' GPs) from each case into NVivo 11. The computer I used was encrypted in accordance with University of Utah requirements. Data were de-identified by deleting all names and identifying information (e.g., names, including medical-professional names; and locations, including where the patient was receiving treatment). De-identified data were shared with my dissertation committee through University of Utah College of Nursing Box on secure servers.

Data Screening and Cleaning

I screened data to assess for outliers, missing data, excess data, and any other issues or oddities (Van den Broeck, Cunningham, Eeckels, & Herbst, 2005). Duplicate data were removed.

Analysis

Using the Statistical Package for the Social Sciences (SPSS), I generated descriptive statistics (frequency counts, percentages, median and mean scores) to characterize the distribution of sociodemographic characteristics, including patient gender, caregiver gender, guest gender, caregiver role, and patient’s cancer diagnosis. Descriptive statistics were obtained for the other variables, including types of social support received (*informational, emotional, esteem, network*, *tangible*, *none*). I used multiple types of analysis based on the aims: Aim 1—content analysis; Aim 2—directed content analysis; Aim 3—the results of the directed content analysis from Aim 2 were used to perform an examination of the match; Aim 4—data visualization for the two exploratory case studies.

Aim 1: To Explore the Caregiver's Experience as Expressed on CaringBridge

Content Analysis

To meet the first aim of the study, I utilized content analysis to examine the caregivers' JEs on CaringBridge. Coding occurred in two phases, preliminary and final (Saldaña, 2009). For the first case, each JE was read from beginning to end. During this first reading, I took notes on patterns, topics, or themes, and assigned preliminary codes (Saldaña, 2009). After preliminary review and coding of all caregiver JEs for the first case, I reviewed and coded each subsequent case following the same process. In addition, I kept notes of common patterns, themes, and topics across cases. After preliminary coding was completed for all cases, I began the second round of coding, in which codes were either combined or split based on the results of the data, until the final codes were determined (Saldaña, 2009). See Appendix B for the content-analysis coding manual. Intercoder reliability is discussed below.

Aim 2: To Describe the Types of Social Support (Informational, Tangible, Emotional, Network, Esteem, vs. No Request for/ Offer of Social Support) Patients and Caregivers Request in Journal Entries and the Social Support Guests Offer in Guestbook Entries

Directed Content Analysis

I conducted directed content analysis on all cases using a pre-existing social-support framework that was determined to be applicable and was expanded-on in the pilot study (Hsieh & Shannon, 2005). I read each posting several times to identify passages that reflected requests for and offerings of social support. A predetermined coding schema used: SSBC (Cutrona & Suhr, 1992; Hsieh & Shannon, 2005). The five categories of social support used for coding were *emotional*, *tangible*, *informational*, *network*, and *esteem* (Cutrona & Suhr, 1992; see Table 8 for examples). Data that did not match the code were analyzed after the initial coding to decide if the content represented a new category of social support or was a subcategory of one of the five types of support. I examined data that did not match any of the codes from the SSBC for any other significant emerging findings. Once the content analysis was completed for each of the postings, the codes, and the content of the social-support postings were compared to note any similarities or differences in themes across the different CaringBridge sites and postings. See Appendix C for the social-support coding manual.

Intercoder Reliability

I assessed intercoder reliability for both the content and directed content analysis coding using percent agreement and a Cohen’s Kappa of 0.7, because this was an early, exploratory study (Lombard, Snyder-Duch, & Bracken, 2002). A second person independently coded a randomly selected subset of the 10 cases using the coding manuals (Appendices B and C). The subset included 10% (*n* = 44) of the patient/caregiver JEs and requests for social support and 10% (*n* = 277) of GPs for offerings of social support (Lombard et al, 2002). Any disagreements in coding were evaluated by both of us to find agreement.

Table 8

Brief Definitions of Social-Support Behavior Codes

Support-Type Code	Purpose of Communication
Informational Support	
Suggestion/Advice	Offers ideas and suggests actions
Referral	Refers the recipient to other sources of help
Situation Appraisal	Reassesses or redefines the situation
Teaching	Provides detailed information, facts, or news about the situation or skills needed to deal with the situation
Tangible Support	
Loan	Offers to lend the recipient something (including money)
Direct Task	Offers to perform a task directly related to the stress
Indirect Task	Offers to take over one or more of the recipient’s other responsibilities while the recipient is under stress
Active Participation	Offers to join the recipient in action that reduces the stress
Willingness	Expresses willingness to help
Esteem Support	
Compliment	Expresses positive things about the recipient or emphasizes the recipient’s abilities
Validation	Expresses agreement with the recipient’s feelings about the situation
Relief of Blame	Tries to alleviate the recipient’s feelings of guilt about the situation
Network Support	
Access	Offers to provide the recipient with access to new companions
Presence	Offers to spend time with the person, to be there
Companions	Reminds the person of the availability of companions, of others who are similar in interests or experiences
Emotional Support	
Relationship	Stresses the importance of closeness and love in relationship with the recipient
Physical Affection	Offers physical contact, including hugs, kisses, hand-holding, shoulder patting
Confidentiality	Promises to keep the recipient’s problem in confidence
Sympathy	Expresses sorrow or regret for the recipient’s situation or distress
Listening	Attentive to comments made by the recipient
Understanding/Empathy	Expresses understanding of the situation or discloses a personal situation that communicates understanding
Encouragement	Provides the recipient with hope and confidence
Prayer	Prays with the recipient

Note. Examples of codes. Adapted from “Controllability of Stressful Events and satisfaction With Spouse Support Behaviors,” by C. E. Cutrona & J. A. Suhr, 1992, *Communication Research, 19*(2), p. 161. Adapted with permission.

Aim 3: To Examine the Relationship Between the Types of Social Support (Informational, Tangible, Emotional, Network, Esteem, versus No Request for/Offer of Social Support) Patients and Caregivers Request in Journal Entries and the Social Support Guests Offer in Guestbook Entries

Matching of Support

I compared the results of the social-support codes for JEs and GPs. This was done by comparing each JE to the GPs that followed it for the next 24 hr and then for the next 7 days. Some guests wrote in the guestbook prior to any JEs being entered, and these were included in the analysis and identified as unsolicited social support. If the caregivers wrote a JE and no guests responded that day, or on subsequent days until the next JE or end of the case, an additional "dummy" entry was added and coded as no offer of social support. The 2,430 GPs and 36 placeholder entries totaled 2,466 "guestbook offers." I compared each type of support requested by caregivers to the support offered by guests to determine if they matched.

Aim 4. To Explore the Response (Social Support Type and Direction) of the CaringBridge Social-Support Network to the Patients' and Caregivers' Postings Using Data Visualization Techniques

Data Visualization

Data visualization involves using different analytic tools to organize data so that it is easier to understand and interpret (UCLA Institute for Digital Research and Education, 2017). In order to address Aim 4, how the social network responds to patients and caregivers on CaringBridge, I utilized a variety of data-visualization techniques, including network, temporal, and multidimensional analysis. Social network analysis has commonly been used in the social sciences to explain how social networks function

(Borgatti, Mehra, Brass, & Labianca, 2009). Temporal analysis (timelines/longitudinal graphs) and multidimensional analysis (histograms/bar charts/pie charts) have also commonly been used to visualize quantitative data along with descriptive statistics (Kellar & Kelvin, 2013).

In an exploratory study, I examined 3 cases. All GPs and JEs were mapped for individual analysis of each of the 3 cases and for comparisons across patients and caregivers to determine whether patterns existed. I collected characteristics related to JEs and postings (e.g., caregiver relationship to patient; frequency and length of JEs), and conducted social-network analysis on each CaringBridge site to identify the number of individual nodes (number of patients, caregivers, or guests), the degree of each node (as determined in the pilot study; the size of each node based on the volume of connections between individuals), the number of postings each individual (patient, guest, or caregiver) had made to the site, the number of links between nodes (how patients, caregivers, and guests were connected to each other; who responded to others' postings), and the directionality of the relationships. Directionality was operationalized by determining to whom the postings were directed. These data were graphed using Gephi and Excel to produce a visual representation of the networks. I compared these graphs across the networks to determine if there were similarities and differences between them. Additional longitudinal graphs were created to show how social support changes over time.

CHAPTER 4

CANCER CAREGIVERS’ EXPERIENCES AS EXPRESSED THROUGH THEIR OWN WORDS ON CARINGBRIDGE

Abstract

The purpose of this retrospective, longitudinal, descriptive qualitative study was to explore caregivers’ experiences as expressed on CaringBridge. The study setting was online on the health-communication social-media site, CaringBridge. Twenty public-access CaringBridge sites were identified for the study. In total, 36 caregivers journaled on CaringBridge on behalf of the 20 patients. Qualitative content analysis was conducted and identified the following major categories in caregivers’ online CaringBridge journals: sharing patient health information, promoting cancer awareness/advocacy, social support, caregiver burden, daily living, emotions (positive and negative), and spirituality. This study increases the understanding of the caregiver experience as expressed on CaringBridge. Many caregivers appeared to feel pressure to post in real time, apologizing for delays in posting as well as explaining why there were delays. Implications for nursing include the following: clear communication to cancer patients and caregivers regarding the plan of care helps them to communicate to their friends and families; and the use of “teach back” can help to assess their understanding. Nurses can discuss with caregivers the use of social-media sites such as CaringBridge for efficient communication

to their social networks. Caregivers using social media focus their communication on the patient, including sharing information about the plan of care and daily living. Caregivers do not often disclose their negative emotions or their needs to their guests, and so may not fully benefit from the support guests can provide. Social media can aid caregivers in communicating with the family.

Introduction

It is estimated that in 2017, nearly 1.7 million people will be diagnosed with cancer and nearly 600 thousand cancer patients will die in the United States (American Cancer Society [ACS], 2017). Most of these patients will at some point require the help of an informal caregiver. Informal caregivers are frequently family members who volunteer to provide unpaid care to patients (Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, 1998). Caregivers of cancer patients are often over the age of 55 and are more often women (Duggleby et al., 2010; Kent et al., 2016; Kim et al., 2012; NCI, 2017a; Schaepe, 2011; Shaw et al., 2013; van Ryn et al., 2011)

Caregivers' roles and tasks vary based on the cancer patient's diagnosis, symptoms, and comorbidities (Ellis, 2012; van Ryn et al., 2011). Caregivers may be involved in assisting the patient with activities of daily living (Duggleby et al., 2010; Gofton & Graber, 2012; Saria et al., 2017), financial and household activities (Dubenske et al., 2008; Given et al., 2011; Saria et al., 2017), helping the patient to navigate the health care system (Saria et al,, 2017; Shaw et al,, 2013), providing symptom management, and monitoring for side effects (Dubenske et al,, 2008; Given et al,, 2011; Shaw et al,, 2013). Their work life may be altered, which may lead to financial and legal stressors (Dubenske et al., 2008). The emotional toll of caregiving can lead to depression and anxiety, making caregiving even more difficult (Lambert et al., 2012; Saria et al., 2017).

Social support can help alleviate caregiver distress and burden, and improve quality of life and physical health (Bowman et al., 2009; Choi et al., 2012; Downe-Wamboldt et al., 2006; Ownsworth et al., 2010). Family caregivers who report higher levels of perceived social support also report lower levels of loneliness or depressive symptoms (Sahin & Tan, 2012) and lower levels of caregiver burden, including lower impact on their own health, schedule, and finances (Shieh et al., 2012). Early descriptive findings of social media use to share the cancer experience indicate that patients and families feel they benefit from the emotional and spiritual support offered by visitors to these sites, appreciating the convenience of communicating to large groups of people quickly and connecting with other individuals with similar experiences and diagnoses (Anderson, 2011; Bender et al., 2012; Bender et al., 2011; Kim & Chung, 2007; Suzuki & Beale, 2006).

The use of social media for general communication and specifically for health-related information and communication is increasing (Prestin et al., 2015). Caregivers are at the forefront of health-related users; they use social media more than both noncaregivers and patients (Pew Research Center, 2013). A number of social media sites, such as CaringBridge and CarePages, specifically focus on supporting patients and families during a health event. CaringBridge has an average of 300,000 visitors per day and CarePages has over a million unique visitors per month (CarePages, 2017; CaringBridge, 2015). The individual websites are centered on the patient, although, in the case of CaringBridge, caregivers comprise the majority of site owners (K. Palmstein, personal communication, April 23, 2013). Since the focus of the site is the patient, it may affect what caregivers express about their own experiences. Caregivers may fear being judged by their social network, so they may limit how much they share (Family Caregiver Alliance [FCA], 2014). They may expect or perceive criticism and disapproval (Lepore & Revenson, 2007). In this study, I examined how caregivers work within the framework of a social-media site dedicated to the patient. I explored how caregivers balanced their needs and the patient's needs in their writings, and examined whether caregivers used the website for their own support.

Increased understanding of the caregiver experience can help nurses identify caregivers' needs, create social-media interventions to meet those needs, and prevent the spread of misinformation (Kent et al., 2016). This chapter explores the experiences of cancer caregivers as expressed in their own words on the website CaringBridge. How are the activities of caregiving described by caregivers? Do caregivers write about the psychosocial impacts of the cancer diagnosis on themselves? If so, what do they write about? Are losses related to caregiving described in caregivers' writings? If so, what losses? Are benefits related to caregiving described in caregivers' writings? If so, what benefits?

Methods

A retrospective, longitudinal, descriptive, qualitative design was used to conduct content analysis of CaringBridge sites; specifically, the JEs written by caregivers. CaringBridge sites are created by patients and/or families to communicate with others and allow others to follow the families' cancer journeys. Individual sites contain multiple written entries, including a short biography (*My Story*), JEs (in which caregivers and patients write about their cancer experiences), GPs (in which guests write to the patient and/or caregivers), and a planner (in which caregivers and patients can coordinate care needs with guests). These entries are written by a variety of individuals, including the patient, family/friend caregivers, other family members, friends, and acquaintances. The focus of this study and the content analysis was on the caregivers' writings within the JEs for selected cases.

Only low privacy open-access CaringBridge sites were included in the analysis. CaringBridge privacy settings at the time of the study included low privacy sites that the public could view without logging onto CaringBridge or receiving an invitation from the site owner (CaringBridge, 2016). Low privacy sites comprised approximately 30% of all CaringBridge sites (K. Palmstein, personal communication, April 23, 2013). Because publicly available data were used, this study was determined to be "nonhuman subjects research" and an exemption was granted from the institutional review board.

Case Selection

Case selection on CaringBridge was based on the four regions of the United States designated by the U.S. Census Bureau (n.d.). I selected the largest city, by population, for each region in order to include more ethnically diverse cities in the sample: Northeast—New York, NY; South—Houston, TX; Midwest—Chicago, IL; West—Los Angeles, CA. Despite using city names for the search, cases were from cities other than the search terms used; see Table 9 for the actual locations of the cases.

Each case consisted of JEs by the caregiver(s) of the cancer patient. Eligible CaringBridge cases met the following criteria: the cancer patient/caregiver had

Table 9

Location of Cases

Region	City	Number of Cases Included
Northeast	New York, NY	4
	New Haven, CT	1
South	Houston, TX	2
	Baltimore, MD	1
	Orlando, FL	1
	Chattanooga, TN	1
Midwest	Chicago, IL	2
	Milwaukee, WI	1
	Rochester, MN	1
	Iowa City, IA	1
West	Los Angeles, CA	4
	Spokane, WA	1
	Total	20

selected open settings with no restrictions (i.e., open access); postings were written in English; the patient was >21 years of age (when patient age could not be determined, the case was not used), the cancer was at any stage (I–IV), at least one oncology-patient caregiver (including family and friends of the patient) must have posted the majority of the JEs (>50%), and the case must have been created at least 6 months prior to the study start date to ensure that there were sufficient data available. Patients' JEs were excluded from this analysis, as the focus of the study was on the caregivers' experiences. I identified caregiver JEs by examining each JE for the sign-in name (the individual the website identified as the writer of the JE), who signed the text of the JE, and/or the use of pronouns (e.g., use of he/she to describe the patient rather than I/me). The sign-in name did not always reflect who wrote the posting, so the other identifying information provided was used to identify whether the author was the patient or caregiver.

Within the cases found using the city search terms, 61 cases met criteria; each case contained multiple JEs. Eight of the 61 cases had been analyzed previously in a pilot study and were therefore excluded. The number of JEs per case ranged from 1 to 255, with a mean of 50 and an *SD* of 56.3. Due to the large amount of content available for each case, for reasons of practicality, I made a decision to select a sample of just 20 cases from the remaining 53 cases. Within the 20 cases, there were a total of 440 JEs available for analysis; however, since the focus of the study was on caregivers, only the 392 JEs with writings from caregivers were examined.

Demographic Variables Collected

Demographic data were collected based on what was available in CaringBridge, as access to the patients' medical records was not possible. The characteristics collected included role of the writer (patient, caregiver, guest), patient's cancer type, patient gender, caregiver gender, guest gender, and caregiver relationship to patient.

Content Analysis

I captured JEs and downloaded them into NVivo 11 software from the CaringBridge website (QSR International, n. d.). The unit of analysis was each JE written by a caregiver. I completed primary coding in two phases: preliminary and final (Saldaña, 2013). For the first case, I read each JE from beginning to end. During the first reading, I took notes on patterns, topics, and themes, and used open coding to create a set of preliminary codes (nodes) and subcodes (Saldaña, 2013). After preliminary review and coding of all caregiver JEs for the first case, 6 subsequent cases were reviewed and new codes (nodes) were added until saturation was reached and no new codes were identified. Overlapping codes were permitted, meaning that the same text section could be double coded. I kept memos of common patterns, themes, and topics across cases. After preliminary coding was completed, the second round of coding began, in which codes were either combined or split, based on the data, until a final set of parsimonious and meaningful codes were determined (Saldaña, 2013). During this phase of coding, I utilized expert review by several of the researchers (Susan L. Beck, Wen-Ying Sylvia Chou, and Lee Ellington) to ensure that cogent themes were created and a final manual was created to aid in further coding.

Rigor

Intercoder reliability was assessed by having a second experienced coder independently (AnnMarie Lee Walton) code a randomly selected subset of 10% of the 20 cases using the coding manual (Lombard et al., 2002; see Appendices B and C). The subset included 10% (*n* = 44) of caregiver journal entries. Any disagreements in coding were evaluated by both coders to find agreement. The Cohen's Kappa for percent agreement was 0.715, which is acceptable (Lombard et al., 2002).

Results

Demographics

Please see Table 10 for descriptive statistics for the journal entries included in this study. Patients and caregivers described the disease in their own words, so there were not always specific medical diagnoses provided; nonetheless, it appeared that multiple types of cancers were represented. In total, 36 caregivers wrote on the 20 sites on behalf of the

Table 10

Descriptive Statistics of the Selected 20 Cases

Statistics for All Journal Entries (Patient and Caregiver)	Value(s)
Total number of cases	20
Sum of journal entries	440
Lowest number of journal entries	1
Highest number of journal entries	53
Mean number of journal entries	22
Median number of journal entries	22.5
Mode number of journal entries	14
Sample *SD* of journal entries	13.63

patients. The majority of caregivers were women (*n* = 21, 58.3%), and caregivers wrote the majority of all journal entries (*n* = 380.5, 88.5%). The patient died in 50% (*n* = 10) of the 20 cases. Demographic information for the patients and caregivers is presented in Table 11.

Categories

I identified seven main categories of ways caregivers described their experiences or the experiences of the patient: *sharing patient health information*, *promoting cancer awareness/advocacy*, *social support*, *caregiver burden*, *daily living*, *emotions—positive and negative*, and *spirituality* (see Table 12). Many of the categories tied-in closely with one another, often overlapping. For example, while describing patients' plans of care, caregivers were often positively focused and hopeful about the outcomes of treatment, so the categories of both sharing patient health information and positive emotions were

Table 11

Demographics of the Selected 20 Cases

Characteristic	*N* (%)
Patients	20
Male	7 (35%)
Female	13 (65%)
Cancer Types	20
Hematologic (acute and chronic leukemias, Hodgkin's and non-Hodgkin's lymphomas, and multiple myeloma)	6 (30%)
Solid tumor (brain, breast, colon, esophageal, lung, ovarian, pancreatic, ureter, and unknown primary)	14 (70%)
Caregivers	36
Male	12 (33.3%)
Female	21 (58.3%)
Unable to determine	2 (5.6%)
Entry written by a couple	1 (2.8%)
Caregivers Per Case	20
Cases with 4 caregivers	2 (10%)
Cases with 3 caregivers	1 (5%)
Cases with 2 caregivers	8 (40%)
Cases with 1 caregiver	9 (45%)
Caregiver Relationship to Patient	36
Spouse	10 (27.8%)
Child	14 (38.9%)
Sibling	2 (5.6%)
Child-in-law	1 (2.8%)
Friend	3 (8.3%)
Unknown	6 (16.7%)

Table 12

Categories of Caregivers' Descriptions of Experiences

Theme	Examples
Sharing Patient Health Information	He is still talking about going to *** and doing experimental treatment. It sounds like he is really going to push that as soon as we get through the next few weeks and repeat the CT of abdomen. *** is back in the hospital. We are looking forward to an update on her counts tomorrow morning, but it still looks like she will be able to go home this week. Mom's heading to *** today for a host of pre-chemo tests and medications she needs to get started on. If the plan holds, we will be starting her on her chemotherapy treatment on Tuesday ***. The details about how long, how often, etc. are still forthcoming.
Promoting Cancer Awareness/ Advocacy	The real reason I wanted to share this here is to say listen to your own body and if something doesn't seem right don't ignore it. Bumps, lumps and the occasional night sweat don't always mean something's wrong, but they can mean something's wrong--it's worth the $25 co-pay to find our [*sic*] for sure. We're sure many of you have heard a lot of the "cancer cures" from well meaning [*sic*] friends and family. Unfortunately there is everything from snake oil salesman to faith healers to charlatans to conspiracy theorists with a product, and every one [*sic*] is sincere. We are still trying to double check everything just to be sure we are doing everything possible to beat this cancer. I have found that rather than trying to read the reams of information about a particular "cure", I first see if it meets certain standards. Here is a web sight [*sic*] that helps: http://quackwatch.org/01QuackeryRelatedTopics/cancer.html
Social Support	We have had so many people praying for no side effects from the chemo She still looks beautiful to me and has a smile and laugh that will fill the room! He did a little research and peppered a few friends and family members who work in the medical field and found out that it wouldn't impact the test results if he listened to music *** visited yesterday *** brought us delicious food.
Requests	Pray for her this week as she under goes [sic] surgery for her port. And that it will be healed enough by Monday that it won't be too painful for her next round of chemo. She will have a DVD player in her room in the hospital - we would love any suggestions for fun/funny movies we can rent for her during her stay! If you have any ideas - please leave a note in the guestbook or send me an email :-) if anyone has any recommendations for *** nursing aide services, let us know! Always good to have trusted recommendations The *** household is officially open for business, and open for very BRIEF visits from friends. Mom loves seeing people and catching up with everyone, but she doesn't have a ton of energy for long visits. If you want to come by, late mornings or late afternoons seem to be the best time; just please call ahead of time to confirm the time works for Mom and Dad. To help support *** during this process, we have set up a fundraising page through ***. Your generosity is greatly appreciated and contributions will help *** in many ways, including with: Hospital bills, Medication costs, Living expenses

Table 12 (Continued)

Theme	Examples
Requests (continued)	such as rent, utilities, food, Travel expenses such as taxis to and from the hospital and airfare for her family, who must be on-hand to care for her
Caregiver Burden	the driving back and forth is going to get expensive Meanwhile our Dad has lost his significant other of 40 plus years and lives alone now . . . which has been a concern to us as he is 86 years old and not so steady on his feet. . . . So we are busy getting Lifeline for him and some handicap bars in his bathroom. It's so hard to see her not feeling good. So as I sit at the computer drinking a glass (or two) of wine feeling guilty that I didn't get to return many of the calls, texts or emails from all those who care about *** well being [sic] and want to see her or know how she's doing She will have a restricted diet and I'll know more about that tonight but bringing her food whether it be breakfast, lunch, or dinner will be big as it's been hard for me to get home between work and school and it will be hard for me to make food and be sure she eats. It took ***, *** and I to get him in the car and back to the cancer center *** is weary as well, with his driving down to *** from work in *** once in the middle of the week on his day off and then once or twice on the weekends to bring *** back and forth. He's also wondering why over 100 people have visited his site and there's only one comment in the guestbook. I didn't have an answer for him there. Sorry we haven't posted in awhile [sic], it's hard to describe daily life. That being said, it may be a little while until I send out another update but I wanted to keep everyone in the loop the best that I could as it has been difficult to field all the phone calls that have been received in the most efficient manner. The Chemo she will get this time will not be as strong as the last so she should come thru it fine, I hope. That is why I took this time to go.
Daily Living	Mom woke up this morning and started picking up the house a little and had more energy than she's had in probably 3 weeks. She rode with me to take *** to school and to run a couple errands He went shopping for a whole new wardrobe with Mom and even helped her out with weeding some of the gardens this past weekend. While he will still be out of work for a few more weeks, he went in and paid a visit to *** last week He's also driving on his own now and looks forward to getting back to work!
Emotions	
Positive	*** and I are both gracing her with our presence at chemo today and have been giggling and enjoying family time while we sit in this room freezing our keesters [sic] off :). We had the party at mom and dads and it was just family, but it was a perfect way to celebrate the day. *** felt well enough to play golf one day - he did run out of gas on about the 14th hole, but was so happy to feel well enough to play Don't get me wrong, the cancer is still there, but shrinking is what we are after at this point. Overall her body is strong and she is doing well Thanks so much for your prayers! Thanks so much for all the guestbook signings! She read them over again while she was back at home and was tickled at all the love and support. They make her feel

Table 12 (Continued)

Theme	Examples
Positive (continued)	incredibly loved and give her some great smiles and laughs.
	Mom has had nurses [sic] aides with her 24/7, and they have been amazing. They have all gone above and beyond the call of duty, and have made Mom feel comfortable and well cared for. They also give us some great peace of mind. We are truly grateful for them, and for all the doctors, nurses, and staff at ***.
Negative	Of course, all the "what ifs" come back in and confusion over what to do. Fear can take over at times.
	In addition, my mom is growing tired of the "roller coaster ride" of being in and out of the hospital
	Obviously this wasn't the news we were hoping for. My mom was counting on making it the 3 months then having a break so the news was very disappointing.
Spirituality	God has this!
	. . . our faith that God is good and watching over her is a comfort and blessing.
	Our prayers are being answered!
	. . . very calm and trusting in the Lord to guide her through this experience.
Inspirational Quotes	“For I know the plans I have for you,” declares the Lord, “plans to prosper you and not to harm you, plans to give you hope and a future. 12 Then you will call on me and come and pray to me, and I will listen to you. 13 You will seek me and find me when you seek me with all your heart.”
	I came across this brief quote and wanted to share it with everyone: Nothing is impossible, the word itself says ‘I'm possible’! Audrey Hepburn

present. Positive emotions were also seen when caregivers described their daily lives.

Sharing Patient Health Information

Caregivers shared information on the patient's care, symptoms, and side effects. Much of the focus of their journal entries was on sharing patients' plans of care. This included describing appointments and conversations with providers. They wrote about when the patient was hospitalized and when they were discharged to home. Caregivers focused on describing treatments and tests, such as chemotherapy, radiation, procedures (e.g., port placement, colonoscopy, biopsy), imaging tests, laboratory tests, and surgeries. They wrote about upcoming plans, delays, and results, and described the patients' health status. They shared side effects they were to anticipate as well as the side effects and symptoms experienced by the patient. In several cases, they wrote about stopping treatment and determining whether to go on hospice care.

Promoting Cancer Awareness/Advocacy

A small subset of caregivers used the CaringBridge site to promote cancer awareness and advocacy. They encouraged others to get checked up when something was wrong, and to share their story so others could learn from it. They promoted websites to donate to cancer causes or provided information on how to become a bone marrow donor. One caregiver even shared a website to help others identify fake cancer cures.

Social Support

The social support theme included both the support the caregivers and patients requested as well as the support they received. Caregivers requested support from CaringBridge guests in several ways. The most common requests were for prayers, but they also requested visitors for the patient. Additional support requests were for the provision of meals, for others to be registered as bone marrow donors, for transportation of the patient to and from appointments, and for the provision of financial support. A small subset of caregivers requested information for both clinical (e.g., why the patient's blood counts dropped, or what resources there were for home nursing aides) and nonclinical needs (e.g., DVD recommendations; videos of inspirational speeches by coaches or other individuals). Caregivers used journal entries to provide emotional and esteem support to the patients; they often encouraged and complimented the patient in their writings.

Caregivers also wrote about support received. Many of them wrote about the emotional support guests to the site provided, including their prayers and encouragement, and visits (network support) and tangible support provided to the patient and/or caregiver (e.g., meals provided to the family or taking the patient to appointments).

Caregiver Burden

Burdens described included financial burdens, dealing with noncancer-related stressors, schedule changes, and health concerns. Caregivers had expenses to manage, such as the costs of traveling to care (for the patient). They often mentioned dealing with noncancer-related stressors such as moving to a new home or having other sick family members. Having to rearrange their schedule or being unable to find time to take patients to all of the necessary appointments were concerns addressed by several caregivers. Caregivers described not knowing how to plan their day because appointments were not always on time, or as short or long as planned. They dealt with their own health issues, such as a pregnancy or illness. Infections were especially concerning to some caregivers, as they worried about making the cancer patient sick, thereby possibly causing a delay in treatment. Some caregivers wrote about how emotionally difficult it was to see the patient suffering, and how tiring caregiving could be.

Alleviating the concerns of CaringBridge readers was a focus of many of the caregivers. Caregivers tried to prevent guests from worrying about either the patient or the caregiver. They often told the CaringBridge audience when to expect information or that no news was good news. Apologies were seen fairly often for delays in writing.

These informal caregivers discussed formal caregivers in a positive manner, complimenting their credentials, skills, and/or bedside manner to reassure the audience that the patient was receiving good care. They communicated about CaringBridge-related issues such as the site being down or accidentally posting an incomplete post. They explained their actions to the readers; for example, why they needed to limit visitors or why they had not posted recently. Many of the caregivers expressed the difficulty they had writing about the complexity of the patient's cancer diagnosis, and their disappointment at how the cancer patient's treatment was going. One caregiver even struggled with how to explain to the patient why visitors came to the site but were not writing in the guestbook; caregivers and patients could see that individuals were viewing the site even if the guests were not posting.

Daily Living

Caregivers posted about life outside of cancer; this included things such as future plans, or a description of their day or the patient's day. Some were able to go on vacation or simply enjoy time with their family at home. They wrote entire posts about a day in the life of the patient, describing the meals they ate, visitors they had, and different things they did during the day, such as running to the store or cleaning the house. This tied closely into the next theme, positive emotions, as the caregivers described the ability of the patient and family to savor/take joy in their day-to-day life. Many expressed appreciation for being able to just run errands or clean around the house. They described having a “normal” day as a positive thing; because cancer had changed their lives by preventing normal days, they cherished this sense of normalcy.

Emotions—Positive and Negative

Caregivers expressed both positive and negative emotions in their writings. The emotions shared were those of both patients and the caregivers themselves. Often caregivers expressed hope, kept a positive focus, and savored daily life events. They were hopeful that treatments would work and that patients’ symptoms would improve. Caregivers wrote about how they and the patients were trying to make the most of the little things; for example, they wrote about how wonderful having a normal weekend could feel, or their child, grandchild, niece, or nephew being born. This savoring and experiencing joy was evident in many of the cases. Caregivers expressed gratitude/thanks for the support they received from their CaringBridge network and formal caregivers (doctors, nurses, dieticians, and so forth), and for other informal caregivers who helped them out in their day-to-day life. Although less common, caregivers expressed negative emotions, including feelings of anger, frustration, loss, and fear; some shared how angry, sad, or overwhelmed they felt. More often than not, this was at times of uncertainty, such as waiting for test results or procedures that would provide a clue to the patient’s next steps, or whether treatment was working. In addition, they shared their sadness at the passing of their loved one. Even at these times, however, they also focused on the positive, sharing how the patient was surrounded by family and friends and passed away peacefully.

Spirituality

Some caregivers expressed their spirituality and the spirituality of the patient in their writings. They wrote about reading or talking to spiritual leaders to help them deal with the uncertainty of the cancer diagnosis. They praised God often and for small and large wins. Many used inspirational or spiritual quotes that had helped them to deal with the cancer experience. In cases in which spirituality was expressed, it was one of the major themes throughout their writings. Several entries were highly spiritual, and included writings about how they were handling things spiritually, and requests for prayers from their CaringBridge guests.

Discussion

The predominant focus of caregivers' writings on CaringBridge was the patient. Most of the writings were straightforward descriptions of the patient's plan of care or their daily life. Social support was requested and offered, and examples were shared to demonstrate the unique support systems had by each patient and caregiver. Caregivers described some of their burdens, but only a few used CaringBridge as a platform for describing the impact of caregiving on their own physical and/or emotional health. Overall, caregivers focused on the positive in their writings, and many of the posts reflected a hopeful and positive outlook on the patient's cancer trajectory. Of interest, they often expressed both positive and negative emotions in the same entry, which further demonstrated their attempts to stay positive even during the most difficult transitions.

Examples of these transitions include starting chemotherapy, being discharged to home after hospitalization, finishing the last chemotherapy treatment, and (most often) after the patient’s death. In several cases, the writings included a large amount of spiritual content.

The needs of caregivers as identified in current literature include information about disease/treatment; how to carry out caregiving tasks; how to relate to the patient, family, or other individuals; financial and legal assistance; help with coordination of care; and transitions from hospital to home (Dubenske et al., 2008; Shaw et al., 2013). A few caregivers reached out to their CaringBridge network to meet these needs; for example, one caregiver requested help transporting the patient to and from appointments. More often than not, though, caregivers did not request help.

While communicating with family and friends is often a caregiver role, social media simplifies this role by allowing the caregiver to communicate with multiple people at once; at the same time, the opportunity to provide real-time updates can make such communication burdensome. Some caregivers wrote about why there were delays in writing, often in response to guests asking for updates when the caregiver(s) or patient had not posted for a while.

Examining caregivers’ words on the social-media platform presented a challenge, which was determining whether something written was explicit or implied. Because this study was limited to public-access data, we did not contact the writers. Both coders focused on coding caregiver entries that were explicitly stated by the caregivers. Making a determination about the explicit/implied nature of an entry was most difficult for the theme of caregiver burden. Implied burdens were described in the writings; however, with few exceptions, it was uncommon for caregivers to be explicit about the burdens they were experiencing. For example, if a caregiver wrote about traveling back and forth between appointments but did not explicitly state that this was exhausting or difficult to manage, it was not coded as caregiver burden; however, if a caregiver explicitly stated that he or she was struggling with the demands of caregiving, this was coded as burden. One caregiver could experience the same amount of financial losses and high number of appointments as another caregiver, but might not find it as burdensome. This could be due to the support systems in place for the caregiver, or to other factors, including the severity of the patient's symptoms and their relationship with the patient (Bianchi, Flesch, Alves, Batistoni, & Neri, 2016; Kent et al., 2016; Shieh et al., 2012). Due to the inability to interpret how each individual was affected by caregiver responsibilities, implicit burdens and struggles were not coded as burdens.

This issue of implicit versus explicit could impact the support caregivers received. They did not often explicitly share their own feelings or burdens, except in times of crisis. When the patient was at key transition points, caregivers often shared their worries and concerns. This phenomenon was especially true when a patient was transitioning to the end of life or when waiting for the results of crucial tests; research has shown that caregiver distress increases when these transitions occur (McGuire et al., 2012; Northouse, Katapodi, et al., 2012; Shaw et al., 2013). If caregivers are open about their feelings and burdens, this may help the CaringBridge social-support network step up and offer more support at these critical times.

Caregivers may receive greater support by offering gratitude for support they received, as well as by making requests for support. Caregivers often thanked CaringBridge guests for the social support they provided. Early studies showed that gratitude is linked to an increased perception of social support (Wood, Froh, & Geraghty, 2010; Wood, Maltby, Gillett, Linley, & Joseph, 2008). Gratitude and social support may also positively impact posttraumatic growth (Wu, Zhou, Liu, & Chen, 2014; Zhou & Wu, 2016). It is not known whether gratitude is a result of greater perceived social support (i.e., by recognizing the social support received, are you more grateful for the support network you have?); nor is it known if grateful individuals are provided more social support and thus are more able to perceive the support they receive. The implications of this early research could indicate that being grateful may make caregivers more receptive to online social support and help caregivers have more social support directed to them.

Nursing Implications

Nurses often recommend the use of social-media sites to cancer patients and caregivers as a way for them to communicate with their family and friends. Many of these sites are adding additional tools to help support patients with informational and tangible needs (Carezone, 2017; CaringBridge, 2014). Caregivers may need support in how to communicate the plan of care. Nurses can provide education to caregivers during appointments or hospital admissions about the plan of care; answering questions and clarifying the plan for patients and caregivers can make it easier for them to communicate those plans to others. It is important to keep in mind that the education nurses and other members of the health care team provide is often shared on these websites, so it is crucial to ensure that the information provided is clear and correct. Nurses can provide support for caregivers struggling with when and how often to communicate on the websites. They can reassure caregivers that communication should take place when it is the right time for them. If caregivers feel overwhelmed by the task of communicating, nurses can help them to identify resources and support to help them with the task of writing JEs.

Conclusions

Research specific to health-communication websites such as CaringBridge and to caregivers of adult cancer patients is limited (Hamm et al., 2013; Kent et al., 2016). This study provides a description of what a sample of cancer caregivers were willing to share with their CaringBridge support network. In the cases examined, some caregivers shared negative emotions, while others did not. Some caregivers reached out and requested support, while others did not. Understanding why some caregivers share or request support and others do not can help clinicians support caregivers more fully. More research is needed to assess whether the variations seen in this study are true across different patient/family populations. Research should also examine if there are variations in needs and benefits across different patient/family populations (Hamm et al., 2013). Future research should include input from the caregivers themselves; the lack of this is a limitation of the current study. It is crucial to get the feedback of caregivers and patients to understand how to make social media work for them, with minimal burden and maximum benefit. Finally, future research should explore how gratitude impacts support received, and if grateful individuals are more likely to benefit from computer-mediated support. If caregivers are able to share their feelings, burdens, and needs with the community, then they may receive more support.

CHAPTER 5

THE TYPES OF SOCIAL SUPPORT REQUESTED AND RECEIVED BY CANCER CAREGIVERS ON CARINGBRIDGE

Abstract

The objectives of this study were to describe the types of social support caregivers request and the social support guests offer on CaringBridge; and to examine the relationship between the types of social support caregivers request and the social support guests offer on CaringBridge. A retrospective, longitudinal, descriptive approach was used to examine 20 public-access CaringBridge sites; each site constituted one case. The Social Support Behavior Code system was applied to cancer-caregiver journal entries and to guestbook postings to identify five types of social support. Requests for support and offers of support were examined for matches between them for each type of social support (*emotional, esteem, informational, network, tangible,* and *no social support requested/offered*). Cancer caregivers requested most types of social support from their CaringBridge network. The highest requests were for emotional support, whereas esteem support was not requested; however, in most posts, caregivers did not request any type of support (*n* = 238, 61.18%). Guests offered all types of social support regardless of whether or not it was requested, but predominately offered emotional support. When

support was requested, 66.67% of requests were matched with support within 24 hr and 70.24% within 7 days. These findings suggest that social media platforms such as CaringBridge may be a means of providing support to cancer family caregivers. Future research should explore ways to ensure that caregivers are eliciting helpful support and to examine the benefits to caregivers when the network responds with support.

Introduction

As our society becomes more connected via the Internet, research is increasingly focused on how social support may be provided using technology (Yao et al., 2015). Social media is the use of the Internet to create virtual communities in which data are shared (Pew Research Center, 2017b). According to the Pew Research Center (2017b), nearly 70% of Americans use some type of social media. It is uniquely positioned to provide a platform for social support to be expressed to cancer caregivers wherever they may be, and throughout the care continuum, as it can reach them even in isolation at home or in the hospital (Yao et al., 2015). Examples of social media sites used by cancer patients and caregivers include CaringBridge, CarePages, PatientsLikeMe, Facebook, Twitter, YouTube, LIFECommunity, online support groups, and professional and personal websites/blogs (Anderson, 2011; Bender et al., 2011; Chou et al., 2011; De la Torre-Díez et al., 2012; Frost & Massagli, 2008; Keim-Malpass & Steeves, 2012; Song et al., 2012).

It is important to identify how social support may help caregivers during difficult times. Social support has been linked to psychological and physical effects on individuals (Barth et al., 2010; Thompson et al., 2013; Uchino et al., 2012). Poor social support is linked with increased incidence of anxiety and increased comorbid depression (Manne et al., 1999; Thompson et al., 2013). Physical impacts from poor social support include higher morbidity and mortality from cardiovascular disease, cancer, and infectious diseases (Barth et al., 2010; Ell et al., 1992; Lee & Rotheram-Borus, 2001; Pinquart & Duberstein, 2010). Conversely, perceiving high social support results in a lower risk of all-cause mortality (Holt-Lunstad et al., 2010). Social support's physical effects are as significant as the effects of smoking, exercise, and obesity on cardiovascular and immune function (Holt- Lunstad et al., 2010; Uchino et al., 2012). The potential benefits of social support can lead to better outcomes for caregivers; however, caregivers' needs for social support can be equal to or greater than patients' needs due to the added stressors of caregiving (Dubenske et al., 2008; Given et al., 2012; Given et al., 2011; Shaw et al., 2013).

With the complexity of the cancer trajectory, there can be many changes to a caregiver's role; for example, a spouse caregiver may previously have relied on the patient to do the housework or manage the finances, but must now take up that role while the patient is unable or limited in ability (Dubenske et al., 2008; Given et al., 2011; Shaw et al., 2013). Along with these changing roles, caregivers' needs increase as they take on more tasks but do not have time to care for themselves (Dubenske et al., 2008; Given et al., 2011; Given et al., 2012; Shaw et al., 2013). Caregivers need support to function in their new role and to meet their needs.

As for social support received by caregivers on social media, little is known. In one small study examining social-media preferences of cancer survivors and caregivers, caregivers reported wanting to use social media to receive social support (Badr et al., 2015). Most studies examining social support provided by social media have consisted of intervention studies of social-support groups (Hamm et al., 2013); however, very few of these studies were focused on caregivers (Namkoong et al., 2012).

The focus of the current study was on the types of social support requested by caregivers of cancer patients and the types of support offered by guests on a social-media website. Types of support have been defined many different ways, but frameworks mostly overlap conceptually. For this study, social support was divided according to the five major domains identified by Schaefer, Coyne, and Lazarus (1981): *informational*, *emotional*, *esteem*, *network*, and *tangible*. Informational support involves offering suggestions or advice; examples of this include expressing sympathy or offering encouragement (Cutrona & Suhr, 1992). Esteem support occurs when an individual validates the feelings or compliments the recipient of the support (Cutrona & Suhr, 1992). Network support is about connecting the caregiver to their community; it is about companionship and connectedness (Cutrona & Suhr, 1992). Tangible support involves offering to assist with actual tasks (Cutrona & Suhr, 1992).

Social support provides a buffer for individuals during stressful events such as those experienced on the cancer trajectory (Cohen & Wills, 1985). How the buffering works is impacted by a concept called *optimal matching*. Optimal matching postulates that social support is best received when it is what the receiver wants or needs (Cutrona & Russell, 1990; Tian & Robinson, 2009). In other words, if a caregiver wants information on the patient's diagnosis, they benefit from receiving informational support; however, they may not benefit as much from receiving emotional support when what they are seeking is information. This is also true of the other types of support. Unasked-for support and unsolicited advice may make individuals feel incompetent (Smith &

Goodnow, 1999); caregivers could feel that the network is questioning their competence in caring for the patient. The lack of matched support has been linked to increased distress (Merluzzi, Philip, Yang, & Heitzmann, 2016).

Objectives

In this research study, I aimed to (a) describe the types of social support (*informational, tangible, emotional, network, or esteem, vs. no request for/offer of social support*) caregivers requested in social-media website JEs and the types of social support guests offered in GPs; and (b) examine the relationship between the types of social support caregivers requested in JEs and the social support guests offered in GPs to see if they matched. Examining the optimal matching of support will contribute to understanding how caregivers' JEs and family and friends' GPs create a social support network in the digital age.

Methods

Design

I used a retrospective, longitudinal, descriptive research approach to examine the social media platform CaringBridge. CaringBridge is one website cancer patients and their caregivers use to communicate to their social networks about the patient's disease and experience. Patients and caregivers write JEs and then guests in their social networks can respond in GPs. The University of Utah IRB exempted this research study from formal IRB review because all cases included were public-access only.

Sample

Twenty public-access CaringBridge sites were examined. Participants were not recruited. Each site was dedicated to one patient and constituted one case. Cases were selected according to the following criteria: 50% or more of the JEs had to be written by the caregiver; cases were open-access; only the English language was used; the case involved an adult patient >21 years (when patient age could not be determined, the case was not used); the cancer was at any stage (I–IV); and the case had to be created at least 6 months prior to the study start date, to ensure that there was sufficient data available. A detailed description of case selection is provided in Chapter 4. The JEs of cancer caregivers and GPs by guests to the site were examined. See Figure 9 for a breakdown of the selection process used to identify the JEs and GPs included in the sample.

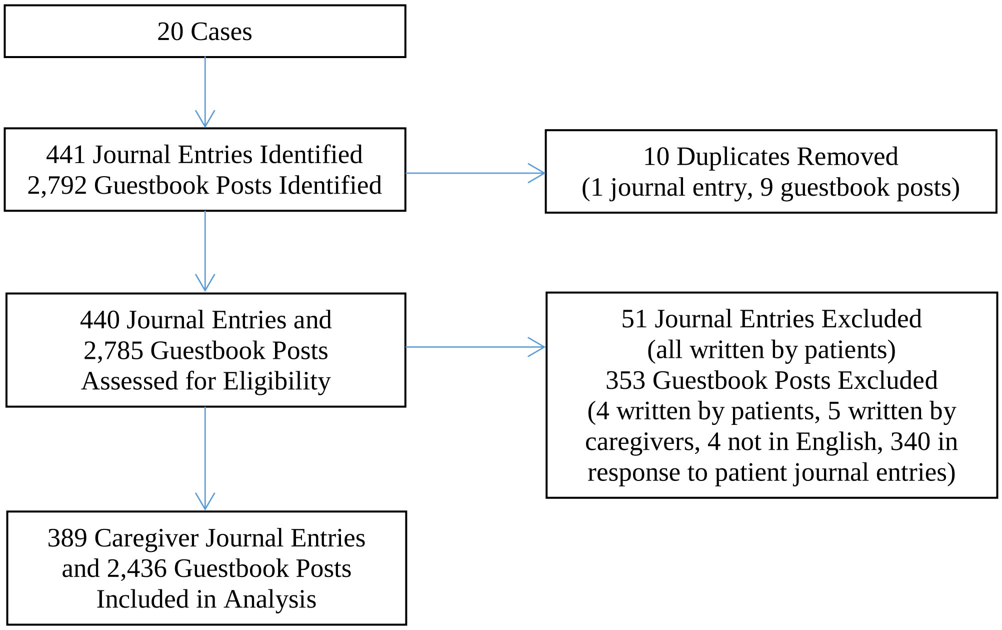


Figure 9. Flow diagram of selection process
for analysis of the 20 cases.

Measures

I identified and collected variables for patient, guest, and caregiver relationship characteristics as follows: patients' cancer types (as described in each case), writers' roles (patient, caregiver, or guest), sex (male, female, unable to determine), and caregivers' relationship to the patient (spouse, child, sibling, friend, unknown). Additional variables included social support requested and received. Social-support variables were identified using a predetermined coding schema based on SSBC (Cutrona & Suhr, 1992; Hsieh & Shannon, 2005). The five categories of social support coded were *emotional*, *tangible*, *informational*, *network*, and *esteem* (Cutrona & Suhr, 1992).

Procedures

After identifying CaringBridge cases that met the selection criteria, I captured JE and GP textual data and downloaded them into NVivo 11 software (QSR International, n. d.). All corresponding role and relationship characteristics of the writers were de-identified (all names removed and an identification code assigned for each writer) and then entered and stored in the REDCap software on secure servers. Each type of support for each JE and GP was coded in NVivo 11 and reentered in REDCap. Additional information tracked included the number of entries by caregiver, number of entries by patient, and number of entries by guests.

Analysis

The units of analysis were all JEs written by cancer caregivers and all GPs written by guests to CaringBridge for each of the 20 cases, with the exception of the 340 GPs responding to patients' JEs. I conducted directed content analysis on all cases using a pre-existing coding framework (Hsieh & Shannon, 2005). Each posting was read several times to identify passages that reflected requests for and offerings of social support. More than one type of support could be present in the JE requests or guestbook offers, and these were double-coded. It is important to note that for a subset of the tangible support offerings, the CaringBridge "in tribute" donations were considered tangible support. In-tribute donations are to support CaringBridge; however, it was clear that at least some writers thought the donations went to the patient. These donations often appeared alone with the words "In tribute." If they were accompanied by text, the additional text was coded for all types of social support, not just tangible.

Intercoder reliability was assessed using Cohen's Kappa for percent agreement. A second coder independently coded a randomly selected subset of the 20 cases. The subset included 10% (*n* = 44) of caregiver JE requests for social support and 10% (*n* = 277) of GPs for offerings of social support. Any disagreements in coding were evaluated by both coders to find agreement. After negotiating, the Cohen's Kappa for percent agreement for both the JE and GP coding were 0.715 and 0.749, respectively, which are both acceptable (Lombard et al., 2002).

The results of the social-support codes were compared for JEs and GPs. This was done by comparing each JE to the GPs that followed it for the next 24 hr and then for the next 7 days. Some guests wrote in the guestbook prior to any JEs being written, and these were included in the analysis and identified as unsolicited social support. If the caregivers wrote a JE and no guests responded that day, or on subsequent days until the next JE or end of the case, an additional dummy (placeholder) entry was added and coded as no offer of social support (*n* = 36). The 2,430 GPs and 36 placeholder entries totaled

2,466 guestbook "offers." Comparisons were made of each type of support requested by caregivers to the support offered by guests, to determine if they matched.

Results

Demographics

The average number of JEs per case was 22 (*SD* = 13.63) and the average number of guestbook responses per case was about 139 (*SD* = 86.28; see Table 13). Twenty cancer patients with various types of cancer were represented in the sample (see Table 14). Solid tumors (i.e., brain, breast, colon, esophageal, lung, ovarian, pancreatic, ureter, and unknown primary) comprised the majority of cases (70%, *n* = 14). Hematologic malignancies (acute and chronic leukemias, Hodgkin's and non-Hodgkin's lymphomas

Table 13

Descriptive Statistics: Journal Entries and Guestbook Postings From 20 Cases

Statistics	Value(s)
Journal Entries	
Total number of cases	20
Sum of JEs	440
Lowest number of JEs	1
Highest number of JEs	53
Mean number of JEs	22
Median number of JEs	22.5
Mode number of JEs	14
Sample *SD*	13.63
Guestbook Postings	
Total number of cases	20
Sum of GPs	2,769
Lowest number of GPs	6
Highest number of GPs	295
Mean number of GPs	138.5
Median number of GPs	128.5
Mode number of GPs	267
Sample *SD*	86.28

Table 14

Demographics: Journal Entries and Guestbook Postings From 20 Cases

Characteristic	*N* (%)
Patients	20
Male	7 (35%)
Female	13 (65%)
Cancer Type	20
Hematologic	6 (30%)
Solid	14 (70%)
Caregivers	36
Male	12 (33.3%)
Female	21 (58.3%)
Unable to determine	2 (5.6%)
Entry written by a couple	1 (2.8%)
Caregiver Relationship to Patient	36
Spouse	10 (27.8%)
Child	14 (38.9%)
Sibling	2 (5.6%)
Child-in-law	1 (2.8%)
Friend	3 (8.3%)
Unknown	6 (16.7%)
Guests	1,098
Male	219 (19.9%)
Female	796 (72.5%)
Unable to determine	56 (5.1%)
Entry written by a couple	27 (2.5%)

and multiple myeloma) were also represented in the cases (30%, *n* = 6). Females were the majority of CaringBridge users among patients (65%, *n* = 13), caregivers (58%, *n* = 21), and guests (73%, *n* = 796). Due to selection criteria, only a small number of patients' JEs were found (12%, *n* = 51), and these were not included in subsequent analysis.

Identifying Types of Support Requested and Offered

Requests for Support

The 36 cancer caregivers wrote 389 JEs on CaringBridge; of these, only 151 (38.82%) contained at least one request for support. The most common requests were for *emotional* support (27.76%, *n* = 108); these primarily consisted of requests for prayers. Other types of support were requested, including *informational,* present in less than 1% of JEs (*n* = 3); network, present in 7.97% (*n* = 31); and *tangible,* present in 6.68% (*n* = 26); although most JEs (*n* = 238, 61.18%) did not request social support. For examples of the support requests, see Table 15.

Informational requests ranged from questions about patient and caregiver understanding of medical terminology used by providers to specific requests for movies or resources. Network requests were unique in that there were occasions when caregivers requested not to have visitors due to the ramifications of the patient's disease and cancer treatment. For example, when a patient's blood counts were low and he or she was at risk for infection, caregivers requested no visitors; when caregivers requested network support, it was usually after these times, when they essentially gave the "all clear" for visitors. Caregivers also requested network support upon the patient's death (50%, *n* = 10) by requesting the guests' presence and providing information about visitation and funeral plans. Tangible support requests ranged from help with meals to rides and

Table 15

Examples of Types of Support Requested and Offered

Support Type	Requests	Offers
Emotional	Pray for her this week as she undergoes surgery for her port. And that it will be healed enough by Monday that it won't be too painful for her next round of chemo	You were on my mind several times today. Just wanted to drop by and let you know that and that I am still praying for you. You are part of our of our [sic] family. We love you guy's more than you know. We have experienced alot [sic] of life together. With God's mighty hand involved, there will be many more years to come. This is just another test that *** will pass with flying colors.
Esteem	[Not requested by caregivers].	You were an incredible advisor and teacher and I would not be anywhere near the student or man I am today without you. I want to thank you for everything you taught me during our time together. Even your teaching on James Joyce alone would have made you one of the most influential teachers I've ever had, but you offered so much more. . . . such a vivacious, loving, brilliant, humorous, kind and generous spirit.
Informational	if anyone has any recommendations for South Bay nursing aide services, let us know! Always good to have trusted recommendations	Wife in ICU + Daughter at 8th Grade dance + Son in Volleyball game = ***, the Father of the Year! That's the finger device to determine oxygen levels. Just one thought on hydration—it is possible to do it yourself if you get a port. I was hesitant at first but then I was hooking *** up while talking on the phone. Then he was hydrating himself. Remember the American Cancer Society is a great help. They help with getting you to appointments and treatments, etc. Use them at no cost to you. I did volunteer work for them for about a year and did see how much good they do
Network	The *** household is officially open for business, and open for very BRIEF visits from friends. Mom loves seeing people and catching up with everyone, but she doesn't have a ton of energy for long visits. If you want to come by, late mornings or late afternoons seem to be the best time; just please call ahead of time to confirm the time works	I will come to see you Monday night See you Tuesday at the chemo bar. As you may remember, my sister has been a successful survivor and it has been well over 10 years. I offer her as a person who can talk with you if you would like. She received such strength by being connected to others who had gone through the bone marrow procedure. Please let me know and she will call you or you can call her! There are very few out there who actually know what you are going through Just know that we are available for anything you need

Table 15 (Continued)

Support Type	Requests	Offers
Tangible	To help support *** during this process, we have set up a fundraising page through. . . . Your generosity is greatly appreciated and contributions will help *** in many ways, including with: Hospital bills, Medication costs, Living expenses such as rent, utilities, food, Travel expenses such as taxis to and from the hospital and airfare for her family, who must be on-hand [sic] to care for her	Let me offer something to you. If *** needs someone to take her to chemo, doctor's office or cook a meal, please call me. I have lots of vacation and would love to take some to help her. . . . will bring dinner anytime! [sic]

financial help. Several cases provided information about fundraisers so guests could help the patient and family cover cancer treatment expenses and day-to-day living expenses. Esteem support was not requested in any of the cases. See Figure 10 for a breakdown of types of support within the 168 social support requests.

Guest Responses

Guests offered social support in the majority of the 2,430 GPs (98%, *n* = 2,413). Each type of social support was offered at least once in the writings of guests; however, emotional support was the dominant type offered, appearing in 95% (*n* = 2,353) of GPs; esteem support was present in 23% (*n* = 572), informational support in 3% (*n* = 68), network support in 18% (n = 439), and tangible support in 9% (*n* = 223). For examples of the types of support offered, see Table 16.

Guests offered emotional support in the form of encouragement and prayers

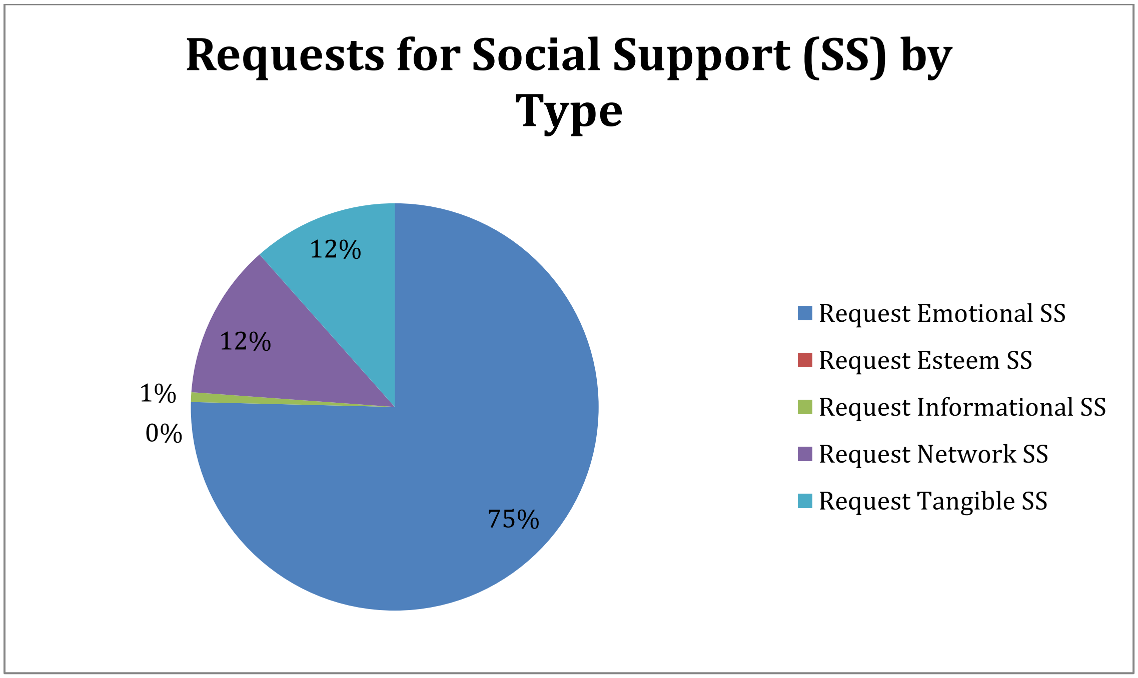


Figure 10. Requests for social support by type.

Table 16

Requests for Support by Type

Requests	*n* (%)	Range	Median	Mean (*SD*)
Requests for Support				
Total	168 (100%)	0–29	6	8.4 (8.17)
Emotional	108 (64%)	0–24	3.5	5.4 (6.21)
Esteem	0 (0%)	--	--	--
Informational	3 (2%)	0–1	0	0.15 (0.37)
Network	31 (18%)	0–10	1	1.55 (2.42)
Tangible	26 (15%)	0–7	1	1.3 (2.11)
Requests That Received a Matching Response From at Least One Guest Within 24 Hr				
Total	112 (66.6%)	0–16	4	5.6 (4.73)
Emotional	93 (86.11%)	0–16	3	4.65 (4.69)
Esteem	0 (0%)	--	--	--
Informational	1 (33.33%)	0–1	0	0.05 (0.22)
Network	15 (48.39%)	0–5	0	0.75 (1.25)
Tangible	9 (34.62%)	0–3	0	0.45 (0.83)
Requests That Received a Matching Response From at Least One Guest Within 7 Days				
Total	118 (70.24%)	0–19	4	5.9 (5.48)
Emotional	98 (90.74%)	0–19	3.5	4.9 (5.35)
Esteem	0 (0%)	--	--	--
Informational	1 (33.33%)	0–1	0	0.05 (0.22)
Network	16 (51.61%)	0–5	0	0.8(0.28)
Tangible	15 (57.69%)	0–7	0	0.75(1.65)

through the ups and downs of cancer treatment. Many guests offered esteem social support to both patients and caregivers. Guests praised caregivers for caring for the patient or complimented the patient on how well they handled the adversity of the cancer diagnosis. Informational support was offered in a limited amount, but the support offered was often very specific, offering resources to the patient, recommendations for products and resources, and advice on how to deal with the impact of cancer on their life. Network support consisted primarily of requests to visit the patient, but there were a few instances in which guests reminded caregivers that they knew someone who had experience with a similar diagnosis and treatment, and offered to connect the patient with the individual. Tangible support offers were often nonspecific, offering to do anything the patient or family needed; other tangible offers were specific, such as providing rides when requested by the caregiver, and meals. See Figure 11 for types of support represented within the 2,413 social-support offers.

Match Between Social Support Requested and Social Support Received

I examined the data set for each type of support (emotional, esteem, informational, network, tangible, or no request/offer) to evaluate whether the type offered matched the type requested (see Tables 16 and 17). Throughout the cases, there were JEs that contained multiple requests for different types of social support; for example, a

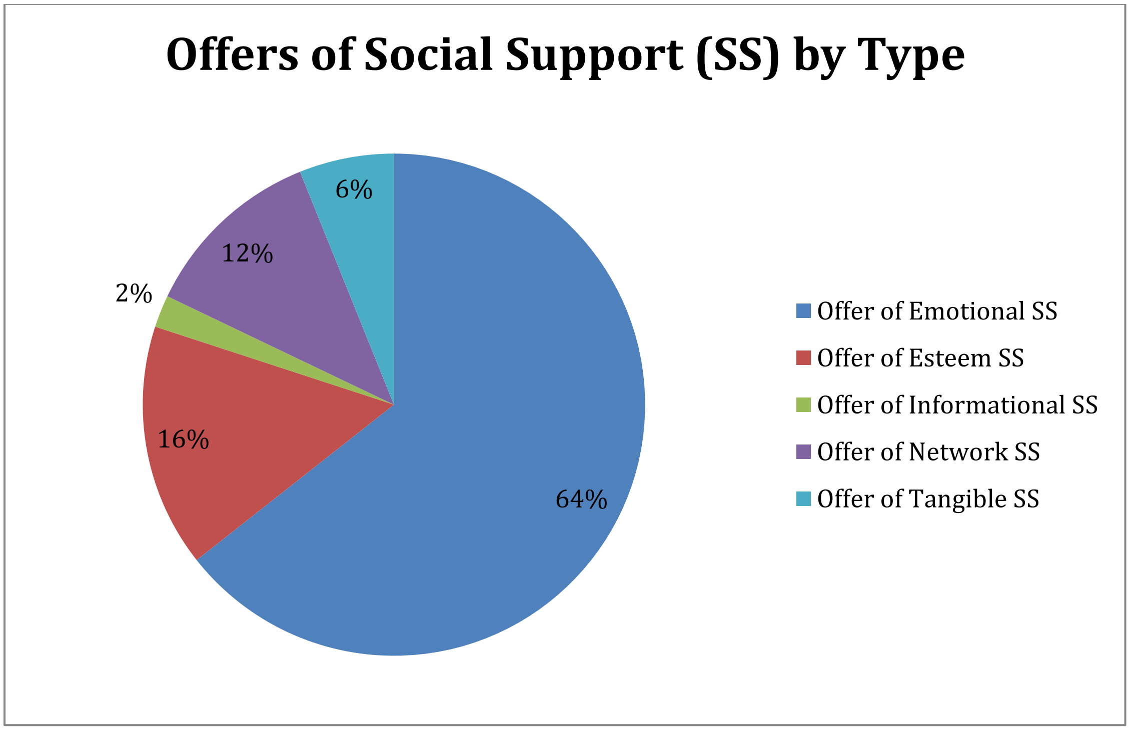


Figure 11. Offers of social support by type.

Table 17

Offers of Support by Type

Offers of Support	*n* (%)	Range	Median	Mean (*SD*)
Total Guest Posts	2,466 (100%)	6–252	117	123.3 (76.91)
Guest Offers of Support	2,413 (100%)	6–250	113	120.65 (76.67)
Emotional	2,353 (97.51%)	6–244	109.5	117.65 (74.85)
Esteem	571 (23.7%)	1–76	20	28.6 (22.81)
Informational	68 (3.15%)	0–23	2	3.8 (5.24)
Network	440 (18.23%)	0–73	17	21.55 (18.89)
Tangible	223 (9.24%)	1–37	7	11.15 (10.68)
Responses That Were Matched to Solicited Support Within 24 Hr				
Total	626 (25.94%)	0–103	21.5	31.3 (29.27)
Emotional	601 (25.54%)	0–103	20.5	30.05 (29.17)
Esteem	0 (0%)	--	--	--
Informational	1 (1.47%)	0–1	0	.05 (.22)
Network	33 (7.5%)	0–24	0	3 (6.42)
Tangible	12 (5.38%)	0–7	0	0.85 (1.84)
Responses That Were Matched to Solicited Support Within 7 Days				
Total	1,121 (46.46%)	0–143	60.5	56.05 (45.39)
Emotional	1,072 (45.56%)	0–138	53.5	53.65 (44.13)
Esteem	0 (0%)	--	--	--
Informational	1 (1.47%)	0–1	0	.05 (.22)
Network	60 (13.64%)	0–24	0	3 (6.42)
Tangible	17 (7.62%)	0–7	0	0.85 (1.84)
Responses That Were Unsolicited Support (no request, and support provided >7 days after request)				
Total	1,756 (72.77%)	6–204	85.5	87.8 (62.59)
Emotional	1,281 (54.44%)	1–167	67	64.05 (51.07)
Esteem	571 (100%)	1–76	20	28.55 (22.87)
Informational	67 (98.53%)	0–23	1.5	3.35 (5.22)
Network	380 (86.36%)	1–61	15	19 (16.29)
Tangible	206 (92.38%)	1–36	5.5	10.3(9.86)

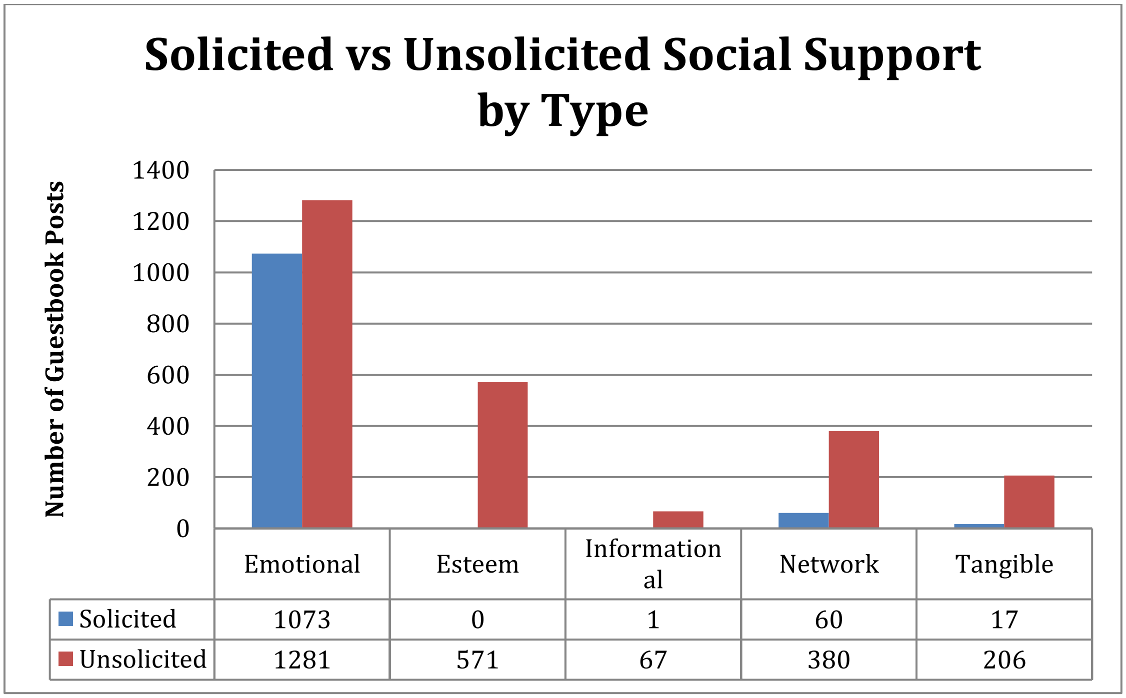
caregiver may have requested both emotional and tangible support in the same JE. This was also true for GPs, as guests would sometimes offer more than one type of support in their GP. For the purpose of the analysis, however, comparisons were made between the type of support requested (yes/no) and the type of support offered (yes/no) for each of the support types (emotional, esteem, informational, network, tangible, and no request/offer). For example, a caregiver request for emotional support was compared to the guest offerings of emotional support.

Of the 168 requests for support, 70.24% (*n* = 118) received a matched response from at least one guest within 7 days. In fact, most of the caregivers' requests received matched support within the first 24 hr after the caregiver wrote their JE (*n* = 112, 66.67%). Within 24 hr, about a third of informational (*n* = 1, 33.33%) and tangible (*n* = 9, 34.62%) requests were matched, nearly half of network requests were matched (*n* = 15, 48.39%), and the majority of emotional requests were matched (*n* = 93, 86.11%). After 7 days, the number of matched requests increased only minimally in most instances: emotional increased from 86.11% to 90.74% (*n* = 98); network increased from 48.39% to 51.61% (*n* = 16); tangible increased by 23.07 % after 7 days (*n* = 15, 57.69%), and no further matches for support were made for informational support.

With regard to the 2,413 GPs that offered support, nearly half of the time (*n* = 1121, 46.46%) the support offered matched the support solicited by caregivers. There was also a very high volume of unsolicited support, with 72.77% of 2,413 support posts (*n* = 1,756) offering unsolicited support. Unsolicited support and solicited support at times occurred in the same GP (*n* = 464, 19.23%). Emotional (*n* = 1,281, 72.95% of 1,756 unsolicited) and esteem (*n* = 571, 32.52% of 1,756 unsolicited) support showed the highest volumes of unsolicited social support. Esteem support was always unsolicited, as it was never requested by caregivers. Informational support was the least-offered type of support, whether it was solicited (*n* = 1, <.01% of 657 solicited) or unsolicited (*n* = 67, 3.82% of 1,756 unsolicited). See Figure 12 for comparisons of solicited and unsolicited support by type.

Discussion

In this study I aimed to identify the types of support requested by caregivers and offered by guests on CaringBridge. Requests for emotional, informational, network, and tangible support were identified in the caregivers' writings. In turn, guests responded with offers of emotional, esteem, informational, network, and tangible support. Literature has shown that social-media platforms such as CaringBridge are primarily used for



	Emotional	Esteem	Informational	Network	Tangible
🟦 Solicited	1073	0	1	60	17
🟥 Unsolicited	1281	571	67	380	206

Figure 12. Solicited versus unsolicited social support by type.

emotional support (Anderson, 2011; Gage-Bouchard, LaValley, Mollica, & Beaupin, 2017) and tangible support (Gage-Bouchard et al., 2017); however, this study showed that in addition to emotional support, network support is sometimes requested and other types of support (i.e., esteem, network, and tangible) are offered on CaringBridge. These findings demonstrate that CaringBridge and other social-media platforms are an avenue for caregivers to request and potentially receive the full breadth of support types.

Because informational support is provided by guests, it is important to learn if what is shared by both caregivers and guests is accurate. While this study identified what types of information (e.g., what devices are used for, how to care for IV sites, resources, and so forth) are shared, it did not focus on the accuracy of the information shared. Early research has demonstrated that while much of the health information shared by cancer caregiver networks is medically accurate, there are times when inaccurate information or unproven treatment information is shared on social media (Gage-Bouchard, LaValley, Warunek, Beaupin, & Mollica, 2017). Individuals often rely on their friends and family for advice, and may not trust what are actually reputable sources for fear of obtaining false information; this may be especially true in this era of fake news. If caregivers or guests are not sharing accurate information, cancer patients and caregivers may follow inaccurate and possibly dangerous advice and recommendations.

The second aim of this study was to determine how well the support requested matched the support offered. Requests for emotional and tangible support received matched offers more than half of the time, whereas caregiver requests for informational and network support received matched support less than half of the time. These unmet requests for informational and network support suggest that caregivers’ needs are not being met when those types of requests are being made (Cutrona & Russell, 1990). It may be that guests are reaching out outside of social media when informational and network requests are made (e.g., calling the caregiver directly or going to the patient's or caregiver's home). These results may be further compounded by the fact that two thirds of the time, caregivers did not make any requests for support, but instead primarily devoted their entries to providing information (see Chapters 4 and 5). When caregivers did not request support, guests nevertheless responded with different types of support, especially emotional and esteem support. This is a significant finding—that support is offered simply because of the caregivers' disclosure of the patients' stories—and is consistent with an emerging model of social-support elicitation and provision (Wang et al., 2015).

Wang and colleagues (2015) posited that disclosure is often an impetus for support because it helps guests to perceive the needs of the patient or caregiver. Telling the patients' stories allows guests to see what both the patient and the caregiver are experiencing, and they may perceive needs even if those needs are not explicitly requested. Support may also be beneficial if it matches the needs of the individual (Merluzzi et al., 2016); for example, it was unlikely for caregivers to request esteem support, but the validation and compliments regarding their care for the patient may have been needed, so while the match is not to a specific request, it is still meeting, or matching with, a need.

The matches between tangible support requested and offered may benefit from a tool CaringBridge created called the *Planner*, which debuted shortly after the majority of examined sites were started. The Planner functions as an online calendar to help caregivers make specific requests for tangible support (i.e., meals, transportation to and from appointments, help with childcare or pets; CaringBridge, 2014). While in this study I did not examine the Planner (because of privacy restrictions), it was clear from the support offered that guests wanted to provide tangible support. Many of the guests made general offers of tangible support, such as, “We are available for anything you need.” Guests may make general offers because they do not know the needs of the patients and caregivers; however, tools such as the Planner could help identify these needs so that support can meet the tangible needs of caregivers.

Study Limitations

The ability to determine if offers match requests is limited because of the variability in how guests may have read the JEs. Some guests may have read multiple entries from multiple days prior to writing their response, so they may have been responding to many requests and not just those from the most recent days. By also examining the matches of support at 24 hr and 7 days, we observed that most support is offered quickly (within 24 hr). Because the study was limited to what was written on the sites, we could not take into account the support received outside of social media. In some cases, patients and caregivers specified that they were receiving support from different individuals, but this was not included in this analysis as it was outside of the CaringBridge network. Only 43.18% of caregivers’ JEs requested support, and findings from prior studies suggest that caregivers primarily use CaringBridge to share information (Anderson, 2011). It is possible that members of the caregivers’ networks may have responded in person rather than online, and that caregivers made requests offline. The support measured was limited to what was observed on CaringBridge.

Another limitation of this study was the inability to measure support adequacy, how perceived and received support aligned (Gottlieb & Bergen, 2010). Even if support is received, it may not be perceived as supportive by the individual. Perceived support is the support an individual thinks is available to him or her, while received support is the actual support given to the individual (Gottlieb & Bergen, 2010; Uchino et al., 2012). Perceived and received social support may not align when individuals do not perceive that the support received is responsive to their needs. This misalignment may cause the receiver of support to feel vulnerable, and may lower his or self-esteem (Uchino, 2009). While we were able to identify the support offered to patients and caregivers, we do not know how the patients and caregivers perceived the support; they may have found it helpful even when it was not requested or did not specifically meet their requests, or they may not have found it helpful.

Clinical Implications

Caregivers are often isolated by their caregiving responsibilities (e.g., during patient hospitalization, while traveling for treatment, when providing direct care; Given et al., 2011) and have difficulty maintaining social ties (Williams & Bakitas, 2012). They may focus their time and attention on the caregiving at hand and may not have the time or resources to direct their attention to their social network. These combined difficulties may decrease the amount of support they receive from their regular support network. Computer-mediated social support may be an efficient way to reach individuals who are isolated from their support network, and to provide benefit to caregivers (Mikal et al., 2013). The initial diagnosis and changes in the cancer trajectory often prompt one’s social-support systems to engage and provide resources for coping; however, this support may diminish as time passes due to the chronic nature of cancer (NCI, 2017a). If caregivers continue to reach out to their CaringBridge network and request support, the guests may stay engaged and supportive, especially in providing emotional support. Future research should explore how to help caregivers reach out and ask for support. Researchers should explore ways to ensure that caregivers are eliciting helpful support and examine the benefits to caregivers when the network responds with support. As use of the Internet continues to increase, it is also important to understand what types of health information are shared. The knowledge obtained through this future research can inform how physicians, nurses, pharmacists, and other members of the health care team aid caregivers in understanding the potential benefits of tapping into this valuable resource.

CHAPTER 6

A VISUAL EXPLORATION OF THE CARINGBRIDGE SOCIAL-SUPPORT NETWORKS' RESPONSE TO PATIENTS' AND CAREGIVERS' POSTINGS: A LONGITUDINAL, DESCRIPTIVE, EXPLORATORY STUDY

Abstract

This study serves as a proof of concept for the use of data visualization to aid in the description of how social support from social media changes over time. Cancer creates a need for informal caregivers to support the patient in various ways. Social support is beneficial to caregivers; however, caregivers are often isolated from their in-person social networks. CaringBridge, an online site, may serve as a health communication tool to help individuals provide social support to caregivers; however, limited research has examined how online social networks respond to caregivers' journal entries over time and at the different transition points of a patient's cancer experience (e.g., diagnosis, hospitalization, discharge home, end of life). Data-visualization tools offer a unique way to do this. The objective of this study was to use data-visualization techniques as a proof of concept to explore the response (social support type and direction) of the CaringBridge social-support network to the patients' and caregivers' postings. For the three CaringBridge sites selected, the directionality of support and patterns of support were explored using data-visualization techniques, including social network, temporal (longitudinal graphs), and multidimensional analysis (histograms). From these analyses, differing patterns of support emerged. All 3 cases demonstrated that support fluctuated over time. Offerings of support increased at specific transition points, when caregiver distress and needs often increase. This case study demonstrates the proof of concept: data visualization is a beneficial tool for examining social-media data over time. Future research should examine the benefits to caregivers when the network responds with support, and develop ways to prevent support from fluctuating over time.

Introduction

Describing scientific studies in a meaningful way can be a difficult task. The Committee on the Science of Science Communication at the National Academies of Sciences, Engineering, and Medicine (2017) recommends that scientists tell the story of their data rather than only present the data numerically. Their recommendations recognize the value of numeric data while also recognizing that numeric data alone are often difficult for many people to understand. The committee recommends using numeric data along with a story to best disseminate research. By telling the story of the data numerically, narratively, and visually, it allows for the findings to be more accessible to the scientific community and the general public, and may offer novel insights. Data visualization can translate numerical data into a more understandable format while also offering an efficient yet compelling approach to consolidating and presenting individual stories. With that in mind, in this study I explored how best to tell the story of the complex and evolving cancer patient and caregivers' social networks on the Web site, CaringBridge.

Background

A cancer diagnosis is a significant, life-changing event for cancer patients, which extends to their informal caregivers, including friends and families. The experiences of cancer patients and caregivers vary based on cancer type, treatment options, goals of treatment, and the progress and setbacks each family experiences along the way (Dubenske et al., 2008; Ellis, 2012; Given et al., 2011; Shaw et al., 2013). One of the key support systems for cancer patients is their informal caregivers, who are crucial in providing care and support (NCI, 2017a). The demands on caregivers increase as the patient nears the end of life (Institute of Medicine [IOM], 2015). With a shift to more home-based care at the end of life, caregivers are now doing the work that was previously done by health care providers.

Support may be provided to patients and caregivers from their social networks. These networks are often comprised of other family members, friends, acquaintances, and coworkers. At the beginning of the cancer trajectory, social-support networks are often active and engaged, but the support can trail off as time goes on (NCI, 2017a). While social support may decrease over time, the patients’ symptom burden, caregivers’ burden, caregivers’ distress, and patients’ and caregivers’ needs often increase, especially for patients who are near the end of life (Chi & Demiris, 2017; Finucane, Lugton, Kennedy, & Spiller, 2017; Hartnett, Thom, & Kline, 2016). The disconnect between increasing needs for social support and decreasing offers of social support could lead to undue burdens and distress for both patients and caregivers.

Telling the Story

CaringBridge, a social-media website that facilitates individual social networks, provides a unique resource for retrospective, longitudinal research that explores how social support changes over time. In order to capture the complexity of these fluctuating networks, I applied data visualization analysis to publically available numerical and narrative data. This chapter serves as a proof of concept that data visualization tools are useful to examine social support offered on social media, and the tools help tell the story of how social support evolves. Data visualization involves using different analytic methods to organize complex data to make it easier to understand and interpret (UCLA Institute for Digital Research and Education, 2017), and has been utilized to uncover patterns and stories in data that may not be easy to observe in more traditional analysis methods.

In the present study, I used a multimethod approach to explore how different data-visualization methods could elucidate the story of social support on social media. Data visualization in social media is a growing field of research (Valente & Pitts, 2017). Previous studies have used data visualization to examine social networks on social media (Matsuda et al., 2017; Nsoesie et al., 2016; Rabarison et al., 2017; Valente & Pitts, 2017). As shown in the literature, social network analysis (SNA) is the data-visualization tool most commonly used to capture the relationships between members of online social networks on a variety of health-related topics (Rabarison et al., 2017; Valente & Pitts, 2017). Researchers use SNA to examine health communication on websites such as Facebook and Twitter (Rabarison et al., 2017). Additional tools are emerging; for example, Matsuda and colleagues (2017) examined blogs using word-cloud and word-cooccurrence network data-visualization tools to identify medication words that were commonly used together. Other researchers have examined opinion diffusion or information diffusion on social media using various data visualization tools, including spatial and temporal analysis, social network analysis, and OpinionFlow (Nsoesie et al., 2016; Stefanidis et al., 2017; Wu, Liu, et al., 2014).

Although SNA is common, there have been few longitudinal studies of SNA in relation to health communication (Valente & Pitts, 2017). Longitudinal social-network analysis often involves breaking the data into certain time points or episodes (Snijders, 2009). While social-network analysis tools have the option to show temporal (timeline) data (Chu, Wiplfi, & Valente, 2013), the full timeline would have to be exported as multiple "slices" of time. Therefore, two other data-visualization tools, multidimensional analysis and temporal analysis, may better capture the longitudinal data posted by cancer family caregivers and their social networks.

Multidimensional and temporal analyses are among a large variety of data-visualization tools available (UCLA Institute for Digital Research and Education, 2017). Multidimensional analysis (histograms/bar charts/pie charts) is commonly used to examine descriptive data and temporal analysis (e.g., time series data, which involves plotting data over time; Kellar & Kelvin, 2013; Mauri, Elli, Caviglia, Uboldi, & Azzi, 2017.). Temporal analysis has primarily been used in social-media research to demonstrate the diffusion of information about a health-related topic (Nsoesie et al., 2016; Stefanidis et al., 2017), but has not been utilized to examine changes in social support.

Goals of This Study

In this study I aimed to utilize data-visualization tools as a proof of concept for examining the dynamic and ever-changing offers of social support (type and direction) over time in response to cancer caregivers' JEs on CaringBridge. Due to the exploratory nature of this research, a case-study sample of 3 cases was purposively selected to represent the networks that were least, moderately, and most responsive (based on the rate of guestbook responses) from a larger study of social support on CaringBridge (presented in Chapters 4 and 5). All three of these networks followed the caregiver from the establishment of the CaringBridge site until the patient's death and the subsequent last postings. Data-visualization techniques were used to examine three specific research questions: *How often do guests direct social support to caregivers, patients, or families (patients and caregivers)? How does the guest network respond with social support to journal entries over time? What are the patterns of social support?* Caregiver JEs and network responses were examined at different transition points in care (Blum & Sherman, 2010; Dubenske et al., 2008) to uncover patterns of social support that may not have been detected through more traditional analytic methods.

Methods

Data Source and Sample Selection

The three cases examined in this exploratory substudy were selected from the parent study described in Chapters 4 and 5, which focused on cancer caregivers' experiences and the support caregivers received through social media. The data source was CaringBridge, a social-media website focused on the sharing of patients' cancer experiences with their social networks. On CaringBridge, patients and caregivers write

JEs about the patient's cancer experience and guests in turn express their support to patients and caregivers in the guestbook. After receiving IRB exemption, selected websites from the social-media platform CaringBridge were analyzed. Previous analysis included content analysis using the SSBC. Postings appeared from 2012 through 2015. Each case included the writings of caregivers in the JEs and guests' postings in the guestbook. See Table 18 for inclusion/exclusion criteria for the larger study.

For the exploratory analysis conducted in this study, cases were purposively selected from the overall sample of 20 cases; one case was excluded because there were limited longitudinal data. The remaining 19 cases were reviewed based on the rate of GPs per journal entry (JE). Each case was evaluated to verify whether the patient was in the last 6 months of life during the course of the case. Three cases were selected to reflect variation in the mean number of guestbook postings (GPs) in response to caregiver JEs: Case 1 had the lowest average of GPs per caregiver JE; Case 2 had the highest; and Case

Table 18

Inclusion and Exclusion Criteria

Category	Inclusion/Exclusion Criteria
Privacy	Cases with open settings with no restrictions (i.e., open-access)
Language	JEs and GPS were written in English
Patient	Adult (excluded if age could not be determined)
	Any stage of cancer (I–IV)
Caregiver	Included family and friends of the patient; posted the majority of the JEs (>50%)
Guests	There was at least one guestbook posting by an individual other than the patient and caregiver
Length of Time	Case was created at least 6 months prior to the study to ensure that there were sufficient data available.

3 represented the median number of postings among the 19 cases. These cases were selected with the intent to show the variation between the least-, median-, and most-responsive networks to determine if there were similarities or differences in the patterns of support.

Data and Measures

Demographic data were extrapolated, including the role of writer (patient, caregiver, or guest), patient's cancer type, patient's sex, caregivers' sex, guests' sex, and caregivers' relationship to patient. Additional data were extrapolated on whether guests addressed their support to the patient, caregiver, or family (patient and caregiver[s]). Directionality was operationalized in the following way: Are guests' GPs of support directed to the caregiver, the patient, or the family (patient and caregiver[s])? Each case was examined to determine who the individual was addressing in their GP; this was identified through the use of pronouns and names. For example, if the guest addressed a post directly to the patient and did not mention the caregiver(s) or the patient's family, then the posting was assigned a direction to the patient; if the guest wrote, "Our thoughts and love are with you," this was considered to be directed to the patient, because the pronoun "you" alone is often considered to be singular (although it can be used as a plural pronoun), and in many cases individuals will add a qualifier to clarify if the "you" is directed to more than one person (i.e., "you all" or "you guys"; You, 2017). If the guest had written, "Our thoughts and love are with you all," this would have been considered to be directed at the family (patient and caregiver[s]). At times, guests specifically identified family through the use of the word *family*, or addressed their post to the patient and caregiver(s) by name. If the posting did not identify to whom it was directed, it was presumed to be directed to the patient, because it was on the CaringBridge website, which was dedicated to patient and their cancer journey.

Data-Visualization Analysis

Three different types of data-visualization tools were used to explore the data: social network analysis, multidimensional analysis, and temporal analysis. All GPs and JEs were mapped for individual analysis of each of the 3 cases and for comparisons across patients and caregivers to determine whether patterns existed. The goal was to demonstrate how data-visualization tools can aid in the exploration of data and potentially reveal more than do traditional methods of data presentation.

Social-Network Analysis

SNA as a data-visualization tool has been commonly used in the social sciences to explain how social networks function (Borgatti et al., 2009). It uses graphs to visualize similarities (relationships individuals have in common with patient/caregiver/family), social relations (roles—patient, caregiver, guest), interactions (communication/support), and flows (direction of communication/support). SNA was conducted on each selected CaringBridge case to identify the number of individual nodes (each node is a circle that represents an individual; i.e., each patient, caregiver, or guest is represented by the circles in Figures 13, 14, and 15), the degree of each node (the size of each node based on the volume of connections between individuals), the number of links between nodes (how the patients, caregivers, and guests were connected to each other—who responded to another’s posting), and the directionality of the relationships. These data were input into Gephi (Bastian, Heymann, & Jacomy, 2009), a software system that allows for

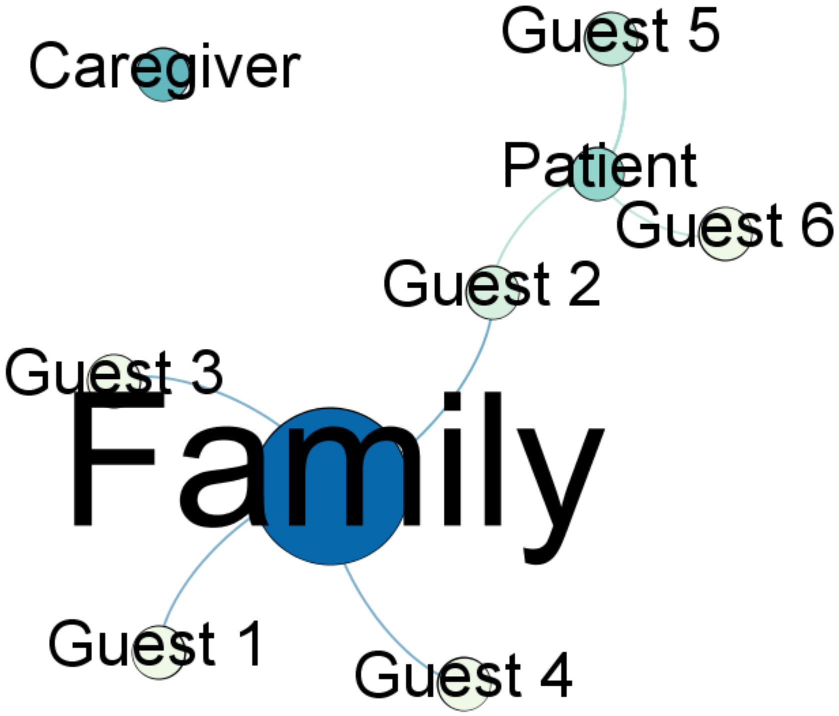


Figure 13. Case 1.

Note. The diagram represents Case 1 and reveals the relationships between the network members (guests, patient, caregiver[s] and/or family).

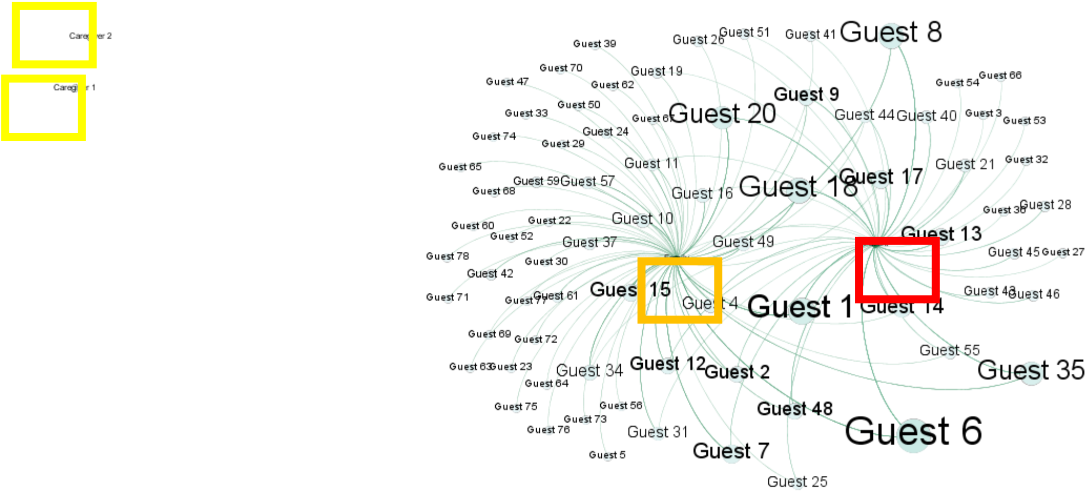


Figure 14. Case 2.

Note. The diagram represents Case 2 and reveals the relationships between the network members (guests, patient, caregiver[s] and/or family) Caregivers are within yellow boxes, family is within an orange box, and the patient is within a red box. The guests with larger nodes and font represent those who posted the most in the guestbook.

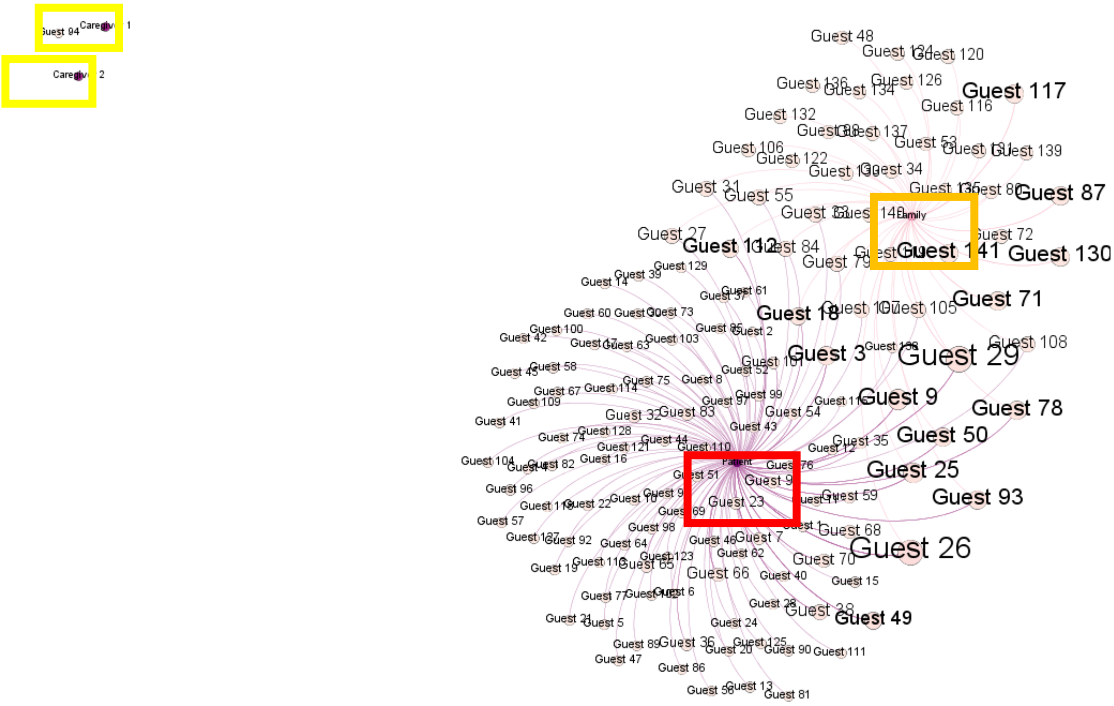


Figure 15. Case 3.

Note. The diagram above represents Case 3 and reveals the relationships between the network members (guests, patient, caregiver[s] and/or family)). Caregivers are within yellow boxes, family is within an orange box, and the patient is within a red box. The guests with larger nodes and font represent those who posted the most in the guestbook.

visualization of a social network (Gephi, 2017). In order to create the final network figure for each case, a series of calculations were conducted within Gephi to bring those who had more support directed to them into the center of the figure and to move those who had less communication directed to them outward, to the edges of the figure (Hanneman & Riddle, 2005).

Multidimensional Analysis

Multidimensional analysis (histograms/bar charts/pie charts) is a common way to utilize data visualization to describe data and descriptive statistics (Kellar & Kelvin, 2013). Multidimensional visual analysis was used to examine how the directionality of social support changed at different transition points. Transitions examined included the onset of the CaringBridge website (prior to and immediately after the initial JE), upon hospitalization, at discharge, at death (if applicable), and at the last JE. Stacked bar charts were created in Microsoft Excel for each transition, to visualize how the direction of social support changed.

Temporal Analysis

Temporal analysis has been used in research and involves the utilization of timelines and/or longitudinal graphs to visualize quantitative data (Kellar & Kelvin, 2013). Each case was examined longitudinally, looking specifically at how social support changed over time. All GPs were coded using a schema based on the SSBC for the parent study described in Chapters 4 and 4 (Table 19). This coding schema included five categories of social support: *emotional*, *tangible*, *informational*, *network*, and *esteem* (Cutrona & Suhr, 1992).

Table 19

Brief Definitions of Social-Support Behavior Codes

Support Type	Purpose of Communication
Informational Support	
Suggestion/advice	Offers ideas and suggests actions
Referral	Refers the recipient to other sources of help
Situation appraisal	Reassesses or redefines the situation
Teaching	Provides detailed information, facts, or news about the situation or skills needed to deal with the situation
Tangible Assistance	
Loan	Offers to lend the recipient something (including money)
Direct task	Offers to perform a task directly related to the stress
Indirect task	Offers to take over one or more of the recipient's other responsibilities while the recipient is under stress
Active participation	Offers to join the recipient in action that reduces the stress
Willingness	Expresses willingness to help
Esteem Support	
Compliment	Expresses positive things about the recipient or emphasizes the recipient's abilities
Validation	Expresses agreement with the recipient's feelings about the situation
Relief of blame	Tries to alleviate the recipient's feelings of guilt about the situation
Network Support	
Access	Offers to provide the recipient with access to new companions
Presence	Offers to spend time with the person, to be there
Companions	Reminds the person of availability of companions, of others who are similar in interests or experiences
Emotional Support	
Relationship	Stresses the importance of closeness and love in relationship with the recipient
Physical affection	Offers physical contact, including hugs, kisses, hand-holding, shoulder patting
Confidentiality	Promises to keep the recipient's problem in confidence
Sympathy	Expresses sorrow or regret for the recipient's situation or distress
Listening	Is attentive to comments as the recipient speaks
Understanding/empathy	Expresses understanding of the situation or discloses a personal situation that communicates understanding
Encouragement	Provides the recipient with hope and confidence
Prayer	Prays with the recipient

Note. Examples of codes. Adapted from "Controllability of Stressful Events and Satisfaction With Spouse support Behaviors," by C. E. Cutrona & J. A. Suhr, 1992, *Communication Research, 19*(2), p. 161. Adapted with permission.

I counted each instance of each type of support to determine the volume for each type offered. Guests provided all five categories of social support as identified in Chapter 5. The number of instances of each type of support per day was calculated, and input into a spreadsheet. Data were graphed using the Web-based application RAWGraphs (Mauri et al., 2017). Different time-series grafts were trialed to determine which graph best showed the story in the data, including area graph, streamgraph, bump chart, and horizon graph. The area graph was selected as the best way to visualize the data across the 3 cases.

Results

Demographics

For the 3 cases selected, the patient was male in Case 1 and female in Cases 2 and 3.The caregivers for all 3 cases were female. The caregiver's relationship to the patient could not be determined for Case 1; for Case 2, the caregivers were the patient's daughters, and for Case 3, the caregivers were the patient's friends. All 3 cases had multiple transitions throughout the patients' cancer journeys, including hospitalizations, discharges home, and the patients' death. See Table 20 for a summary of the 3 cases selected.

Extent to Which Guests Directed Social Support To Caregivers, Patients, and Families

The SNA was utilized to determine the extent to which guests directed support to the patient, caregivers, and family. Each figure reveals the relationships between the network members (guests, patient, caregiver[s] and/or family) for each case. Each circle represents a member ("nodes"), and the directionality of their writings is represented by the lines ("edges") connecting them. The larger the node, the more connections the node

Table 20

Summary of Three Cases

Case	Patient Sex	Cancer Type	Caregiver Sex	Caregiver Relationship to Patient	Length of Case (Days)	JEs	GPs	Rate of GPs & JEs	Transitions # (Type)
1	Male	Lung	Female	Unknown	88	7	10	1.43	4 (hospital, discharge, hospital, death)
2	Female	Lung	Female Female	Child Child	38	14	223	15.93	4 (hospital, discharge, hospital, death)
3	Female	Brain	Female Female	Friend Friend	262	33	215	6.52	8 (hospital, discharge, hospital, discharge, hospital, discharge, hospice, death

had with others in the network. The caregivers for the 3 cases did not direct their JEs to the patient; instead, they were writing to the guests on behalf of the patient.

In Case 1, the majority of guests directed support to the family; no guests directed support to the caregiver alone (see Figure 13). 2 guests, Guest 5 and Guest 6, directed their support solely to the patient. Guest 2 directed support to both the patient alone and to the family, and Guests 1, 3, and 4 directed their support only to the family.

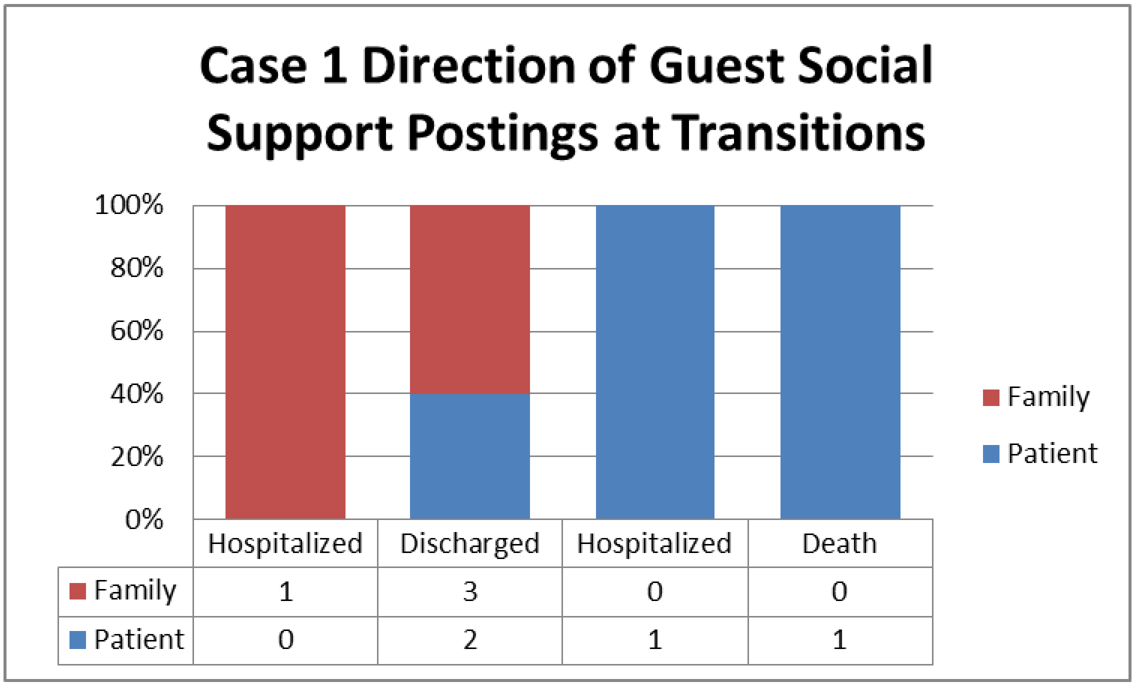
The majority of guests for Case 2 directed support to the family; no guests directed support to the caregiver(s) exclusively (see Figure 14). Many guests directed their support solely to the patient or solely to the family. The guests in the center of the diagram, between the patient and family nodes, directed support to both the patient and the family.

In Case 3 (see Figure 15), most guests directed support fairly equally between the family and the patient; no guests directed support solely to the caregiver. Many guests directed their support solely to the patient or solely to the family. The guests in the center of the diagram, between the patient and family nodes, directed support to both the patient and the family. Guest 94 did not provide support in his or her post, and appears to the left of the caregivers in the diagram, with no ties.

The similarity between all 3 cases was that no one in any of the cases specifically directed their support solely to the caregiver(s). There were also variations in the directionality of support. Directionality of support from the guests was primarily centered on the family for Cases 1 and 2 and was primarily centered on the patient for Case 3.

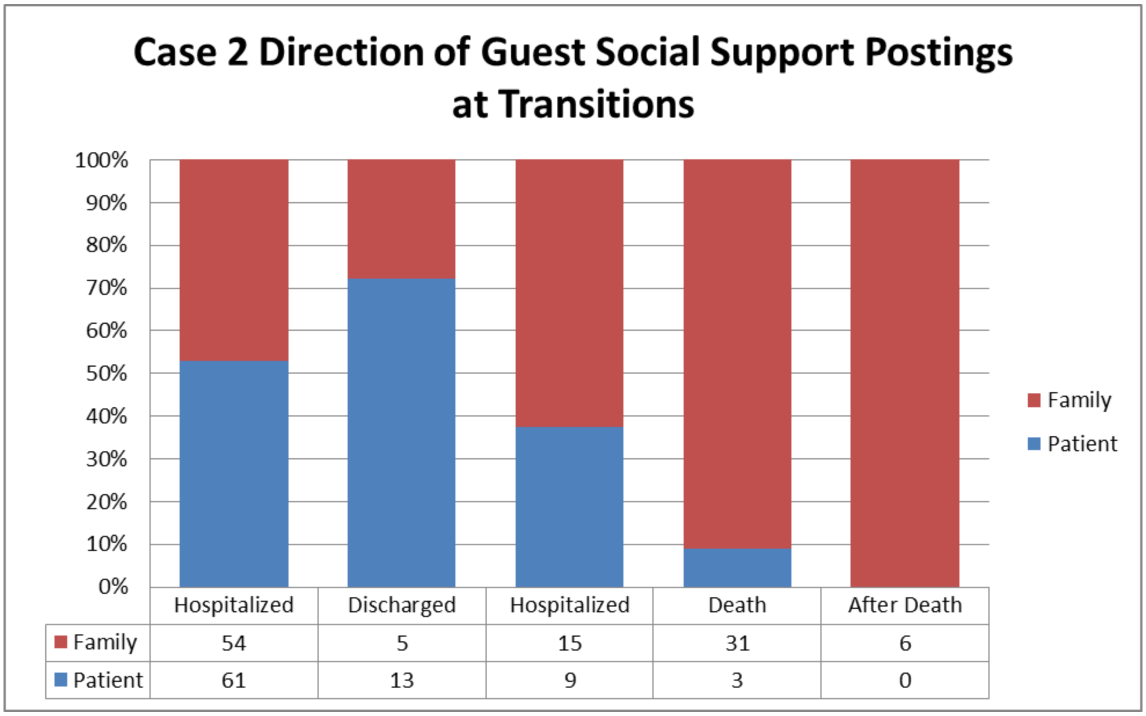
Patterns of Social Support

In the multidimensional analysis, the directionality of social support was examined at different transition points (Figures 16, 17, and 18). Each of the 3 cases had similar patterns of transitions, from initial hospitalization, discharge home, readmission, and death. Case 3 had an additional readmission and a clear transition to end-of-life care as she entered hospice care. The patterns of directionality of social support varied across the 3 cases. Case 1 had a pattern of support being directed to the family and then changing to be directed solely to the patient (see Figure 16). The patient was hospitalized two separate times. The first time the support was directed to the family; however, the second time it was directed to the patient. At discharge from the first hospitalization, there were only 5 GPs: 3 directed to the family and 2 directed to the patient. At death, there was 1 post directed to the patient. The caregiver did not write a JE prior to death



	Hospitalized	Discharged	Hospitalized	Death
🟥 Family	1	3	0	0
🟦 Patient	0	2	1	1

Figure 16. Case 1: Changes in direction of social support at transitions.



	Hospitalized	Discharged	Hospitalized	Death	After Death
🟥 Family	54	5	15	31	6
🟦 Patient	61	13	9	3	0

Figure 17. Case 2: Changes in direction of social support at transitions.

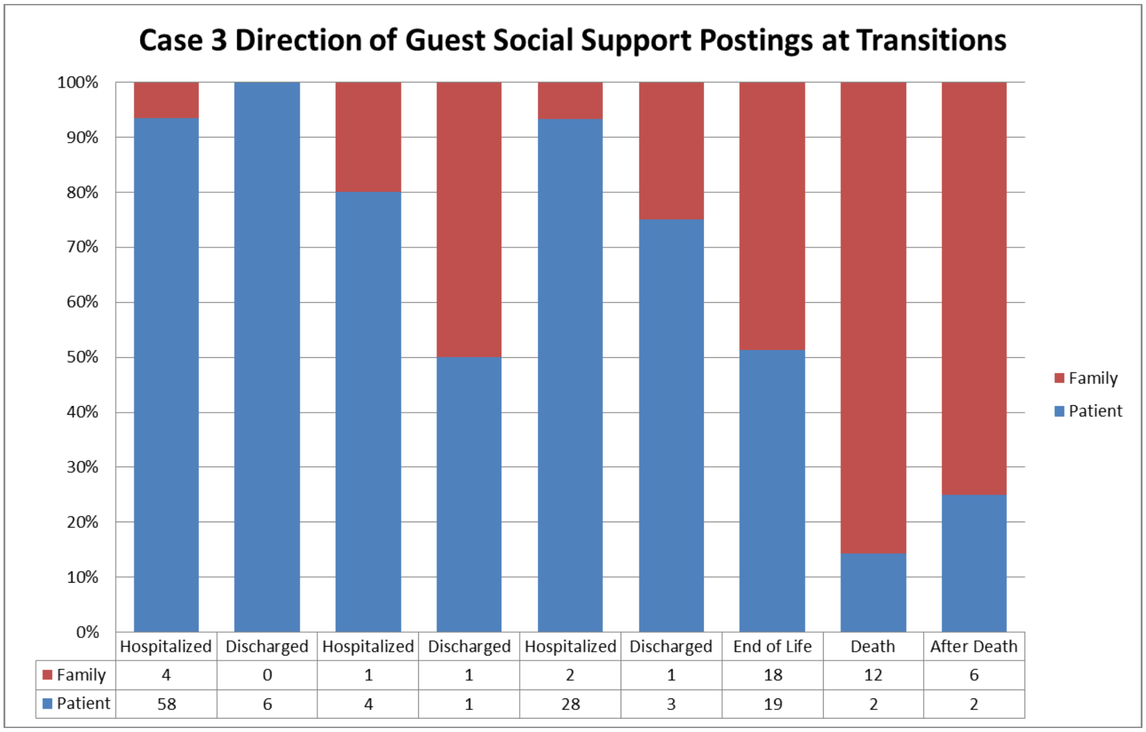


Figure 18. Case 3: Changes in direction of social support at transitions.

to indicate that the patient was at the end of life, other than to inform guests that the patient was hospitalized.

During the first two transition points, Case 2's guests directed support to both the patient and the family, but more often to the patient (see Figure 17). The patient was hospitalized two separate times. The first time, support was directed slightly more to the patient, and the second time, support was directed slightly more to the family, but overall, it was about equal. At discharge, the direction of support was focused primarily on the patient; at death, however, the direction changed dramatically, to be focused on the family. There was no posting prior to death to indicate that the patient was nearing end of life other than that the patient had been hospitalized. Support was directed entirely to the family in the days after the patient died. The after-death period was determined by starting with the caregiver JE that stated the patient had died; 24 hr after this entry, the after-death period began.

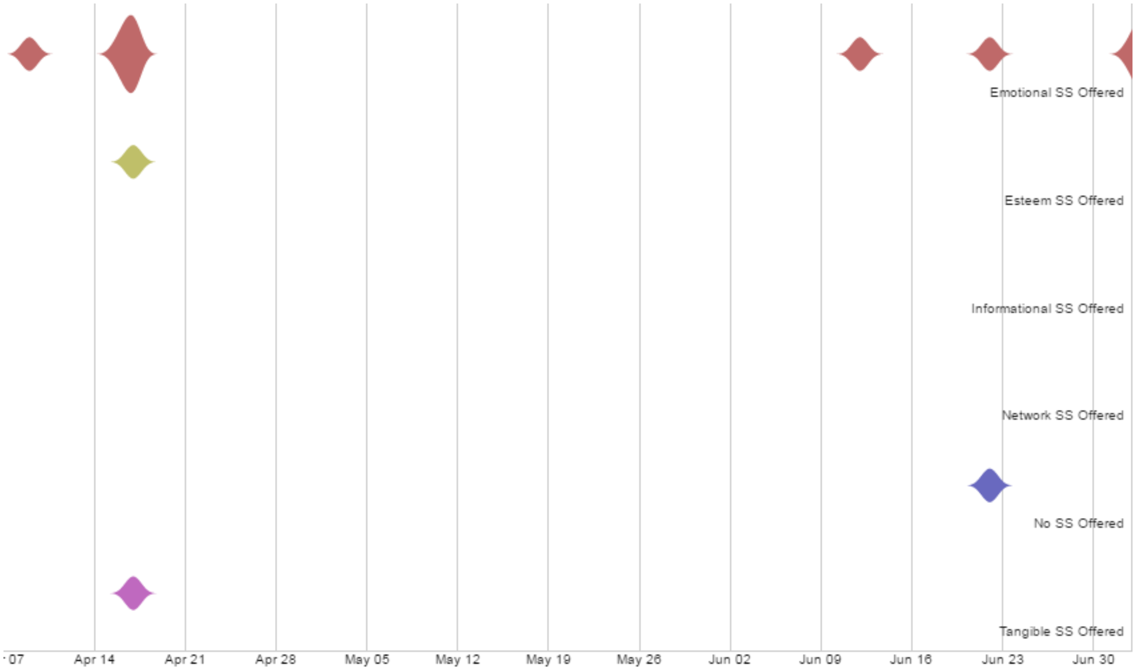
Case 3 was similar to Case 2 in that support was initially directed to the patient and then over time became more directed to the family. One key difference, however, is that support was overwhelmingly directed to just the patient in the beginning (see Figure 18). The patient was hospitalized three separate times, and each time, support was directed primarily to the patient. After the first discharge, support was directed solely to the patient. After the second discharge, the patient transitioned to an inpatient rehabilitation unit, and the support was evenly divided between patient and family. The third time the patient was discharged, support was primarily directed to the patient, but about a quarter of the support was directed to the family. This patient was the only one of the three to transition to hospice. At that time, the support was evenly directed to the patient and the family. At death, however, the social support focused more on the family. This continued in the days after the patient died.

Overall, all these three cases showed some variation in how support was directed at the different transitions. Cases 2 and 3 were more similar, with support being directed primarily to the patient with the initial hospitalization, whereas Case 1's support was directed to the family at this transition. At death, support was more often directed to the family for Cases 2 and 3, but in all 3 cases, at least some support was directed to the patient at the time of death.

How the Guest Networks Responded With Social Support Over Time

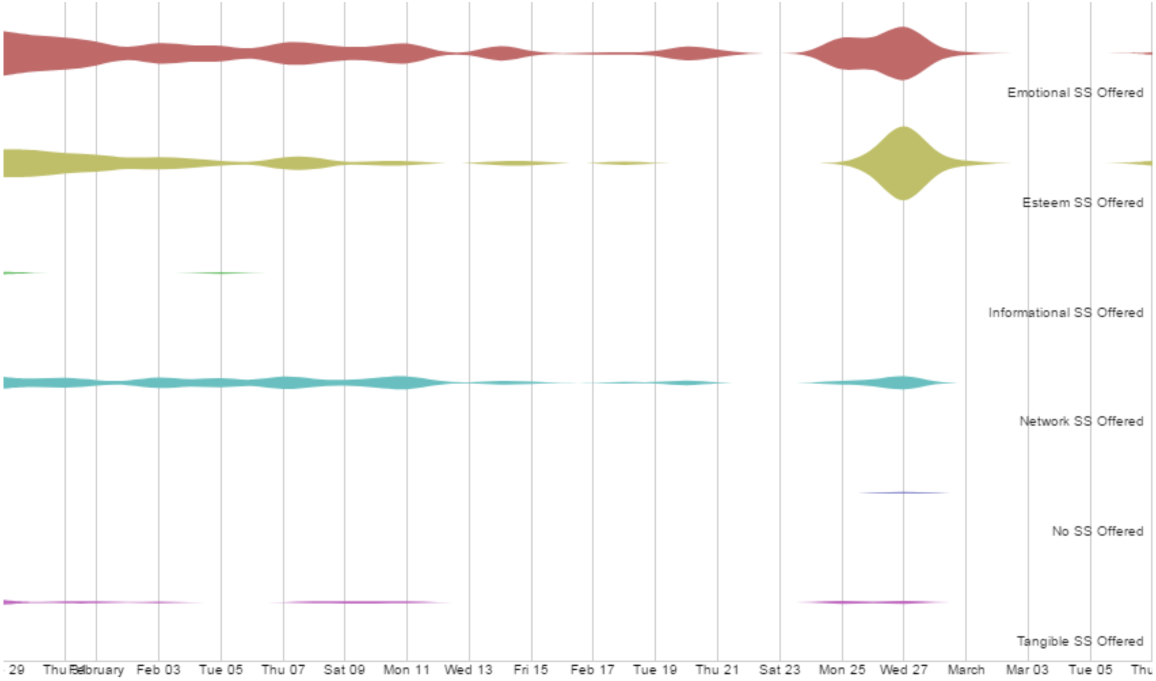
I examined each case to determine which types of support from the SSBC were most prevalent, and made comparisons using temporal analysis. In Case 1, emotional support (see Figure 19, red indicators) was the most commonly offered type, and there was one offering of esteem support (lime green indicator) and one offering of tangible support (purple indicators). The first instance of emotional support occurred after the patient was hospitalized in early April; instances of emotional, esteem, and tangible support occurred after the patient was discharged from the hospital in mid-April. The patient was again hospitalized in late June, when there was another offering of emotional support. The patient died at the beginning of July, and there was one post providing emotional support.

In Case 2, emotional support (see Figure 20, red indicators) comprised the type of support with the highest number of posts over time; however, the guests also offered all other types of support. Esteem support (lime green indicators) was also present over most



Hospitalized Hospitalized Death

Figure 19. Case 1: Social support offered over time.

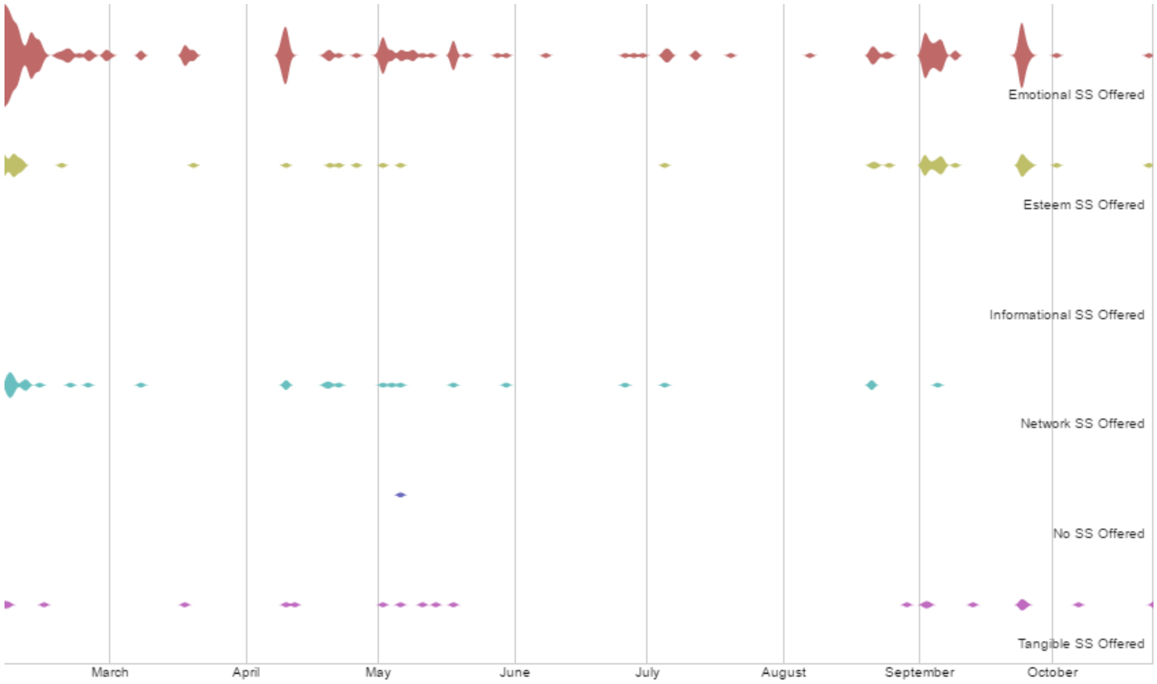


Hospitalized Hospitalized Death

Figure 20. Case 2: Social support offered over time.

of the GPs, and peaked at death. Informational support (dark green indicators) was primarily offered early in the cancer trajectory. Network support (teal indicators) followed similar patterns to emotional and esteem support, being offered over the entirety of the patient’s cancer trajectory. Tangible support (purple indicators) was offered off and on in a few postings, at hospitalizations, between hospitalizations, and at the time of death. The patient was hospitalized twice, in late January and late February, and at those times, the volume of social support increased. In mid-February, the patient was discharged after the first admission, but there was no notable increase in social support. Social-support volume peaked at the time of the patient’s death at the end of February.

In Case 3, emotional support (see Figure 21, red indicators) comprised the type of support with the highest volume over time; however, the guests also offered esteem, network, and tangible support over the entirety of the patient’s cancer trajectory. Esteem



Hospitalized Hospitalized Hospitalized Hospice Death

Figure 21. Case 3: Social support offered over time.

support (lime green indicators) was high upon initiation of the CaringBridge case, and was seen off and on until it increased as the patient entered hospice and subsequently died. Information support was not offered at all. Network support (teal indicators) was offered over the entirety of the case. Tangible support (purple indicators) was primarily offered at the different transitions (hospitalizations, hospice, and death). The patient was hospitalized three times: early February, mid-March, and early May. Increases in the volume of support were notable at each hospitalization. At the end of August, the patient decided to transition to hospice. There was only a small increase in the volume of social support once hospice was decided upon, but the volume slowly increased leading up to the patient's death at the end of September.

Emotional support comprised the highest volume of support across all three cases. Tangible support was offered in all three cases, especially during the early postings;

however, only for Cases 2 and 3 did these offers of support continue. Offers of network support were present in Cases 2 and 3 but not in low-volume Case 1, which may reflect the overall lack of support using CaringBridge for the patient, as the patient's social network was the least responsive and had no GPs that exhibited network support. Cases 2 and 3 also had a high volume of esteem support that was not prevalent in Case 1. Cases 2 and 3 followed very similar patterns of support over the course of the cancer trajectory, with high initial support and continuing increases in volume at times of transition.

In the temporal analysis, the volume of each type of social support changed over time in each of the 3 cases (see Figures 19, 20, and 21). All 3 cases began as the patient was admitted to the hospital. The highest volumes of guest support were seen at two transition points. In Cases 2 and 3, one of the highest-volume times for support was at this initial hospitalization. In Case 3, this was the highest-volume time of all. In Case 1, the highest volume of social support came when the patient was being discharged from the hospital. Each time patients were hospitalized, the volume of support increased. Case 2 had its highest volume of support at the time of the patient's death. At death, Case 3 also showed an increase in support similar to Case 2; however, when the patient in Case 1 died, there was no increase in support. Case 1 had very few GPs across the 2-month interval from the initiation of the website until the patient's death. Figure 22 best represents how the cases differed: Case 1 had small amounts of support over a moderate amount of time, Case 2 had large amounts of support over a short period of time, and Case 3 had moderate amounts of support over a long period of time.

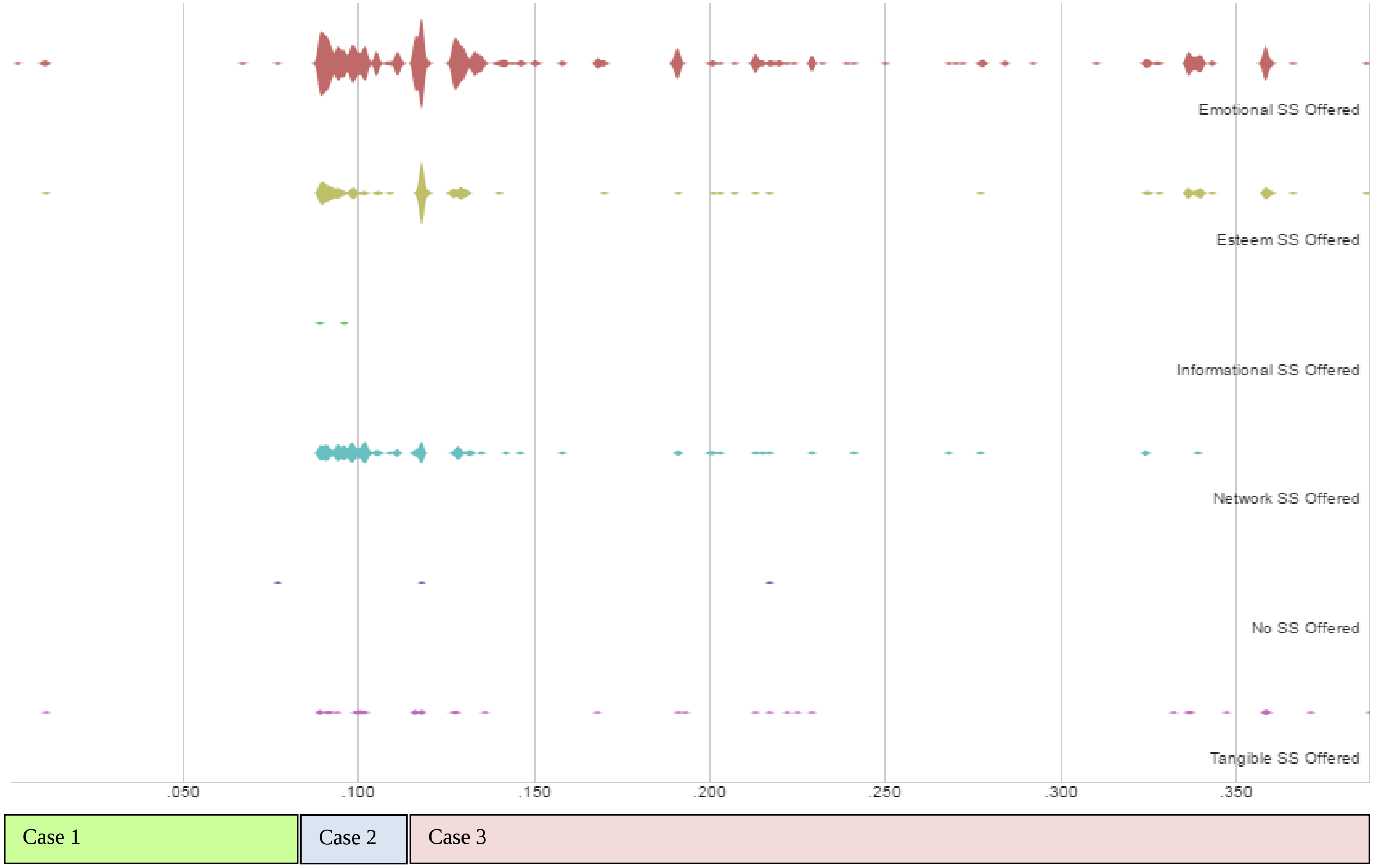


Figure 22. All cases combined.

Note. This graph was created in order to accurately portray the differences in volume of social support for each case over time. Case 1 is the first case and goes until approximately 0.088 on the x-axis. At this point Case 2 begins, and continues until 0.126, which is the beginning of Case 3.

Discussion

The focus of this study was on exploring the responsiveness of CaringBridge social networks for 3 selected cases using data-visualization tools. These tools were selected as a proof of concept for their use in examining social support provided on social media. The initial research question explored how guests directed social support to caregivers, versus patients, versus patients and family caregivers.

In all 3 cases, social support was directed either to the patient alone or to the family (patient and caregivers). Also in all 3 cases, the directionality of support changed over time. In 2 of the cases (Cases 2 and 3), the support began to focus less on the patient and more on the family near the time of the patients' deaths. In Case 1, the opposite was true: support shifted to the patient at death. It is important to note, however, that there was only one GP at the time of the patient's death. In the 3 cases examined, support was never directed solely to the caregiver(s). If caregivers are not mentioned specifically, they may not feel the support is for them, and could potentially feel more isolated.

The temporal analysis helped to demonstrate patterns of support over time, with each figure labeled with the transitions the patients and caregivers were experiencing. Social support often wanes as time passes (National Cancer Institute (NCI), 2017), and this was exhibited in all 3 cases. Each case showed a gradual decline in postings up until death, when there was an increase in postings (see Figures 19, 20, and 21). By comparing all 3 cases longitudinally, these relative lulls in support were more visible and could be matched to the transitions each patient underwent, as well as the times between transitions. It is crucial when using data visualization to examine the context of the visualization, however; for example, Case 2 was the most active network over time, but the timeframe of the network was the shortest. The temporal analysis showed the intensity of support and length of time the support occurred. The high volumes of support offered for Case 2 may have had to do with the severity of the patient's illness within a relatively short period of time, with multiple care transitions in a 2-month period. The patient's lung-cancer trajectory was short and intense. She was hospitalized twice, with intensive care unit stays during both admissions. Because her illness was severe and progressed quickly, the social network may have recognized this and responded accordingly. It is important to understand that data visualization can change how people perceive data. One way to add clarity to data visualization is to clearly and concisely label the graphs (Kellar & Kelvin, 2013). In each of the temporal graphs the transition points were added to improve the visualization.

At the end of life, social support volume increased in all 3 cases, especially emotional and esteem support (see Figures 19, 20, and 21). While these types of social support were found on CaringBridge, other types of social support may have occurred offline. The increase in esteem support at death was an interesting finding. Further investigation into the content analysis from Chapter 5 of Cases 2 and 3 revealed that the esteem support was at times directed to the patient:

> As hard as I have tried, words can't describe the meaning or role you had in my life. As I have been thinking back on basically my entire life, the thing I remember most about you is that you were always there, a constant, a support, a great laugh, levity, and so much more. Always there.

"You touched and encouraged so many with your beautiful soul." Esteem support directed to the patient at death may have been a way for guests to reminisce about the positive qualities of the patient and say goodbye. This could potentially be supportive to caregivers, as esteem support could be a way for caregivers to reminisce with guests about the positive qualities of their loved one. Guests and caregivers writings on social media after death may also reinforce their feelings of connectedness to the network in the loss of their mutually loved patient (Matheson, 2016).

Strengths

This study showed that data-visualization tools can be used to complement other methods (descriptive statistics, content analysis) by illustrating patterns within large amounts of longitudinal social-media data. The 3 cases were a part of a larger data set described in Chapters 4 and 5. A content analysis using the SSBC coded each type of support. Exemplars were shared previously in this dissertation, and descriptive statistics were provided on the number of offers per each type of social support (emotional, esteem, informational, network. and tangible). The exemplars demonstrated the types of support offered in the guests' own words. The descriptive statistics of the types of offered support examined variations between the cases but did not examine variations within the cases themselves, so while the descriptive statistics showed that emotional, esteem, and network support were frequently offered, they did not show the patterns of the offerings. The data-visualization tools used in this exploratory analysis were able to demonstrate the variability within and between cases over time. These tools provided a different lens to the tables of descriptive statistics and allowed the reader to visualize potential trajectories of support, especially as they pertained to transitions/events that were occurring for the patient and caregiver.

Another benefit of data visualization is that there are many opportunities to use open-source software. Both Gephi (2017) and RAWGraphs (Mauri et al., 2017), two of the data-visualization tools used for this case study, are open-source tools that were available online either for downloading (Gephi) or in a Web application (RAWGraphs). The use of open-source software allows researchers to minimize the costs of research while reaping the benefits of using the tools themselves.

Limitations

Data visualization of social support on social media is feasible but does have limitations. SNA is best used for reciprocal relationships to see how individuals respond to one another (Barabasi, 2012); however, as CaringBridge guests do not typically write to one another and caregivers and patients do not typically post in the guestbook, the bidirectionality of communication is limited. Due to the limited number of cases examined, there may be further patterns of social support demonstrated on these sites that were not captured in this small exploratory study. The scalability of the longitudinal area graph did not clearly show the volume of social support across the cases in a similar manner. The RAWGraphics software (Mauri et al., 2017) did not allow for changing volumes of support in the time-series data to show the data similarly. This caused Case 1 to appear to have larger volumes of support than Case 2 or 3 at times, when this was not the case. This was a limitation of comparing across differing times. In order to combat this scaling issue, I created a separate figure showing all of the cases together to illustrate the differences between cases (see Figure 22).

In order to describe the data the volume of support was used; however, volume of support is not the definitive indicator of the quality and effectiveness of support offered. This study was limited to CaringBridge, but there may be other channels (online and offline) used to offer support. Lastly, this research was limited to what was written and cannot describe what was not explicitly stated.

Conclusions

This is the first known study to use exploratory data visualization to examine social support offered to caregivers on social media. The study demonstrated how data visualization can be a useful additional tool in analyzing and interpreting data. It built on previous work described in Chapters 4 and 5 by providing a way to describe how the social support described changed over time. While this was a small exploratory study, the findings may help to inform future work using data visualization to understand how these tools can be used to show how support is directed and changes over time. Future work should build on the use of data-visualization tools to aid in telling the story of how social support is offered on social media. One of the most impactful findings of this work was the responsiveness of the network at different transition points, as well as the decline in social support when caregivers' needs were greatest—at the end of life (Dubenske et al., 2008)—and the subsequent increase in support at the patient's death. While these findings are not generalizable, they do open up areas for potential future research on how to ensure that social support does not wane at times when it is needed most. Researchers should also examine the benefits to caregivers when the network responds with support at different transition points; these increases in the number of postings, as well as the emotional, esteem, and network support, may be beneficial for caregivers.

CHAPTER 7

SUMMARY

Introduction

Cancer caregivers often have unmet needs (Butow et al., 2014). Caregivers with limited social networks and social support experience higher levels of caregiver burden and depression and less satisfaction with life (Pottie, Burch, Montross Thomas, & Irwin, 2014). Social support that meets caregiver needs may reduce psychological burden and minimize the adverse physical effects of caregiving (Northouse, Williams, et al., 2012; Reeves et al., 2014). Evidence indicates that most cancer caregivers are open to using technology to aid in the care of patients (Lapid et al., 2015), and many caregivers are actively using social media (Pew Research Center, 2013). If caregivers are able to use social media to demonstrate their needs, they may be able to elicit the response of their support networks on social-media websites such as CaringBridge.

The model of social support elicitation and provision guided the three research aims of this project (Wang et al., 2015). A key tenet of this model is that what an individual posts/discloses on social media can affect the social support they receive. Wang et al. (2015) posited that self-disclosure may lead others to perceive emotional needs and provide emotional support, and that asking questions may lead others to perceive informational needs and provide informational support. Additionally, if the writer posts positively framed informational self-disclosure, others may perceive their informational needs and provide informational support. The study informing this model (Wang et al., 2015) found that both the perceptions of the network and what individuals write affects the type of social support received. While in the current study I used this model as its foundation, the model was adapted to adjust for the focus and broader definition of social support to be examined, and to address the concept that caregivers may provide self-disclosure as well as disclosing the patient's needs. The revised model is depicted in Figure 23.

In this study, I aimed to understand how a cancer caregiver's social network on CaringBridge responded to the needs of caregivers based on their disclosures as well as their requests for support. The social support elicitation and provision framework guided the analysis and interpretation of guests' support based on the elicitation strategies

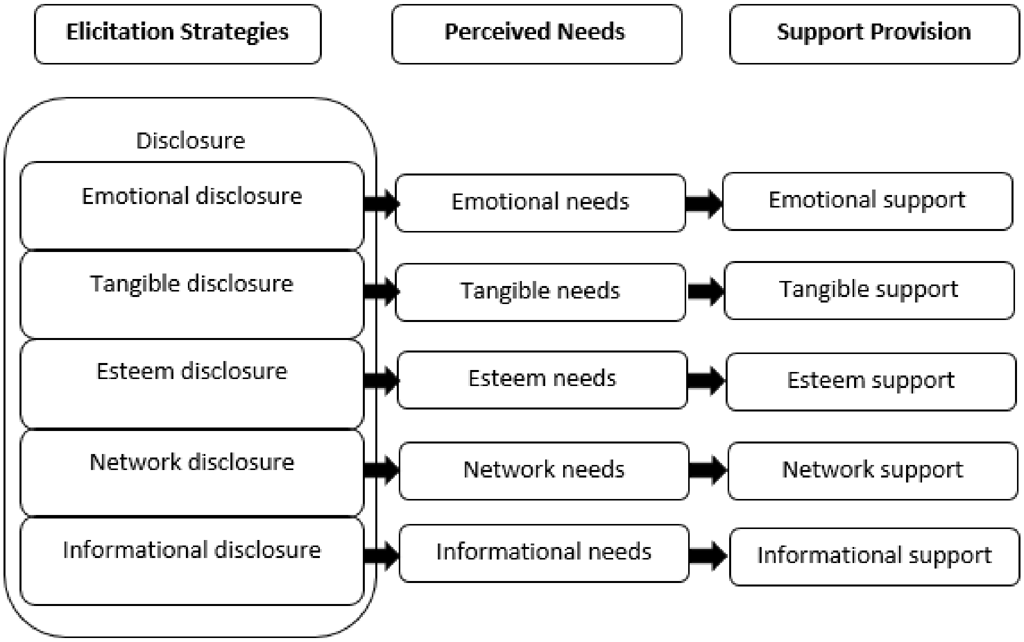


Figure 23. Conceptual framework of CaringBridge modified social support elicitation and provision.

caregivers used in their JEs. Caregivers' JEs were examined to evaluate the categories of elicitation disclosures. In addition, caregivers' specific requests for support were evaluated along with the matching of support by guests. Social support provided over time was examined in 3 cases. Data visualization was used as a proof of concept to show how caregivers' descriptions of transitions in the patient's care (hospitalization, discharge home, end-of-life care, and death) impacted the support provided and the direction of support.

Results

The elicitation strategies of the model of social support elicitation and provision were examined in Aims 1, 2, and 3. The focus of Aim 1 was to examine what caregivers wrote about the cancer experience (disclosure). Caregivers disclosed patient health information, promoted cancer awareness/advocacy, described or requested social support, disclosed caregiver burden, described daily living, disclosed emotions (positive and negative), and disclosed spirituality. Aims 2 and 3 were to specifically examine caregivers' disclosure of support needs and the matching of support provided by guests in GPs. While caregivers made some requests for social support in their JEs, most often caregivers did not request any type of support: 61.18% of JEs contained no such request. One hundred and fifty-one caregiver JEs contained 168 requests (38.82%). The most common type of support requested was emotional support (64.29%, n = 108), and emotional support was also the highest volume of support offered by guests (97.51%, n = 2,353). Informational, network, and tangible support were also requested and esteem, informational, network, and tangible support were also provided in GPs. Aims 2 and 3 indirectly explored how the guests perceived the needs of the patients and caregivers. The guests likely responded with support based on what they perceived patients needed and potentially what caregivers needed. Because the focus of caregiver JEs was most often about the patient, it is likely the network was responding to perceived patient needs. Aim 3 specifically examined the reciprocal relationship between support requested and support received. Esteem support was never requested, so related matches were not examined. Most requests for support were matched with offers of the type of support requested within 24 hr (*n* = 112, 66.67%).

Aim 4 further explored the provision of support and examined how the direction of support changed over time in the 3 cases examined using data-visualization techniques. The focus of this work was to demonstrate that data visualization is feasible: indeed, it demonstrated visually how support changed over time. The 3 cases all involved patients who were in the last 6 months of their life and who subsequently died. In all 3 cases, support was directed to either the patient or the family, but there were no specific GPs directed solely to the caregiver. The first case had the least-responsive network, and the support provided was primarily focused on the family. Case 2 had the most-responsive network, and the support provided was fairly evenly split between the patient and family. Case 3 had a median-responsive network, and the support provided was also directed more toward the family. Cases 2 and 3 showed that support was directed at the patient until close to the patient's death, when the focus of support was on the family. All 3 cases showed decreasing support over time.

Discussion

This research reinforces the findings described in current social-media literature, showing that caregivers primarily use social-media platforms for sharing patient health information and for receiving emotional support (Anderson, 2011; Gage-Bouchard et al., 2017; Kim, 2009; Kim & Chung, 2007; Lu, Wu, Liu, Li, & Zhang, 2017). Other findings that were also consistent with the existing literature were the sharing of caregiver burdens (Gage-Bouchard et al., 2017), promoting cancer awareness/advocacy (Gage-Bouchard et al., 2017), requests for informational and tangible support (Gage-Bouchard et al., 2017; Lu et al., 2017), and sharing emotions (Lu et al., 2017). Caregivers did not often disclose their negative emotions or their needs to their guests, and so likely did not fully benefit from the support guests could have provided. With few exceptions, it was uncommon for caregivers to be explicit about the burdens they were experiencing; however, we know caregivers experience significant distress, anxiety, depression, and caregiver burden, especially at transitions (Chi & Demiris, 2017; Finucane et al., 2017; Hartnett et al., 2016; McGuire et al., 2012; Northouse, Katapodi, et al., 2012; Shaw et al., 2013). Disclosing negative emotions may be difficult for caregivers, as they may fear being judged by their social network (FCA, 2014). Individuals may anticipate or perceive social constraints from their network in the form of criticism and disapproval (Lepore & Revenson, 2007). Many online resources for caregivers highlight the anger, guilt, shame, frustration, and other negative emotions caregivers often feel but are afraid to share (FCA, 2014; Jacobs, 2017; NCI, 2014). Lu et al. (2017) compared the sharing of emotions between patients and caregivers on social media and found that patients were more likely to share emotions than caregivers.

This study showed additional new categories of caregivers’ experiences shared on social media: a focus on daily life outside of the cancer diagnosis and a focus on spirituality. The focus on daily life may be a reflection of the value of quality of life to patients and caregivers. All individuals value quality of life (CDC, 2016b). Both patients and caregivers desire a return to normalcy and old routines (Hamilton et al., 2017; Raque-Bogdan et al., 2015; Sjovall, Gunnars, Olsson, & Thome, 2011). Caregivers demonstrated these desires and values in their writings. A focus on spirituality has been shown to benefit patients and families as a source of hope and strength (Hamilton et al., 2017). This may also explain the importance of focusing on the positive in the caregivers' writings as a way to maintain hope.

One new finding from this study is that caregivers use CaringBridge to request network support; this has not previously ben shared in the literature as a use and benefit of social media. This may be due to researcher bias that the focus of social media is online, and not on in-person interaction. It was clear in this study that caregivers were using CaringBridge to facilitate in-person network support by requesting visitors and identifying times when visits could occur.

Guests' offerings of emotional, informational, and tangible support were also consistent with findings from previous studies (Anderson, 2011; Gage-Bouchard et al., 2017; Lu et al., 2017). Our findings of offers of esteem and network support were not mentioned in any known caregiver social-media studies, but may have been present in the writings of guests in those studies. The SSBC framework may have helped to identify these types of support more clearly than open coding. Having clearly articulated definitions and examples of the types of support may make it easier to identify all of them.

Gratitude for social support may also have an impact on the response of the CaringBridge social network. One of the subcategories of the cancer caregivers' JEs was gratitude; caregivers often thanked CaringBridge guests for the social support they provided. While this was not directed reciprocal social support to the guests, it was an acknowledgement that the caregivers read what the guests wrote, were very grateful for the support received, and may have benefitted from it. Early studies showed that gratitude is linked to an increased perception of social support (Wood et al., 2010; Wood et al., 2008). Gratitude and social support may also positively impact posttraumatic growth (Wu, Zhou, et al., 2014; Zhou & Wu, 2016). It is not known whether gratitude is a result of greater perceived social support (i.e., *By recognizing the social support received, are you more grateful for the support network you have?*). Nor is it known if grateful individuals are provided more social support and thus are more able to perceive the social support they receive. The implications of this early research could indicate that being grateful may make caregivers more receptive to online social support and help them have more social support directed to them. Future research could examine how gratitude impacts support received and if grateful individuals are more likely to benefit from computer-mediated support. This work could also focus on determining if exhibiting gratitude may help to prevent support fluctuation over time.

Data-visualization tools proved to be a beneficial way to identify patterns of social support. For the 3 cases examined, social support decreased as time passed, which is consistent with known patterns of social support (NCI, 2017a). In all 3 cases, support was not directed solely to the caregiver who wrote the JEs; instead, the offers were directed to the patient alone or to multiple individuals—the patient and other family members and/or in combination with the caregiver. For 2 of the cases, the direction of support shifted more to the family as the patient died. If support is not consistently directed to caregiver, they may not perceive that support offered on CaringBridge is intended for them; however, because caregivers are often part of the family unit, they may feel that support offered directly to the patient is also beneficial to them. Caregivers often have difficulty asking for help and support (NCI, 2016). Caregivers focus on the patient and often forget to meet their own needs or make requests that could benefit them. While these findings are not generalizable, they do show some possible patterns of support to examine in future research.

Limitations

Little research has focused on caregivers' experiences of social support on social media. While this study focused on an emerging area of research, there were still limitations present. Much of the analysis in this study relied on the coding of one individual (me). My biases may have impacted the findings in each of the three studies; for example, the content analysis, use of the SSBC, and determinations of direction of support were primarily coded by me. To diminish my potential biases, members of my dissertation committee reviewed my decisions throughout the process. In addition, 10% of the JEs and GPs were coded by a second person, with a Cohen's Kappa for percent agreement for both JE and GP coding within acceptable ranges (at 0.715 and 0.749, respectively; Lombard et al., 2002). Despite careful attention, researcher biases may still exist. Because the content analyses shaped the further analyses, it would be valuable to have other individuals examine the same cases to determine if similar findings resulted.

This study was limited to the support observed on CaringBridge. Due to the data being only what was documented online, it was not possible to determine caregivers' perceptions of the effectiveness of the support unless individual caregivers made specific comments stating that the support was appreciated or helpful. Furthermore, more support may have been provided on other online sites (i.e., Facebook, Twitter, GoFundMe, Lotsa Helping Hands, and so forth) or offline than what was seen on CaringBridge. While some caregivers did write about the support they received outside of CaringBridge, not all did so.

Another limitation was the use of cities for search terms. Due to the restrictions of the CaringBridge search engine, cities were the most successful method piloted to identify patients; however this limited the results to individuals residing in cities. Social media may be beneficial to individuals in rural locations, as it can also reach those in isolation. Early research on rural social media use indicates that users prefer higher privacy settings and have fewer connections/relationships (Gilbert, Karahalios, & Sandvig, 2010). With these variations from urban social media users, they may also have differing disclosure patterns on websites such as CaringBridge. Future research should examine rural social media use.

During the course of this study, the CaringBridge website was continually evolving and changing; for example, at the time of this publication, the site no longer has low privacy cases, creating restrictions/barriers for future research. The format of the website changed throughout the study, including how patients and caregivers viewed JEs and GPs, and new elements such as the Planner were added, which may have limited tangible support requests and offers to that part of CaringBridge. Another example is that there are now two guestbook locations where guests can post: comment sections on each JE and a section called *Well Wishes*. The *Tributes* have been separated from the comments, and *Well Wishes* and are in a separate section. The rapidly changing aspects of social media make it difficult for research findings to reflect current use of social-media sites (McFarland & Ployhart, 2015). This study shows a snapshot in time (2009–2015, although most cases occurred 2012–2013) of how CaringBridge was used, and it is possible that many of the same categories of experiences provided by caregivers, as well as support requests, may continue to be present in JEs and GPs.

Implications and Recommendations for Future Research

As social media use by caregivers continues to grow, the opportunities for future research increase. Caregivers have more opportunities for social-media access with increasing smartphone use, making social-media applications readily available to more people. The Pew Research Center (2017a, 2017b) estimated that 77% of adults owned smart phones and 69% of adults used social media as of November 2016. With increasing access and use, the volume of data available from these types of communication are constantly increasing and provide an ever-expanding data set to better understand the experiences of cancer caregivers.

Future research should examine other types of social media caregivers are using. Caregivers' Instagram, Facebook, and Twitter accounts may better demonstrate support provided directly to caregivers, as they are websites centered on the caregiver, as opposed to CaringBridge, which is centered on the patient, though much of what is written on these sites could continue to be focused on the patient. Facebook and Instagram are the most utilized social-media websites for adults (Pew Research Center, 2017b); however, due to the time constraints of caregiving, caregivers may not socialize and may not use their regular social-media sites as often (NCI, 2016; Williams & Bakitas, 2012). Due to the limited time caregivers have, wherever they post is likely to be devoted to discussing the patient. It is unknown if caregivers use multiple social-media platforms; if this is the case, future research needs to focus on helping guests understand how valuable focused support of caregivers can be.

With the difficulty caregivers experience in sharing their emotions (FCA, 2014; Jacobs, 2017; NCI, 2014), perhaps anonymous applications may be a better avenue for understanding the caregiver experience. One such application, Whisper (2017), allows individuals to write anonymously about whatever they want; caregivers posting here may be more honest about their experiences because of the anonymity of the site. They may also connect with other caregivers with similar experiences without feeling judged by their in-person social network. Social-media sites such as CaringBridge or CarePages bring together acquaintances as well as close family and friends. Caregivers may fear the impact of what they disclose to these groups because their words could follow them beyond CaringBridge.

Because a major focus of caregivers' writings was sharing the patients' health information, and because informational support was provided by guests, it is important to learn if what is shared by both caregivers and guests is accurate. While this study identified what types of information are shared, it did not focus on the accuracy of the information shared. Early research has demonstrated that while much of the health information shared by cancer-caregiver networks is medically accurate, there are instances in which inaccurate information or unproven treatment information is shared on social media (Gage-Bouchard et al., 2017). As use of the Internet continues to increase, it is important to understand what types of health information are shared. The knowledge obtained through future research can inform how physicians, nurses, pharmacists, and other members of the health care team aid caregivers in understanding the potential benefits of and issues with obtaining health information on social media.

Recommendations for Clinical Practice

There was a lot of variation in the caregivers who wrote in the 3 cases on CaringBridge. Some were directly caring for the patient and filled the more traditional family caregiver role. Others' primary role was communicating on the website, and they did not provide direct care to the patient. Perhaps identifying these secondary caregivers would be helpful, because they were often the ones who shared how burdensome caregiving was for the primary caregivers. Secondary caregivers may be better able to discern the needs of the patient and the caregiver, and may be more willing to share these needs with the CaringBridge network. Nurses can help families determine who would best be the person to update the network.

Future roles of clinical caregivers could involve working with social-media sites to revise or create coaching tools to aid caregivers in asking for support, as well as tools that can advise/coach guests on how to respond to requests and meet the needs of caregivers. Clinicians could share their clinical expertise with social-media websites and different clinical applications to help identify ways cancer caregivers can elicit helpful support. For example, newer Web applications, such as Carezone (2017), have been created to help caregivers get organized, create "to do" lists, and so forth; some of these applications even have similar journal options to CaringBridge. Family caregivers of cancer patients can use the journals for documenting events and symptom management, and share them with their networks (Carezone, 2017). Additional benefits of Carezone include a calendar for caregivers to track appointments, applications to keep medication lists or receive information on health issues, and a place to save pertinent medical documents to the application. The “to do” list application is similar to the Planner in CaringBridge. Both tools allow caregivers to create tasks that need to be completed and to ask for guests to sign up to complete the tasks. Carezone does not have a guestbook component, so while tangible support can be met through the “to do” list, caregivers’ emotional, esteem, and network support needs may not be met.

Conclusion

As cancer patient and caregiver use of social media grows, websites that aim to help them communicate around a health event have been shown to be beneficial (Anderson, 2011; Gage-Bouchard et al., 2017; Lu et al., 2017). Future research should explore ways to ensure that caregivers elicit helpful support, examine the benefits to caregivers when the network responds with support, and develop ways to prevent support from fluctuating over time.

APPENDIX A

SEARCH STRATEGY

The background literature review for this dissertation was based on a search of the Cumulative Index of Nursing and Allied Health Literature (CINAHL); PsycINFO, from the American Psychological Association; and the National Center for Biotechnology Information (NCBI) search engine PubMed. Due to the burgeoning nature of the literature on social media, it was important to expand the search terms to capture the full scope of the issues at hand. Keywords used included *social media*, *caringbridge*, *carepages*, *facebook*, *blog*, and *patientslikeme*, all used separately and in combination with *cancer* and *oncology*. The primary focus of this study was caregiver use of social media, which required additional search terms to be added in combination and alone, including *caregivers*, *social support*, *meaning making*, *cognitive processing*, *journaling*, *expressive writing*, *online*, *offline*, *cancer*, and *oncology*. Editorials and commentaries were excluded. Source materials were limited to and selected from English-language research published in peer-reviewed journals. Pediatric and adult literature, including qualitative and quantitative studies, were included in the review. Abstracts of the articles were reviewed for pertinence to cancer, caregivers, and social media.

APPENDIX B

MANUAL FOR CODING OF CANCER CAREGIVERS’ EXPERIENCES IN CARINGBRIDGE

GENERAL INFORMATION

First read the site from first journal entry to last journal entry. Note any emerging themes (for ex: caregiver writings on psychosocial impacts of the cancer diagnosis on themselves, activities of caregiving, losses related to caregiving, benefits related to caregiving).

When coding, sentences may be broken apart for different codes but only one code can be used for any specific phrase.

WHO SHOULD BE CODED?

Journal entries:

- Caregiver (code as Case # Caregiver Relationship, for example: 1 Caregiver Husband)
    - Document Gender, and relationship to patient as able

CODING SPECIFICS & EXAMPLES:

CONTENT ANALYSIS (journal entries only).

Assign preliminary codes to each journal entry while taking notes on patterns, topics, or themes.

Once preliminary coding is complete, a reexamination of the codes will begin where codes will be either combined or split based on the results of the data until the final codes are determined.

APPENDIX C

MANUAL FOR CODING SOCIAL SUPPORT IN CARINGBRIDGE

GENERAL INFORMATION

First read the site from first journal entry to last journal entry and then from 1st guestbook Entry to last guestbook entry for a general impression of the site. Note any emerging themes (for ex: frequent stories about the patient/reminiscing; call for prayer answered with prayers by guests).

Code starting with the 1st guestbook entry. Then go to the journal entries that correspond to that entry (i.e. all entries from date/time stamp of the first journal entry to right before the date/time stamp of the second journal entry)

Continuing coding guestbook entries within the time frames between each journal entry.

When coding, sentences may be broken apart for different codes but only one social support code can be used for any specific phrase.

WHO SHOULD BE CODED?

Journal entries:

- Caregiver (code as Case # Caregiver Relationship, for example: 1 Caregiver Husband)
    - Document Gender, and relationship to patient as able
- Patient (code as Case # Patient, for example: 1 Patient)
    - Document Gender, and diagnosis of patient as able

Guestbook postings:

- All visitors are individually identified as guests (code as Case # Guest #, for example: 1 Guest 1)
    - Document Gender, and relationship to patient as able
    - Before adding guest review the existing guest codes to see if guest has already been assigned an identifier (Case # Guest #)

OVERVIEW OF SOCIAL SUPPORT CODES FOR PATIENT AND CAREGIVER JOURNAL ENTRIES:

Request Support
Emotional
Esteem
Informational
Network
Tangible
No request for social support

OVERVIEW OF SOCIAL SUPPORT CODES FOR GUESTBOOK POSTINGS:

Emotional Social Support (from SSBC)
Esteem Social Support (from SSBC)
Informational Social Support (from SSBC)
Network Social Support (from SSBC)
Tangible Social Support (from SSBC)
Unknown Social Support
No offer of social support

CODING SPECIFICS & EXAMPLES:

REQUEST SUPPORT (journal entries only)

Code the section of the journal entry in which social support is requested. The requests for support will be based on the guestbook codes for the categories of social support (adapted from the SSBC). See below for further information based on the SSBC.

1. Emotional: prayer requests
2. Esteem: "tell me that I'm doing the right thing"
3. Informational: referral request (Pharmacist, MD, or other health care caregiver), ask for suggestions/advice
4. Network: ask for visitors
5. Tangible: child care, transportation, housework (cooking, cleaning, yard work)

NO REQUEST FOR SOCIAL SUPPORT (journal entries only)

Entire journal entry does not contain a request for support. For example, entry may only provide information.

EMOTIONAL SOCIAL SUPPORT (from SSBC) (guestbook entries only)

Emotional support is directed to the patient and/or caregiver specifically.

1. Relationship- stresses the importance of closeness and love in relationship with the recipient
   Example:
   - *You are so very special to me.*
2. Physical affection- offers physical contact in post (primarily hugs, kisses)
   Example:
   - *Sending you a big hug from a far*
   - *Xoxo*
3. Sympathy- expresses sorrow or regret for the patient/caregiver's situation or distress
4. Listening- guestbook posts that respond back to what was entered in the journal entry
   - *I really enjoy everything you have been writing*
5. Understanding/empathy- expresses understanding of the situation or communicating understanding
6. Encouragement- provides the recipient with hope and confidence
   - *You will get through this.*
7. Prayer- states they are praying for the patient, caregiver and/or family

ESTEEM SOCIAL SUPPORT (from SSBC) **(guestbook entries only)**

Think of esteem support as things that could be factually true about the patient or caregiver. Emotion and Esteem support can be very similar so look at the examples to ensure what you are coding is validation vs. encouragement.

1. Compliment- says positive things about the recipient or emphasizes the patient or caregiver's abilities.
    - *You are so strong*
    - *You are so full of life.*
2. Validation- expresses agreement with the patient or caregiver's perspective on the situation.
    - *You are right to feel the way you are feeling.*
    - *I would do the exact same thing.*
3. Relief of blame- tries to alleviate the patient or caregiver's feelings of guilt about the situation
    - *It is not your fault.*
    - *You have done everything you could.*

INFORMATIONAL SOCIAL SUPPORT (from SSBC) **(guestbook entries only)**

1. Suggestion/advice- Offers ideas and suggests actions
    - *Maybe you should take a vacation.*
2. Referral- Refers the recipient to formal health care givers (e.g. MD, Pharmacist, Nurse, etc.)
    - *You should see Dr. *****
3. Teaching- provides detailed information, facts about cancer diagnosis, treatment, end of life, survivorship or about skills to deal with cancer. May give examples from own life.
    - *When I was pregnant I used ginger tea for nausea and it helped a lot/worked really well.*
    - *I did *** therapy and that worked.*

NETWORK SOCIAL SUPPORT (from SSBC) **(guestbook entries only)**

1. Access- offers patient or caregiver access to new companions
    - *My aunt *** lives near there and she would love to spend time with you.*
2. Presence- offers to spend time with the person, to be there
    - *I would like to come visit you when you are ready for visitors.*
3. Companions- Reminds the person of availability of companions, others with shared interests or experiences. Reminding the patient or caregiver that even though you are a patient or caregiver you are more than those roles. Think of this as belonging support- you have a place to belong; you belong to a group. You are not alone.

- *My sister has the same diagnosis as you.*
- *All of us at book club miss you and are thinking of you.*

TANGIBLE SOCIAL SUPPORT (from SSBC) **(guestbook entries only)**

1. Loan- offers to lend the patient or caregiver something (money, a walker, home care equipment)
2. Direct task- offers to perform a task directly related to the cancer care

- *I'm going to come and watch dad (if dad is the patient).*
- *I can bring you to any appointments you have.*

3. Indirect task- offers to take over one or more of the caregiver or patient's other responsibilities while the recipient is under stress

- *I want to bring you dinner*
- *I'm going to come and watch dad (if dad is not the patient).*
- *I'm around tomorrow and can watch the kids for you during your appointment.*

4. Active participation- offers to join the recipient in action that reduces the stress
5. Willingness- expresses willingness to help

- *If you need anything we are here for you.*
- *Let us know if you need anything.*

UNKNOWN SOCIAL SUPPORT (guestbook entries only)

This is for codes that you are uncertain of. If you question whether it is one type of social support or another put it in this code. Later will work with Maija to determine where it fits best.

****Situation Appraisal- Reassess or redefines the cancer diagnosis (may fit better under emotional or under esteem support but originally from informational social support within the SSBC). Watch for this one and put here.

NO OFFER OF SOCIAL SUPPORT (guestbook entries only)

Entire journal entry does not contain a request for support. For example, entry may only provide information.

REFERENCES

American Cancer Society. (2017). *Cancer facts & figures 2017*. Retrieved from https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2017/cancer-facts-and-figures-2017.pdf

Anderson, I. K. (2011). The uses and gratifications of online care pages: A study of CaringBridge. *Health Communication, 26*(6), 546–559. doi:10.1080/10410236.2011.558335

Anderson, M., & Perrin, A. (2017).*Tech adoption climbs among older adults*. Retrieved from www.pewinternet.org/2017/05/17/tech-adoption-climbs-among-older-adults/

Badr, H., Carmack, C. L. & Diefenbach, M. A. (2015). Psychosocial interventions for patients and caregivers in the age of new communication technologies: Opportunities and challenges in cancer care. *Journal of Health Communication, 20*(3), 328–342. doi:10.1080/10810730.2014.965369

Balatsoukas, P., Kennedy, C. M., Buchan, I., Powell, J., & Ainsworth, J. (2015). The role of social network technologies in online health promotion: A narrative review of theoretical and empirical factors influencing intervention effectiveness. *Journal of Medical Internet Research, 17*(6), e141. doi:10.2196/jmir.3662

Barabasi, A. L. (2012). Network science: Luck or reason. *Nature, 489*, 507–508. doi:10.1038/nature11486

Barth, J., Schneider, S., & von Kanel, R. (2010). Lack of social support in the etiology and prognosis of coronary heart disease: A systematic review and meta-analysis. *Psychosomatic Medicine, 72*, 229–238. doi:10.1097/PSY.0b013e3181d01611

Bastian, M., Heymann, S., & Jacomy, M. (2009). Gephi: An open source software for exploring and manipulating networks. *International Conference on Web and Social Media, 8*, 361–362.

Beaudoin, C. E., & Tao, C. C. (2007). Benefiting from social capital in online support groups: an empirical study of cancer patients. *CyberPsychology & Behavior, 10*(4), 587–590. doi:10.1089/cpb.2007.9986

Bender, J. L., Jimenez-Marroquin, M., & Jadad, A. R. (2011). Seeking support on Facebook: A content of analysis of breast cancer groups. *Journal of Medical Internet Research, 13*(1), e16. doi:10.2196/jmir.1560

Bender, J. L., Wiljer, D., To, M. J., Bedard, P. L., Chung, P., Jewett, M. A. S., . . . Gospodarowicz, M. (2012). Testicular cancer survivors' supportive care needs and use of online support: A cross-sectional survey. *Supportive Care in Cancer*. . doi:10.1007/s00520-012-1395-x

Bernard, H. R., & Ryan, G. W. (2010). *Analyzing qualitative data: Systematic approaches.* Los Angeles, CA: Sage.

Bianchi, M., Flesch, L. D., Alves, E. V. da C., Batistoni, S. S. T., & Neri, A. L. (2016). Zarit burden interview psychometric indicators applied in older people caregivers of other elderly. *Revista Latino-Americana de Enfermagem*, *24*, e2835. doi:10.1590/1518-8345.1379.2835

Blum, K., & Sherman, D. W. (2010). Understanding the experience of caregivers: A focus on transitions. *Seminars in Oncology Nursing*, *26*(4), 243–258. doi:10.1016/j.soncn.2010.08.005

Borgatti, S. P., Mehra, A., Brass, D. J., & Labianca, G. (2009). Network analysis in the social sciences. *Science, 323*(5916), 892–895. doi:10.1126/science.1165821

Bowman, K. F., Rose, J. H., Radziewicz, R. M., O'Toole, E. E., & Berila, R. A. (2009). Family caregiver engagement in a coping and communication support intervention tailored to advanced cancer patients and families. *Cancer Nursing, 32*(1), 73–81.

Braun, M., Mikulincer, M., Rydall, A., Walsh, A., & Rodin, G. (2007). Hidden morbidity in cancer: Spouse caregivers. *Journal of Clinical Oncology*, *25*(30), 4829–4834. doi:10.1200/JCO.2006.10.0909

Butow, P. N., Price, M. A., Bell, M. L., Webb, P. M., & deFazio, A. (2014). Caring for women with ovarian cancer in the last year of life: A longitudinal study of caregiver quality of life, distress and unmet needs. *Gynecologic Oncology*, *132*(3), 690–697. doi:10.1016/j.ygyno.2014.01.002

CarePages. (2017). *About CarePages, Inc*. Retrieved from http://cms.carepages.com/CarePages/en/About

Carezone. (2017). *Carezone: Features*. Retrieved from https://carezone.com/features

CaringBridge. (2014). *CaringBridge offers more ways for people to connect and care during any health event*. Retrieved from https://www.caringbridge.org/newsroom/news-releases/caringbridge-offers-more-ways-to-connect-and-care

CaringBridge. (2015). *2015 annual report*. Retrieved from https://www.caringbridge.org/assets/ugc/content/2015_Annual_Report_v23_ONLINE.pdf

CaringBridge. (2016). *Privacy policy*. Retrieved from https://www.caringbridge.org/privacy-policy

Cassidy, T. (2013). Benefit finding through caring; The cancer caregiver experience. *Psychology and Health, 28*(3), 250–266. doi:10.1080/08870446.2012.717623

Centers for Disease Control and Prevention. (2016a). *Caregiving: A public health priority*. Retrieved from www.cdc.gov/aging/caregiving/

Centers for Disease Control and Prevention. (2016b). *Health-related quality of life (HRQOL): HRQOL concepts*. Retrieved from https://www.cdc.gov/hrqol/concept.htm

Chi, N. C., & Demiris, G. (2017). Family caregivers' pain management in end-of-life care: A systematic review. *American Journal of Hospice and Palliative Care, 34*(5), 470–485. doi:10.1177/1049909116637359

Choi, C. W., Stone, R. A., Kim, K. H., Ren, D., Schulz, R., Given, C. W., . . . Sherwood, P. R. (2012). Group-based trajectory modeling of caregiver psychological distress over time. *Annals of Behavioral Medicine, 44*(1), 73–84. doi:10.1007/s12160-012-9371-8.

Chou, W. Y. S., Hunt, Y., Folkers, A., & Augustson, E. (2011). Cancer survivorship in the age of YouTube and social media: A narrative analysis. *Journal of Medical Internet Research, 13*(1), e7. doi:10.2196/jmir.1569

Chu, K.-H., Wipfli, H., & Valente, T. W. (2013). Using visualizations to explore network dynamics. *Journal of Social Structure, 14*, 4.

Clerici, C. A., Veneroni, L., Bisogno, G., Trapuzzano, A., & Ferrari, A. (2012). Videos on rhabdomyosarcoma on YouTube: An example of the availability of information on pediatric tumors on the Web. *Journal of Pediatric Hematology Oncology, 34(8),* e329–e331. doi:10.1097/MPH.0b013e31825886f8

Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*, 310–357.

Cutrona, C. E., & Russell, D. W. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 319–366). New York: John Wiley & Sons.

Cutrona, C. E., & Suhr, J. A. (1992). Controllability of stressful events and satisfaction with spouse support behaviors. *Communication Research, 19*(2), 154–174. doi:10.1177/009365092019002002

Daly, B. J., Douglas, S., Lipson, A. & Foley, H. (2009). Needs of older caregivers of patients with advanced cancer. *Journal of the American Geriatrics Society,* *57*(Suppl. 2), 293–295. doi:10.1111/j.1532-5415.2009.02516.x.

De la Torre-Díez, I., Díaz-Pernas, F. J., & Antón-Rodríguez, M. A. (2012). A content analysis of chronic diseases social groups on Facebook and Twitter. *Telemedicine Journal and E-Health, 18*(6), 404–408. doi:10.1089/tmj.2011.0227

Delgado-Guay, M. O., Parsons, H. A., Hui, D., De la Cruz, M. G., Thorney, S., & Bruera, E. (2013). Spirituality, religiosity, and spiritual pain among caregivers of patients with advanced cancer. *American Journal of Hospice and Palliative Care, 30*(5), 455–461. doi:10.1177/1049909112458030

DiGiacomo, M., Lewis, J., Nolan, M. T., Phillips, J., & Davidson, P. M. (2013). Transitioning from caregiving to widowhood. *Journal of Pain and Symptom Management, 46*(6), 817–825. doi:10.1016/j.jpainsymman.2013.01.005

Downe-Wamboldt, B., Butler, L., & Coulter, L. (2006). The relationship between meaning of illness, social support, coping strategies, and quality of life for lung cancer patients and their family members. *Cancer Nursing, 29*(2), 111–119.

Drevdahl, D. J., & Shannon Dorcy, K. (2012). Transitions, decisions, and regret: Order in chaos after a cancer diagnosis. *Advances in Nursing Science, 35*(3), 222–235. doi:10.1097/ANS.0b013e318261a7a7

Dubenske, L. L., Wen, K., Gustafson, D. H., Guarnaccia, C. A., Cleary, J. F., Dinauer, S. K., & McTavish, F. M. (2008). Caregivers' differing needs across key experiences of the advanced cancer disease trajectory. *Palliative and Supportive Care, 6*, 265–272. doi:10.1017/S1478951508000400

Duggan, M., Lenhart, A., Lampe, C., & Ellison, N. B. (2015). *Parents and social media: Mothers are especially likely to give and receive support on social media.* Retrieved from www.pewinternet.org/2015/07/16/parents-and-social-media/

Duggleby, W. D., Penz, K. L., Goodridge, D. M., Wilson, D. M., Leipert, B. D., Berry, P. H., . . . Justice, C. J. (2010). The transition experience of rural older persons with advanced cancer and their families: A grounded theory study. *Biomed Central Palliative Care, 9*(5), 1–9. doi:10.1186/1472-684X-9-5

Eddens, K. S., Kreuter, M. W., Morgan, J. C., Beatty, K. E., Jasim, S. A., Garibay, L., . . . Jupka, K. A. (2009). Disparities by race and ethnicity in cancer survivor stories available on the Web. *Journal of Medical Internet Research, 11*(4), e50. doi:10.2196/jmir.11

Edwards, S. B., Olson, K., Koop, P. M., & Northcott, H. C. (2012). Patient and family caregiver decision making in the context of advanced cancer. *Cancer Nursing, 35*(3), 178–186. doi:10.1097/NCC.0b013e31822\86f6

Ell, K., Nishimoto, R., Medianski, L., Mantell, J., & Hamovitch, M., (1992). Social relations, social support and survival among patients with cancer. *Journal of*

Psychosomatic Research, 36, 531–541.

Ellis, J. (2012). The impact of lung cancer on patients and carers. *Chronic Respiratory Disease, 9*, 39–47. doi:10.1177/1479972311433577

Ellis, J., Lloyd Williams, M., Wagland, R., Bailey, C., & Molassiotis, A. (2013). Coping with and factors impacting upon the experience of lung cancer in patients and primary carers. *European Journal of Cancer Care, 22*(1), 97–106. doi:10.1111/ecc.12003

Family Caregiver Alliance. (2014). *Emotional side of caregiving*. Retrieved from https://www.caregiver.org/emotional-side-caregiving

Farmer, A. D., Bruckner Holt, C. E., Cook, M. J., & Hearing, S. D. (2009). Social networking sites: A novel portal for communication. *Postgraduate Medical Journal, 85*(1007), 455–459. doi:10.1136/pgmj.2008.074674

Finucane, A. M., Lugton, J., Kennedy, C., & Spiller, J. A. (2017). The experiences of caregivers of patients with delirium, and their role in its management in palliative care settings: An integrative literature review. *Psycho-Oncology, 26*(3), 291–300. doi:10.1002/pon.4140

Frost, J. H., & Massagli, M. P. (2008). Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another's data. *Journal of Medical Internet Research, 10*(3), e15. doi:10.2196/jmir.1053

Gage-Bouchard, E. A., LaValley, S., Mollica, M., & Beaupin, L. K. (2017). Cancer communication on social media: Examining how cancer caregivers use Facebook for cancer-related communication. *Cancer Nursing, 40*(4), 332–338. doi:10.1097/NCC.0000000000000418.

Gage-Bouchard, E. A., LaValley, S., Warunek, M., Beaupin, L. K., & Mollica, M. (2017). Is cancer information exchanged on social media scientifically accurate? *Journal of Cancer Education*. doi:10.1007/s13187-017-1254-z

Gephi. (2017). *About Gephi*. Retrieved from https://gephi.org/about/

Gilbert, E., Karahalios, K., & Sandvig, C. (2010). The network in the garden: Designing social media for rural life. *American Behavioral Scientist 53*(9), 1367–1388. doi:10.1177/000276410361690

Girgis, A., & Lambert, S. (2009). Caregivers of cancer survivors: The state of the field. *Cancer Forum, 33*(3), 167–171.

Given, B. A., Given, C. W., & Sherwood, P. R. (2012). Family and caregiver needs over the course of the cancer trajectory. *Journal of Supportive Oncology, 10*(2), 57–64.

Given, B. A., Sherwood, P. R., & Given, C. W. (2011). Family and caregiver needs over the course of the cancer trajectory. *Cancer Epidemiology, Biomarkers and Prevention, 20*, 2015–2021. doi:10.1158/1055-9965

Gofton, T. E., & Graber, J. (2012). Identifying the palliative care needs of patients living with cerebral tumors and metastases: A retrospective analysis. *Journal of Neuro-Oncology, 108*, 527–534. doi:10.1007/s11060-012-0855-y

GoFundMe. (2017). *How it works*. Retrieved from https://www.gofundme.com/tour

Goldzweig, G., Merims, S., Ganon, R., Peretz, T., Altman, A., & Baider, L. (2013). Informal caregiving to older cancer patients: Preliminary research outcomes and implications. *Annals of Oncology, 24*(10), 2635–2640. doi:10.1093/annonc/mdt250

Gottlieb, B. H., & Bergen, A. E. (2010). Social support concepts and measures. *Journal of Psychosomatic Research, 69*(5), 511–520. doi:10.1016/j.jpsychores.2009.10.001

Götze, H., Brähler, E., Gansera, L., Polze, N., & Köhler, N. (2014). Psychological distress and quality of life of palliative cancer patients and their caring relatives during home care. *Supportive Care in Cancer*, *22*(10), 2775–2782. doi:10.1007/s00520-014-2257-5

Hamilton, J. B., Worthy, V. C., Moore, A. D., Best, N. C., Stewart, J. M., & Song, M. K. (2017). Messages of hope: Helping family members to overcome fears and fatalistic attitudes toward cancer. *Journal of Cancer Education, 32*(1), 190–197. doi:10.1007/s13187-015-0895-z

Hamm, M. P., Chisholm, A., Shulhan, J., Milne, A., Scott, S. D., Given, L. M. & Hartling, L. (2013). Social media use among patients and caregivers: A scoping review. *BMJ Open, 3*(5), e002819. doi:10.1136/bmjopen-2013-002819

Hanneman, R. A., & Riddle, M. (2005). *Introduction to social network methods.* Riverside, CA: University of California, Riverside

Hartnett, J., Thom, B., & Kline, N. (2016). Caregiver burden in end-stage ovarian cancer. *Clinical Journal of Oncology Nursing, 20*(2), 169–173. doi:10.1188/16.CJON.169-173

Hoerger, M., Chapman, B. P., Prigerson, H. G., Fagerlin, A., Mohile, S. G., Epstein, R. M., . . . Duberstein, P. R. (2014). Personality change pre- to post-loss in spousal caregivers of patients with terminal lung cancer. *Social Psychological and Personality Science.* doi:10.1177/1948550614524448

Holt-Lunstad, J., Smith, T. B., & Layton, J. B. (2010). Social relationships and mortality: A meta-analysis. *PLOS Medicine, 7*(7), e1000316. doi:10.1371/journal.pmed.1000316

Hsieh, H., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*, 1277–1288. doi:10.1177/1049732305276687

Institute of Medicine. (2015). Dying in America: Improving quality and honoring individual preferences near the end of life. Washington, DC: National Academies Press.

Internet World Stats: Usage and Population Statistics. (n. d.). *United States of America Internet usage and broadband usage report*. Retrieved from www.internetworldstats.com/am/us.htm

Iredale, R., Mundy, L., & Hilgart, J. (2011). An online resource of digital stories about cancer genetics: Qualitative study of patient preferences and information needs. *Journal of Medical Internet Research, 13*(3), e78. doi:10.2196/jmir.1735

Jacobs, B. J. (2017, July 6). *Repeat after me: I am a good caregiver*. Retrieved from www.aarp.org/home-family/caregiving/info-2017/tips-for-caregivers-stay-positive-fd.html?intcmp=AE-HF-CRC-CARE101-SPOT3

Joseph, R. P., Keller, C., Adams, M. A., & Ainsworth, B. E. (2015). Print versus a culturally-relevant Facebook and text message delivered intervention to promote physical activity in African American women: A randomized pilot trial. *BMC Women's Health*, *15*(30). doi:10.1186/s12905-015-0186-1.

Keim-Malpass, J., & Steeves, R. H. (2012). Talking with death at a diner: Young women’s online narratives of cancer. *Oncology Nursing Forum, 39*(4), 373–378, 406. doi:10.1188/12.ONF.373-378

Kellar, S. P., & Kelvin, E. A. (2013). *Munro’s statistical methods for health care research.* Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Kent, E. E., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. Y. S., Shelburne, N., . . . Huss, K. (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer, 122*(13), 1987–1995. doi:10.1002/cncr.29939

Kim, S. (2009). Content analysis of cancer blog posts. *Journal of the Medical Library Association*, *97*(4), 260–266. doi:10.3163/1536-5050.97.4.009

Kim, S., & Chung, D. S., (2007). Characteristics of cancer blog users. *Journal of the Medical Library Association, 95*(4), 445–450. doi:10.3163/1536-5050.95.4.445

Kim, Y., Spillers, R. L., & Hall, D. L. (2012). Quality of life of family caregivers 5 years after a relative’s cancer diagnosis: Follow-up of the national quality of life survey for caregivers. *Psycho-Oncology, 21*, 273–281. doi:10.1002/pon.1888

Kontos, E. Z., Emmons, K. M., Puleo, E., & Viswanath, K. (2010). Communication inequalities and public health implications of adult social networking site use in the United States. *Journal of Health Communication, 15*(Suppl. 3), 216–235.

Lakey, B., & Cohen, S. (2000). Social support theory and measurement. In S. Cohen, L. Underwood, & B. Gottlieb (Eds.), *Measuring and intervening in social support* (pp. 29–46). New York: Oxford University Press.

Lam, C. G., Roter, D. L., & Cohen, K. J. (2012). Survey of quality readability and social research of websites on osteosarcoma in adolescents. *Patient Education and Counseling.* doi:10.1016/j.pec.2012.08.006

Lambert, S., Girgis, A., Lecathelinais, C., & Stacey, F. (2012). Walking a mile in their shoes: Anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. *Supportive Care in Cancer*. doi:10.1007/s00520-012-1495-7

Lapid, M. I., Atherton, P. J., Clark, M. M., Kung, S., Sloan, J. A., & Rummans, T. A. (2015). Cancer caregiver: Perceived benefits of technology. *Telemedicine and e-Health, 21*(11), 893–902. doi:10.1089/tmj.2014.0117

Lee, M., & Rotheram-Borus, M. J. (2001). Challenges associated with increased survival among parents living with HIV. *American Journal of Public Health, 91*, 1303–1309. doi:10.2105/AJPH.91.8.1303

Lepore, S. J. (2001). A social-cognitive processing model of emotional adjustment to cancer. In A. Baum & B. Andersen (Eds.), *Psychosocial interventions for cancer* (pp. 99–118). Washington, DC: American Psychological Association.

Lepore, S. J., Buzaglo, J. S., Lieberman, M. A., Golant, M., & Davey A. (2011). Standard versus prosocial online support groups for distressed breast cancer survivors: A randomized controlled trial. *BioMed Central Cancer, 11*, 379. doi:10.1037/0278-6133.15.2.135

Lepore, S. J., & Revenson, T. A. (2007). Social constraints on disclosure and adjustment to cancer. *Social and Personality Psychology Compass, 1*(1), 313–333. doi:10.1111/j.1751-9004.2007.00013.x

Lo, C., Hales, S., Braun, M., Rydall, A. C., Zimmermann, C., & Rodin, G. (2013). Couples facing advanced cancer: Examination of an interdependent relational system. *Psycho-Oncology, 22*(10), 2283–2290. doi:10.1002/pon.3289

Lombard, M., Snyder-Duch, J., & Bracken, C. C. (2002). Content analysis in mass communication: Assessment and reporting of intercoder reliability. *Human Communication Research, 28*, 587–604.

Lotsa Helping Hands. (2015). *How it works*. Retrieved from http://lotsahealpinghands.com/how-it-works/

Lu Y., Wu Y., Liu J., Li J., & Zhang, P. (2017). Understanding health care social media use from different stakeholder perspectives: A content analysis of an online health community. *Journal of Medical Internet Research, 19*(4), e109. doi:10.2196/jmir.7087

Maher, C., Ferguson, M., Vandelanotte, C., Plotnikoff, R., De Bourdeaudhuij, I., Thomas, S., . . . Olds, T. (2015). A Web-based, social networking physical activity intervention for insufficiently active adults delivered via Facebook app: Randomized controlled trial. *Journal of Medical Internet Research, 17*(7), e174. doi:10.2196/jmir.4086

Manne, S. L., Pape, S. J., Taylor, K. L., & Dougherty, J. (1999). Spouse support, coping, and mood among individuals with cancer. *Annals of Behavioral Medicine, 21*, 111–121.

Matheson, J. L. (2016). Loss. In J. Carlson & S. B. Dermer (Eds.), *The Sage encyclopedia of marriage, family and couples counseling* (p. 978). Thousand Oaks, CA: Sage.

Matsuda, S., Aoki, K., Tomizawa, S., Sone, M., Tanaka, R., Kuriki, H., & Takahashi, Y. (2017). Analysis of patient narratives in disease blogs on the Internet: An exploratory study of social pharmacovigilance. *Journal of Medical Internet Research Public Health Surveillance, 3*(1): e10. doi:10.2196/publichealth.6872

Mattson, M., & Gibb Hall, J. (2011). *Health as communication nexus: A service learning Approach*. Dubuque, IA: Kendall Hunt.

Mauri, M., Elli, T., Caviglia, G., Uboldi, G., & Azzi, M. (2017). RAWGraphs: A visualisation platform to create open outputs. *Proceedings of the 12th Biannual Conference on Italian SIGCHI*. New York: ACM. doi:10.1145/3125571.3125585

Mazzotti, E., Sebastiani, C., Antonini Cappellini, G. C., & Marchetti, P. (2013). Predictors of mood disorders in cancer patients' caregivers. *Supportive Care in Cancer*, *21*(2), 643–647. doi:10.1007/s00520-012-1663-9

McFarland, L. A., & Ployhart, R. E. (2015). Social media: A contextual framework to guide research and practice. *Journal of Applied Psychology, 100*(6), 1653–1677. doi:10.1037/a0039244

McGuire, D. B., Grant, M., & Park, J. (2012). Palliative care and end of life: The caregiver. *Nursing Outlook, 60*(6), 351–356; e320. doi:10.1016/j.outlook.2012.08.003

Meleis, A. I. (2010). Transition theory. In M. R. Alligood & A. M. Tomey (Eds.), *Nursing theorists and their work* (7th ed., pp. 416–432). St. Louis, MO: Mosby.

Merluzzi, T. V., Philip, E. J., Yang, M., & Heitzmann, C. A. (2016). Matching of received social support with need for support in adjusting to cancer and cancer survivorship. *Psycho-Oncology, 25*(6), 684–690. doi:10.1002/pon.3896

Merolli, M., Gray, K., Martin-Sanchez, F., Mantopoulos, S., & Hogg, M. (2015). Using social media while waiting in pain: A clinical 12-week longitudinal pilot study. *Journal of Medical Internet Research Protocols*, *4*(3), e101. doi:10.2196/resprot.4621

Mikal, J. P., Rice, R. E., Abeyta, A., & DeVilbiss, J. (2013). Transition, stress, and computer-mediated social support. *Computers in Human Behavior, 29,* A40–A53. doi:10.1016/j.chb.2012.12.012

Morse, J. (2004). Theoretical saturation. In M. S. Lewis-Beck, A. E. Bryman, & T. Futing Liao (Eds.), *The Sage encyclopedia of social science research methods* (Vol. 1, pp. 1122–1123). Thousand Oaks, CA: Sage.

Namkoong. K., DuBenske, L. L., Shaw, B. R., Gustafson, D. H., Hawkins, R. P., Shah, D. V., . . . Cleary, J. F. (2012). Creating a bond between caregivers online: Effect on caregivers' coping strategies. *Journal of Health Communication, 17*(2), 125–140. doi:10.1080/10810730.2011.585687.

National Academies of Sciences, Engineering, and Medicine; Division of Behavioral and Social Sciences and Education; Committee on the Science of Science Communication: A Research Agenda. (2017). The complexities of communicating science. *Communicating Science Effectively: A Research Agenda (2).* Washington, DC: National Academies Press. Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK425709/

National Cancer Institute. (2014). *Caring for the caregiver*. Retrieved from https://www.cancer.gov/publications/patient-education/caring-for-the-caregiver.pdf

National Cancer Institute. (2017a). *Family caregivers in cancer: Roles and challenges* (PDQ®). Retrieved from https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq#section/all

National Cancer Institute. (2017b). *Understanding cancer: Cancer statistics*. Retrieved from https://www.cancer.gov/about-cancer/understanding/statistics

Nijboer, C., Tempelaar, R., Triemstra, M., van den Bos, G. A., & Sanderman, R. (2001). The role of social and psychologic resources in caregiving of cancer patients. *Cancer*, *91*(5), 1029–1039.

Northouse, L., Williams, A. L., Given, B., & McCorkle, R. (2012). Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology, 30*(11), 1227–1234. doi:10.1200/JCO.2011.39.5798

Northouse, L. L., Katapodi, M. C., Schafenacker, A. M., & Weiss, D. (2012). The impact of caregiving on the psychosocial well-being of family caregivers and cancer patients. *Seminars in Oncology Nursing*, *28*(4), 236–245. doi:10.1016/j.soncn.2012.09.006

Nsoesie, E. O., Flor, L., Hawkins, J., Maharana, A., Skotnes, T., Marinho, F., & Brownstein, J. S. (2016). Social media as a sentinel for disease surveillance: What does sociodemographic status have to do with it? *PLoS Currents*, *8*. doi:10.1371/currents.outbreaks.cc09a42586e16dc7dd62813b7ee5d6b6

Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. (1998). *Informal caregiving: Compassion in action*. Retrieved from http://aspe.hhs.gov/pdf-report/informal-caregiving-compassion-action

Ostwald S. K. (2009). Who is caring for the caregiver? Promoting spousal caregiver's health. *Family & Community Health, 32*(Suppl. 1), 5–14. doi:10.1097/01.FCH.0000342835.13230.a0

Overberg, R. I. , Alpay, L. L., Verhoef, J., & Zwetsloot-Schonk, J. H. M. (2007). Illness stories on the Internet: What do breast cancer patients want at the end of treatment? *Psycho-Oncology, 16*(10), 937–944.

Overberg, R. I., Otten, W., de Man, A., Toussaint, P., Westenbrink, J., & Zwetsloot-Schonk, B. (2010). How breast cancer patients want to search for and retrieve information from stories of other patients on the Internet: An online randomized controlled experiment. *Journal of Medical Internet Research, 12*(1), e7. doi:10.2196/jmir.1215

Ownsworth, T., Henderson, L., & Chambers, S. K. (2010). Social support buffers the impact of functional impairments on caregiver psychological well-being in the context of brain tumor and other cancers. *Psycho-Oncology, 19*(10), 1116–1122. doi:10.1002/pon.1663

Ozbay, F., Johnson, D. C., Dimoulas, E., Morgan, C. A., Charney, D., & Southwick, S. (2007). Social support and resilience to stress: From neurobiology to clinical practice. *Psychiatry, 4*(5), 35–40.

Patel, R., Chang, T., Greysen, S. R.. & Chopra, V. (2015). Social media use in chronic disease: A systematic review and novel taxonomy. *American Journal of Medicine*. doi:10.1016/j.amjmed.2015.06.015

Perrin, A. (2015). *Social media usage: 2005–2015*. Retrieved from www.pewinternet.org/2015/10/08/social-networking-usage-2005-2015/

Perz, J., Ussher, J. M., Butow, P., & Wain, G. (2011). Gender differences in cancer carer psychological distress: An analysis of moderators and mediators. *European Journal of Cancer Care, 20*(5), 610–619. doi:10.1111/j.1365-2354.2011.01257.x

Pew Research Center. (2013). *How online family caregivers interact with their health online.* Retrieved from www.pewinternet.org/2013/06/20/how-online-family-caregivers-interact-with-their-health-online/

Pew Research Center. (2017a). *Mobile fact sheet*. Retrieved from www.pewinternet.org/fact-sheet/mobile/

Pew Research Center. (2017b). *Social media fact sheet*. Retrieved from www.pewinternet.org/fact-sheet/social-media/

Pew Research Center's Internet and American Life Project. (2011). *The social life of health information, 2011*. Retrieved from http://pewinternet.org/~/media//Files/Reports/2011/PIP_Social_Life_of_Health_Info.pdf

Pinquart, M., & Duberstein, P. R. (2010). Associations of social networks with cancer mortality: A meta-analysis. *Critical Reviews in Oncology/Hematology, 75*, 122–137. doi:10.1016/j.critrevonc.2009.06.003

Pottie, C. G., Burch, K. A., Montross Thomas, L. P., & Irwin, S. A. (2014). Informal caregiving of hospice patients. *Journal of Palliative Medicine, 17*(7), 845–856. doi:10.1089/jpm.2013.0196

Prestin, A., Vieux, S. N., Chou, W. Y. S. (2015). Is online health activity alive and well or flatlining? Findings from 10 years of the Health Information National Trends Survey. *Journal of Health Communication, 20*(7), 790–798.

QSR International. (n. d.). *NVivo 11 for Windows: The most advanced analysis tools for your qualitative research needs.* Retrieved from www.qsrinternational.com/nvivo-product/nvivo11-for-windows

Rabarison, K. M., Croston, M. A., Englar, N. K., Bish, C. L., Flynn, S. M., & Johnson, C. C. (2017). Measuring audience engagement for public health Twitter chats: Insights from #LiveFitNOLA. *JMIR Public Health Surveillance, 3*(2), e34. doi:10.2196/publichealth.7181

Raque-Bogdan, T. L., Hoffman, M. A., Ginter, A. C., Piontkowski, S., Schexnayder, K., & White, R. (2015). The work life and career development of young breast cancer survivors. *Journal of Counseling Psychology, 62*, 655–669. doi:10.1037/cou0000068.

Reeves, D., Blickem, C., Vassilev, I., Brooks, H., Kennedy, A., Richardson, G., & Rogers, A. (2014). The contribution of social networks to the health and self-management of patients with long-term conditions: A longitudinal study. *PLoS One, 9*(6), e98340. doi:10.1371/journal.pone.0098340

Şahin, Z. A., & Tan, M. (2012). Loneliness, depression, and social support of patients with cancer and their caregivers. *Clinical Journal of Oncology Nursing, 16*(2), 145–149. doi:10.1188/12.CJON.145-149

Saldañna, J. (2009). *The coding manual for qualitative researchers*. Thousand Oaks, CA: Sage.

Saldaña, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). London: Sage.

Saria, M. G., Courchesne, N. S., Evangelista, L., Carter, J. L., MacManus, D. A., Gorman, M. K., . . . Maliski, S. L. (2017). Anxiety and depression associated with burden in caregivers of patients with brain metastases. *Oncology Nursing Forum, 44*(3), 306–315. doi:10.1188/17.ONF.306-315

Schaefer, C., Coyne, J. C., & Lazarus, R. S. (1981). The health-related functions of social support. *Journal of Behavioral Medicine, 4*, 381–406.

Schaepe, K. S. (2011). Bad news and first impressions: Patient and family caregiver accounts of learning the cancer diagnosis. *Social Science and Medicine, 73*, 912–921. doi:10.1016/j.socscimed.2011.06.038

Schlossberg, N. K. (2011). The challenge of change: The transition model and its applications. *Journal of Employment Counseling, 48*(4), 159–162. doi:10.1002/j.2161-1920.2011.tb01102.x

Secretary's Advisory Committee on Human Research Protections. (2013). *Considerations and recommendations concerning Internet research and human subjects research regulations with revisions.* Retrieved from www.hhs.gov/ohrp/sachrp/mtgings/2013%20March%20Mtg/internet_research.pdf

Setoyama, Y., Yamazaki, Y., & Namayama, K. (2011). Benefits of peer support in online Japanese breast cancer communities: Differences between lurkers and posters. *Journal of Medical Internet Research, 13*(4), e122. doi:10.2196/jmir.1696

Shaw, J., Harrison, J., Young, J., Butow, P., Sandroussi, C., Martin, D., & Solomon, M. (2013). Coping with newly diagnosed upper gastrointestinal cancer: A longitudinal qualitative study of family caregivers' role perception and supportive care needs. *Supportive Care in Cancer, 21*, 749–756. doi:10.1007/s00520-012-1575-8

Shieh, S. C., Tung, H. S., & Liang, S. Y. (2012). Social support as influencing primary family caregiver burden in Taiwanese patients with colorectal cancer. *Journal of Nursing Scholarship, 44*(3), 223–231. doi:10.1111/j.1547-5069.2012.01453.x

SignUpGenius. (2017). *Features*. Retrieved from www.signupgenius.com/features

Sjovall, K., Gunnars, B., Olsson, H., & Thomé, B. (2011). Experiences of living with advanced colorectal cancer from two perspectives—Iinside and outside. *European Journal of Oncology Nursing, 15*(5), 390–397. doi:10.1016/j.ejon.2010.11.004

Smith, J., & Goodnow, J. J. (1999). Unasked-for support and unsolicited advice: Age and the quality of social experience. *Psychology and Aging, 14*(1), 108–121. doi:10.1037/0882-7974.14.1.108

Snijders, T. (2009). Longitudinal methods of network analysis. In B, Meyers (Ed.), *Encyclopedia of complexity and system science* (pp. 5998–6013). New York: Springer-Verlag.

Song, H., Nam, Y., Gould, J., Sanders, W. S., McLaughlin, M., Fulk, J., . . . Ruccione, K. S. (2012). Cancer survivor identity shared in a social media intervention. *Journal of Pediatric Oncology Nursing, 29*(2), 80–91. doi:10.1177/1043454212438964

Stefanidis, A., Vraga, E., Lamprianidis, G., Radzikowski, J., Delamater, P. L., Jacobsen, K. H., . . . Crooks, A. (2017). Zika in Twitter: Temporal variations of locations, actors, and concepts. *JMIR Public Health and Surveillance, 3*(2), e22. doi:10.2196/publichealth.6925

Sutherland, N. (2009). The meaning of being in transition to end-of-life care for female partners of spouses with cancer. *Palliative and Supportive Care, 7,* 423–433. doi:10.1017/S1478951509990435

Suzuki, L. K., & Beale, I. L. (2006). Personal Web home pages of adolescents with cancer: Self-presentation, information dissemination, and interpersonal connection. *Journal of Pediatric Oncology Nursing, 23*(3), 152–161. doi:10.1177/1043454206287301

Teixeira, R. J., & Pereira, M. G. (2013). Psychological morbidity, burden, and the mediating effect of social support in adult children caregivers of oncological patients undergoing chemotherapy. *Psycho-Oncology, 22*(7), 1587–1593. doi:10.1002/pon.3173

Thoits, P. A. (2011). Mechanisms linking social ties and support to physical and mental health. *Journal of Health and Social Behavior, 52*(2), 145–161. doi:10.1177/0022146510395592

Thompson, T., Rodebaugh, T. L., Perez, M., Schootman, M., & Jeffe, D. B. (2013). Perceived social support change in patients with early-stage breast cancer and controls. *Health Psychology, 32*(8), 886–895. doi:10.1037/a0031894

Tian, Y., & Robinson, J. D. (2009). Incidental health information use on the Internet. *Health Communication, 24*(1), 41–49. doi:10.1080/10410230802606984

Uchino, B. N. (2009). Understanding the links between social support and physical health: A life-span perspective with emphasis on the seperability of perceived and received support. *Perspectives on Psychological Science, 4*(3), 236–255. doi:10.1111/j.1745-6924.2009.01122.x

Uchino, B. N., Bowen, K., Carlisle, M., & Birmingham, W. (2012). Psychological pathways linking social support to health outcomes: A visit with the “ghosts” of research past, present, and future. *Social Science & Medicine, 74*(7), 949–957. doi:10.1016/j.socscimed.2011.11.023

University of California, Los Angeles Institute for Digital Research and Education. (2017). *GIS, visualization and modeling program*. Retrieved from https://idre.ucla.edu/programs/gis-visualization

U.S. Census Bureau. (n.d.). *Census regions and divisions of the United States*. Retrieved from www.census.gov/geo/maps-data/maps/pdfs/reference/us_regdiv.pdf

U.S. Department of Health & Human Services. (2003). *OCR privacy brief: Summary of the HIPAA privacy rule*. Retrieved from www.hhs.gov/ocr/privacy/hipaa/understanding/summary/

Valente, T. W., & Pitts, S. R. (2017). An appraisal of social network theory and analysis as applied to public health: Challenges and opportunities. *Annual Review of Public Health, 38,* 103–118. doi:10.1146/annurev-publhealth-031816-044528

Van den Broeck, J., Cunningham, S. A., Eeckels, R., & Herbst, K. (2005). Data cleaning: Detecting, diagnosing, and editing data abnormalities. *PLoS Medicine, 2*(10), e267. doi:10.1371/journal.pmed.0020267

van Ryn, M., Sanders, S., Kahn, K., van Houtven, C., Griffin, J. M., Martin, M., . . . Rowland, J. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psycho-Oncology, 20,* 44–52. doi:10.1002/pon.1703

van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Seydel, E. R., & van de Laar, M. A. F. J. (2008). Self-reported differences in empowerment between lurkers and posters in online patient support groups. *Journal of Medical Internet Research, 10*(2), e18. doi:10.2196/jmir.992

Wang, Y. C., Kraut, R. E., & Levine, J. M. (2015). Eliciting and receiving online support: Using computer-aided content analysis to examine the dynamics of online social support. *Journal of Medical Internet Research, 17*(4), e99. doi:10.2196/jmir.3558

Whisper. (2017). *Community guidelines*. Retrieved from http://whisper.sh/guidelines

Williams, A., & Bakitas, M. (2012). Cancer family caregivers: A new direction for interventions. *Journal of Palliative Medicine, 15*(7), 775–783. doi:10.1089/jpm.2012.0046

Williams, G., Hamm, M. P., Shulhan, J., Vandermeer, B., & Hartling, L. (2014). Social media interventions for diet and exercise behaviours: A systematic review and meta-analysis of randomised controlled trials. *BMJ Open, 4*(2), e003926. doi:10.1136/bmjopen-2013-003926

Wood, A. M., Froh, J. J., & Geraghty, A. (2010). Gratitude and well-being: A review and theoretical integration. *Clinical Psychology Review, 30*(7), 890–905. doi:10.1016/j.cpr.2010.03.005

Wood, A. M., Maltby, J., Gillett, R., Linley P. A., & Joseph, S. (2008). The role of gratitude in the development of social support, stress and depression: Two longitudinal studies. *Journal of Research in Personality, 42*, 854–871. doi:10.1016/j.jrp.2007.11.003

Word, D. L., Coleman, C. D., Nunziata, R., & Kominski, R. (2000). *Demographic aspects of surnames from Census 2000*. Retrieved from https://www2.census.gov/topics/genealogy/2000surnames/surnames.pdf

World Health Organization. (2017). *Sample size*. Retrieved from http://apps.who.int/medicinedocs/en/d/Js6169e/7.6.html

Wu, X., Zhou, X., Liu, L., & Chen, J. (2014). Social support and deliberate rumination mediate the relationship between gratitude and post-traumatic growth in adolescents at 4.5 years after Wenchuan earthquake. *Psychological Science, 37*(5), 1148–1153.

Wu, Y., Liu, S., Yan, K., Liu, M., & Wu, F. (2014). OpinionFlow: Visual analysis of opinion diffusion on social media. *IEEE Transactions on Visualization and Computer Graphics, 20*(12), 1763–1772. doi:10.1109/TVCG.2014.2346920

Yao, T., Zheng, Q., & Fan, X. (2015). The impact of online social support on patients' quality of life and the moderating role of social exclusion. *Journal of Service Research, 18*(3), 369–383. doi:10.1177/1094670515583271

You. (2017). In *Dictionary.com*, Retrieved from www.dictionary.com/browse/you

Zhou, X., & Wu, X. (2016). Understanding the roles of gratitude and social support in posttraumatic growth among adolescents after Ya'an earthquake: A longitudinal study. *Personality and Individual Differences, 101*, 4–8. doi:10.1016/j.paid.2016.05.033