“I’m still here”: an Ethnographic Exploration of Public Twitter Use among People Living with Advanced Cancer

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science

Institute of Health Policy, Management and Evaluation
University of Toronto

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Abstract

Twitter is the most public of all social media platforms, and yet some users turn to this platform to share intimate details about their health. This ethnography explores public Twitter use among people living with advanced cancer with the aim of describing their Twitter activities and their perspectives on their use. Six latent themes were generated by analyzing 2,731 original tweets published by 8 authors and interview transcripts from 10 participants: 1) Constructing Identity Through Textual Selfie, 2) Resisting Social Death, 3) Accounting for Time, 4) Finding Freedom in Obscurity, 5) Creating a Living Legacy, and 6) Fighting for What’s Right. Through these themes, I argue that the technological affordances of Twitter can be used to counteract the inhibiting aspects of liminality. In using Twitter publicly, they declare ‘I’m still here’ to themselves, the people around them, and the world at large.
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For Alicia, Mildred, Jimmy, and Nanci.
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Introduction
Chapter 1: Introduction

1.1 Research Problem

Social media has become ubiquitous in the last decade as Internet technology pervades into the daily lives of most people, becoming constitutive of what it means to be human (Miller & Horst, 2013:4; Hallett & Barber, 2014). Social media has become part of how we experience all aspects of life, including health and illness, as the lines between “offline” and “online” life blur into different experiences rather than separate lives. With the rise in popularity of social media, health professionals and researchers have become interested in this new mode of communication. Over the past decade, research on social media use in health care has grown as we learn about social media’s role as part of the illness experience.

Because tweets are indexed in Google, Twitter is the most public of all social media platforms, and yet some users turn to this platform to share intimate details about their health. The research has yet to explore why some people choose to use Twitter publicly in the context of their health and what they gain from its use.

1.2 Rationale

Patients report using many different social media platforms as part of the illness experience to increase knowledge, communicate with doctors, gain social support, exchange advice, and for self-care (Antheunis, Tates & Nieboer, 2013). One platform patients use is Twitter. While research into Twitter’s use in consumer health grows year after year, most often the focus of such research is on the content of messages and the connections between actors. There has been little variation in terms of the methods or aims of existing research and thus the existing literature is fairly narrow in focus. In January 2017, 100 million users were active on Twitter each day (Aslam, 2017), yet Twitter research in consumer health rarely includes the perspectives of users. The literature thus far has focused primarily on describing what and how health topics are discussed on Twitter.
As online social environments have become integrated into daily living, it is important that we get a deeper understanding of Twitter’s place and importance within a wider sociocultural context. In 2014, Hardin put forth an appeal to Twitter researchers to move beyond description and instead begin to make sense of the larger sociocultural impacts of Twitter use:

“The next logical step after we have a good sense about [what Twitter is, how people use it, and for what purpose they use it] is to pursue studies that put a much higher priority on the wider sociocultural context and on theory. In other words, providing much more substance about what all this tweeting really means and its implications for what we already know. What is consequential and how so?” (Hardin, 2014)

Previous research on Twitter’s use among patients is built from the assumption that people use Twitter publicly as solutions for finding information and meeting peers experiencing similar issues, yet it is not clear why patients would compromise their privacy when there are more reliable ways to achieve these goals that better maintain their privacy.

1.3 Purpose

As a starting point to address this gap, the purpose of this exploratory study is to gain insight into why people living with metastatic, incurable, terminal and/or chronic cancers (referred to as ‘advanced cancer’ throughout) choose to publicly disclose their health status on Twitter by studying their perspectives and public activities. I chose to focus this study on people living with advanced cancer because of the tension between society’s discomfort with death and the public nature of Twitter use. As a patient group, people living with advanced cancer are unique in that they experience liminality (being ‘in-between’ living and dying) while continuing to live seemingly ‘normal’ lives for long periods of time. Though they have unique needs when compared to other cancer patients, they are largely understudied and their presence is often ignored or overlooked.
1.4 Study Objective

This study uses a qualitative interpretive framework and ethnographic methodology to explore the public use of Twitter among people living with advanced cancer. The aims of this research study were to describe Twitter activities and behaviours of people living with advanced cancer, and to gain insight into their perspectives about their use.

1.5 Roadmap

Chapter 2 provides background information on Twitter and what is currently known about its use in consumer health and cancer. Prior to determining the focus for this study, I surveyed the literature on Twitter and consumer health to understand what topics, methods, and aspects of Twitter had been studied previously to identify gaps in the literature that could be addressed. Given the prevalence of cancer, it was unsurprising that cancer had been the most popular health condition researched within the consumer health and Twitter literature. There were no studies that specifically focused on Twitter use among advanced cancer patients. I conducted a second literature review, specifically focusing on Twitter use among cancer patients, and updated it periodically throughout the duration of this study. I provide a summary of each study and the pertinent findings, then summarize the methodological and contextual gaps that exist in the current literature. I end the chapter by introducing the technological affordances of Twitter by providing an overview of the features and functions that make Twitter unique from other online social spaces.

In Chapter 3 I detail the paradigm, methodology, theoretical positioning, and overarching ethical considerations that influenced the study design. As this study aims to explore how individuals understand their Twitter use, the design aligns with the interpretivist paradigm and uses an ethnographic methodology. I position myself within the study by providing a reflexive account of my background and experiences that are relevant to the topic. In an effort to negotiate a balance between the ethical principles of “free and informed consent” and “right to anonymity and privacy”, I opted to collect data by extracting tweets from public Twitter profiles and conducting (private) key informant interviews instead of following typical participant
observation procedures. I make explicit how Twitter data was conceptualized in this study because there is no single way to define social media data. Finally, I end the chapter by summarizing key thoughts on rigor in qualitative research and described how I addressed procedural and substantive rigor throughout this study.

Chapter 4 provides detailed procedural information on how data was collected and analyzed. I used two methods of data collection to capture different aspects of Twitter use: tweet extracts and informant interviews. For each method I describe the process for selecting and/or recruiting informants, how data was collected, and the specific ethical issues that were negotiated. I end the chapter by describing how data from the two sources were brought together and analyzed to provide insight for the purposes of this study. I used the analytic method described by Boellstorff, Nardi, Pearce, and Taylor (2012) for their ethnographic work (which is very similar to Braun and Clarke’s [2006] thematic analysis) to inductively generate latent themes.

Chapter 5 provides a summary of the characteristics of the data samples collected in each the tweet extracts and the interviews.

In Chapter 6 I provide a rich description of the 6 latent themes generated during data analysis and support the findings with demonstrative quotes from the interview transcripts and tweet extracts.

Chapter 7 describes the substantive contributions of the findings by placing the themes in context within the literature on Twitter use in cancer and the experiences of people living with advanced cancer, as a means of providing new insight into Twitter use among people living with advanced cancer. Beyond the substantive knowledge gained from the findings, this study also offers some unique insights into the methods used to study Twitter use, primarily in that it combined content analysis of tweet extracts and key informant interviews to gain a more holistic view of Twitter use, and found ways to balance ethical practice and effective methods to move the study forward. The limitations of this study are also discussed, followed by some suggestions of areas for further research.
Chapter 8 concludes this study by first discussing my personal reflections on the knowledge gained and my insights on the study design. I then end the chapter by summarizing my conclusions.
Chapter 2: Background

As part of this research, I have conducted two separate literature reviews about Twitter use in consumer health. The first was conducted prior to determining the focus of my thesis as a means of identifying new areas to study. The second review had been ongoing throughout the project as a means of gaining knowledge about cancer and Twitter use to provide insight into my findings. Below I summarize each review, including the gaps I have identified from each review. I end the chapter with an overview of Twitter, specifically focusing on the features and technological affordances that make it unique when compared to other online social spaces.

2.1 Literature Review of Twitter Use in Consumer Health

In November 2014, prior to determining the topic for this study, I surveyed the health literature to understand what was known about Twitter’s use in consumer health and the methods used to study the topic.

2.1.1 Method

I followed Williams, Terras and Warwick’s (2013) method for retrieving articles for consideration: a PubMed database search was conducted on November 8, 2014 using the search string “tweet OR twitter” and returned 629 results. After some evaluation, the authors determined PubMed was the best place to conduct a structured search for literature because the search would be repeatable by any other researcher, regardless of their access to subscription services (Williams, Terras & Warwick, 2013). Of the publicly available databases, PubMed returned the most meaningful results; BioMed Central returned too few results, all of which were returned in the PubMed search, and Google Scholar returned any publication that had a ‘Share This On Twitter’ button (Williams, Terras & Warwick, 2013). Articles returned in the PubMed search were screened four times, as described below, to determine inclusion.
2.1.1.1 Inclusion Criteria

I also used Williams, Terras, and Warwick's (2013) work on classifying medically-related Twitter publications as a framework. They propose a system with 5 dimensions for classifying Twitter articles: the focus of the paper (Focus), how much data was collected and analyzed (Data), the standpoint or perspective of the paper (Domain), the methodological approach taken in the paper (Method), and the aspect or characteristic of Twitter that was considered (Aspect) (Williams et al., 2013). Each dimension has three to five categories which, altogether, capture the breadth of papers published on Twitter. These dimensions were used to define the inclusion criteria as follows:

1. Focus: “Twitter-focused” (“Twitter Mentioned” excluded)
2. Data: “Small”, “Medium” or “Large” datasets (“Not data based” excluded)
3. Domain: “General Communication” or “Targeted Communication” (“Academic”, “Medical Professional Communication”, and “Guides” excluded)
4. Method: “Analysis” or “Examination” (“Design and Development” excluded)
5. Aspects: “User”, “Message”, and “Technology” (“Concept” was excluded)

For classification purposes, categories within each dimension were considered mutually exclusive with the exception of the Aspect dimension as some articles could be classified as both “User” and “Message”.

2.1.1.2 Screening

The first screening review followed Williams, Terras, and Warwick's (2013) process for removing irrelevant articles by title review. All titles published before 2007 (n=22) were removed, as it was previously established no research on the social media site was published before that year. Articles using “tweet” or “Twitter” in another context were removed (n=17), as were articles without abstracts, as these were deemed ‘news stories’ (n=113). A list of publishers of ‘news stories’ was recorded and verified, and an additional search was conducted to remove any other articles from these sources (n=12). Those articles that were published in languages other than English were also removed from the dataset for practical reasons (n=17).
A second title review screening was conducted by reading the remaining article titles (n=448) to identify and remove those that were not about health (n=91), social media (n=69) or either (n=18). During the review, articles that primarily examined a social media site other than Twitter (for example, blogs, Instagram, or Facebook) were also removed from the dataset (n=15). All articles that did not clearly meet exclusion criteria (for example, articles with vague titles) remained in the dataset for further verification during the subsequent screening rounds.

The third screening review was conducted by reading the abstracts of the remaining articles (n=255) to determine if the publication met the Focus (“Twitter Focused”) and Data (“Small”, “Medium”, or “Large” datasets) inclusion criteria. Those abstracts that did not report data (n=78) or who's focus was not specific to Twitter (n=76) were removed from the dataset.

The fourth and final screening review of the remaining 101 articles’ abstracts was conducted to categorize the Domain, Method, and Aspect dimensions to identify those articles relevant to this study. Those articles with the Domain dimension categories of “Academic” and “Medical Professional Communication” were removed from the dataset (n=38), as were those with the Method dimension category of “Design & Development” (n=25). All remaining articles (n=38) were categorized as “Message”, “User”, or both on the Aspect dimension (see Figure 1:
Summary of Literature Screening). Of the 38 articles that met all the inclusion criteria, 4 were not accessible and thus were not included in the review, resulting in a final dataset of 34 articles.

Figure 1: Summary of Literature Screening

<table>
<thead>
<tr>
<th>Williams et al. methods for removing irrelevant articles</th>
<th>Titles remaining</th>
</tr>
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<tbody>
<tr>
<td>Searched Pub Med for “twitter” or “tweet”</td>
<td>629</td>
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<tr>
<td>Removed studies published prior to 2007 (n=22)</td>
<td>607</td>
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<tr>
<td>Removed non-English studies (n=17)</td>
<td>590</td>
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<tr>
<td>Removed “twitter” or “tweet” used in different context (n=17)</td>
<td>573</td>
</tr>
<tr>
<td>Removed articles without abstracts (n=113)</td>
<td>460</td>
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<td>Removed articles published in news/magazines (n=12)</td>
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<tr>
<td>Title review</td>
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<td>Removed titles not related to health or social media (n=18)</td>
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<td>Removed titles not about health (n=91)</td>
<td>339</td>
</tr>
<tr>
<td>Removed titles not about social media (n=69)</td>
<td>270</td>
</tr>
<tr>
<td>Removed titles focused on social media other than Twitter (n=15)</td>
<td>255</td>
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<td></td>
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<tr>
<td>Removed abstracts with no data (n=78)</td>
<td>177</td>
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<tr>
<td>Removed abstracts not specifically about Twitter (n=76)</td>
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<tr>
<td>Removed abstracts with Domain “Academic” or “Medical Professional Communication” (n=38)</td>
<td>63</td>
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<td>Removed abstracts with Method “Design &amp; Development” (n=25)</td>
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2.1.2 Critical Review

The first studies on Twitter and consumer health did not appear until 2010 and increased rapidly within the subsequent years. The methods used to study Twitter and consumer health, however, had been much the same across the literature, resulting in a narrow understanding of Twitter and consumer health. For example, 29 studies used keyword searches of Twitter data to collect the study sample data; of those, 26 studies used keyword searches to identify and extract individual messages\(^1\), while the remaining 3 studies used keyword searches to identify profiles of interest

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\(^1\) Chew & Eysenbach, 2010; Love, Himelboim, Holton & Stewart, 2013; Donelle & Booth, 2012; McNeil, Brna & Gordon, 2012; Sanders-Jackson, Brown & Prochaska, 2013; Ahlwardt et al., 2014; Adams, Lomax & Santarini, 2011; Sullivan et al., 2012; Bosley et al., 2013; Harris, Moreland-Russell, Tabak, Ruhr & Maier, 2014; Huang,
(Sugawara et al., 2012; Prochaska, Pechmann, Kim & Leonhardt, 2012; Tsuya, Sugawara, Tanaka & Narimatsu, 2014). Of the remaining studies published at the time of this review, two focused on the tweets mentioning a pre-selected Twitter profile (Greaves et al., 2014; Harris, Moreland-Russell, Choucair et al., 2014), one reported on a case study of a psychotic break triggered by Twitter use (Kalbitzer, Mell, Bermpohl, Rapp & Heinz, 2014), one examined the followers and the followers’ activities of a Twitter account that was deemed problematic (Cavazos-Rehg, Krauss, Gruca & Bierut, 2014), and one conducted an online survey of Twitter users to gain insight on the social supports users received from multiple sources including Twitter connections (Pagoto et al., 2014). These studies have gone some way to uncovering the breadth of Twitter’s use in consumer health - indeed, there were 19 medical topics covered within the 34 studies included - but do not provide much depth.

As for the focus of these studies, most focused on the health-related content (e.g. words and phrases) Twitter users shared. Choosing to study Twitter by counting frequencies of words or measuring the sentiment of messages suggests these researchers conceptualized Twitter as a broadcast messaging system, as though the content of tweets could be understood in isolation from most (if not all) of the context in which they were created. In practice, tweets do not exist in a social vacuum: they are created and interpreted within many different social contexts. When making meaning of online social activity, it is essential to understand the circumstances (contexts) in which the Internet is used and the social spaces that emerge through its use (Hine, 2000:39). The act of creating a tweet has meaning to the author, no matter who (if anyone) reads it (Murthy, 2011). Imagining tweets have meaning when stripped of the context within which they were created hinders our ability to grasp the social significance of Twitter use.
While tweets had been consistently conceptualized as broadcast messages in the literature, the purpose behind conducting research into Twitter’s use in consumer health had been more varied, though still narrowly focused. Studies included in this review had typically explored different components of two facets of Twitter use: the content of tweets, and the actors involved.

Components considered when studying the content of tweets included:

1. the patterns of activity on Twitter, for example, how tweet frequencies changed throughout the week;
2. message themes represented in the tweet extracts;
3. message sentiments of tweet extracts;
4. sources of shared links;
5. correlating patterns in tweet extracts to measures from ‘offline’ sources, usually to gauge Twitter’s ability to act as a proxy or predictive tool.

Components considered when studying the actors included:

6. social network analyses to identify clusters of users who are connected;
7. categorizations of the types of profiles who tweet about a certain topic, for example by geographic location or user type;
8. examinations of how Twitter use has impacted users’ health offline, for example, Kalbitzer et al.’s (2014) report on Twitter use aggravating a patient’s psychosis.

Digital ethnographers Postill and Pink criticize such approaches to social media research as “a particular type of research site filled with texts and/or connections between entities” (2012:124) that over-simplifies our understanding of these sites. Further, connections (followers or followings) on Twitter change by the minute (Murthy, 2011) and these dynamic shifts cannot be captured in a cross-sectional social network analyses. Twitter offers an environment of socialities (social relationships with no clear edges, in constant flux, that operate/exist across boundaries including the online/offline boundary), movement (between different communication means), and routines (practices that include catching-up, sharing, exploring, interacting, and archiving) that cannot be understood by content and social network analyses alone (Postill & Pink, 2012).
2.1.3 Summary

The research on Twitter use in consumer health from 2010 to the end of 2014 has demonstrated that Twitter is used in many different health/disease areas, but researchers have not explored these topics in much depth. In conceiving Twitter as a broadcast mechanism, researchers limit their understanding of tweets as passive containers for words and phrases. The literature has failed to consider that tweets can have effect as active agents (Prior, 2012) – tweets are created as a response to something and their existence can influence future happenings – and the author created the tweet with some purpose in mind. The literature recognizes that tweets exist on a variety of health topics but has yet to explore why the tweets exist in the first place.

2.2 Determining Topic of Study: Advanced Cancer

The preliminary literature review showed that while there had been a broad spectrum of health-related topics covered within the Twitter and consumer health literature, there was not much depth in any one area, and therefore doing more research within any health topic could serve to fill a gap in the literature. I chose to study Twitter use among people living with advanced cancer because of the prevalence of cancer and the unique illness experience. In both my professional and personal use of Twitter I have witnessed several people living with advanced cancer tweet about their experiences. Previous research has not examined why they used such a public and exposed platform to share their experiences with strangers, and this was a gap I was interested in filling.

Below I describe in more detail the prevalence of cancer, how an advanced cancer diagnosis can lead to a type of social death, how living with advanced cancer can be a liminal experience, and the unique goals of people living with advanced cancer.

2.2.1 Prevalence of Cancer

Though there were a range of health topics covered in the 2014 literature review, cancer was covered the most (6 of the 34 studies). Of these 6 studies, 3 focused on prevention and screening (Thackeray et al., 2013; Lyles et al., 2013; Prabhu et al., 2014), and 3 focused on patient use
(Sugawara et al., 2012; Tsuya et al. 2014; Himelboim et al., 2014). It is not surprising cancer has been a popular topic of health research into Twitter given the prevalence of cancer; it is estimated that 1 in 2 Canadians will be diagnosed with cancer while 1 in 4 will die from the disease (Canadian Cancer Society’s Advisory Committee in Cancer Statistics, 2017). In general, patients with cancer are living longer thanks to improved diagnostics and treatments (see for example: Ruiterkamp, et al., 2011; Giordano et al., 2004; Marshall & Sommers, 2016).

Prolonged life means that patients spend more time living and coping with the complexities of life with cancer.

2.2.2 Advanced Cancer and Social Death

Because of these improvements in diagnosis and treatment, patients diagnosed with advanced cancer can live for a longer period in which their health gradually declines, much like in chronic illness (Lobb et al., 2013). People living with cancer may experience a form of social death wherein society and the people around them view them as less socially alive, or not fully human, because of their diminished ability to participate fully in society (Charmaz, 1983). The term ‘social death’ describes a state in which one is considered less alive socially by society and the people around them (Helman, 2000:163). More specifically, social death can be described as becoming disconnected from social life through a series of losses, such as the loss of identity, being unable to take part in daily activities, and the loss of social relationships (Norrwood, 2009 via Borgstrom, 2017). Cancer treatment and side effects can bring about periods of time when patients find it difficult to participate in ‘regular’ daily activities, which ultimately challenges one’s sense of self (Charmaz, 1983; Vilhauer, 2008; Adorno, 2015). “Those who cannot perform conventional tasks and social obligations lose the very means needed to sustain a meaningful life” (Charmaz, 1983:191). A gradual social death can lead to feelings of ‘liminality’, wherein one’s former social identity is lost without developing a new one (Charmaz, 1983).

2.2.3 Liminality and Cancer

Liminality is a concept that comes from van Gennep’s work on rites of passages (1965). Rites of passage occur when a person changes from one social status to another, following three types of
rites: 1) preliminary rites, or rites of separation; 2) liminality rites, or rites of transition; and 3) postliminal rites, or rites of reincorporation (van Gennep, 1965:10-11). Experiencing liminality means being left in an ambiguous state where one no longer has their previous social status but has yet to be given their new status (Turner, 1967:94). The person in a liminal state is structurally invisible in that they are “at once no longer classified and not yet classified” (Turner, 1967:96).

The experience of living with cancer can be understood as a form of liminality. Little et al. (1998) were among the first to demonstrate the applicability of liminality in understanding the experiences of cancer patients. In studying patients with colorectal cancer, they recognized the consistent feelings of boundedness (awareness of limited time, space, and/or personal power), communicative alienation (being unable to put experiences into words that are understood by others), and cancer patientness (identification as cancer patient regardless of medical status) experienced by all patients in the study (Little et al, 1998). While Little et al. (1998) originally positioned liminality as an inhibiting experience, Thompson (2007) argues it can also be generative in that it can lead to significant personal growth, creativity, and strengthening of social connectedness.

2.2.4 Goals of People Living with Advanced Cancer

People living with advanced cancer are a uniquely interesting population to study when compared to other stages of disease or points in the care trajectory because they can continue to live relatively normal lives for long periods of time. As long as people living with advanced cancer see themselves as healthy and are physically active, they do not want nor do they require end-of-life-care, though they recognize that they are one “test result away from experiencing the end of [their lives]” (Thompson 2007). Nissim et al.’s (2012) longitudinal study of people diagnosed with advanced cancer who were not actively dying provides the best insight into the goals and experiences of those included in this study as it is one of the few studies that intentionally and explicitly studied this “in-between” group. Participants in this study struggled to cope with knowledge that they were living ‘on the verge of dying’ but continued to find ways to live dynamically and grow in whatever capacity they could (Nissim et al., 2012). Goals that
were continually present for patients throughout their between-living-and-dying experience were 1) controlling dying by maximizing treatment options and considering suicide as a way to mitigate their future suffering; 2) valuing life in the present by comparing their situation to those that were less favourable and making plans within conservative timeframes; and 3) creating a living legacy, a symbolic immortality, by making a positive impact on the lives of those around them (Nissim et al., 2012).

2.3 Literature Review on Twitter Use among Cancer Patients

Upon choosing to study Twitter use among people living with advanced cancer, I conducted another literature review focusing on Twitter use among cancer patients and updated it periodically throughout the duration of this study.

2.3.1 Method

Mirroring Williams, Terras and Warwick's (2013) method for retrieving articles, I searched the PubMed database using the search string “((cancer OR oncology)) AND (twitter OR tweet)”, with the final search taking place on February 20, 2018. A total of 145 articles were returned and their titles and abstracts were reviewed for relevance. I supplemented this search by conducting an additional search on the Association for Computing Machinery’s (ACM) Digital Library, using the search string “(+twitter +cancer)OR(+tweet +cancer)OR(+twitter +oncology)OR(+twitter +cancer)” on February 26, 2018 and returned 7 results. From both query results, I excluded articles that: 1) were not written in English, 2) were not about Twitter use in the cancer context, or 3) focused on Twitter use among health professionals, medical education, or health promotion (including cancer prevention, screening, and surveillance). A final sample of 11 publications remained, with 10 coming from PubMed and 1 from ACM. Only five of these studies explicitly examined Twitter use among cancer patients (Sugawara et al., 2012; Tsuya et al., 2014; Singh & John, 2015; Crannell, Clark, Jones, James & Moore, 2016; Taylor & Pagliari, 2018), but I included studies focused on ‘general use’ of Twitter in the review below as patients were often included and identified as groups within the study samples. The findings from these 11 studies are briefly summarized below, in order of their publication date.
2.3.2 Article Summaries

Sugawara et al. (2012) analyzed 51 profiles of Japanese Twitter “power accounts” (Twitter users who had more than 500 followers) who identified as cancer patients. The results of the study demonstrate that networks of cancer patients exist on Twitter and cancer-related information is exchanged between them. Among their findings they discovered that patients offered each other psychological support and conversation much more frequently than medical information and news.

Himelboim and Han (2014) examined network clusters of Twitter users who tweeted about breast and prostate cancer to understand how “core” users (users who are regularly active in the cluster) and “visiting” users (users who rarely appear in the cluster) connect with one another and share information. The authors discovered that core clusters for both prostate and breast cancer were primarily made up of individual users and small websites rather than institutions, and these clusters were dense, suggesting more information flow between users within the cluster. Visiting clusters, on the other hand, were usually centered on institutional hubs such as the American Cancer Society.

Tsuya et al. (2014) extracted 200 tweets from all Japanese Twitter users who identified as cancer patients in their profile and analyzed the co-occurrence of nouns within the individual tweets that were deemed relevant to cancer. The authors used this analysis to provide evidence that Japanese cancer patients tweet about their cancer and medically-related information. The authors conclude their manuscript by asserting that cancer patients tweet about medical information, including information about the diagnosis, symptoms, and treatments.

Attai et al. (2015) conducted a survey of Twitter users who participated in the #bcsm (Breast Cancer Social Media) chats to evaluate the chat’s impact on users’ knowledge of different aspects of breast cancer and levels of anxiety. When asked to recall how participating in the chat had impacted them, the survey respondents largely reported improvements in their knowledge of breast cancer and decreased feelings of anxiety. The authors rightly recognize the limitations of their approach - they used an un-validated measure that relied on participant recall, they did not
have a control group, and they could not verify who exactly completed the survey - but maintain that participating in the tweet chat has its benefits and the tweet chats could be a useful complement to standard practices.

Complementary to Attai et al. (2015), Singh and John (2015) analyzed the content of tweets shared on the same hashtag, #bcsm, over a period of one year to evaluate the tweet chat’s effectiveness at supporting patients. The authors used computer algorithms to analyze the level of engagement and the linguistic and psychological content of tweets written by patients both during the scheduled weekly chats and outside of the chats to see how the two settings differed. Their analyses found that users who could be identified as patients “were more engaged and talked more about themselves in coherent, complex ways that expressed positive emotion during the chats as compared to out of chat” (Singh & John, 2015). The authors believed these findings were significant because participants shared personal things in public way. While this argument goes some way to supporting the benefit of tweet chats, the authors did not consider that the hashtag may be applied differently depending on the context. For example, during tweet chats the hashtag is meant to organize a structured conversation. Outside of tweet chats, the hashtag is typically used to connect with the community at large as a means of soliciting or providing information and support. Further, Singh and John did not examine how users decide when to use the hashtag. It is entirely possible that patients share their personal stories outside of the chats, but they do not include the #bcsm hashtag in these tweets.

Park et al. (2016) sought to characterize and assess the credibility of tweets about colorectal cancer from a sample collected over 3 months. In reviewing a sample of medically-relevant tweets, the authors found that nearly 85% of the information were medically correct, nearly 14% were unverifiable (tweets that were too vague and did not provide evidence), and only 1.6% of the tweets contained misinformation. Within their sample, those tweets that had been the most popular (judged by the number of retweets) were more likely to be medically correct than those from a random selection from the same dataset.

Kim, Hou, Han and Himelboim (2016) examined tweets containing the keywords ‘breast cancer’ during several weeks as a means of identifying what factors made other Twitter users more likely
to retweet a message. Their findings showed that the popularity, connectedness, and personal influence of a tweet’s author were statistically significantly related to the likelihood of being retweeted by others. Additionally, tweets containing more positive emotions and fewer tentative words were also statistically more likely to be retweeted. Interestingly, the authors emphasize that social media users are both creators and receivers of content, which has implications for professionals who hope to use social media as part of a communications campaign.

Myrick, Holton, Himelboim and Love (2016) examined how social support (defined in their article as informational and emotional support) is expressed and received on Twitter. They conducted a content analysis of all public tweets using the hashtag #StupidCancer over two years, then categorized tweets in several different ways as a means of understanding the messages. Their analysis found that the majority (66%) of tweets offered informational support, while asking for information and offering emotional support were a moderate portion of the tweets (12% each) and asking for emotional support was very small (less than 5%). They claim their findings support the growing body of literature that demonstrates how emotions affect communication-related outcomes in that tweets including negative emotional expressions (such as anger and sadness) were less likely to be retweeted. Other features of tweets less likely to be retweeted included those containing detailed information, religious references, and expressing empathy. The authors point out two important factors that have not been highlighted in other papers. First, they stress the importance of recognizing how the unique features of Twitter (or other SNS technology) ought to be incorporated in analyses of how social support is exchanged on the tool, citing the unique elements of tweets (the character limit, use of hashtags, reliance on links) and the exposure of use (the public exposure of tweets, ability to interact with any other user in the system). Second, they encourage other researchers to re-conceptualize social support from SNS as “an active, dynamic process that involves asking for support” (Myrick et al., 2016) as users are not simply passive recipients.

Crannell et al. (2016) analyzed a massive dataset of tweets (n=186,406) to investigate correlations between types of cancer diagnoses in users’ profiles and hedonometric analysis of these tweets as a proxy measure for happiness. Their analyses found correlation between highest
measures of happiness (as measured by a quantitative hedonometric analysis using the Language Assessment by Mechanical Turk [LabMT] word list) in tweets with thyroid, breast and lymphoma patients and lowest measures of happiness in pancreatic, lung, and kidney cancer patients. When compared to happiness measures in a control group (time-matched users who were not cancer patients), the average happiness measure of all cancer patients was higher than non-cancer patients. The authors did not include any calculations or comment regarding the statistical significance of the differences in scores between the different groups, so it is difficult to judge the impact of their findings.

Sutton et al. (2017) scraped all public tweets with keywords related to cancer over the course of one week, beginning on September 30, 2016, then narrowed their dataset to those tweets about lung cancer. They coded a random sample of the lung cancer tweets to determine each tweet’s position in the cancer continuum, the structure of the tweet, and to categorize the Twitter user type (individuals, media, or organizations). The authors found that nearly a third (32%) of tweets related to lung cancer treatment, nearly a quarter (23%) related to lung cancer awareness, while other aspects of the cancer continuum were less prevalent (end of life, 16%; prevention and risk, 13%; diagnosis, 6%; early detection, 3%; survivorship, 1%) with another 8% unable to determine the cancer continuum. Users categorized as ‘Individuals’ posted more tweets about lung cancer awareness, prevention and risk, and end-of-life, and fewer tweets about treatment and early detection than those users deemed to be ‘Media’, ‘Organizational’, or ‘Unknown’.

Taylor and Pagliari (2018) studied the final 6 months of tweets written by a terminal cancer patient and determined the digital narrative created by the user mapped onto Reed and Corner’s Cancer Illness Trajectory Phases (2013) and Emanuel and Emanuel’s ‘Framework For a Good Death’ (1998). They also found that the user used Twitter for emotion-focused coping rather than for problem-oriented coping (such as seeking practical advice and solving problems) but suggest this was related to the patient’s professional training as a geriatrician. The authors also suggest that patients share their experiences online as a means of therapeutic coping and to get support from a wider group of people, beyond their friends and family members.
2.3.3 Critical Review

While the literature has explored a range of aspects of Twitter use within cancer, Myrick et al. (2016) point out that previous literature is limited because it fails to consider the unique features of Twitter when conducting their analyses (for the purposes of their manuscript, they largely centre their discussion of Twitter’s uniqueness to the use of hashtags, short-form messages, and the public exposure of posts). What activities take place online and what these spaces become are shaped by what the technology allows (boyd, 2010:39; Hallett & Barber, 2014). Analyses of how the technological affordances of Twitter impact use have largely been missing from the literature on Twitter use among cancer patients.

Further insight into Twitter’s use could also be gained by inviting Twitter users to comment on their use. Apart from Attai et al. (2016), the literature has yet to do so. The underlying assumption behind most of these studies is that cancer patients use Twitter primarily to solve two problems: 1) to access health information, and 2) to obtain health-related support. It is well known that cancer patients report greater satisfaction and perceived psychological benefits when given adequate health information (see for example: Jefford & Tattersall, 2002; Rutten, Arora, Bakos, Aziz & Rowland, 2005; Husson, Mols & van de Poll-Franse, 2010) and when they feel supported by peers (see for example: Ussher, Kirsten, Butow & Sandoval, 2006; Gottlieb & Wachala, 2007; Hoey, Ieropoli, White & Jefford, 2008). What is unclear is why certain people choose to use Twitter – an extremely public platform – to obtain health-related support and information. Certainly, support is available through other means, such as peer support groups, group classes, and online forums that may be more suitable because they are intended to support cancer patients. Health information, too, can be found in a multitude of more reliable ways, such as through health professionals, librarians, and Google searches. These goals alone are not enough to explain why patients choose public self-disclosure on Twitter when the same goals can be achieved privately. Sontag’s seminal piece Illness as Metaphor framed a cancer diagnosis as something that was once shameful.
“Since getting cancer can be a scandal that jeopardizes one’s love life, one’s chance of promotion, even one’s job, patients who know what they have tend to be extremely prudish, if not outright secretive, about their disease.” (Sontag, 1990:8)

It is surprising that people would choose such a public platform to openly discuss a potentially stigmatizing illness. So, what else do people living with cancer gain from using Twitter? This question can only be answered by investigating the experiences and perspectives of cancer patients who use Twitter.

2.4 What is Unique about Twitter?

Public-facing social media (like Twitter, YouTube, and blogging) gives users the opportunity to assert their presence and shape how they want to be seen by the general public. Sociologist Murthy (2012) proposes that people use Twitter as a means to say ‘look at me’ or ‘I exist’. With every message posted, users assert their presence while also communicating something about who they are. Twitter is unique among social media platforms because its use is exposed, it has a low barrier to entry, connections are not required to be reciprocal, and individuals can have as much as (or more) influence than public figures or brands. When combined, these features make Twitter stand out from other social media platforms that it is so often grouped with, such as blogging and Facebook.

2.4.1 Exposed through Searchability

Twitter is the most public of all of today’s social media platforms because it is accessible and easily searched. Like YouTube, Instagram, and blogs, you do not need to have an account to view what is posted on Twitter. However, content in social media formats that focus on multimedia content (such as Instagram or YouTube) can only be found using text-based searches that rely on the metadata provided by the creator and not the entirety of the message; you cannot conduct a text-based search to find videos including certain features or subject matter, unless the creator has included a related term in the metadata. Social media formats designed to share text-based content such as blogs can be public and searchable in their entirety, however there is no
central search that indexes all blog posts and Google indexing does not necessarily capture content from all blogs. In contrast, any public tweet is searchable through the Twitter interface or through Google, and tweets are indexed in their entirety due to their text-based nature, throughout the history of Twitter.

2.4.2 Low Barrier to Entry and Use

Twitter also has the lowest barrier to entry for all social media, as no special equipment beyond an Internet connection is needed to participate, unlike video or photo social media sites that require video or photography equipment. Indeed, Twitter was designed to be mobile: when Twitter first launched, one only needed a cell phone to text message tweets to their timeline. The short character limit (140 at the time of this study, later increased to 280 in late 2017) means that, unlike with blogs, users do not feel obligated to write much, if anything at all. Users can retweet messages from other people without ever creating their own message.

2.4.3 Experimental Relationships with Strangers

Twitter does not require relationships to be reciprocal, but rather fosters asymmetrical relationships (Postill & Pink, 2012) and the building of fandoms. I use the term “fandom” to connote asymmetrical connections we typically think of when we think of celebrities and their fans, as an alternative to “reciprocal relationships”, such as those that occur on Facebook, where both parties consent to the connection. By maintaining a public profile, users grant blanket permission for any Twitter user to follow them and any Internet user to read their tweets. This creates a low barrier to connect with someone and encourages users to experiment with following and unfollowing other users based on changing interests without social consequence. Twitter users feel less obligation to follow people they know than on other social media platforms, and instead follow (and unfollow) others based on their interest in what a user shares. Often, this means following strangers with common interests, usually discovered by reading through a hashtag, participating in a tweet chat, seeing a viral tweet, or even conducting a keyword search using the Twitter search interface. Furthermore, the social environment of
Twitter is more complex than the simple Follow/Following relationships as Twitter users are free to interact with any other (public) user on the system and not just those they follow.

2.4.4 Human-Mediated Amplification

Though powerful figures like government leaders and mainstream celebrities have an advantage to increase their fandom because of their notoriety, authority and social position do not necessarily translate into greater influence on social media. Individuals can build a significant fandom through their social media activities alone (Norman, 2012). Apart from the “While you were away” feature\(^2\) and paid advertisement tweets, Twitter does not use a computer algorithm to amplify or increase the reach of different messages\(^3\). Instead, virality on Twitter is human-mediated, meaning that exposure to tweets created by those outside of your connections happens only when someone you follow deems it important enough to share (retweet). Murthy, Gross and Longwell (2011) discovered that the volume of followers within two degrees of a particular user was over 30 million users, or roughly 1/6th of the Twitter network as it existed at the time of their analysis. Tweets written by everyday people can and do get widely shared across the platform on a regular basis.

2.5 Chapter Summary

There are several aspects of Twitter’s use within consumer health that have gone underexplored, largely stemming from the limited methods used to study Twitter and consumer health. First, tweets are often viewed as broadcast messages that are meant to be consumed and not as things that are created in response to, and to encourage, other actions. Second, health research on Twitter is often based on the assumption that patients use Twitter for peer support or to gain information without considering other possible motivators or values in its use. Including user

\(^2\) A feature that highlights a few popular tweets from your connections since your last log in.

\(^3\) This was accurate at the time of the study, but has since changed where Twitter is promoting popular tweets and/or likes from the people you follow.
perspectives in future research would help illuminate other possible factors contributing to its use. Lastly, previous research has not contextualized their findings by discussing how the unique technological affordances of Twitter influence its use. Twitter is unique among social media platforms because its use is exposed, it has a low barrier to entry, connections are not required to be reciprocal, and individuals can have as much as (or more) influence than public figures or brands. The uniqueness of Twitter has largely been ignored when discussing patients’ use of the platform in relation to their health.
Methods
Chapter 3: Study Design

This study aligns with the interpretivist paradigm and uses ethnography as its methodology, as the study aims to explore how individuals make meaning of their Twitter use through naturalistic and grounded methods, as discussed in more detail in the “Paradigm” and “Methodology” sections. While the study does not align with any grand- or mid-range theories, my subjectivity (experiences, knowledge, values, and assumptions) has played an integral role in my approach, and thus I provide a reflexive account of my subjectivity to make these explicit in the “Theoretical Positioning” section. The design of this study was heavily influenced by ethical issues that are unique to conducting observational research on social media, such as the dilemma caused by the ethical principles of “free and informed consent” and “right to anonymity and privacy”. How I negotiated this ethical dilemma is described in the “Overarching Ethical Consideration” section. Definitions of Twitter data vary depending on discipline of the researcher, how one chooses to view tweets, and whether one believes tweets are public and published, private an unpublished, or some combination in between. I provide a discussion on how I defined Twitter data as research material to make explicit how data was conceptualized in this study. I end the chapter by summarizing key thoughts on rigor in qualitative research and describe how I aimed to address procedural rigor by carefully detailing all steps of this study and substantive rigor by making clear how my background and experiences influenced my interpretations.

3.1 Paradigm: Interpretivism

This study is exploratory and focuses on the perspectives of individuals to better understand what it means to identify as someone living with advanced cancer within a public Twitter profile. The focus on individuals and the meanings they make as a means of seeking understanding aligns with the interpretivist paradigm (Scotland, 2012).

Inherent in the interpretivist paradigm is the belief that meaning is constructed through the interaction of consciousness and the world rather than something that exists and can be discovered/uncovered independently, or the epistemology of subjectivism (Scotland, 2012), also
commonly called constructivism (Crotty, 1998:42). Subjectivism views knowledge as culturally derived and historically situated. From the ontological perspective, interpretivism and subjectivism are situated in realism, or the belief that reality is individually constructed and that reality differs from person to person (Scotland, 2012). Interpretivist methodologies are aimed at understanding phenomenon from the individual’s perspective through the co-construction of data by the researcher and the participant, with nuances of the phenomenon being uncovered through thick description (Scotland, 2012). Data collection methods are chosen to guide, not dictate, participants’ responses with the aim of providing insight into behaviour, actions, and perceptions, and analyses are the researcher’s interpretations of these responses (Scotland, 2012).

3.2 Methodology: Ethnography

The methodology used for this study is ethnography. Ethnography is an exploratory methodology that allows the researcher to adapt their methods and the focus of their inquiry while they participate in the culture being studied. In ethnographic research the study design emerges or evolves as the researcher is in the field, and is not typically laid out plainly before the study begins. The purpose of ethnography is to study activities in the contexts where they naturally occur; it is not usually clear what those contexts or activities are without having intimate knowledge of the culture.

Ethnographic research examines the shared beliefs, values, behaviours, and language of a cultural group (Creswell, 2007) by collecting unstructured data from a variety of sources on people’s actions in everyday settings (Hammersley & Atkinson, 2007:3). The ethnographer documents experiences and observations in field notes (Hammersley & Atkinson, 2007:141) and ideas, hunches and impressions in field journals or memos (Hammersley & Atkinson, 2007:150) as, or shortly after, they occur. Interpretation is generated from the data to shed light on the explicit and implicit characteristics that bind or make up a cultural group (Hammersley & Atkinson, 2007:3).

Traditional ethnography takes place in person, but with the emergence of the Internet, ethnographic studies of life online began to emerge in the early 1990s (Boellstorff et al.,
2012:26). Like traditional ethnography, online ethnography also uses a grounded approach, eschewing \textit{a priori} beliefs of what happens within an online social system, to make sense of emerging social practices specific to local contexts (Hine, 2008).

3.2.1 Sampling in Ethnographic Research

Ethnographic research entails sampling different people (informants), time, and contexts within the selected setting (Hammersley & Atkinson, 2007:35). Below I provide an overview of the setting and sampling of informants as it applies to the broader study. Specific details on sampling time and contexts, and further details on sampling informants for each collection method used are described in the Plan of Inquiry chapter.

3.2.1.1 Setting

One must weigh practical considerations when determining which setting is best suited for ethnographic study (Hammersley & Atkinson, 2007:30). My more than 8 years of experience working in various roles within the Cancer Education team at Princess Margaret Cancer Centre means I have familiarity with the medical language and some of the overarching issues people with advanced cancers may face, diminishing some practical issues that may be experienced by individuals without this familiarity. My years of experience as a Twitter user means I am familiar with how the platform works and understand the language informants may use to describe their use. Because I am a long-time user of Twitter, particularly in health and cancer care, I have established rapport with some influential Twitter users within cancer groups. As such, this rapport may increase the level of trust and credibility potential informants perceive in me.

3.2.1.2 Informants

As my interest lies in understanding the experience of people living with advanced cancer, informants were limited to those who were directly impacted. While there are other individuals who use Twitter in the context of advanced cancer (for example, families, caregivers, friends), this study focuses only on those affected. Informants were also limited to those who could speak and read English and who had a Twitter profile.
3.3 Theoretical Positioning & Reflexivity

Because this is an exploratory study on a topic that has not been previously studied, the study design does not align with any grand- or mid-range theory (Boellstorff et al., 2012:46; Carter & Little, 2007) but does apply relevant theories inductively in the analysis. However, theory plays a role in any and all parts of research, whether central or peripheral to the phenomenon under study (Sandelowski, 1993b). The ontological and epistemological orientations and disciplinary perspectives of the researcher influence the research question and study design, whether or not they are acknowledged by the researcher (Sandelowski, 1993b).

Unlike quantitative methods, qualitative research relies on the observations made and noted by the researcher, placing the researcher at the centre of all stages of the study (Brodsky, 2008). Reflexivity “is a process that challenges the researcher to explicitly examine how his or her research agenda and assumptions, subject location(s), personal beliefs, and emotions enter into their research” (Hsiung, 2008). Practicing reflexivity ensures a researcher’s values are made explicit throughout their work (Bryman, Teevan & Bell, 2012:96) to reflect on how their perspectives may influence interpretation and line of inquiry (Mays & Pope, 2000).

Some academics consider the researcher’s subjectivity as something to be questioned, bracketed out, or checked against, framing it as a bias inherent in the research that is somehow meant to be overcome (see for example: Hsiung, 2008; Lichterman, 2017). Other academics, such as Eakin and Mykhalovskiy (2003), Brodsky (2008), and Sandelowski (1993b), counter that thinking by framing the researcher’s subjectivity and (experiential) knowledge as assets to be embraced throughout the research process. The knowledge a researcher brings into their studies is crucial for readers to understand the process taken and the substance of the writing (Eakin & Mykhalovskiy, 2003). Brodsky (2008) further clarifies that the researcher’s subjectivity is what inevitably leads to a narrowing the research focus when conducting research that involves rich data.

I now turn to a brief discussion of my subjectivity as a means of acknowledging and introducing how my experiences and values have influenced this study.
3.3.1 My Background

Online social spaces have played an important role in my life since I was a pre-teen. Growing up in a remote and rural town, I relied on Internet chatrooms and forums to meet others from around the globe who shared common interests. Throughout the years my interests and choice of platform has evolved. Roughly 8 years ago, I signed up for Twitter and have since become a daily user.

In July 2011, Health Care Social Media Canada (#hcsmca) founder Colleen Young invited me to join her Twitter community upon learning that I was managing a health organization’s Twitter profile. In joining the #hcsmca I began to see how Twitter could be used as a professional development tool by connecting with like-minded people. Participating in chats introduced me to new perspectives and contacts from around the world that I would not have had access to otherwise. Through this experience I began to understand that viewing Twitter simply to broadcast my ideas prevented me from actualizing the networking benefits and development opportunities of the platform.

My interest in studying people living with advanced cancer stems from a life-long interest in health and medicine that has recently focused on end-of-life issues. Upon taking an introductory anthropology course in my undergraduate studies, my interests shifted away from biomedicine to medical anthropology. Unbeknownst to me at the time, I chose to shift to medical anthropology because it aligned with my worldview as a constructivist rather than the positivist worldview inherent in biomedicine (a fact I did not uncover until I had taken an introduction to qualitative research course). Since the winter of 2010, I have worked at Princess Margaret Cancer Centre, first in Patient Education and eventually moving to the Web & Digital Innovation team. In my 8 years of working in cancer care, I’ve come to be familiar with some of the issues cancer patients face.

As an active Twitter user who works at a cancer centre, I have some connection to Twitter communities and users who actively participate in cancer-related discussions. I have mutual “following” connections to some cancer patients who are well-known among cancer patients and
have some notoriety as cancer patient advocates, which may have given me some credibility in the eyes of cancer patients whom I do not know. I do not actively participate in cancer-related health chats, nor do I regularly tweet about cancer. Here highlights what separates me as the researcher from the informants I am studying. While I may be an “insider” in my Twitter use, I am not living with advanced cancer and only am familiar with the experience through listening to the stories of those who have chosen to share and reading published literature.

While my life-long experiences and interests have certainly led me to studying Twitter use among those living with advanced cancer, the crux for this project stemmed from meeting Alicia, a woman a few years my senior who had advanced stage ovarian cancer. Alicia had attended an event hosted by my department and blogged about the experience. I saw the blog post circulating on Twitter and was curious what it said. It was far from a glowing review. Reading her blog post was an important moment for me as it forced me to see how society ignores people living with terminal illness because it makes us uncomfortable. I immediately began following Alicia on Twitter.

Alicia was a professional writer and a talented story-teller, and it showed through her tweets. Between sharing her experiences of nausea, reactions to new treatments, and the grief she felt in facing her own mortality, she would live-tweet her impressions while reading the entire “Little House” series, promote her latest publication or event, or post photos of her four-legged companions. I had lost loved ones to cancer before but the experience of living with advanced cancer had always been a mystery to me. Reading Alicia’s tweets was the first time I saw the difficulty and complexity of side effects and psychological experiences one could go through while otherwise trying to maintain a “normal” life.

When I started following Alicia, she knew that short of a miracle, she would not be cured and was on treatment to extend and improve her quality of life. Nearly two and a half years later, those life-extending treatments had run out. On her blog (which she promoted on Twitter) she shared that her oncologist had given her 6 months to live. In the months leading up to this announcement, her blog posts and tweets had become meager. It was clear that her health was
deteriorating and had been for some time. Just forty-three days after her announcement, she died in hospital.

I had never met Alicia ‘in real life’, though I’m sure our paths had crossed many times. We had had some brief, passing conversations on Twitter, but I would not call her a friend. Yet her life and death impacted me in ways I did not anticipate. I was working on my initial Twitter and consumer health literature review when I saw a mutual Twitter connection tweet that Alicia had died. It was the evening before my 30th birthday, and I had been taking time off work to make progress on an end-of-term assignment. At the time I had already planned to study Twitter use in cancer as my thesis project, but her death prompted me to shift my focus to a topic that felt more meaningful: to leverage my privilege as a health services researcher to amplify the voices of those who often get ignored. In a way, this research study is part of her legacy.

### 3.3.2 My Assumptions

Because of my experience using Twitter in a health and medical setting and my position working in patient-centred services at a cancer centre, I began this study with certain expectations or assumptions about informants’ experiences. Below I describe my assumptions that influenced the study design. I discuss my assumptions about what I would find in the Challenged Assumptions section of Chapter 7.

Prior to beginning this study, I expected to find that informants used Twitter as a type of ritual (a repetitive behaviour without a direct overt technical effect; Helman, 2000:156) aimed at ‘healing’, as conceptualized by Kleinman (1973) as illness made meaningful, personal suffering is shared, and the individual is reincorporated into the social body. Early in the analysis phase, I set these notions of ritual and healing aside as they hindered my ability to immerse myself in the data and see the depth within it.

For the tweet extracts, I assumed Twitter use could be seen based on tweeting, retweeting, and liking activity. There are important Twitter activities one can also do that are less visible or invisible to an outsider such as following and unfollowing, exploring through search and clicking
hashtags, sending direct messages, and simply consuming tweets without contributing, however these actions were not possible to observe. Since the focus of this research is on exploring public use of Twitter, I felt it was not necessary to include these actions in the analysis beyond what details were shared during informant interviews.

I assumed that users made an active/conscious decision to “go public” with their cancer diagnosis on Twitter, as it would be unlikely that one would be coerced or forced to reveal such information against their will. Similarly, I assumed their continued use of Twitter indicated that they viewed Twitter as a positive or productive space for themselves as it would be unlikely for a user to continue voluntary use if their experiences were largely negative or not valuable.

3.4 Overarching Ethical Considerations

Ethical research is about respect for persons, justice, and beneficence (Markham, Buchanan & AoIR Ethics Working Committee, 2012). Ethics shape the design of all research studies to some extent; however, there are special considerations that affect social media and other online research. In the digital world, it is of utmost importance to recognize that all digital data is a product of human creation (Markham et al., 2012; Rooke, 2013), and thus, it is important to maintain the security of research subjects (Rooke, 2013). In an environment like Twitter where personal data is archived and searchable by the general public, how exactly is that done in practice?

Without having a solid understanding of how potential informants use Twitter (a goal of this research study is to provide some insight on this), it is difficult to know how to navigate the ethical issues that have come up. The ethical principles of “free and informed consent” and “right to anonymity and privacy” are in direct conflict when conducting typical ethnographic research on Twitter. By broadly disclosing your intent as an ethnographer, you are also disclosing the identities of those who were under study. On the other hand, using covert means to conduct ethnographic research could be considered deceptive and does not give participants the opportunity to opt-out of being studied. As a best course of action, I explored the related
literature to become aware of all the possible considerations, then weighed out the best options for the research that protected the informants and maintained the integrity of the data.

Below I detail the broad ethical issues that impacted the study design. Ethical considerations that impacted specific methods or steps are discussed as they arose in the Methods section. For ease of readability, the overarching ethical considerations are discussed beginning with data collection, then data storage, and ending with data reporting. Note, however, that these issues did not necessarily arise in such a linear fashion.

3.4.1 Data Collection

In ethnographic research, it is expected that data collection begins with a wide topic of interest and becomes refined as the ethnographer reflects on the data collected (Hammersley & Atkinson, 2007:3-4). As this study aimed to build contextual understanding of Twitter use in health care, the methods outlined below are less structured than in experimental or evaluative designs (Maxwell, 2013:88). The study design was emergent as there are no previous studies within academic literature that have explored the topic and I was not sure what I would find.

A common method used in ethnographic studies is participant observation, which entails “behaving as” informants in the study (Spradley, 1980:59). According to the University of Toronto Social Sciences and Humanities Research Ethics Board’s Guidelines for Ethical Conduct in Participant Observation (n.d.), a researcher using participant observation is to “disclose and disseminate as broadly as possible through general announcements or other more informal means the researcher’s purpose, research topic, and data gathering method” as part of the ongoing informed consent process.

While this approach may be appropriate for traditional, in-person settings, it creates an ethical dilemma in online social spaces. The Guidelines for Ethical Conduct in Participant Observation (University of Toronto Social Sciences and Humanities Research Ethics Board, n.d.) also stress the importance of taking extreme care to maintain confidentiality of the information gathered as part of the research. Twitter made all public tweets since the platform's inception available in their search and Google is including tweets in search results (“Tweets take flight in the Google
app”, 2015). Disclosure of researcher's participation and maintaining the confidentiality of information are mutually exclusive when the research setting is archived, searchable, and public. The simple act of identifying oneself as an ethnographer interested in an area of study will forever be retrievable, thus eliminating any possibility of protecting the data collected.

To find balance between the ethical issues involved in this study, I used passive participant observation to collect data from Twitter (Spradley, 1980:59-60) with the purpose of describing Twitter activity and behaviours. I also recruited informants to participate in semi-structured interviews with the purpose of understanding their perspectives about their use. Viewing Twitter use from multiple perspectives allowed me to explore different aspects of Twitter use among those living with advanced cancer (Maxwell, 2013:102) and compare observed activities to the interpretations of the informants (Boellstorff et al., 2012:170-171). For ease of readability, the process for each method is discussed separately in the Plan of Inquiry chapter.

### 3.4.2 Data Storing

All collected data and subsequent analytic documentation were stored in an encrypted folder that was only decrypted when in use (University of Toronto, 2008). Data were backed-up daily onto an encrypted external hard drive.

Data collected in this study were encrypted and will be stored for 5 years following the termination of this REB application. Upon completion of data analysis and the final thesis manuscript, data were archived onto an encrypted DVD that were kept in a locked cabinet. All digital files on the computer hard drive were deleted and the external hard drive was formatted. When 5 years have passed from the date of REB termination, the DVD will be destroyed by a DVD shredder.

### 3.4.3 Data Reporting

In constructing reports resulting from data collected in this study, I have taken care to minimize risk of identifying informants. Today’s search engines make it incredibly easy for the average person to retrieve digital information (Shklovski & Vertesi, 2013). Although only some of the
data collected in this study was retrieved through a digital search (the tweet extracts), unique identifiers from the interview data may be combined with the context of this study and Twitter or other public data, and lead back to the informant (Elgesem, 2002; Zimmer, 2010; Shklovski & Vertesi, 2013). “Anonymization relies… on limiting the number of unique features specific to the people or context in question” (Shklovski & Vertesi, 2013). It is the researcher’s responsibility to ensure informant’s identities continue to remain protected following the publication of the research study, even if it restricts the study’s impact within the larger academic field (Shklovski & Vertesi, 2013). Therefore, I took extra care to remove potentially identifying details from quotes used in the Findings chapter, as described in detail in the Interview section of the Plan of Inquiry chapter.

3.5 Defining Twitter Data as Research Material

In addition to the ethical issues described above, it is necessary to discuss what Twitter data is when using Twitter as a research site. Below I discuss specific questions that have defined how Twitter is conceptualized in this study: 1) what Twitter represents as a setting, 2) what the Twitter profile represents in relation to the person creating it, and 3) what tweets represent as research materials. How one answers these questions impacts further decisions about the study design. I discuss my conceptualizations below.

3.5.1 What is Twitter as a Research Setting?

In defining Twitter as a research setting, questions about where Twitter data falls in the public/private and published/unpublished dichotomies (Hudson & Bruckman, 2004) impact how one approaches data collection and data reporting. Twitter’s Terms of Service (n.d.) clearly state that the content shared is the intellectual property of the user, however the platform exists to help “publish” this information:

“You understand that your Content may be syndicated, broadcast, distributed, or published by our partners. […] We encourage and permit broad re-use of Content on the Twitter Services. The Tweet API exists to enable this.” (“Terms of Service”, n.d.)
While any tweet posted from a public profile is technically (and legally) public, when conducting qualitative research, it is important to respect users’ expectations of privacy, regardless of the legal or technical situation (McKee, 2013; Boellstorff et al., 2012:135). It is unclear if users understand all the implications of sharing a tweet on a public Twitter profile. For example, while tweets containing hashtags may be understood as public – the intent of using a hashtag is to index the topic of the tweet so other users can find it – replies (tweets beginning with “@username”) are only displayed in the feeds of the author, the recipient, and any other Twitter user who follows both profiles. Twitter users may feel a normative sense of privacy, that is, privacy protected by social norms rather than by restricting access, when sending replies because they may believe only the recipient and any mutual followers (a small subset of users) will see the tweet. Additionally, Twitter users with few followers may also feel a normative sense of privacy because of their low number of followers.

For the purposes of this study, I consider all tweets that are not replies to be considered published and public. While ‘reply’ tweets are technically public, I only saw those replies where I followed both the sender and the recipient, and not those sent to or received by others not on my lists. Including those I could see would be unbalanced both in terms of privacy and data quality.

3.5.2 What is the Twitter Profile?

Depending on the theoretic orientation of the research, the Twitter profile can be conceptualized in different ways. For example, the Twitter profile can be considered an online representation of the ‘person’, a cultural production created by an ‘amateur artist’, or an open source database for mining answers to research questions (Heilferty, 2011). In Heilferty’s review (2011), they found most health care research views social media data as an extension of self, or human subject’s research. When focusing solely on Twitter, most research that has been published at the time of writing this chapter view Twitter as an open source database, as evident by the extensive amount of studies running content and sentiment analyses on data extracted from Twitter via keyword searches (see for example: Cavazos-Rehg et al., 2014; Hanson, Burton, et al., 2013; Sugawara et al., 2012; Tsuya et al., 2014). The notion of Twitter activity as an artistic presentation does not appear to be represented in the health-related literature.
In this study, I consider the Twitter profile to be an artistic representation of self as users can freely emphasize certain characteristics while concealing others (Heilferty, 2011). The Twitter profile is crafted in such a way that users only need to provide what information they choose rather than being wholly representative of the person behind the screen. Conceptualizing the Twitter profile as an artistic representation of self aligns with Boellstorff’s (2012) belief that social media messages are an index (“point back to”) of the human behind the screen. Further, I consider tweets to be ‘textual selfies’. Selfies are informal, in-the-moment snapshots that represent current-version of self, which stands in contrast to self-portraits that are enduring projections of who we are (Fausing, 2013). To expand on this analogy, if a tweet is analogous to a selfie, then a written biography is analogous to a self-portrait. For the purposes of this study, I consider the Twitter profile to be comprised of a series of textual selfies.

3.5.3 What are Tweets as Research Materials?

Data extracted from social media can be conceived in different ways such as narratives, observational data, or documents. Though the tweets were extracted within a chronological framework, the aim of this study was not narrative in nature (to examine how people tell stories [Bernard, 2000:441] or to capture shared details of a lived experience [Creswell, 2007:55]). Neither was I observing Twitter activities in the sense one would normally use the term, as I was downloading and reviewing data outside the Twitter interface at a later time. Instead, I conceptualized the tweets collected in this study as documents. Documents serve as both containers of content and active agents that have use and function (Prior, 2012). Documents are routinely created in response or in reference to other documents, a concept called ‘intertextuality’, with the intention of influencing future actions (Bazerman, 2004). Twitter use relies heavily on intertextuality through its functions such as retweeting, replying, and embedding hyperlinks. Conceptualizing tweets as documents allows for considering why the tweet was created, what it is in response to, and what action it provokes in addition to examining the content contained within them.
3.6 Rigor and Research Quality

Criteria for assessing qualitative studies such as ethnography differ from those used in quantitative research. There is some contention within qualitative research practices as to what quality qualitative research looks like. For example, notable research methodologists Lincoln and Guba (1985) posit that qualitative research be assessed by the criteria of 1) credibility, 2) transferability, 3) dependability, and 4) confirmability. Dixon-Woods, Shaw, Agarwal & Smith (2004) recognize that there are universal prompts to help assess qualitative research, such as: Are the research questions clear? Are the research questions suited to qualitative inquiry? Are sampling, data collection, and analysis methods clearly described? Are sampling, data collection, and analysis methods appropriate to the research question? Are the claims made supported by sufficient evidence? Are the data, interpretations, and conclusions clearly integrated? Does the paper make a useful contribution? They note, however, that the combination of methodologies to methods possible in qualitative research means that there are specific questions that can be asked of some research studies that would not be appropriate for others (Dixon-Woods et al., 2004). Rudestam and Newton (2007) suggest attending to reliability (replicability of study under similar circumstances), internal validity (how well do the constructions match what the participants said), and external validity (providing a thick description that allows for transferability to other settings).

In constructivist or interpretive qualitative research, however, it is assumed that there are multiple realities that are made meaningful by individual experience, and thus assessing research through a set of guidelines is not faithful to the spirit of qualitative work (Sandelowski, 1993a). Eakin and Mykhalovskiy point out that gauging the quality of a qualitative study based on meeting certain “rules and procedures of analytic technique is not very productive because there is no direct relationship between specific techniques and specific analytic outcomes” (2003:191). They argue that rather than gauging the quality of qualitative research by focusing on the procedural appropriateness, readers use a substantive approach instead. A substantive approach places less emphasis on the ‘appropriateness’ of methods used and instead uses procedural information provided to understand the position and process the researcher took in their analysis,
as a way of orienting themselves to the research question and the author’s interpretations (Eakin & Mykhalovskiy, 2003). While it is important that the epistemology, theoretical perspectives, methodology, and methods all make sense together and suit the research question, it is also important that the researcher re-presents their interpretations in a way that enhances the readers’ knowledge and understanding of the phenomenon under study (Sandelowski, 1993a; Eakin & Mykhalovskiy, 2003).

Throughout this study I have been mindful of procedural rigor as explained by Dixon-Woods et al. (2004) and Rudestam and Newton (2007), and substantive rigor emphasized by Eakin and Mykhalovskiy (2003). To address procedural rigour, I have carefully detailed the process taken to conduct this research, repeatedly judged my interpretations against the data collected from informants to ensure the findings were grounded in the data and took care to provide enough context surrounding the findings to make meaningful conclusions. To address substantive rigour, I have provided a brief introduction to my subjectivity (see Theoretical Positioning & Reflexivity), I have positioned myself as an integral part in all stages of this research, and I have included the informants’ voices in a way that authentically conveys and represents their experiences and feelings.

3.7 Chapter Summary

This study is an ethnography, rooted in an interpretivist paradigm, that explores use of Twitter among those living with advanced cancer. My subjectivity as an active Twitter user, professional experience in cancer education, and a witness of Twitter use at end-of-life bring some familiarity with the social environment (and possibly some credibility with potential informants), though I remain an outside observer as I do not truly know the experience of living with advanced cancer. As a means of balancing ethical concerns around conducting observational research on Twitter, I did not use the typical participant observation method common in ethnographic research, and instead extracted tweets and interviewed informants to collect data (details of these methods are described in the next chapter). I define Twitter as a public and published setting where profiles are an artistic representation of the person behind the screen and Twitter timelines are living
documents in which a user actively writes new history in response to, and to influence future, actions. I aimed to address procedural rigor by carefully detailing all steps of this study and substantive rigor by making clear how my background and experiences influenced my interpretations.
Chapter 4: Plan of Inquiry

This study used two methods of data collection as a means of understanding different aspects of Twitter use: tweet extracts were used to describe public activities and behaviours while informant interviews were used to understand informants’ perspectives. For ease of readability, each method of data collection is discussed separately. The Data Analysis section details how the two datasets were brought together to form the analysis.

4.1 Method 1: Tweet Extracts

Tweet extractions were used to describe the public activity and behaviours of people living with advanced cancers. Below I describe the data collection methods, sampling procedure, and ethical considerations for the tweet extraction portion of this study.

4.1.1 Collection Methods

4.1.1.1 Document Boundaries

The boundaries for tweet extractions were based on those used for document analysis as outlined in Kuper, Whitehead and Hodges (2013).

Authors: Authors were Twitter users who publicly identify as living with advanced cancer, with a public Twitter profile, who primarily tweeted in English. Twitter profiles that appeared to represent brands (such as organizations, governments, businesses), memorials (accounts that are run in memory of someone who has died of cancer), or children (accounts that are run by adults on behalf of children living with cancer) were not be included in this study. Further, while it may be possible to identify informants based on Twitter actions (for example, Chretien, Tuck, Simon, Singh and Kind’s [2015] Twitter ethnography on medical education students used ‘chain sampling’ of informants’ contacts to identify other potential informants), using screening methods that may infer a health condition diagnosis upon a user increases the potential harm to
informants should their anonymity become compromised. Only those users who explicitly stated they were living with advanced cancer were included in this analysis.

Authors for tweet extracts were identified by searching the biographies of public Twitter profiles for keywords related to advanced cancer, such as “metastatic cancer”, “stage IV/4 cancer”, “incurable cancer”, and “#metsMonday” (see Appendix A: Search Strategy for Tweet Extract Authors for the detailed search strategy). Upon confirming a Twitter user met inclusion criteria for the study, they were added to a private Twitter list, visible only to me. The rationale for using a private list is discussed in greater detail in the Protecting Identities section later on in this chapter.

Note that for ease of distinguishing types of informants, I use the phrase ‘tweet authors’ throughout when describing informants who were included in the dataset through the tweet extraction process.

**Time:** Extraction of tweets began on September 9, 2015 and ended on January 8, 2016 for a total span of 4 months. In general, a researcher’s aim is to observe the fullest and most representative range of scenarios possible (Hammersley & Atkinson, 2007:37). These 4 months were selected to obtain data during popular and pertinent cancer awareness months – October is National Breast Cancer Awareness Month, and November is both Lung and Pancreatic Cancer Awareness Months (“Cancer Awareness Calendar 2015”, n.d.) – as well as less active months of September, December and part of January to ensure some temporal variation.

**Genre:** The genre of documents included in this study were messages posted on Twitter. It is common for tweets to include links to external websites that contain additional information relevant to the tweet. These pages were looked at to help contextualize the tweet, but an in-depth analysis of these documents did not take place as the focus of this study was on Twitter use.

The Twitter platform allows users to produce different types of texts that are used in a variety of social contexts. Known types of texts include original tweets, retweets, replies (tweets beginning with a “@username”), mentions (where a user includes another user’s Twitter handle in a post), or tweet chats (a predetermined time and day when multiple Twitter users log on and tweet about
a particular topic, usually using a hashtag to aggregate the conversation). These types of texts and any others that emerge through the tweet extractions were included in the study, with the exception of replies. Replies were not included in the study because the only replies captured in the tweet extracts were those where both the sender and recipient were tweet authors in this study; I felt it best to remove these tweets from the dataset as they would not be visible to me in other circumstances. Further rationale for not including replies is in What is Twitter as a Research Setting? in Chapter 3.

**Intended Audience:** It is unclear who the intended (real and imagined) audiences are for any tweet. Functionally speaking, public tweets are accessible and discoverable by any Internet user as tweets are indexed in Google, the world’s most popular search engine. Certainly, some Twitter users tweet knowing their posts can be found broadly. Most likely, most Twitter users tweet with an intended audience in mind that may be determined by the context and the content of the tweet. For example, tweets containing hashtags are likely viewed as having an audience that extends to any Twitter user who is interested in the hashtag topic. Tweets that are replies (begin with `@username`) are likely viewed as having a much narrower audience: the sender, recipient, and anyone who follows both profiles. As noted in the Genre section, I removed all reply tweets from the dataset before analysis.

### 4.1.2 Extraction & Data Cleaning Process

Each day throughout the study period, tweets published by authors were extracted using NVivo’s NCapture extension for Google Chrome. NCapture files were imported into an NVivo project file to merge the data from all export files into one database.

NCapture extracted many facets of each tweet: the unique tweet ID assigned by Twitter; the username of the original author, text, and publishing time (year, month, day, hour, minute and second) of the original tweet; the tweet type (if it was an original tweet or a retweet); the username of the retweeter; a count of how many times the tweet was retweeted; all hashtags and usernames included in the tweet; the name, location, website URL, and biography provided in the original author’s profile; the number of tweets, followers and followings of the original
author; and the location coordinates of where the tweet was sent, if geolocation services were activated. NVivo’s output of these details proved difficult to manipulate during analysis. For example, duplicate tweets could not be removed from the dataset and numbers (such as the ‘date’ and ‘number of retweets’) were not computed as values and thus could not be sorted in a meaningful way. The table of tweet extracts was exported to Excel to allow for data manipulation. Additional columns were added to aid with sorting and filtering, and data were removed where tweets were duplicate or authors were not eligible for inclusion (either the author was included in error or they had changed their status partway through the study so they no longer met inclusion criteria). See Appendix B: Tweet Extracts Data Cleaning for a summary of all steps taken to clean the tweet extracts data. Following data cleaning, the data tables were re-imported into NVivo for coding.

4.1.3 Ethical Considerations

4.1.3.1 Protecting Identities

Ensuring informants remain anonymous is a fundamental right of research participants (McKee, 2013). On Twitter, you can see who any public profile follows or who follows them: if I followed authors included in this study it would put informants' identities at risk of exposure. To obscure identification of authors under observation, I instead used a privately-managed list that was only accessible through my personal Twitter account. Private lists are not visible to the public, nor can the individual user determine who has put them on what list. In case my Twitter account became compromised during the data collection period, I concealed the list name by matching naming conventions I already used that did not immediately disclose the purpose of the list. When the tweet extraction period ended, I deleted the list.

4.1.3.2 Informed Consent

While observation without participation is better justified from an ethics perspective, naturalistic observation of Twitter is not without problems. Complete overt observation within Twitter presents the same ethical dilemma as participant observation. One alternative option is to collect
informed consent through private means but observe publicly available actions. Chretien et al. did this in their ethnography of medical education students (2015), though previous research on chat rooms and consent suggests asking for opt-in/opt-out may not be viable for situations where potential informants do not support the presence of the researcher (Hudson & Bruckman, 2004). It was unclear how tweet authors would respond to being studied in this study.

Other studies have forgone informed consent entirely and conducted their research covertly, for example the numerous studies that have conducted content analysis of keyword searches on publicly-available Twitter data (see for example: Cavazos-Rehg et al., 2014; Hanson, Burton, et al., 2013; Sugawara et al., 2012; Tsuya et al., 2014). Criticisms of conducting covert research on online social spaces (also called ‘lurking’) are that it serves a personal purpose, does not benefit the users or user group, and can be interpreted as voyeurism (Eysenbach & Till, 2001; Elgesem, 2002; Heilferty, 2011). This ‘harvesting’ of information can be considered opportunistic particularly because users did not generate information for the purposes of being studied, even though the information was intentionally made public by the user (Heilferty, 2011; McKee 2013; Moreno, Fost & Christakis, 2008).

I recognize that there is merit to this argument when discussing online social spaces as a whole. As I have described in the “Defining Twitter Data” section in the previous chapter, public non-reply tweets are published and public, meaning informed consent is not necessary to study these materials. As per Article 2.1(c) in the University of Toronto’s Guidelines & Practices Manual for Research Involving Human Subjects (2007) and the Tri-Council Policy Statement (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010:37), the research involves no more than minimal risk to subjects, waiving informed consent is unlikely to adversely affect the rights and welfare of the subjects, the research could not practicably be carried out if a waiver was required, and the research study does not involve a therapeutic intervention.

4.1.3.3 Data Storage

While informed consent is not necessary, it is important to maintain responsible use of data extracted. In using NVivo’s NCapture software, personal details (such as name, geographic
location, and geographic coordinates, when included with a tweet) were captured with the tweet extracts automatically. In traditional research environments, all identifying information collected during observational research would be coded, with the key stored in a separate file (University of Toronto, 2008). Given that conducting a keyword search of a partial tweet will retrieve the original post, it is impossible to remove all identifying information from the data collected through Twitter. Instead, all data exported from Twitter were stored in an encrypted folder that was only be decrypted when in use (University of Toronto, 2008).

4.1.3.4 Data Reporting

Ethical considerations for reporting online data need to consider not only what data is currently available, but also what data could become available as the software and/or technology evolves. For example, early Twitter studies that have published direct quotes without collecting informed consent had obscured the users Twitter handle to protect their identity; however, Twitter’s announcement that all public tweets are searchable through Google’s mobile and desktop search (“Tweets take flight in the Google app”, 2015) means that these users can now be easily identified. It is impossible for a researcher to predict future features of the technology or software used in their study, however, when studying online data without informed consent it is important to consider how data is linked to individual users and limit how that data is shared in final reports. In the Findings section of this thesis, tweet extracts were only included to demonstrate concepts that could not be demonstrated with interview quotes. These tweets were only included if they were still publicly available at the time of writing this manuscript (for example, the author did not delete the tweet or their account, or they did not make their profile private).

4.2 Method 2: Interviews

Semi-structured interviews were used to better understand the perspectives of those living with advanced cancers who publicly disclosed their health status on Twitter. Below I describe the recruitment procedure, data collection methods, and ethical considerations for the interview portion of this study.
4.2.1 Recruitment

As this study aims to recruit people who use Twitter for health it is appropriate to use online methods to recruit participants. Unlike traditional methods of recruitment (such as posters, approaching individuals in clinics, etc.), online recruitment leaves a trail of data that is accessible to third parties that the end user may not be aware they are leaving (Curtis, 2014; Bender, Cyr, Arbuckle & Ferris, 2017). Cookies are used to track user activity across the Internet, then this data is aggregated into a profile and the data sold to third parties (Curtis 2014). While it is impossible to prevent recruitment actions from being tracked, one can prevent these trackers from collecting personal and sensitive information about a user through the careful use of language in recruitment materials, namely using language that does not immediately disclose personal information that could be stigmatizing (Bender et al., 2017).

I initially attempted to recruit participants through broadcasting on Twitter. Despite receiving a lot of attention, this strategy proved unsuccessful. Instead, using a personal approach by sending targeted invitations and simplifying the informed consent process resulted in an effective recruitment strategy. Below I discuss the strategies I tried and comment on their success.

4.2.1.1 Initial Recruitment Strategy

My initial recruitment strategy followed closely the recruitment strategy used by Bender et al. (2017) that was designed in consultation with the University Health Network’s Research Ethics Board. I published a recruitment blog post and posted carefully worded tweets that were crafted to gain interest from a broad range of Twitter users. I used messages that attracted a broad audience for two reasons: first, to increase the reach of the blog post (I asked those who visited the blog post to share the post with their Twitter followers, a strategy that had worked well for O’Connor, Jackson, Goldsmith and Skirton’s online survey [2014]); and second, to prevent third-parties from inferring personal health information about those users who clicked the link as I was intending to interview Twitter users who met the inclusion criteria who may not have publicly disclosed their health status. I also appended health care-related hashtags to the end of tweets to increase visibility within Twitter communities. Blog comments had to be manually approved by
me before being published in response to the blog post to prevent the inadvertent disclosure of health information by a commenter. This recruitment process was approved by the University of Toronto Research Ethics Board in August, 2015. See Appendix D: Recruitment Blog Post for the blog post, Appendix E: Sample Recruitment Tweets for the list of tweets, and Appendix F: Hashtags Used for Recruitment Tweets for the list of health care-related hashtags used for this recruitment strategy.

This strategy was effective at increasing the visibility of the recruitment blog post. Within minutes of posting the first recruitment tweet, prominent Canadian health journalist André Picard had retweeted it to his followers. Throughout the recruitment campaign, I posted 11 tweets. To my knowledge, the blog post was shared on Twitter another 72 times (44 retweets of my posts, 13 mentions, and 15 retweets of those mentions) and resulted in 322 visits to the recruitment blog post within the first 4 months of publishing. However, I did not receive a single email query because of these visits, leading me to conclude that this recruitment strategy was ineffective (see Figure 2: Initial Recruitment Strategy). I received my first and only email inquiry from this recruitment method 16 months after first publishing the blog post; the inquiry came from someone who was not eligible for the study.

Figure 2: Initial Recruitment Strategy

<table>
<thead>
<tr>
<th>Initial Recruitment Process:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Post study information blog post</td>
</tr>
<tr>
<td>2. Tweet about it using relevant hashtags</td>
</tr>
<tr>
<td>3. Ask others to retweet</td>
</tr>
<tr>
<td>4. Wait for potential participants to email</td>
</tr>
<tr>
<td>5. Send study information letter and informed consent form</td>
</tr>
<tr>
<td>6. Wait for participant to send signed consent form</td>
</tr>
<tr>
<td>7. Schedule interview with participant</td>
</tr>
<tr>
<td>8. Conduct interview</td>
</tr>
</tbody>
</table>

**Success Measures:**

- Blog post pageviews: 322
- Email inquiries received: 0 in the first 4 months
- Completed interviews: -
4.2.1.2 Revised Recruitment Strategy

Reflecting on the recruitment strategy, I recognized it relied on many chance encounters. First, the tweet would need to appear in an eligible user’s timeline, then the eligible user would have to see and read it. With 500 million tweets posted per day (Aslam, 2017), the chances were very small that my tweet would reach the right Twitter users, even with the help of retweets from my network. Once an eligible Twitter user saw and read my tweet, they would have to decide they were interested enough to click the link and read the blog post, then they would need to decide if they were eligible for the study and send an email to the address provided. Asking someone to sign up for something that they then have to arrange for at a later date adds burden of participation.

I developed an updated recruitment process that aimed to reduce the burden of participating while maintaining ethical practice. Adapting the recruitment process used by Sperber (2016), I revised the recruitment strategy to send public messages directly to Twitter users who appeared to meet the study criteria. In these messages, I invited Twitter users to read more about the study in the blog post and to contact me via email if they were interested in participating. I only approached those users who had public Twitter profiles and freely disclosed their cancer status in their biography, drastically reducing the potential that my actions could reveal personal and sensitive information about the user.

I added some additional steps to Sperber’s process (2016) to further protect the privacy of potential interview participants. To reduce the chance of someone successfully ungoogling details in this study to reveal the identities of interview participants, on a single day I compiled a list of potential participants who appeared to meet the inclusion criteria, then tweeted to 5-10 users from the list per week, at random, until the list was exhausted. I chose to compile the list at a single time point to make it more difficult for potential participants to be identified later, as, to my knowledge, users can only search against details currently available in a user’s biography. Before contacting a user, I rescreened each Twitter biography to make sure it still met the inclusion criteria. I also checked if the account was still active. For the purposes of this study, I considered an account to be active if the Twitter user had made a post within the previous 30
days. Four weeks after sending the recruitment tweet, I deleted the message from my timeline to prevent future ungoogling and subsequent identification of interview participants. This process was approved by the University of Toronto Research Ethics Board in February 2016. See Appendix G: Strategy for Recruiting Interview Participants for the full process on identifying and approaching potential interview participants.

This strategy was effective in increasing email inquiries. Using this strategy, I approached 33 Twitter users and received 10 email inquiries. Of those inquiries, only 2 led to completed interviews (6 did not respond to my emails while 2 decided not to participate; see Figure 3: Revised Recruitment Process).

Figure 3: Revised Recruitment Strategy

<table>
<thead>
<tr>
<th>Revised Recruitment Process:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Create list of eligible Twitter users</td>
</tr>
<tr>
<td>2. Screen out inactive accounts</td>
</tr>
<tr>
<td>3. Tweet request and email address to user</td>
</tr>
<tr>
<td>4. Wait for potential participants to email</td>
</tr>
<tr>
<td>5. Send study information letter and informed consent form</td>
</tr>
<tr>
<td>6. Wait for participant to send signed consent form</td>
</tr>
<tr>
<td>7. Schedule interview with participant</td>
</tr>
<tr>
<td>8. Conduct interview</td>
</tr>
<tr>
<td>9. Delete tweet</td>
</tr>
</tbody>
</table>

* bolded and coloured text to emphasize revision

Success Measures:

- Users approached: 33
- Email inquiries received: 10
- Recruited participants: 2

4.2.1.3 Final Recruitment Strategy

Upon reflection, the paper-based informed consent form hindered recruitment in an otherwise entirely digital study, and the standardized reply sent to each inquiry may not have been effective at maintaining interest. A third and final strategy was developed and approved by REB that
simplified and personalized the inquiry reply and allowed informed consent to be captured verbally on the interview transcript. I also sent up to two follow-up emails to each email inquiry, 1 week after my previous email, to improve response. Upon implementing this final strategy, I recruited 8 additional participants (see Figure 4: Final Recruitment Process).

**Figure 4: Final Recruitment Strategy**

<table>
<thead>
<tr>
<th>Final Recruitment Process:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Create list of eligible Twitter users</td>
</tr>
<tr>
<td>2. Screen out inactive accounts</td>
</tr>
<tr>
<td>3. Tweet request and email address to user</td>
</tr>
<tr>
<td>4. Wait for potential participants to email</td>
</tr>
<tr>
<td>5. <strong>Send study information letter and suggest an interview date</strong></td>
</tr>
<tr>
<td>a. If no response, send follow-up email 1 week later</td>
</tr>
<tr>
<td>b. If still no response, send final follow-up email 1 week later</td>
</tr>
<tr>
<td>6. Schedule interview with participant</td>
</tr>
<tr>
<td>7. Start interview by recording verbal consent</td>
</tr>
<tr>
<td>8. Conduct interview</td>
</tr>
<tr>
<td>9. Delete tweet</td>
</tr>
</tbody>
</table>

*bolded and coloured text to emphasize revision*

**Success Measures:**

- Users approached: 60
- Email inquiries received: 17
- Recruited participants: 8

### 4.2.1.4 Recruitment language and clarification on eligibility

Some email respondents were unclear if they met the eligibility criteria as posted on the blog post and included in the study information letter. The language used to identify eligibility criteria was as follows:

We are looking for volunteers who:

- are living with a metastatic, stage IV, advanced, or chronic cancer diagnosis
use Twitter to talk, learn, or share updates about your health
- can speak and read English
- are 18 years old or over

When asked for clarification on what was meant by ‘living with’ these types of cancer, I responded by asking if that was how the potential informant would describe themselves, to be ‘living with’ cancer (for example, describing themselves as being “in remission” rather than being “cured” or a “cancer survivor”). When asked for clarification on what was meant by ‘chronic cancer’, I responded by suggesting that if their diagnosis meant that they expected to be in the care of an oncologist for the rest of their lives. I acknowledge the clinical grey area created in using this language to identify potential interview participants. My intention was to speak with informants who expected to be in cancer care for the remainder of their lives; potential interview participants who felt they were cured or cancer-free, regardless of their medical diagnosis, did not meet the inclusion criteria.

### 4.2.1.5 Recruitment Success

In total, 93 Twitter users were approached to be interviewed. Of those 93 users, 27 (29%) made email contact with me; 5 declined because they did not feel they met criteria or were no longer interested or able to participate, and 12 stopped responding to emails before an interview time could be scheduled, resulting in 10 completed interviews. I received one additional email inquiry resulting from the passive blog recruitment, however the potential informant felt they did not meet eligibility criteria for the study and thus did not participate.

Note that for ease of distinguishing types of informants, I use the term ‘interview participant’ throughout when referring to those informants who were interviewed for this study (as noted earlier, I use ‘tweet author’ when referring to informants who were included in the tweet extracts).
4.2.2 Collection Methods

Interview questions focused on Twitter use in general and in relation to health and cancer diagnosis. Informed consent was negotiated through email exchanges and confirmation – a signed consent form for the first 2 interviews and recorded verbal confirmation for the remaining 8 interviews – was obtained from each informant prior to beginning the interview. See Appendix H: Interview Guide for guiding questions and interview script.

Basic demographic information about interview participants was intentionally not solicited before or during the interviews as these details were not reliably available for tweet authors. The Twitter profile is constrained; the open-text field for biographic information is limited to 160 characters, and additional details such as location and website URL are optional. Given the limited and optional nature of the Twitter profile, it was impossible to reliably determine details such as cancer diagnosis, gender, age, education levels, location, employment status, or ethnic background about the tweet extract authors. When using Twitter, one comes to know another user (and possibly learn their demographic details) based on what bits of information the user shares over time. When speaking with interview participants, it fit within the normal use of Twitter to only know the personal details that they shared of their own volition.

Interviews were conducted verbally either through Skype or telephone, recorded, and transcribed. Interview participants were assigned a gender-neutral pseudonym at the time of transcription, and a record matching the pseudonym to the informant’s contact information was stored in a separate, encrypted file (University of Toronto, 2008). Where interview participants referenced names of people, places, or other details that could be used to identify them, the details were replaced with generic descriptors at the time of transcription (for example, “University of Toronto” would be replaced with “[large urban university]”). Original interview recordings were maintained for reference purposes and stored in a separate encrypted folder, only until data analysis was complete.
4.2.3 Ethical Considerations during Interviews

Beyond the technology used to coordinate the interviews, ethical considerations for this portion of the research study mirror typical interviews with potentially vulnerable groups. Care to prioritize the well-being of the informant over the need for data collection and the right to withdraw from the study before, during, or after data has been collected remain rights of the interview participants.

4.2.3.1 Capacity to Provide Informed Consent

Patients who are terminally ill or are under the influence of drugs may be cognitively impaired, reducing their capacity to make informed decisions (Pimple, 2012). It is possible that potential participants in this study could be cognitively impaired because of the stage of their disease or the medical treatment they are receiving. From an ethical standpoint, it is important that potential participants can make a reasoned and voluntary decision to participate, and that they understand the research they are agreeing to (Pimple, 2012). Additionally, the researcher must take special care to ensure sufficient protection for the privacy and confidentiality of participants (Pimple, 2012). While the risks to informants participating in this research are minimal (i.e., it is not an interventional study nor is the intent to discuss distressing topics), I have embedded mechanisms to minimize burden and protect the privacy and confidentiality of interview participants within the study design, as discussed below.

4.2.3.2 Prioritizing Informant's Well-being

While the purpose of this interview was not specifically to discuss death and mortality, given the reality of informant's diagnosis, it was possible that these or other sensitive topics (such as dealing with changing relationships, coping with the loss of peers, etc.) would be mentioned during the interview. The tone of the interview was framed to minimize emotional risks as I am not adequately trained to respond to distress. Before beginning the interview, participants were reminded that they could skip any question or end the interview at any time. I was also prepared to pause or end the interview if a participant became distressed. If a participant were to become
distressed enough to end the interview, I had a document that contained information about emergency services available across the world and several scripted lines to help talk through the situation with the interview participant. I was to remain on the line with the participant in distress until they chose to end the call. At the suggestion of the University of Toronto’s Research Ethics Board, the interview script for all participants ended by suggesting the informant reach out to their health care team or an online support should they experience distress following the interview. See Appendix I: Guide for Informants in Distress (Interviews) for the full guide for responding to a distressed person.

4.2.3.3 Withdrawal

Interview participants had the option of withdrawing their data at any time during or following the interviews, up until the point of data analysis. The study information sheet and informed consent statement explained and reiterated that a participant should contact me if they wanted to withdraw part or all of their data, but that once data analysis had begun, this was no longer possible. No interview participant exercised this option.

4.2.3.4 Data Storage

Informed consent forms and email communications between myself and interview participants were stored in an encrypted folder (University of Toronto, 2008) and named using 3-digit, numeric ID codes so that interview participant information was not disclosed in the file name. All recordings and transcriptions of interviews were stored in an encrypted folder (University of Toronto, 2008).

An Informant Key Code file, which was also encrypted, was the only place where the numeric ID code used to name the informed consent file, the pseudonym used to name the interview transcript file, and the informant’s real name were associated with each other.
4.2.3.5 Data Reporting

Maintaining anonymity of the interview participants in published reports for this study mirror those used in typical informant interviews. Quotes from the transcripts were used selectively to illuminate the study’s findings, keeping the generic descriptors to obscure personally identifying information and using the previously assigned pseudonyms in place of informant's names. Additionally, quotes that did not contain identifying information but may contain unique features that could lead to a specific individual (Shklovski & Vertesi, 2013) were not used or else were modified (as indicated) to reduce or eliminate threads that may trace back to the specific interview participant.

4.3 Data Analysis

Qualitative data analysis involves “searching across a data set… to find repeated patterns of meaning” (Braun & Clarke, 2006:86). Below I describe the analytic steps I took, drawing heavily on Boellstorff et al.’s Ethnography and Virtual Worlds: A Handbook of Methods (2012:159-176), Braun and Clarke’s thematic analysis (2006), and Sandelowski’s description of qualitative analysis (1995). The steps are presented in a linear progression for ease of description; however, in practice the process involves movement back and forth between the different steps until the analysis is complete (Braun & Clarke, 2006).

Analysis began with data immersion through reading and re-reading collected materials (field notes, interview transcripts, tweet extracts) in their entirety to become intimately acquainted with the materials (Boellstorff et al., 2012:164-165; Sandelowski, 1995). Next, the materials were ‘tagged’ (unstructured text markup such as annotations and impressions) and ‘coded’ (more structured text markup that typically uses higher-level constructs) to deconstruct the data, allowing data extracts to be identified and concepts to be systematized (Boellstorff et al., 2012:165).
Data collected through tweet extracts and interviews were coded as separate bodies of work to bring forward the unique perspectives in each type of data, using two sets of questions to guide the analysis:

**Guiding questions for Tweet Extracts:** Tweet extracts were coded to gain a better understanding of tweet authors’ activities and behaviours on Twitter. I generated codes for the tweet extracts by asking questions such as:

1. What topics does the informant post about (both original tweets and retweets)?
2. When/in what contexts does the informant post about their health?
3. How does the informant use hashtags? For what purpose? What words/terms do they use?
4. What purpose does the informant’s tweets serve?
5. What actions do the informant’s tweets encourage?
6. Why was this tweet published at this time and by this person?
7. How does this tweet relate to other tweets?
8. How does this tweet relate to the informant’s cancer experience?
9. What is this tweet (directly or indirectly) responding to?
10. Who is the intended audience of this tweet?

**Guiding Questions for Interview Transcripts:** Interview transcripts were coded to gain a better understanding of interview participants’ perspectives of their Twitter use. I generated codes from the interview transcripts by asking questions such as:

1. How does the informant view or understand their Twitter use (in relation to other communication technologies)?
2. How does the informant describe their Twitter use? For example, what activities does the informant describe doing on Twitter?
3. What topics or types of messages does the informant post on Twitter? What topics or types of messages do they not post on Twitter?
4. What social norms does the informant hold about Twitter use? in relation to other communication technologies?

5. How does the informant describe their audience? Who do they believe are reading their tweets?

6. How does the informant’s Twitter use intersect with their offline lives?

7. For what purpose does the informant use Twitter?

8. What value does the informant get from using Twitter?

In using different guiding questions for each type of data, two coding schemas were generated. Each coding schema was refined and reapplied to the data systematically until each coding schema was deemed complete. I generated a total of 71 codes: 36 codes from the interview transcripts and 35 codes from the tweet extracts.

Once coding was complete, I examined the coding schemas to identify relationships between codes, a process called thematicizing (Boellstorff et al., 2012:166-167). I reviewed all codes looking for any patterns, linkages, and juxtapositions appearing in the materials that alluded to broader, more significant, or connecting concepts that could tie codes together (Boellstorff et al., 2012:166-167). Braun and Clarke describe two types of themes that could be generated in this step: 1) semantic themes are those themes that stay close to the words used by informants and are typically descriptive, 2) latent themes are those themes that examine the underlying ideologies that shape what informants say and do and are more interpretive in nature (2006). As my intent with this study was to explore Twitter use beyond a surface description, I generated latent themes for this study.

Once identified, I carefully checked over the themes to ensure they represented the data extracts and the corpus as a whole and reflected on the themes to ensure each theme was distinct (Braun & Clarke, 2006). At this point in the analysis I recognized how the themes generated in this study related to previous research on social media and/or the experiences of people living with advanced cancer. I used the existing literature inductively to help refine and clarify the themes I interpreted in this study and better situate my findings for future scholars (Boellstorff et al., 2012:174-175; Braun & Clarke, 2006).
In total, I generated 6 themes from the codes. These themes are introduced and discussed thoroughly in Chapter 6 (see Appendix K: Coding Schemas Mapped to Themes for coding schemas and themes).

4.4 Chapter Summary

In this chapter, I detailed how tweet extracts and participant interviews were used to capture different aspects of Twitter use. Boundaries for the tweet extracts were tweets, excluding replies, written by authors who had public Twitter profiles, primarily tweeted in English, and had identified themselves as living with advanced cancer in their biography. Authors’ tweets were extracted every day from September 9, 2015 to January 8, 2016 using NVivo’s NCapture extension for Chrome. Following some challenges with the original interview recruitment strategy, I used targeted messages sent to Twitter users who appeared to meet eligibility criteria to recruit interview participants for this study. A total of 10 participants were recruited and interviewed. Data from the tweet extracts and the informant interviews were coded separately then brought together through thematic analysis, generating 6 latent themes.
Findings
Chapter 5: Descriptive Findings

In this chapter, I provide a summary description of the tweet extract and the interview participants’ samples.

5.1 Tweet Extracts Sample

Tweets (original tweets and retweets) made by tweet authors were extracted from Twitter daily from September 9, 2015 until January 8, 2016 (121 days). Throughout the study period, a total of 37,141 tweets were extracted from 144 potential authors (those users included on the private list). Fifty-one of the authors included on the private list did not tweet during the 4-month period. Of the 93 active tweet authors, 9 authors and their tweets (2921 tweets) were removed from the dataset because they were deemed ineligible for the study: 6 authors were included in error (they did not actually meet the inclusion criteria for the study); 2 authors changed their biographies to remove inclusion criteria at some point during data collection, and; 1 author made their profile private during the study period. Another 744 tweets were deemed to be ‘replies’ (as discussed in the Data Cleaning section) and removed from the dataset. The remaining dataset included a total of 33,446 tweets – 13,491 original tweets and 19,955 retweets – from 84 tweet authors.

As described in the Data Analysis section of the previous chapter, an early step in the analysis process was to read and re-read collected materials to become intimately acquainted with the materials (or ‘data immersion’; Boellstorff et al., 2012:164-165; Sandelowski, 1995). As I extracted tweets, I spent time reviewing what was collected to become familiar with the tweet extracts at a broad level. Some tweet authors wrote specifically and almost exclusively about cancer, but these tweet authors were not the norm. Rather, most tweet authors tweeted about a range of topics including, but not limited to: current cultural events, such as the 2015 Supermoon and blood moon, and Starbucks’ red cup controversy; world events, such as the Syrian refugee crisis, and the 2015 terrorist attacks in Paris; politics and political propaganda (data collection took place during the US presidential primaries and the Canadian federal election); celebrity and entertainment news; live-tweeting television events, such as various sports games, award shows, and popular shows; adoption profiles for pets; missing persons reports; contests and giveaways;
memes, hashtag games, and jokes; recipes; healthy lifestyle tips; personal updates, including those not relating to their illness; promoting their own or others professional work; wishing other Twitter users well, or amplifying their milestones; historical facts; social causes, such as mental health services and domestic violence prevention; inspirational quotes and imagery; religious quotes; and snapshots of their personal lives, such as photos of their family, friends, and pets. Tweets collected during extraction appeared to represent the breadth of topics similar to what any other Twitter user would tweet.

5.1.1 Anonymous Use

It is worth noting that only a small number of tweet authors included in the tweet extracts relied on Twitter’s flexible username policy to remain fully or partially anonymous by using pseudonyms or variations of their names. Fully anonymous users have profiles that do not contain their name, their username does not appear to be derived from their name (for example ‘@ElmosFriend342’), and they do not use a personal photo in their profile. Partially anonymous users have taken some steps to obscure their identity to make it more difficult to associate their Twitter profile to them. They may provide partial details of their name (for example, ‘Alaina C’), their username may be a variant of their name (for example, ‘@ACisSoCool’), a nickname, or may not be derived from their name at all, and they may use a personal photo in their profile that prevents them from being immediately identifiable (for example, an extreme close-up of their eye). Of the 84 tweet authors included in this study, 6 were fully anonymous, 12 had taken some steps to obscure their offline identities, and the remaining 66 appeared to associate their Twitter profile with their offline identity.

5.1.2 The Problem with Retweets

Though I originally set out to include all retweets in my analysis, in practice this proved to be difficult. boyd, Golder and Lotan’s (2010) research on retweeting behaviour indicated at least 12 different reasons why Twitter users retweet - and they acknowledge this is not an exhaustive list: 1) to amplify or spread messages to new audiences, 2) to entertain or inform their own followers, 3) to comment on a tweet, 4) to make one’s presence as a listener known, 5) as an act of public
agreement, 6) to validate others, 7) in response to a retweet request, 8) to draw attention to someone as an act of support, 9) to draw attention to less visible tweets, 10) to save a tweet for future reference, 11) to increase the chances of a topic becoming more visible through the ‘trending topics’ algorithm, or 12) to invite others into an ongoing conversation. In most cases, it was difficult if not impossible to determine why tweet authors retweeted the messages they chose to retweet, and thus it was difficult to interpret the meaning behind the retweet. boyd, Golder and Lotan also describe retweeting as being “both a productive communicative tool and a selfish act of attention seeking” (2010:6), which, when applied generally to any retweet, does not provide insight or further clarification on how to interpret it. Therefore, I decided to code original tweets only, and used retweets only to get a sense of the author (for example, what types of messages they shared, how often they used Twitter, etc.).

5.1.3 Too Many Tweets

Even without coding retweets, the dataset was much larger than I could feasibly analyze at 13,491 tweets. Additionally, the volume of data posed a technical barrier as my computer could not process the file. I used purposive sampling to select tweet authors who represented the variety of Twitter users captured in the overall sample for in-depth analysis (Maxwell, 2013:98). After familiarizing myself with the corpus of all extracted tweets at a broad level, I created a summary table of the activities and high-level description of all authors who were active during the tweet extraction period. Summary data included:

- **Counts of author’s tweet activity**: how many tweets they posted during the study timeframe; how many of those posts were original tweets; how many of those posts were retweets.
- **Profile details**: what username they use (for example, was their Twitter username a pseudonym or did it appear to represent their name).
- **Following and followers**: how many followers the author had at the start and end of the study timeframe; how many Twitter accounts the author followed at the start and end of the study timeframe.
• **Average number of tweets (original tweets and retweets) posted per day they were active.**

Following this cursory summary, I selected tweet authors who presented as interesting cases due to their profile, their activities, or both, and began reviewing their tweet extracts in greater detail. Tweet authors were selected purposively to ensure the sample included a range of different activity levels, anonymity, and number of followers. As tweet authors were selected and reviewed, emergent sampling was used to select additional tweet authors who appeared to represent activity levels, anonymity, and number of followers that were not included through other tweet authors. See Appendix C: Tweet Extracts Informants for an anonymized tweet extracts summary table.

### 5.1.4 Final Sample Analyzed

In total, I analyzed 2,731 original tweets (20% of all original tweets) and reviewed 6,490 retweets (32% of all retweets), published by 8 authors (9.5% of all tweet authors). Three authors selected for analysis were fully anonymous, 2 were partially anonymous, and 3 did not appear to hide their identities. For the purposes of gauging activity levels, I categorized tweet authors based on their average number of posts (original tweets and retweets) per day. I considered those who tweeted an average of 16 times or more per day (or an average of once per waking hour) to be extremely active, those who tweeted an average of 2 to 15 times per day as moderately active, and those who tweeted an average of one or fewer times per day to be lightly active. I selected 2 tweet authors who were extremely active, 4 who were moderately active, and two who were lightly active during the study period. For comparison, the average number of tweets per user per day for the entire dataset of tweet extracts was just over 5 tweets per day, ranging from an average of fewer than 1 to 32 tweets per day. At the beginning of the study period, authors selected for analysis had a range of followers that spanned from 50 to 4,400 Twitter users. For comparison, the average number of followers for all authors at the beginning of the study period was 1,745 Twitter users, ranging from fewer than 100 to 34,000 followers.
5.2 Interview Participants Sample

A total of 10 interviews were conducted for the interview portion of this study. Interview recordings averaged 36 minutes, with a range from 25:10 to 52:10. All interviews took place between February and November 2016. Interview participants reported being Twitter users for an average of 6 years before the interview, with a range from approximately 2.5 years to 8 years. Although not formally part of the line of inquiry, eight interview participants provided a rough timeline on when they received their (first) advanced cancer diagnosis prior to participating in the interview. The average of those who provided this information was 3.9 years (47 months) before being interviewed, with a range from 1.25 years (15 months) to 8 years. Three interview participants were diagnosed with cancer before joining Twitter and went public with their diagnosis upon signing up. Of the seven interview participants who were Twitter users at the time of their diagnosis, two had disclosed their diagnosis on Twitter immediately, one had done so after 1 month, one had done so after 7 months, another after 8 months, and another took 12 months. It is unclear when the last informant went public with their cancer diagnosis on Twitter (see Appendix J: Summary of Interviews for a breakdown of the specific timelines and lengths of interviews).

During the interviews, participants often mentioned other social media platforms within the first few questions of the interviews and provided examples of how they used these other tools (for example, referring to their experience using Facebook or a blog). Though interview participants often and easily switched between talking about Twitter and other types of social media within the same question, they clearly distinguished between what was “appropriate” or “meant” to be posted on Twitter versus other social media platforms or online social spaces.

As part of wrapping up the interviews, I asked all interview participants what made them want to participate in this study. All ten interview participants replied with some variation of having the desire to help others if they were in the position to do so. Responding to and following through on a call for their help from me, a stranger, suggests that these interview participants are not likely representative of all Twitter users who were eligible for this study. Although the data collected through these interviews no doubt emphasized the ‘giving’ aspects of their Twitter use,
there were also plenty of examples of other aspects of their Twitter use that demonstrated a more fulsome picture of the breadth of how Twitter is conceived and used by people living with advanced cancer. The analysis that follows is not a quantitative judgement of how often these things happen, but rather an exploration of how Twitter is understood and used. The tweet extracts allowed for the examination of behaviours as a means of identifying aspects that may not have been represented in the interviews.
Chapter 6: Thematic Findings

In this chapter, I provide details on the 6 themes that illuminate how informants’ Twitter use related to their advanced cancer diagnoses, ordered from those that impacted informants’ views of themselves most to those that impacted the view of others.

1. ‘Constructing Identity Through Textual Selfie’ relates to how informants recognized that posting their thoughts and feelings on Twitter allowed them to become more self-aware.

2. ‘Resisting Social Death’ relates to informants’ need to continue participating in normal social life while experiencing limitations due the side effects, treatment, or change in lifestyle from having cancer.

3. ‘Accounting for Time’ relates to informants’ view of Twitter as a way of marking off time and creating a living record of how they spend their time.

4. ‘Finding Freedom in Obscurity’ relates to how, unlike in other social spaces, informants felt what they said on Twitter was under less scrutiny, leading to greater feelings of freedom to share thoughts that may be uncomfortable or emotionally upsetting to their loved ones.

5. ‘Creating a Living Legacy’ relates to informants’ intent to make a positive impact on the lives of those around them - including strangers - by publicly sharing their experiences living with cancer.

6. ‘Fighting for What’s Right’ complements ‘creating a living legacy’ in that it still relates to informants’ intent to making a positive impact, however, informants do so by using anti-social tactics such as spamming, calling out, and trolling.

I discuss the themes here going from those that impacted informants’ views of themselves, to their use impacting how other people viewed them, to how twitter used impacted how society at large viewed them.
6.1 Constructing Identity through Textual Selfies

Twitter was viewed as one social media platform where informants could express their inner thoughts relatively openly and freely without gaining unwanted attention from their followers. For example, interview participant Lee\(^4\) used Twitter to make sense of thoughts or emotions that may be overwhelming them, particularly when the thoughts were not something they wanted to share with someone else in person. Lee viewed Twitter as the best place to share these thoughts because it did not seem appropriate to share “bursts of 10 or 15 posts” on Facebook.

*Lee: “The things that I post on Twitter are definitely more stream of consciousness and I don’t clog up my Facebook feed in the same way. It’s kind of nice on days when my emotions are, or my thoughts are, just sort of going a mile a minute, that I can say something. When I’m alone and I just need somebody to talk to, it’s like, OK. I can just talk to myself on Twitter.”*

Lee was the only interview informant who specifically mentioned using Twitter to talk to themselves, though there is evidence that other interview participants were better able to understand themselves through their Twitter use. For example, Pat felt their Twitter use helped them synthesize and explore their thoughts about cancer.

*Pat: “It’s helped me communicate better about it [having cancer]. I feel like it’s- since there’s the character limit and all of that I’m not exactly writing long essays. But I feel like when I’m processing the state that I’m in, I find that it’s a good place where I can kind of synthesize that and share it with others.”*

Using Twitter to explore thoughts and feelings had the added benefit of a receptive and supportive audience. Pat shared a specific incident in which they were questioning the need to

\(^4\) Note that all interview participants were assigned gender-neutral pseudonyms at transcription, used throughout the manuscript, to protect their confidentiality.
make meaningful experiences when these experiences would die with them. Instead of being concerned for Pat’s mental or emotional wellbeing, one of Pat’s Twitter friends simply acknowledged the question as resonating with them.

*Pat: “At one point I was feeling like what is the point of having memorable experiences by myself if I am probably going to be dying soon? ‘Cause those experiences will just die with me. And a friend just kind of replied to that and the idea that my own thoughts were resonating with and making other people think. That was a rewarding experience as well.”*

6.1.1 Theme Summary

Twitter is often recognized as a place of self-expression, but it is also important self-discovery. Whether posting photo selfies, sharing humour, or writing out their thoughts, the informants in this study used their Twitter timelines to create ‘textual selfies’, to say something about who they are and to find out who they are becoming.

6.2 Resisting Social Death

Informants used Twitter to stay socially active and to let them express aspects of their lives that were not about cancer. As I described in the Background chapter, people living with advanced cancer may experience a social death wherein they become disconnected from social life through a series of losses (Charmaz, 1983; Norwood, 2009 via Borgstrom, 2017). In being an adaptable, accessible, and public social space, Twitter offers people living with advanced cancer a way to resist social death by allowing them to represent themselves as multi-faceted human beings who participate in society.

6.2.1 Representing the Full Self

Most informants used their Twitter profiles to represent themselves wholly, showing the world that they were more than just a cancer patient. Most informants did not limit their Twitter use to cancer and instead used their profile to communicate about a variety of topics. Pat was the only
interview participant who spoke specifically about the importance of sharing facets of their life beyond their cancer diagnosis as part of their self-expression on Twitter, in part for their own sake of keeping track of the aspects of their life that were not about cancer.

Pat: “I’d say that [using Twitter has] been an exercise in sharing the parts of my life that are about disease and the parts of my life that aren’t about disease. And when being a patient becomes being almost a full-time job, it becomes easy to lose track of that.”

Other informants appeared to take similar actions, though they were less explicit about their purposes. For example, interview participant Morgan stressed that they mostly shared cancer information but they still tweeted about other things sometimes as a way of keeping their followers interested.

Morgan: “[I tweet about] metastatic breast cancer awareness, legislation, how we’re being discounted, facts about things, my initiatives in advocacy. Once in a while I’ll do sports posts <laughs>. Nutrition. I’m big into nutrition as being a form of how to cope with cancer. Exercise. [...] I try not to bore people that all I do is sit here and talk about metastatic breast cancer, so people just don’t think I’m a pain in the butt or disregard my... I try to give a variety so I don’t look like I’m just constantly on there just for that, and disregard me.”

Other interview participants used their Twitter account to connect with others from a wide range of their interests. For example, Kris followed comedians, musicians, and other Star Wars fans. Jamie specifically said they did not follow many other cancer patients and instead followed users who’s work they were interested in.

Jamie: “I follow a lot of people that I know. [...] I follow a lot of diverse people on Twitter so it’s kind of all over the map and they’re tweeting about things related to their work, whether they’re artists or musicians or writers. I wouldn’t say that I follow a lot of cancer patients at all. There’s one that comes to mind who I follow, but she’s primarily a journalist so most of her tweets are related to that.”
Many authors included in the tweet extracts did not tweet about cancer or health despite publicly identifying as someone living with advanced cancer, but rather focused on current events and personal interests. Participating in routine and commonplace Twitter conversations about current events – such as live tweeting a TV show, commenting on world events, or sharing the latest viral meme – establishes and reaffirms a user’s connection to the zeitgeist of the time. It says to the world ‘I was a part of this’. Indeed, with some of these Twitter users it would not be apparent they were living with advanced cancer were it not included in their Twitter biography. While there were certainly informants who predominantly tweeted about cancer, this group represented a minority of those included in the study. Most people living with advanced cancer seem to use Twitter to build and maintain social connections beyond other cancer patients.

6.2.2 Enabling Adaptive (but Tenuous) Social Connection

Some interview informants discussed how Twitter helped them continue to feel social even when their cancer or treatment left them unable to participate socially in other ways. For example, when I asked Sam how being on Twitter had changed the way they thought of themselves, Sam shared how they used Twitter to remain connected when they were in isolation because of their cancer treatment.

Sam: “You’re not alone. I mean, cancer’s a disease. When I had to get my autologous stem cell transplant, you’re 5 months in isolation booths. [...] Having the online community keeps you involved, keeps you with a group of people with similar experience...”

Beyond medical isolation, the symptoms of advanced cancer and the side effects of treatment can be taxing on a person’s energy. Twitter offered informants a way to maintain some social activity in a way that was manageable for their energy levels. For example, Lee explained how the brief encounters they witnessed on Twitter allowed them to keep social in a way they could handle:

Lee: “One of the worst aspects for me personally of having gone through cancer treatment is that I had to withdraw, completely, from society. I physically was unable to
do things. Emotionally I was very, very overwhelmed, and Twitter allowed me to stay connected in a way that I was not otherwise able to, stay connected. That there’s this greater world out there and I can catch these little fleeting moments and thoughts of what was happening with other people and I didn’t feel quite as alone.”

While Lee took comfort in using Twitter to see what others were up to, Pat gained comfort in being able to “put themselves out there” when their side effects left them feeling disconnected. Being able to load up Twitter whenever they needed to reconnect, combined with the mobile access and minimal effort it took to send a tweet, meant that informants could be social as little or as much as they needed, regardless of barriers that impacted their lives offline.

As much as Twitter allowed informants to maintain social activity in ways that was easy for them, the feeling of being connected or not being alone was tenuous and easily slipped away if a post was ignored. After Sam explained how Twitter connected them with other people living with the same type of cancer, I struggled with phrasing a follow-up question. Sam jumped in with their own question, one that had not crossed my mind to ask.

Sam: “Are there points that it makes you feel alone, or feel minimized?”

Alaina: “Yeah, is that something that you feel?”

Sam: “You’re not physically reaching out and calling someone on the phone to interact. If you try to interact passively and anonymously through Twitter, you may or may not get a response and that may not be exactly what you want or need, if you totally rely on Twitter. [...] Sometimes if you just throw something out there and no one reacts. There’re certain things that shouldn’t be on Twitter. You should be calling a human being and basically looking in their eyes and so they see, as a cancer patient, you’re kind of scared. You can’t look in someone’s face on Twitter.”

The tweet extracts of Twitter user @jmmjhughes showed how social rejection from lack of response could play out on Twitter. One morning, @jmmjhughes asked their followers to help improve their mood by sending them funny pictures.
After nearly 8 hours of not receiving a response, they tweeted a sarcastic message that called out their followers for not responding.

jemmjhughes95: “Well at least I know when I’m feeling down people on here will cheer me up ,will they heck not one .now calling the Samaritans they can help” 2015-09-10 4:17 PM

It takes no effort for a tweet to go unnoticed by others or for it to not be responded to. While Twitter can present an opportunity for people living with advanced cancer to participate in society in a way that meets their needs, the feeling of social connection in dependent on responses from other Twitter users.

6.2.3 Theme Summary

Twitter enabled informants to freely and relatively easily participate in society, even when physical limitations prevented them from joining other social settings. Though all informants publicly acknowledged their cancer diagnosis in their Twitter biographies, most did not focus their Twitter use specifically on cancer and instead used the public social platform to represent their multiple (and dynamic) interests and to participate in events as they unfolded. Twitter served to partially fulfill the social needs of informants, particularly at times when cancer, its treatments, and side effects made these needs difficult to fulfill in other ways. However, when informants’ tweets do not get acknowledged or responded to, it can leave them feeling more alone and dejected.

6.3 Accounting for Time

Being more aware of the passing of time was an experience that underscored many informants’ Twitter use. Much like an accounting ledger used for bookkeeping, Twitter use was viewed as a ledger for recording of how they spent their time. Much like an accounting ledger records
financial debits, credits, and loans, Twitter served as a record of time wasted, celebrated, or borrowed. The event-driven focus of Twitter combined with informants’ awareness of their limited time prompted informants to be more mindful of how they spent their time, whether they chose to spend it on Twitter or elsewhere.

### 6.3.1 Twitter Use as Ledger of Time

The placeholder text in Twitter’s input tweet box asks ‘What’s happening?’, prompting users to provide their followers with insight into their current happenings. It is unsurprising then that every tweet author included in the tweet extracts had, to some degree, tweeted or retweeted about current events as they were unfolding. Within the scope of their personal lives, many informants (both interview participants and tweet authors) used Twitter to provide their followers with updates about their health (see Figure 5: Sample tweets showing personal updates).

**Figure 5: Sample tweets showing personal updates**

- LuluChange14: “Wasted time: Day 2 after chemo. Barely here. Why does this have to kick so hard? Am I one of the lucky ones? #521900EveryYear” 2015-10-17 6:39 PM
- LageDor49: “Back from hospital. Seeing my oncolog at main hospital later this month. Feeling OK.” 2016-01-05 10:35 AM
- jmmjhughes95: “First day in a week & half I feel human again ,flu knocks you for six & with the cancer on top ive felt like crap.” 2015-11-01 8:27 AM

Tweeting these personal updates also meant informants created a personal history of their experiences. For example, during our interviews, both Casey and Jamie loaded up their Twitter profiles and began reading through their tweet histories as a way to help remember their past activities. While Sam did not seem to look through their profile while we talked, they did explain that they made posts using a certain hashtag so they could easily retrieve posts later. In using Twitter to document the present, informants built a ledger that allowed them to revisit the past as they felt the need to do so.
6.3.2 Twitter Use as a Time Wasted

Informants’ underlying feelings about the passing of time affected how they viewed their Twitter use. For example, some informants tried to restrict the amount of time they spent on Twitter because they felt it was a poor use of their time. Pat described their Twitter use as something that could sometimes be an “idle bad habit”. When I asked for clarification on what they meant by the phrase, they shared that Twitter use sometimes felt like a mindless and socially-detached way to pass the time.

Pat: “When I spend too much time there I feel like I’m wasting my time. I guess when it’s just a default behaviour and I’m not being mindful about it, I feel a little bad about my Twitter use because I don’t feel like I’m actually connecting with anyone. I feel like I’m just... trying to pass time. And time is something that I’m very anxious about because of the uncertainty of my life with the cancer.”

Informants like Pat recognized that it was easy for Twitter to fill their time if they weren’t mindful about it, and they expressed concern about letting the precious resource slip away on something that did not feel meaningful to them. To them, time spent on Twitter could represent time wasted.

6.3.3 Twitter Use as a Time Celebrated

Other informants seemed to find that marking off their day-to-day life on Twitter was a way to celebrate the time they were alive. For example, when asked when they found themselves using Twitter, Alex responded with an enthusiastic “All the time!” and eagerly listed the many different Twitter activities they had already done on the day we spoke.

Tweet author @Lagedor49 appeared to also take pleasure in tweeting to mark off every day that they could do so. The content of their tweets was typically unexceptional - for example, updates about local weather, sharing historical facts, or retweeting about current events - but the frequency of tweets, an average of 25 tweets per day, showed how they lived on Twitter.
Following a 42-hour period where they did not tweet, @Lagedor49 blamed technological issues for their inactivity.


While being inactive for less than two days may go unnoticed for the average Twitter user, the frequency of @Lagedor49’s posts made their absence noticeable. Indeed, this was not the only time @Lagedor49 posted a message to break the silence: twice, after not tweeting for about 13 hours, they simply and succinctly tweeted “Still here!”. On New Years’ Day 2016, they commemorated the coming of the new year, which they did not expect to be alive for, with a message containing the same sentiment,

Lagedor49: “2016! Never thought it would happen to me six months ago! Happy new year!” 2015-01-01 5:43 AM

For informants like @Lagedor49 and Alex, posting on Twitter was a way to celebrate their continued lives.

6.3.4 Twitter Use as a Time Borrowed

For other informants still, Twitter’s reminder of the passing of time evoked feelings of living on borrowed time. Some of these informants appeared to be driven to use Twitter while they could to vocalize the injustice they felt for their diminishing time left. These informants typically expressed that they were “living on borrowed time” or had somehow lived beyond their prognosis. For example, tweet author @Carolinajeji quoted a tweet from another Twitter user, reporting from an academic conference, and added their own commentary. The original tweet highlighted how median survival rates for metastatic breast cancer had improved to 56 months; @Carolinajeji’s response draws attention to how they had already surpassed the median by 6 months.
Tweet author @Carolinajeji’s tweets often depicted a sense of urgency that likely stemmed from not knowing how much longer they had until they would die. By seeing themselves as living on borrowed time, their Twitter use tended to focus on using what time was left to say the things they needed to say.

Reminders of living on borrowed time also stemmed from connecting with other patients who were living with advanced cancer. Interview participant Jamie had developed a friendship with another cancer patient who had the same type of cancer and was taking the same treatment. Since the friend had died, Jamie felt an added layer of grief when they experienced their own good news.

* Jamie: “And unfortunately she passed away in the spring. It was really... very sad. But I am connected with her mother and her widower on Facebook, which is nice but also hard. I mean, every time I post about a good scan results, it’s never far from my mind. [...] and you know they’re happy for you but they have someone that they lost to the same disease. So it’s hard.”

While the social support gained from connecting with other patients was no doubt a powerful experience of Twitter and social media use, relating closely to others who died from their cancer brought forth additional feelings of grief and possibly guilt when informants were doing well or continuing to survive beyond their expected prognosis.
6.3.5 Theme Summary

Using Twitter brings about an innate awareness of the passing of time for people living with advanced cancer. Informants’ underlying feelings about the passing of time influenced how they viewed their Twitter use: those who expressed concern about having limited time viewed their Twitter use as time wasted; those who expressed gratitude for continuing to live viewed their Twitter use as time celebrated; those who expressed grief and anger for having limited time left viewed their Twitter use as time borrowed. The event-driven nature of Twitter urged informants to be more mindful about their time, however they chose to spend it.

6.4 Finding Freedom in Obscurity

Informants felt a unique sense of freedom offered by the obscurity they experienced on Twitter, even if they associated their Twitter profile with their offline identity. Unlike other social media platforms such as Facebook, informants felt that what they posted on Twitter was under less scrutiny by others because they were relatively unknown or less visible, which allowed them to be more expressive and free.

6.4.1 Nonymous but Unknown

Some interview participants experienced a sense of freedom on Twitter because they considered themselves unknown, usually because they had few followers or the followers they did have did not know them offline.

Though related, being unknown is distinct from being anonymous. Unknown users are those who feel their offline identities are camouflaged within Twitter’s large user base while anonymous users actively hide their offline identities by dissociating their Twitter account from their personal information to separate their online activities from their offline lives. In some cases, using full anonymity appeared to be a mechanism to shield themselves from repercussions of their anti-social Twitter activity. For example, fully anonymous user @AstonishingFMan regularly targeted other Twitter users or public figures with sarcasm and degrading language to express disagreement. Of the 191 original tweets by @AstonishingFMan collected during the
study period, only one was related to cancer: a criticism of “Obamacare”. For most other anonymous users in the tweet extracts, it was less clear why they chose to use a pseudonym. For example, user @Lagedor49 was completely anonymous but did not appear to engage in any anti-social or otherwise deviant Twitter behaviours. Most informants, however, did not take many (if any) steps to hide their personal information or offline identity, instead relying on being unknown to control their privacy.

Interview participants’ concerns about privacy stemmed from their perceived visibility - or how closely they felt others were monitoring their activity - rather than the public availability of the platform. As they felt their Twitter use became more visible, they gave more thought to what they were posting, though it did not usually stop them from sharing personal details. Robin was the only interview participant who consciously changed their Twitter behaviour as they felt their visibility increased to a level they did not like.

Robin: “I would consider myself a minor celebrity in <city 1>. And in <city 2>, not near as much. I don’t know, for whatever reason I wanted to kind of walk away from that, I suppose. There would be news anchors, for example, in <city 1> who knew who I was and would retweet what I did and that sort of thing. So I’ve been a lot more low-key in the last few years with Twitter.”

For other interview participants, increased visibility did not necessarily prevent them from posting sensitive or personal information, but rather, they became more careful about the kind of information they shared and how they chose to express their thoughts. During our interviews, both Pat and Alex walked me through the various online social spaces they used and what they posted on each. Alex could not explain why they chose to share certain details on one platform versus the other, but they did notice a shift in what they tweeted as their visibility increased because of their professional work.

Alex: “I have an awareness that I’ve started to become a more public person and that makes me feel like I have to be a bit more careful with what I say in case could be taken or used in a way that I don’t feel comfortable.”
Pat felt Twitter was confoundedly more anonymous despite its public accessibility, due in part to their understanding that Twitter social norms are more forgiving of candid or undeveloped comments than in other forms of communication.

*Pat: “In a way, it’s more public than other social media, but in a way, it feels more anonymous in that I’m just kind of stating things to the world. [...] I feel like there’s this community agreement on Twitter that you can - to some degree - be candid about your experience with strangers and other people and there’s kind of like a <pause> shared community where they can come and listen or not.”*

For Pat, this sense of anonymity meant they felt more comfortable sharing thoughts and feelings that may prompt unwanted reactions from their audience in other social settings. Twitter gave Pat an outlet to be more authentic when exploring thoughts and feelings about their life, death, and cancer. However, as they felt their tweets were under more scrutiny from those close to them, Pat began to censor themselves more, despite their best attempts not to.

*Pat: “A few months ago my mother figured out how to use Twitter and so now she follows me. So I’ve tried to kind of pretend like she isn’t. [...] I don’t really want to be censoring myself but I do feel a little weird with my mom watching it so closely. Which she denies she watches it so closely but I think she’s now reading every single tweet. [...] There are definitely a few times where there are things I would like to tweet that are about my mom <half laugh> and our relationship, and cancer, and the intersection of those. I generally don’t do that anymore <laugh>. I kind of try to not think about that too much <laugh>.”*

### 6.4.2 Being More Authentic

Despite taking extra care about what and how they said things on Twitter as their visibility increased, none of the interview participants expressed concern with “going public” with their cancer diagnoses. The interview participants seemed to hold the view that cancer was part of
who they were and it was not something they wanted to hide. Interview participant Lee said that they did not feel like themselves when holding back their cancer diagnosis.

Lee: “I cannot be my authentic self if I’m holding something that large back. It goes against the fabric of who I am, and I’ve done that before with other things. For instance, my last pregnancy [...] I didn’t tell my family until I was almost seven months pregnant. And that was really difficult for me. I felt like this [cancer] is now a part of who I am and it’s no different than discussing if I get a sunburn or if my favourite sports team wins. It simply exists in my universe in a way that I had to confront, and because I had to confront it, it was natural for me to be public about it.”

Lee expressed how Twitter use allowed them to be more authentically themselves and allowed them to see others as their more authentic self. Lee believed that what someone posted on Twitter revealed aspects of the person’s character that may not always be seen in face-to-face situations because they felt Twitter social norms allowed people to be less filtered.

Lee: “The reality is that we may have all of these other things going on and, for some reason, that simple microblogging platform allows me to see it a little bit easier. Because people are willing to say things on there that- Maybe that’s what they really think, or they’re able to spit something out, and it’s always different than their public face. [...] Tweets tend to be very revealing about people whether they intend them to be or not. So, I really enjoy that I can get a little bit of insight into people.”

6.4.3 Theme Summary

Informants experienced a certain freedom in feeling unknown or invisible on Twitter that made them comfortable sharing thoughts and feelings that they may not have shared in other social situations. Despite Twitter being publicly accessible, interview participants felt their activity was hidden amongst the activity of others, creating a sense of individual invisibility that allowed them to express themselves in ways that felt authentic. Even though their tweets could be easily found by those that knew them as they did not actively try to dissociate their Twitter profile from
their offline identities, they did not seem concerned with people reading them as they felt there was an unspoken social norm that Twitter allows users to be more authentic and in the moment.

6.5 Creating a Living Legacy

Informants viewed their Twitter use as a way to change beliefs and knowledge of others. I use the phrase ‘creating a living legacy’ as defined by Nissim et al. (2012) as making a positive impact on the lives of the people around them while they still can. Many informants believed sharing their experiences publicly would positively influence how individuals and society at large understood advanced cancer. Informants used Twitter to build a form of symbolic immortality by positively influencing the lives of other Twitter users. Importantly, interview participants focused on the impact of their Twitter use in the present and did not talk about how their tweet archive may impact the lives of others posthumously (though it is unclear if this is because it was not included in the line of inquiry or if they simply had not considered it).

6.5.1 Sharing Cancer Knowledge

Many interview informants said their decision to “go public” with their cancer diagnoses was driven by the belief that sharing their hard-won knowledge would prevent other cancer patients from experiencing the same hardships. For example, interview participant Casey’s primary goal with their Twitter profile was to curate helpful information for other cancer patients and distribute it to a wide audience.

*Casey:* “There were times I would share jokes knowing that laughter is the best medicine. I would share news items if I heard something in the news that ‘hey, this medicine is getting a break-through designation from the FDA’ and ‘it’s going to be used here’ or ‘here’s information on the clinical trial’. I tried to share anything that would be in those realms of information, education, and inspiration, humour, really helping people cope.”
6.5.2 Comforting Strangers Impacted by Cancer

Casey also actively sought out other Twitter users to provide comfort and support. Casey reported caring so deeply for others that they would regularly search for tweets with the phrase ‘just diagnosed with cancer’ and reply with a link to a blog post that the tweet author might have found helpful. Casey felt that reaching out to others was a small way they could help others feel connected to someone and provide them with some more practical help.

Yuki took a more personal approach when providing comfort to others. During our interview, Yuki described using Twitter to build a friendship with someone who was struggling to cope, and helping him cope by introducing him to other people experiencing a similar situation:

Yuki: “There was a guy in there [on Twitter] whose wife had just been diagnosed. And she’s also younger, like me, and they have young kids. And he was looking for information and kind of panicking. And so I connected with him and then I helped him meet other young families in the group. We’ve remained friends since then. I think that was really powerful for him. To know that there was, there were people living with this.”

6.5.3 Role Modeling Hope and Positivity

Informants viewed sharing their lives publicly as a way of inspiring or being a role model for others, both those living with cancer and those who are not. For example, all-around, interview participant Kris dealt with their cancer diagnosis with a great deal of positivity and hope, saying that they tried not to let their diagnosis impact their life too much and they continued to do all the things they did before they were diagnosed. Kris felt strongly that letting one’s prognosis impact their lives was a shame because there was no way to know what the numbers meant on an individual basis. On Twitter (and surely in their offline life), Kris used their hope, positivity and position as an advanced cancer patient to encourage other cancer patients to live their best lives.

Kris: “I try to tell people that time is so irrelevant and you just need to do your best every day, and to be a good person and to try to bring love and happiness into the world. Because whether you have these numbers in front of you or not, you don’t know how
many days you have left. So make this the best life possible, not just for yourself but for those around you, or those that you may have never seen and the only way they’ll ever know you is through this electronic medium.”

Though their positivity was primarily intended to inspire hope in other cancer patients, Kris has been a role model to those who are not living with cancer as well. Kris’s exceptional perspective provides a clear example of how informants’ behaviour on Twitter can position them as a role model for anyone.

Kris: “I’ve had people say that my attitude and how well I handle tough issues that are going on with me has helped them re-examine things in their own lives. And to really put priority on the things that matter. And to not lose their cool with the little things. […] And that’s been very kind.”

6.5.4 Informing Those Without Cancer on the Reality of Cancer

At other times, improving the lives of other cancer patients meant changing others’ understanding of cancer. Interview participants Morgan and Alex both reported that their disease was not well understood by most people and that they were open about their experiences as a way to change how their followers without cancer understood it.

Alex: “… breast cancer is such a frustrating disease because everyone's aware of it, but the majority of people think it's easily curable. And to me, maybe on my social media, like Twitter, it gives us an opportunity to change the conversation a bit - to reframe things, to raise awareness about the fact that there is still work that needs to be done, research that needs to be done - if women are going to stop dying, and men […] I do think that Twitter is a useful tool in getting information to people in small enough bites that they can actually dissect it.”

Pat specifically addressed problematic comments made by their Twitter connections to affect individuals’ understanding of the perspectives of people living with advanced cancer. A Twitter connection of Pat’s had tweeted something disparaging about colostomy bags, something that
Pat felt stigmatized for needing as an integral part of their medical care. Pat respectfully addressed the comment with their friend and found it led to them feeling more comfortable being open with their medical experiences.

6.5.5 Being Open for Others to Learn

In addition to actively contributing to conversations about cancer on Twitter, some informants saw their Twitter use as contributing to change in a more passive way. By publicly using Twitter to detail their experiences, these informants were creating an open invitation for strangers to learn what life is like living with advanced cancer. Informants found it perfectly normal for strangers to strike up conversations with each other on Twitter based on what they have tweeted or what was included in the Twitter profile. Morgan chose to be public about their cancer experience on Twitter to invite strangers to learn more about advanced cancer if they were interested while those who were not could easily ignore their messages without any social consequence:

*Morgan: “Twitter is more of, if they’re interested then they will engage you. If not, it will just be disregarded [...] If something is of interest to them then they will go further. If it’s not, it’s just gone by the wayside.”*

6.5.6 Theme Summary

Informants felt a need to share their experiential knowledge publicly with others as a way to ‘pull back the curtain’ on life with advanced cancer to inspire hope in others. By positively influencing the lives of other people, informants could create some positivity from their negative experiences which felt rewarding to themselves.

6.6 Fighting for What’s Right

Twitter has become well-known for the anti-social behaviour that runs rampant within the platform, most notably around issues of politics and human rights. Some informants in this study regularly engaged in these tactics as a means of correcting behaviour or information that runs
counter to their beliefs and values. Like ‘creating a living legacy’, the intention behind ‘fighting for what’s right’ is to improve the conditions for those living with advanced cancer (including themselves), but it differs in that it relies on correcting behaviours and beliefs rather than inspiring positive change. Tweet extracts included examples of authors using spam (sending unsolicited messages in excess; ‘Spam’, 2018), call outs (publicly shaming individuals or organizations for behaviours that are deemed inappropriate or offensive; ‘Call out’, 2018), and trolling (deliberately antagonizing others by posting disruptive content; ‘Troll’, 2018). These behaviours were done individually or through coordinated group efforts to target a specific Twitter profile or hashtag. In using public techniques to shame or correct “bad” behaviours, informants draw attention from other Twitter users, expanding the reach of the message while also bringing a sense of validation in receiving positive attention from others. While these anti-social tactics were used in a variety of contexts, I focus the discussion on their use within the illness experience.

6.6.1 Spamming for Visibility

Spamming involves sending an excessive number of unsolicited tweets that ask the receiver to do something that benefits the sender. When a single message is sent to multiple profiles, informants asked receivers to help increase the visibility of the message. For example, @Carolinajeji used spamming as a “virtual protest” in support of more research into metastatic breast cancer. Over 31 minutes, @Carolinajeji tweeted virtually identical messages to 39 prominent Twitter handles of US politicians, musicians, actors, TV personalities, and entertainment organizations including Taylor Swift, Barack and Michelle Obama, and MTV. The message asked these users to tweet using the hashtags #DontIgnoreStageIV and #PinkToBlack, presumably to raise awareness of metastatic breast cancer research:

Carolinajeji: “.@MusicNegrito will you please participate in our virtual protest to support more MBC research? tweet #dontignorestageiv #pinktoblack” 2015-11-23 1:25:12 PM

Although the receivers of these tweets did not share the original tweet by retweeting, the posts were retweeted 5 times by other Twitter users.
6.6.2 Calling-out to Publicly Shame

When spamming is directed at one Twitter profile the intent is usually to ‘call out’ the user’s problematic behaviour to influence their future behaviour. Calling out involves publicly shaming individuals or organizations for statements of behaviours that are deemed inappropriate or offensive. The intention is to draw unwanted attention to the individual or organization in a public format as a means of increasing the pressure to change or admit wrongdoing. By far, the largest health-related target for calling out among informants was the Komen Foundation. Interview informant Morgan described how they continuously called-out the Komen Foundation for not funding metastatic breast cancer research, though their tweets have largely been ignored by Komen.

Calling out is also used when the informant has been personally wronged or as a means of individual benefit. For example, interview participant Yuki shared that they had successfully called out their insurance company to cover their cancer medicine after more private tactics failed to get them their medicine. Similarly, tweet author @jmmjhughes called out the government disability program (Department for Work and Pensions, or DWP) and the Secretary of State for Work and Pensions, Iain Duncan Smith (often referred to by his initials IDS), in a series of tweets spanning several days when their claim was rejected (see Figure 6: Sample tweets of calling out). Though it is unclear if publicly calling out of the government had any impact on the eventual reversal of the decision, calling out the government gained @jmmjhughes attention that they had previously not had: their first tweet received 16 retweets and 6 likes, which was an unusually high response compared to their other tweets collected during the 4-month period of the study.

Figure 6: Sample tweets of calling out

- jmmjhughes95: “#isitok I have terminal cancer & im going to die ,I.D.S thanks for stopping all my benefits now due to your new p.i.ps form” 2015-10-13 5:14 AM
- jmmjhughes95: “#isitok IDS your told you have terminal cancer your family is in shock ,the DWP stop your benefits.your reply im a millionare” 2015-10-13 1:46 PM
• jmmjhughes95: “#isitok Iain Duncan smith if your family member was terminally ill would you let ATOS & DWP deal with them ,if yes bet they got everything” 2015-10-21 7:08AM

6.6.3 Trolling to Disrupt

While spamming and calling out tactics are usually targeted to known offenders, trolling involves actively seeking out Twitter users who have posted “bad” messages and replying with provocative statements that are meant to disrupt the conversation. Trolling can happen as an individual or as part of a coordinated group. On an individual level, tweet authors @LuluChange14 and @KathysKontests co-opted popular hashtag #NoBraDay to call attention to the silliness of the hashtag (see Figure 7: Sample tweets trolling). As part of a group, Morgan described how they participated in a coordinated group effort (organized through Facebook) to troll a Twitter chat to ensure participants were getting the “right” information about breast cancer.

Morgan: “The WWEmoms was one. They were having a Twitter chat for breast cancer, so we jumped on their Twitter chat. Some of us got kicked out just for annoying them, because all we were doing is reiterating facts and asking questions. ‘So when is this going to be done?’, ‘What are your measurements?’, ‘What are your goals?’, ‘So where does this go?’, ‘What's going on?’. So again, we're not-- I wouldn't say we're malicious in any means. We're factual and we just ask questions.”

Using a coordinated effort to address “bad” information had the added benefit of drawing others in by increasing the visibility of the chat to the rest of their Twitter connections.

Morgan: “Other people see that and then people start chiming in. We get engaged with doctors and researchers who then get on our bandwagon and start it and get other people involved.”
Figure 7: Sample tweets of trolling

- Kathyskontests: “We're all aware guys, we need a cure. Don't ignore stage IV, #iamsusan #PinkPowerTODAY” 2015-10-02 07:48 AM
- Kathyskontests: “Calling serious bullshit on #NoBraDay Condescending and insulting to those of us who have lost out breasts to cancer. #GrowUpYouMorons” 2015-10-13 11:25 AM
- LuluChange14: “Taking your bra off on nobraday will not save a single one of the 1430 people who will die of #breastcancer today #521900EveryYear” 2015-10-13 11:24 AM

6.6.4 Theme Summary

Informants relied on anti-social tactics such as spamming, calling out, and trolling when fighting for what’s right. When used in the context of changing beliefs about cancer, informants viewed anti-social tactics as productive. Informants were not ashamed of wielding these tactics to draw attention to and support their cause because they were believed to be effective at correcting “bad” information. While their primary objective was to change problematic behaviour of others, these tactics also increased the visibility of the users who used them, even if only temporary. This temporary increase in positive attention validated the informants’ use of anti-social tactics by rewarding them for their use.

6.7 Chapter Summary

The findings of this study revealed that informants’ public use of Twitter helps them Construct Identity through Textual Selfies, Resist Social Death, Account for Time, Find Freedom in Obscurity, Create a Living Legacy, and Fight for What’s Right. Overall, informants described their use of Twitter as a positive experience that helped them express themselves authentically, thereby positively influencing how they were seen by themselves, other people, and society at large. Informants felt it was important to disclose their cancer on their Twitter biography because
it was a part of them, but they also recognized that there were other parts of themselves that they wanted to represent as well. Informants were aware that their Twitter use was public and could be seen by any Internet user, yet they felt it was one social space where they were free to express themselves as they chose because they did not feel their activities were under as much scrutiny as in other social situations. Though they felt a freedom in the perceived invisibility of their individual tweets, they perceived their visibility as something they could control. For example, they could easily get others’ attention as they wanted by mentioning other users or including a hashtag.
Discussion
Chapter 7: Discussion

I begin this chapter by describing the substantive contributions of this study in relation to the literature on Twitter use in cancer, liminality in cancer patients, and the needs of people living with cancer. Then I describe the methodological contributions this study has made to the literature namely in developing and testing new methods to research Twitter use, determining an effective and ethical method for recruiting interview participants on Twitter, and determining how to define Twitter as a research site to help navigate ethical protocol design and internal consistency. I end the chapter by discussing the limitations of this study design and suggesting some possible areas for future research.

7.1 Substantive Contributions

This study has begun to fill gaps in the literature on Twitter use among patients by providing some answers as to why patients tweet, what patients use Twitter for, and how Twitter’s technological affordances influence its use.

In Chapter 2: Background, I conducted two literature reviews and identified three deficits in how Twitter has been studied that have resulted in the following knowledge gaps: 1) tweets have largely been studied as if they are broadcast messages without asking why the author shared the tweet; 2) there have been no exploratory studies that examine why patients publicly use Twitter in the context of their health, and as a result, previous research has had a limited understanding of what patients use Twitter for; and 3) discussions of Twitter use among patients have not considered how the technology influences its use. The findings of this study provide some answers by suggesting that people living with advanced cancer tweet to declare “I’m still here”, their public use of Twitter can be an emotion-oriented coping tactic, and the technological affordances of Twitter counteract the inhibiting effects of living in a liminal state.
7.1.1 Why Did the Author Tweet?

Previous research on Twitter use in consumer health has focused on describing the content of tweets without attending to why the tweet was created in the first place. Sociologist Murthy (2012) suggests the act of tweeting is a proclamation of existence, regardless of the textual content or message contained within the tweet. In the context of people living with advanced cancer, Twitter use can be understood as a declaration that ‘I’m still here’: that they are still alive, they are still social, and they are still socially alive.

Tweet author @Lagedor49 used the phrase ‘I’m still here’ several times during the 4-month period of data collection. When I first saw them use it, just a few days into data collection, it struck me as an utterly profound statement. @Lagedor49’s joy was palpable, and yet the implications behind the tweet – that each day was not a given – felt heartbreaking to witness. Months later, Yuki used the phrase offhandedly while talking about their decision to publicly disclose their health status on Twitter.

Yuki: “<laughs> not to be morbid, but I wasn’t expected to live very long after I was diagnosed, so that sort of made the decision easy. I sort of saw it as only something that I was going to be doing for a short period of time. But then, I’m still here [emphasis added]...”

I could not ignore the powerful, multiple meanings hidden in these four simple words when coming from people who are one “test result away from experiencing the end of [their lives]” (Thompson, 2007).

‘I’m still here’ is a declaration, simultaneously directed to themselves and to others, that defies prevailing social beliefs that a diagnosis of advanced cancer means debilitating illness, withdrawal from society, and immediate death. At the most surface level in virtual environments, ‘I’m still here’ replaces visual cues to let others know they are still present behind the screen; in the context of advanced cancer, it can also serve to remind others that they are still alive, even if they are not visible in offline social situations. Interpreted another way, ‘I’m still here’ can be a reminder that they are more than their cancer diagnosis, that the aspects of themselves that
existed before their cancer diagnosis are still part of who they are, and that they still have a full
social life that includes hobbies, interests, family, friends, beliefs, and opinions. Interpreted in
yet another way, declaring ‘I’m still here’ serves as a beacon of hope to other cancer patients and
an inspiration to anyone and everyone by showing how they continue to live their best lives even
when facing devastating life circumstances. Public Twitter use gives people living with advanced
cancer the sense that they are being seen – by themselves, other people, and society at large – as
the complex and multi-faceted person that they are.

7.1.2 What do Patients Use Twitter For?

Previous research on Twitter has focused on how it can be used by cancer patients as a problem-
oriented coping tactic. Several studies have found that cancer patients use Twitter to ask for and
provide cancer-related information and psychosocial support (Tsyua et al., 2014; Sugawara et al.,
2014; Myrick et al., 2016), which can increase personal knowledge and decrease feelings of
anxiety (Attai et al., 2016). Cancer patients use both problem-oriented coping tactics and
emotion-oriented coping tactics when managing their disease (Thomsen, Rydahl-Hansen &
Wagner, 2010). Twitter’s use as an emotion-oriented coping tactic has been overlooked in the
literature, except for Taylor and Pagliari’s case study of a terminal cancer patient (2018). The
authors found that the patient under study used Twitter for emotion-oriented coping rather than
to solve problems, suggesting this may be related to the patient’s formal medical training (Taylor
& Pagliari, 2018). The findings from this thesis clarify that cancer patients’ use of Twitter for
emotion-based coping is widespread and not an artefact of patients’ medical knowledge or
training.

7.1.2.1 Twitter as a Microblog

Determining cancer patients use Twitter as an emotion-oriented coping tactic is not surprising
when one is reminded that Twitter can be conceptualized as a ‘microblog’. The literature on
blogging among cancer patients has shown how blogging is used as an emotion-oriented coping
tactic that shapes understanding of what it means to be a cancer patient at the intrapersonal,
interpersonal, and societal levels (McCosker & Darcy, 2012; Chiu & Hsieh, 2012; Odh et al.,
For cancer patients, blogging is an avenue where they can express themselves without inhibition, particularly when it comes to expressing emotions such as grief, anger, and frustration (Chiu & Hsieh, 2012; Odh et al., 2016). Patients struggle to make sense of their identity as the desire to live a ‘normal’ life compounds with the societal expectations placed upon them, and blogging can help them explore these tensions within themselves (Odh et al., 2016).

The public nature of a blog creates a perception of value to the author in that they feel by sharing their story they are potentially helping other cancer patients, both through the information shared and in creating a space where patients can share and express themselves (Chiu & Hsieh, 2012; Odh et al., 2016). In finding others who are receptive to their stories, cancer bloggers find a sense of belonging that can further encourage self-disclosure (King & Moreggi, 1998; Chiu & Hsieh, 2012; Odh et al., 2016). At a societal level, sharing intimate personal details in a public blog influences society’s understanding of cancer and its experiences, primarily through breaking the silence often associated with illness (McCosker & Darcy, 2012). The authentic, shameless, and open sharing of both the extremes and minutiae of life with cancer ‘pulls back the curtain’ for everyone to see (McCosker & Darcy, 2012). These benefits are common to Twitter use as well.

7.1.2.2 Different Technological Affordances

While there are similar benefits gained from blogging and Twitter use, the different technological affordances of each platform add nuance to their value and utility. First, tweets are inherently enmeshed with time. Indeed, the main mechanism for viewing tweets is the Timeline, a term that suggests a record of time past. Although the archive of past tweets exists indefinitely, the volume of tweets posted on a given day combined with the little attention given to most tweets creates an ephemeral feeling to tweeting, as though tweets disappear into the void almost as soon as they are created. Blog posts, on the other hand, are not as enmeshed with time as they can be back-dated, scheduled in advance, and revised at any time. In contrast to tweets, blog posts are understood as having a relatively constant presence that can be revised or altered at will.
Twitter’s character limit forces brevity and encourages spontaneity, while blog posts are usually written reflectively, after-the-fact, and can be revised at a later time. Throughout this manuscript I have argued that a tweet is analogous to a selfie; in generating an in-the-moment record of ‘What’s happening?’, tweets represent a snapshot of life at a particular time. Continuing with this analogy, blogs more closely resemble biographical accounts and, therefore, writing a blog is more akin to producing a self-portrait (an enduring projection of who one is). To create a tweet is to capture a moment; to create a blog post is to document (and revise) history.

Finally, Twitter use allows and encourages users to showcase multiple aspects of themselves through their tweets and the social interactions that take place. Blogging, on the other hand, is focused on a singular topic and centred around the author. Twitter gives users the opportunity to show multiple facets of one’s day-to-day life to the general public, allowing users to shape how they are seen by others. Social interactions are made public for a wide audience to witness through the use of replies, mentions, using hashtags, and quote tweets, and users can contact anyone else within the system. The singular, topic-focus of blogs do not easily allow for users to showcase multiple aspects of their personality. Interactivity on blogs are also relatively hidden because it usually occurs within the comment section of a specific blog post, severely limiting the potential audience. It is difficult, if not impossible, to use blogging as a means of contacting someone or getting their attention; it is only in the comments section where one can respond to a blog post and have the original author see it.

Through blogging and public Twitter use, people living with advanced cancer bring meaning to their illness and suffering, perceiving this exposure to be valuable to other people and society at large. When supported by their readers, expressing themselves without inhibition can bring greater sense of belonging and help them shape their personal understanding of what it means to be an advanced cancer patient. Twitter’s unique technological affordances, however, creates a different experience than what one experiences through blogging. In being enmeshed with time and encouraging spontaneity and in-the-moment expression, Twitter encourages users to post-then-reflect, while blogging encourages the opposite (reflect-then-post). In collapsing social
context into a singular profile, Twitter encourages users to represent the breadth of themselves, while blogging encourages users to delve deep into a singular aspect of their lives.

7.1.3 How do Twitter’s Technological Affordances Influence Its Use?

Apart from Myrick et al.’s (2016) study, the literature has not examined how the technological affordances of Twitter impact its use among people living with cancer. First, recall that Little et al. (1998) describe liminality in people living with cancer as having 3 aspects: 1) communicative alienation, or being unable to put experiences into words that are understood by others; 2) the feeling of boundedness, or being aware of limited time, space, and/or personal power; and 3) cancer patientness, or identifying as a cancer patient regardless of medical status. Recall also how Twitter use is exposed and searchable in being indexed on both Twitter and Google, has a low barrier to entry and use because it was mobile-by-design and has a restricted character count, encourages experimental following of others by allowing asymmetrical connections and interactions between any users within the system, and relies on human-mediated amplification for virality rather than using algorithms to determine what should be widely seen. Below I suggest the technological affordances of Twitter can be used to counteract the inhibiting aspects of liminality, by describing how the 6 themes of this study bridge the concepts of liminality and the technological affordances of Twitter to offer a possible explanation of its use among people living with advanced cancer. See Appendix L: Themes, Aspect of Liminality, and Technological Affordances for a table summarizing how these concepts connect to the themes.

7.1.3.1 Constructing Identity Through Textual Selfies

One aspect of the liminality cancer patients experience is ‘communicative alienation’, or the feeling that no one understands or can hear their experiences, which impacts patients’ abilities to express their feelings (Little et al., 1998; Thompson, 2007; Knox et al., 2016). Twitter use may counteract feelings of communicative alienation by encouraging people living with advanced cancer to explore themselves and their illness through creating textual selfies. The sheer volume of tweets posted and the resulting ephemeral feeling of posting a tweet create social norms of Twitter use that allow users to post candid or unformed/partially-formed thoughts as often as the
feeling strikes. The spontaneity and built-in brevity of a tweet encourages Twitter users to create ‘textual selfies’ that can help users see themselves from an outsider’s perspective, allowing them to see parts they may not have recognized before (Rutledge, 2013). Further, being able to freely express themselves in the moment, even if their thoughts are not fully formed, may help them achieve the critical distance necessary to make sense of their suffering (Frank, 1998).

7.1.3.2 Finding Freedom in Obscurity

At the interpersonal level, communicative alienation results in patients self-monitoring and/or self-censoring their emotions in an effort to protect the emotional wellbeing of their loved ones (Matheison & Stam, 1995; McKenzie & Crouch, 2004; Vilhauer, 2008; Thompson, 2007) or to prevent further estrangement (Charmaz, 1983). Patients need an available other to help them tell their story and, thus, make sense of their experiences (Frank, 1998; Mathieson & Stam, 1995; Thompson, 2007). Twitter use may counteract feelings of communicative alienation by being a place where patients can freely express their thoughts and feelings with fewer social consequences. Informants felt they could express themselves more authentically on Twitter than in other offline and online social environments. Certainly, this is in part because people feel less constrained to express themselves online than they do in offline contexts (Miller & Horst, 2013:15). Twitter users experienced further encouragement to express themselves authentically, however, because they felt invisible, either because they did not know their followers offline or because they were not a public figure.

The asymmetrical connections on Twitter result in users following strangers who share content of interest (Murthy, 2012). Twitter users can easily experiment with who to follow because public Twitter users have already granted blanket permission for any other Twitter user to follow them. As a result, public Twitter users end up accumulating followers who are interested in the content of their tweets rather than those who are following them because of other social obligations. Followers who are largely strangers, therefore, results in having a network with greater social distance between users (Granovetter, 1973). Previous research demonstrated that Twitter users whose networks had fewer shared connections with their followers expressed more emotions than those who had many shared connections with their followers (Kivran-Swaine &
While many Twitter users may not be anonymous, they feel disinhibited when their followers are not people they know in other contexts because there are few, if any, social consequences at stake.

Twitter users understand that their audience chooses what to pay attention to, and thus they feel that only those who are truly interested – be they strangers or known connections – will decide to follow and pay attention to their tweets. In this way, patients feel they are not burdening anyone by sharing their suffering as followers can come and go as they please. In telling their stories on Twitter, people living with advanced cancer find an ‘available other’, who may be unknown, that can better enable them to tell their story and make sense of their experiences (Frank, 1998; Mathieson & Stam, 1995; Thompson, 2007).

### 7.1.3.3 Accounting for Time

A second aspect of the liminal experience is the sense of boundedness, or being aware of their limited time, space and/or personal power (Little et al., 1998; Thompson, 2007). When the goals of cancer treatment shift from curative to managing and extending life, maintaining a good quality of life hinges on having meaningful experiences (Axelsson & Sjoden, 1998; Cohen et al., 1997; Odh, Löfving & Klaeson, 2016). Twitter use may counteract feelings of being bounded in time by creating a type of digital immortality.

Twitter’s constant prompt of ‘What’s happening?’ encourages users to document their time. For people living with advanced cancer, this prompt can serve as a constant reminder of their limited and bounded time, causing their underlying feelings about the passing of time to surface through their feelings about their Twitter use (as time wasted, time celebrated, or time borrowed). No matter how they felt about the passing of time, informants continued to use Twitter anyway, suggesting there is some value in tweeting independent of how one spends their time. As I stated earlier, the simple act of creating a tweet at any given time asserts ‘I exist’ (Murthy, 2012), and Twitter’s timestamp serves as tangible proof that one existed at a particular time. Past tweets represent the most accurate social media record of past experiences as tweets are not editable. Interview participants certainly recognized that their Twitter timeline allowed them to look into
their past. The Twitter timeline, however, also serves as an archival record of their existence, preserving their lived experiences indefinitely through digital immortality (Massimi & Charise, 2009). Their archived and searchable digital record could be used by others indefinitely, to learn from their experiences. While people living with advanced cancer feel their physical presence is bound in time, their Twitter use built a digital immortality that is unbounded.

7.1.3.4 Creating a Living Legacy

Another way people living with advanced cancer cope with boundedness is by creating a form of symbolic immortality through positively influencing how they will be remembered by those who survive them, often in the form of helping others (Nissim et al., 2012). Helping others is not a purely selfless act; in aiding another person, they earned a role that has meaning, value, and recognition, regardless of the value experienced by the receiver (Reissman, 1965; Nissim et al., 2012). Twitter use may further contribute to counteracting feelings of boundedness by helping to create a form of symbolic immortality by framing themselves as an inspiring role model or source of hope for others, beyond their known social circles. Twitter users can interact with any other user in the system. Further, they can tap into existing conversations by searching for keywords or using hashtags and replying at will. People living with advanced cancer used both of these technological affordances to spread their hard-won knowledge to others, in the hopes that it would prevent future hardships. In creating a symbolic immortality through their Twitter use, they created another avenue to experience unboundedness.

7.1.3.5 Resisting Social Death

A third aspect of the liminal experience is cancer patientness, or the constant feeling of being a cancer patient regardless of the medical situation (Little et al., 1998; Thompson, 2007). Cancer treatment and side effects can bring about periods of time when patients find it difficult to participate in regular daily activities, ultimately challenging one’s sense of self (Charmaz, 1983; Vilhauer, 2008; Adorno, 2015). Twitter use may counteract feelings of cancer patientness by enabling people living with advanced cancer to publicly resist social death, which may bring a
sense of reprieve from the realities of living with cancer by providing an available-yet-tenuous tether to ‘normal’ social life.

The Twitter persona represents multiple aspects of oneself in one profile, a concept called context collapse (Marwick & boyd, 2011). Users can control which aspects of their lives are represented on Twitter and choose how much to share of each. For example, Twitter allows users to mask, minimize, or maximize the visibility of their cancer at will, while continuing to participate in different social activities online. Twitter users can mask the effects of cancer by participating in social events or making social connections when they are physically unable or restricted to do so offline. Users can minimize their cancer by creating a Twitter persona that reflects multiple facets of the whole-self, where their cancer status is but one of many parts of them. Though all informants publicly acknowledged their cancer diagnosis in their Twitter biographies, most did not focus their Twitter use specifically on cancer and instead used the public social platform to represent their multiple (and dynamic) interests and to participate in events as they unfolded.

Twitter also served to partially fulfill the social needs of informants when it was difficult to fulfill these needs in other ways. Twitter’s mobility and built-in brevity creates a low barrier to entry and use and allows users to remain socially connected to some degree, regardless of whatever else is happening in one’s life.

7.1.3.6 Fighting for What’s Right

In living with advanced cancer, there are certain societal expectations regarding how one should behave. The social stigma surrounding death and the overwhelming focus on positive and uplifting cancer stories that dominate popular cancer discourse hinder patients’ abilities to express themselves, and surrounds patients in feelings of blame, regret, rejection, and being misunderstood (McKenzie & Crouch, 2004; Mayer, 2010; Danesh, Belkora, Volz & Rugo, 2014). Society’s expectations that cancer patients ‘fight’ to survive and maintain hope for a cure at all costs (Adorno, 2015) are not realistic standards, particularly for those to whom a cure is unavailable and slowing progression of disease is the only option. Twitter use may counteract
feelings of cancer patientness by giving people living with advanced cancer the space and voice to subvert these expectations by publicly maintaining hope for a life with meaning and fighting against misinformation and systematic injustices. Activities on Twitter are exposed to others, which can increase the reach of messages and serve as an invitation for spectators to join in on conversations. This exposure also opens up users to receiving social validation when others give them positive attention. In fighting for what’s right on Twitter, people living with advanced cancer aim to improve conditions for those living with advanced cancer (including themselves) by correcting behaviours and beliefs of society at large.

7.2 Methodological Contributions

This study contributes to the methods of studying Twitter by developing a new way to research Twitter use, advancing the ethics of Twitter research through finding an ethically-balanced and effective process for using Twitter to recruit interview participants, and positing three questions to define Twitter as a research site.

7.2.1 New Ways of Researching Twitter Use

Using ethnographic methods illuminated aspects of Twitter use that have gone unrecognized and unexplored in previous health research. Previous studies relying on content and/or social network analyses were only able to speculate as to why patients use Twitter. Attai et al.’s (2015) study of #bcsm use incorporated some informant feedback in their analysis, however, their study was not limited to cancer patients and instead focused on a specific community made up of various roles (e.g., patients, health professionals, supporters, etc.). Combining insights gained from content analyses of Twitter activity with patient perspectives from informant interviews allowed me to look at Twitter use from multiple angles and see a more holistic view of what Twitter use means to patients. The tweet extracts provided evidence of their activities, such as how often informants tweeted, what and how often they share about their personal health, and what other topics they share about. Speaking to Twitter users highlighted unseen aspects of their use, such as how their activities changed when they felt their tweets were under more scrutiny by others and choosing to be open about their cancer experience on Twitter so others who were interested could learn
from them. It also brought forward facets of their use that were unexpected, such as the importance of providing (rather than getting) support and the feeling that Twitter was more anonymous than other online social spaces. In moving beyond description (Hardin, 2014), this study has begun to identify how patients make meaning of their Twitter use.

7.2.2 Effective and Ethical Recruitment Using Social Media

Navigating the ethics of conducting health research on Twitter can be complex, and ethical concerns can result in developing a study design that is difficult to execute or, worse, not able to answer the research question. Though there is no one way to do ethical research on Twitter, I have developed an effective and ethical strategy for recruiting interview participants on Twitter that other researchers may find useful.

This study was the first to use Twitter as a tool for recruiting people living with advanced cancer for research interviews. Through several iterations, I was able to find a recruitment method that was fruitful while also minimizing the potential harm that could come to research participants by exposing their personal information. I was not able to recruit a single eligible informant within the first 4 months of using broadcast recruitment methods, despite the relative virality of my recruitment materials. Instead, directly contacting individuals who appeared to meet eligibility criteria using Twitter replies proved to be far more successful for recruiting the target population. I deleted any and all recruitment tweets I directed to potential informants 4 weeks after making contact in an effort to prevent ungoogling and help obscure interview participants’ identities. I leveraged Twitter’s inability to search the history of Twitter biographies (that is, the Twitter platform will only search current biography details) to further obscure and protect potential informants by generating a list of potentially eligible Twitter users on a single day, then contacting 5-10 per week after re-screening for eligibility over the course of several months. This process ensured I did not contact someone who no longer identified as living with advanced cancer while also preventing me from contacting the same user multiple times.
7.2.3 How to Define Twitter as Research Material

Through developing this research study, I had determined 3 important questions that helped me define Twitter as a research site. Having answers to these three questions helped me navigate the ethical issues raised in doing Twitter research, but also helped ensure I kept internal consistency throughout the study. Answering these questions could help other researchers with the same aspects of their studies.

Prior to designing this study, I put considerable thought into how I was defining Twitter data. Reviewing existing literature led me to 3 questions that I needed to answer to design an ethical protocol that maintained internal consistency throughout. First, I asked what Twitter represents as a research setting, focusing specifically on the public/private and published/unpublished dichotomies as these would impact my approaches to data collection and reporting. Consideration as to what the social norms of privacy, rather than simply what was actually accessible, helped to determine what would be understood as public at a societal level. Next, I asked what the Twitter profile represents in relation to the person creating it: personal data, an artistic representation, or an open source database. Finally, I asked what tweets represent as research materials, positing that they could be viewed as narratives, observational data, or documents, depending on what the research question was and how one chose to study tweets. I had not seen any literature that pulled these three questions together when discussing ethics of researching Twitter, nor did any study address these questions in their Methods sections. I found addressing these questions were essential for me to design an ethical protocol that remained internal consistency throughout the study.

This study conceptualized tweets as public and published, except for replies which were deemed private; the Twitter profile as an artistic representation of self; and tweets-as-research-materials as documents. This is the first study I am aware of to define tweets and the Twitter profile in such a way.
7.3 Limitations

While this novel approach to studying Twitter has offered new insights that could not have been found using other methods, there are limitations that must be acknowledged.

7.3.1 New Method of Study

First, the study design necessarily deviated from methods typically used in ethnography because of ethical concerns. Using active participant observation wherein one ‘behaves as’ a member of the group would have compromised the privacy and confidentiality of informants because of the public and searchable nature of tweets. Instead, I created a new type of study design that used private informant interviews in conjunction with reviewing public tweets to best protect informants’ ethical rights. In doing so, I was not able to have the full ethnographer experience, for example, because I was not able to build relationships with informants beyond the one-time interviews, nor was I able to test my ideas in the field or probe deeper into emerging areas of interest. As this was a new type of study design, I did not have the benefit of procedural insights from previous researchers, and thus the methods used created some unexpected challenges that had to be resolved, such as determining a fruitful and ethical strategy for recruiting interview participants and sampling within the tweet extracts to make the task of analysis manageable and meaningful.

7.3.2 Cross-Sectional Analysis

The length of time I spent collecting tweets was also relatively short for an ethnographic study, and therefore could not provide insight on how use (at the individual or group level) evolved over time. Taylor and Pagliari (2018) have shown that it is possible to link the Twitter narrative to a patient’s stage in the cancer illness trajectory, which suggests that there may be detectable changes in Twitter use over time. Given the volume of tweets extracted within the short timeframe, a longitudinal study of changes in Twitter use was not feasible without the assistance of enhanced computing (either by having a more powerful processor or using an algorithm to assist with analysis).
7.3.3 Focus on Tweeting as Use

Third, this analysis focused heavily on what and how one shares messages on Twitter. In using a Twitter list to manage tweet authors and relying on NCapture to collect tweets, there were only certain types of tweets and certain metadata fields available for analysis. Using the Twitter list allowed me to capture the original tweets and retweets of each tweet author, however I was not able to see the ‘replies’ between users except when they were both included on the list. This limitation meant I was not able to examine the social interactions between tweet authors and other Twitter users. Using NCapture was a simple and cost-effective way of extracting tweets on a regular basis and provided metadata such as number of times a tweet was retweeted, the date and time of the tweet, and the Twitter biography of the original tweet author. It did not, however, provide number of times a tweet was liked or replied to, meaning I was not able to fully assess how tweets were responded to by others. Further research on non- and less-visible aspects of Twitter such as lurking, searching, private messaging, and liking could complement this study and provide a deeper understanding of Twitter use.

7.3.4 Self-Selection of Interview Participants

Finally, recruitment of interview participants relied on self-selection, which resulted in a sample that skewed toward informants who had been living with their diagnosis for several years and been Twitter users for more than a year. In living with cancer for several years and being (at least) moderately familiar with Twitter, it is possible the perspectives of interview participants differ from individuals more recently diagnosed with cancer and/or new(er) to Twitter. This study does not, however, make claims of generalizability as it is not the goal of qualitative research.

7.4 Future Research

Conducting this ethnography led me to think of several research topics that could be worth pursuing in future studies. I detail some of my thought below.
7.4.1 Building More Knowledge on Twitter Use in Advanced Cancer

Conducting this research highlighted additional aspects of Twitter use and advanced cancer that could be expanded upon. Querying interview participants about their specific Twitter actions or contextualizing their understanding of their Twitter use with their collected tweet extracts could provide additional insight, beyond what this study has found. The self-selection of interview participants in this study led to recruiting a sample who were predominantly longer-term cancer patients and longer-term Twitter users. Developing a recruitment strategy to specifically target newer patients and/or newer Twitter users would add further nuance to the findings presented in this study. Similarly, developing a recruitment strategy to target lapsed Twitter users to better understand why they stopped using Twitter would provide further understanding into what people living with advanced cancer get (or do not get) from their Twitter use.

7.4.2 Using These Methods in Other Situations

The procedures developed in this study could also be used to explore Twitter use among other patient populations. Replicating this study with other chronic conditions such as non-advanced cancer, rheumatoid arthritis, diabetes, or mental health conditions would shed light on what aspects of Twitter use discovered in this study are universal versus which ones are specific to certain illness experiences.

7.4.3 Emergent Topics Uncovered During this Study

Through conducting this ethnography, I uncovered two research topics I find particularly interesting. The first topic is digital legacy, as discussed by Massimi and Charise (2009). The focus of this ethnography was on Twitter actions, but I did not explore informants' perspectives on their Twitter profile after they had died. It is worth exploring what people living with advanced cancer think about their Twitter use in relation to creating a digital legacy. For example, do they recognize their Twitter profile as a form of digital legacy? Have they thought about and planned what will happen to their Twitter account when they die? What do they think about someone reading their tweets years after they die?
The second topic of interest that surfaced during this research was a Twitter activity that I had not witnessed in my personal or professional use. Some Twitter users participate in what I will call "stock photo tweeting groups". Essentially, there are Twitter users who post what appear to be stock images, sometimes (but not always) including a text comment, and oftentimes mentioning other Twitter users. In some cases, I witnessed these tweets mentioning dozens of other Twitter users. Other Twitter users then reply to the tweet with another image, usually one that has some visual similarity to the original image (for example, if the original image was of a lion, replies may be other images of lions or other wild cats). Very little text was exchanged between users in the thread, creating opportunity for tweeting to cross language barriers. I find these groups fascinating and would like to learn more about why individuals participate and how they understand their participation.

7.5 Chapter Summary

Twitter allows people living with advanced cancer to declare “I’m still here” – to themselves, to others, and to society – in ways that other online social spaces do not. While previous research has explored Twitter use as a problem-solving tactic among cancer patients, this study supports the Taylor and Pagliari’s (2018) findings that Twitter can also serve as an emotion-oriented coping tactic. The findings of this study suggest the technological affordances of Twitter may allow people living with advanced cancer to counteract the inhibiting experiences of liminality. This study also contributes toward the methods of studying Twitter in that methods for collecting data were new, it found an effective and ethical strategy for recruiting interview participants on Twitter, and it developed 3 questions to help guide future researchers in defining Twitter in their studies. Finally, there were several limitations to this study. The necessary deviation from standard ethnography methods meant participant observation was not conducted, the length of time spent in the field was significantly shorter than most ethnographic research and I could not analyze changing use over time, using NCapture and a Twitter list to collect data limited what aspects of Twitter use could be analyzed, and the self-selection of interview participants resulted in a sample of longer-term cancer patients who had been active on Twitter for some time. As a result of my study, further research could be conducted to add further nuance to our
understanding of Twitter use among people living with advanced cancer, for example, by studying lapsed Twitter users to understand why they no longer use it or studying other patient populations to better understand which aspects of Twitter use are unique to people living with advanced cancer.
Chapter 8: Researcher’s Reflections and Conclusion

8.1 Reflections on Knowledge Gained

The findings in interpretive research are the researcher’s interpretations of participants’ responses (Scotland, 2012), and thus most of my knowledge gained in conducting this study is detailed in the Findings section of this manuscript. There were, however, a few bits of information I learned about Twitter use that did not fit directly into the analysis but are worth mentioning. I came to realize that Twitter use is paradoxical on several levels, it is incredibly diverse in its utility, and some of my assumptions of Twitter use based on my own experiences have proved to be incorrect. Each of these three topics are described in more detail below.

8.1.1 The Twitter Paradox

From a knowledge perspective, what struck me as most interesting in this study was how Twitter use was a paradox on several different levels, namely between how it feels to use Twitter and the reality of the technology. First, Twitter is somehow a social space where it feels safe to share one’s vulnerabilities while being nymous, even though users understand that their activities are exposed to anyone on the Internet. Second, the act of tweeting feels ephemeral – like putting a drop of water into a river, a tweet gets absorbed into the stream and disappears almost instantaneously – even though tweets are digitally archived and easily searchable through Twitter or Google. Finally, Twitter use somehow feels more authentic than other online social spaces, and yet users still self-censor and edit what they say before tweeting. Informants’ understanding of Twitter as a social environment contradicts the technological reality.

8.1.2 Exposure to Twitter Use I Had Not Witnessed Before

Conducting this study exposed me to Twitter users who I would not normally pay attention to, and this helped me recognize how insulated I had been with respect to the users I followed in my personal use. While I did not enjoy being subjected to the misogynistic and racists tweets of some users, there were others whose use intrigued me: one specific case was a user who
regularly retweeted visually stunning stock photos. Prior to beginning this study, most of the
users I followed on Twitter were related to my profession in some way; either they were former
#hcsmca members that I had connected with on a chat, or they were involved in health care and
social media in other ways. Since starting this study, however, I have expanded who I follow to
intentionally include people from different backgrounds and with different life experiences so I
could learn from perspectives beyond those I am exposed to in other areas of my life.

8.1.3 Challenged Assumptions on the Expectations of Twitter Use

Because of my experience using Twitter in a health and medical setting and my position working
in patient-centred services at a cancer centre, I began this study with certain expectations or
assumptions about informants’ experiences. Some of these assumptions were challenged through
this research.

I expected that recruiting interview participants would have been difficult as I assumed potential
interview participants would not think the value of this research was worth the effort it would
take to participate. While recruitment did prove to be a challenge, it was not for lack of interest
on behalf of the potential participants, but rather because the initial broadcasting recruitment
process was not sufficient to gain their attention. Once I adopted a process that targeted specific
Twitter users, I was much more successful in gaining recruits.

I had also assumed interview participants would have been Twitter users before their diagnosis
and that they would have felt some trepidation in disclosing their cancer diagnosis on Twitter.
Both expectations proved to be inaccurate. Interview participant Yuki, for example, signed up for
Twitter following their cancer diagnosis because other patients recommended a particular tweet
chat. While some interview participants may have experienced some hesitation in disclosing
their cancer diagnosis, both Pat and Lee explained that they could not feel like themselves
without being upfront about their diagnosis.

Based on my previous experience following people living with advanced cancer on Twitter and
the literature I had read, I expected to find that informants predominantly used their Twitter
profiles to talk about their cancer, gain support from other cancer patients, and build relationships with health professionals. I also assumed their Twitter use would be more personal in nature and not for professional gain. These assumptions were both challenged by a few interview participants and many tweet authors: there were many tweet authors who did not talk about their cancer at all; interview participant Jamie explicitly stated they did not follow other cancer patients; only four interview participants mentioned speaking to health professionals on Twitter (Morgan and Sam regularly connected with health professionals while Yuki and Jamie only mentioned connecting with them through tweet chats); and several tweet authors and interview participants Alex and Casey used Twitter (partially or fully) for professional gain. My expectations were built on the assumption that people living with advanced cancer somehow used Twitter differently than other Twitter users, however, their Twitter use is as diverse as any other group of people.

8.2 Reflections on Study Design and Methods

In general, I found the methods I used in this study to serve my purpose. Exploring Twitter use through collecting tweet extracts and conducting participant interviews was an effective way of exploring Twitter use more holistically while better maintaining informant confidentiality than what could have been done using participant observation.

The final interview recruitment strategy also proved to best balance ethical concerns with effective recruitment. Deleting recruitment tweets 4 weeks after approaching a potential informant was sufficient time for them to respond. Most email inquiries came within a week of me approaching a Twitter user, many of which came within two days. Collecting informed consent from interview participants verbally and documenting it in the interview transcripts reduced the burden of participation significantly, while also reducing the number of study files that contained information on informants’ identities.

Despite the general success of the methods used, there were some areas in which I would make changes if I were to conduct this type of study again. I would not use tweet activity to define an active account, I would strike a better balance on effort spent on each data collection method
used, and I would be more respectful of informants’ contributions. I discuss each of these changes in greater detail below.

8.2.1 Using Tweet Activity to Define an Active Account

In this study, I opted not to contact Twitter users who had not tweeted within the previous 30 days, partly because I felt a Twitter absence of this length likely suggested an account was abandoned and partly because I was concerned about burdening those who were unwell. This definition of active Twitter use proved to be completely arbitrary and did not serve as a reliable method for determining whether a Twitter account was active or not. In future studies, I would not use active accounts as an inclusion criterion for the tweet extracts nor as a screening method for potential interview participant recruitment.

First, defining active Twitter accounts as those that tweeted within the previous 30 days resulted in both false positives and false negatives, as I found out when reviewing the tweet extracts. For example, I detected a false positive when reviewing the tweet extracts of an author who tweeted once per week throughout data extraction. Upon examining their tweets, I discovered that their activity had come from an automated tweet service that had not been turned off, but otherwise the account had not been active. In doing a search for the username on Twitter, I could determine that the tweet author had died several months before I began my study. In terms of false negatives, there were 11 tweet authors with gaps of 30 days or more between tweets. These tweet authors could have falsely been screened as inactive.

Second, inactivity did not accurately reflect if someone was in the active dying phase of their illness. While my previous experience witnessing Alicia’s declining health led me to believe that people living with advanced cancer tweeted less as their health deteriorated, there were some tweet authors who proved this was not a universal situation and continued to tweet even when they were in hospice care. This finding is further supported by Taylor and Pagliari’s (2018) study of Kate Granger, who tweeted within the last hours of her life (GrangerKate, 2016).
Third, my concern about burdening someone with a 140-character tweet was unfounded. Tweets from strangers were generally not viewed as intrusive. In fact, some informants disclosed their cancer status in their Twitter biography with the expressed purpose of inviting strangers to learn about the cancer experience. Informants had ways of handling those Twitter strangers who were bothersome. A few interview participants mentioned getting unwanted attention from other Twitter users, but they simply ignored them or used Twitter’s block feature to prevent themselves from being bothered again. I took care not to contact a Twitter user more than once; that action alone was likely sufficient to ensure I was not burdening them.

Ultimately, people living with advanced cancer have agency and can decide for themselves if they are able to and want to participate in research or not. By setting an arbitrary definition of active Twitter use, I took some of that agency away from potential informants without gaining any methodological advantage.

8.2.2 Better Balance Effort Spent on Each Method

Combining insights from the tweet extracts with interview participants’ perspectives proved to be useful for exploring Twitter use beyond what could be determined using content or sentiment analyses alone. However, the amount of effort required to collect, review, clean, summarize, sample, and analyze the tweet extracts was not proportional to the insight they brought to this study. Participant interviews required less effort to conduct, resulted in richer insights, and allowed for probing deeper when statements were unclear. In future studies, I would place more focus on interviews and use tweet extracts as supporting, secondary materials.

While using a computer algorithm to analyze tweets would no doubt save time and effort, there is benefit to manually coding tweets. By manually coding tweet extracts I developed a strong sense of who tweet authors were (or at least who their Twitter personas were) and came to understand the context of their Twitter use. The process of collecting, cleaning, summarizing, and sampling tweets, however, may have been aided with the use of algorithms or computer modelling. For example, using a computer algorithm to generate and identify different Twitter personas based on linguistic characteristics in tweet authors’ profiles would present a much more
sophisticated way of sampling the tweet extract data, rather than relying on blunt criteria such as frequency of tweeting, number of followers, and level of anonymity. An algorithm could also cluster tweet authors based on similarities (such as topics they tweet about or their patterns of use) to better characterize the diversity (or lack thereof) among the sample of tweet authors. Using algorithms to assist with understanding the complete dataset could give a more sophisticated understanding of the data, allowing for better sampling while requiring less manual effort.

Speaking with informants gave me richer data and the opportunity to probe when statements or behaviours were unclear. Rather than spending as much time focusing on the tweet extracts, I would have liked to have continued doing more interviews, aiming to recruit a more diverse sample and evolving the line of inquiry to cover more aspects of use. I also feel my analysis would have benefitted from conducting multiple interviews with the same participants to follow up on topics from their initial interviews or to ask about emergent topics from interviewing other participants.

8.2.3 Being More Respectful of Informants’ Contributions

At the outset of conducting this research, I aimed to treat informants with the upmost respect and took care to reduce potential risks to their privacy and confidentiality. While all procedures used during this study were approved by the University of Toronto’s Research Ethics Board, there were some aspects that were not respectful to informants. If I were to use these procedures again, I would ask tweet authors for permission to study their tweets, give interview participants the option to be interviewed (and credited) as subject matter experts, and provide regular updates on the study progress through a research blog.

Covert research of online social spaces has been rightly criticized for being voyeuristic and opportunistic (Eysenbach & Till, 2001; Elgesem, 2002; Moreno, Fost & Christakis, 2008; Heilferty, 2011; McKee 2013). Although I had the best intentions, some tweet authors may not have wanted their activities to be scrutinized and re-published. While this was not an ethical issue per se, asking tweet authors for permission to use their data would have addressed my
concerns about re-publishing their tweets without consent and I would have felt more comfortable freely sharing tweets within the manuscript. In future studies like this one, I would include a step, likely after collecting tweets but before beginning the analysis, to ask tweet authors for their permission to study and reproduce their tweets.

The interview participants offered valuable insight into Twitter use and advanced cancer that would have been difficult to solicit using non-interview methods. Knowing now how important it was for informants to share their experiences as a means of helping others, I would have liked to have explicitly offered interview participants the option to be treated as subject matter experts and be credited for their contributions. In the final recruitment strategy, I had revised the informed consent form to provide instructions should an informant want to be credited with their name or Twitter name throughout the study. I did not explicitly ask any interview participant if they would like to take that offer and, by default, interview participants’ data were anonymized and given pseudonyms. Giving them the option to be credited as a subject matter expert or to participate anonymously allows informants to be in control of their ideas and their representation.

Finally, it has been close to 3 years since I began collecting data for this study, and over 2 years since I spoke to the first interview participants. In the time since, I have shared very little in terms of the ongoing work or progress I have been making on Twitter or my personal blog. Twitter users who helped circulate my initial recruitment blog post and potential interview participants who have contacted me via email had expressed interest in my study and wanted to be kept informed about its progress. I worry that by not sharing regular progress updates, some informants and interested individuals assumed I abandoned the project. In hindsight, I would have liked to have had a dedicated blog (or, perhaps more fittingly, a Twitter account) to share regular updates about the project as a means of keep those who were interested informed on what has been happening behind the screen.
8.3 Conclusion

This thesis explored the public use of Twitter among people living with advanced cancer. Through two literature reviews, I uncovered three questions that I aimed to address: 1) why do patients create tweets; 2) what do patients use Twitter for; and 3) how do the technological affordances of Twitter influence its use? I found that people living with advanced cancer tweet to proclaim their existence to themselves, other people, and society at large. Much like blogging, patients use Twitter as an emotion-oriented coping tactic, however, the different technological affordances mean that Twitter users tweet-first-then-reflect, while bloggers reflect-first-then-blog. And finally, I found Twitter’s technological affordances may help people living with advanced cancer counteract the inhibiting experiences of liminality.

My work contributes to the literature on public Twitter use by patients by expanding our understanding of what patients use Twitter to achieve. Previous research has established that patients use Twitter to solve problems such as find health information or peer support. This study demonstrates that patients use Twitter for other reasons as well, such as to better understand themselves, to change how society understands advanced cancer patients, and to create digital and symbolic immortality for themselves. In considering why patients publicly tweet, this study provides some evidence that tweeting is meant to draw attention to the user and assert their existence. This is a shift in thinking from previous studies that have placed the value of a tweet in the content of the message. These contributions may be of interest to health professionals who are considering using Twitter as part of their program or research study as it expands the foundational understanding of why patients use Twitter to include activities beyond acquiring support or information.

My work also contributes to the literature on methods for conducting health research on Twitter by offering a new model for studying Twitter that includes patient perspectives in an ethically-balanced and effective way. Combining insights gained from reviewing tweets and interviewing Twitter users provided depth and breadth toward understanding Twitter use. I have successfully negotiated an effective and ethically-balanced approach to recruiting interview participants on Twitter. In combing the literature, I have determined 3 key questions regarding defining Twitter
as a research site that can assist with designing a consistent and ethical research design. These contributions may be of interest to other researchers who are interested in using Twitter to recruit and/or collect data as part of their research to help them design and execute a study with less experimentation to determine what works.
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Appendices
Appendix A: Search Strategy for Tweet Extract Authors

As more people may identify themselves as living with advanced cancer over time, we will conduct a search every two weeks and add any new users to our private list using the following process:

1. Primary investigator will log in to Twitter.
2. Using the search bar, the investigator will search for a relevant keyword (see list below).
3. Primary investigator will click on “Accounts” filter to show only accounts using the keyword searched.
4. All public accounts that do not represent an organization will be added to the private Twitter list named “Pay Attention 2”. This non-descriptive list name was purposely chosen to avoid obvious identification should the Twitter account become compromised.

Twitter is an evolving platform and new search terms or hashtags may arise throughout the duration of the study. Those currently known to be relevant to the incurable cancer population include:

- #metsMonday
- #dontIgnoreStageIV
- #mbc (for Metastatic Breast Cancer)
- #mbcaware
- #mayacc (for Metastatic Adolescent Young Adult Cancer Community)
- #bcmets
- #metastasis
- #mmsm (for Multiple Myeloma Social Media)
- #lifer
- #livingcondensed
- metastatic
- stage 4 / stage IV
- incurable cancer
- cancer lifer
- multiple myeloma
- terminal cancer
Appendix B: Tweet Extracts Data Cleaning

1. Exported NVivo NCapture data to Microsoft Excel to allow for data manipulation.

2. Removed any rows with a duplicate Tweet ID (deduped tweets to ensure they weren’t counted multiple times).

3. Created an “Informant” column to easily see all activity by each informant.
   a. Copied information in “Retweeted By” for tweets that were Retweets, then hid the “Retweeted By” column.
   b. Copied “Username” for original tweets.

4. Used the Excel function “Convert to Number” on the “Number of Retweets” column so the data could be manipulated as a number rather than a string of text.

5. Deleted any tweets appearing in the dataset that were created outside of September 9, 2015 to January 8, 2016 (162 tweets).

6. Deleted 532 tweets that were the result of a third-party app malfunction; the same message was posted a total of 533 times over a 25-hour period (approximately one every 3 minutes) because of an error with a third-party tool (November 21/22).

7. Deleted all data that originated from users who were included in the sample by error (i.e., they did not meet the inclusion criteria; 2432 tweets from 4 users).

8. Removed tweets that were from users who removed inclusion factors from their profile partway through the study.
Appendix C: Tweet Extracts Informants

Tweet authors selected for in-depth analysis are **bolded in orange**.

**Full anonymity**

Profile does not contain a name, their username does not appear to be derived from their name, and they do not use a personal photo in their profile.

<table>
<thead>
<tr>
<th>Twitter Users on List</th>
<th>Tweets posted per day¹</th>
<th>Percent original tweets</th>
<th>Percent retweets</th>
<th>Followers at beginning of study²</th>
<th>Following at beginning of study²</th>
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¹ rounded to the nearest whole number
² rounded to the nearest 100

**Partial anonymity**

Username and/or name in profile and/or display photo appears to be partially representative of their true identity.

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<th>Twitter Users on List</th>
<th>Tweets posted per day¹</th>
<th>Percent original tweets</th>
<th>Percent retweets</th>
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1 rounded to the nearest whole number
2 rounded to the nearest 100

**No anonymity**

Username and name in the profile appear to represent their offline identity.
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<td>881</td>
</tr>
<tr>
<td>Informant56</td>
<td>2</td>
<td>22.0%</td>
<td>78.0%</td>
<td>200</td>
<td>467</td>
</tr>
<tr>
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<td>1</td>
<td>20.3%</td>
<td>79.7%</td>
<td>500</td>
<td>274</td>
</tr>
<tr>
<td>Twitter Users on List</td>
<td>Tweets posted per day(^1)</td>
<td>Percent original tweets</td>
<td>Percent retweets</td>
<td>Followers at beginning of study(^2)</td>
<td>Following at beginning of study(^2)</td>
</tr>
<tr>
<td>----------------------</td>
<td>-----------------------------</td>
<td>-------------------------</td>
<td>-----------------</td>
<td>--------------------------------------</td>
<td>--------------------------------------</td>
</tr>
<tr>
<td>Informant58</td>
<td>1</td>
<td>47.6%</td>
<td>52.4%</td>
<td>2 400</td>
<td>603</td>
</tr>
<tr>
<td>Informant59</td>
<td>1</td>
<td>19.7%</td>
<td>80.3%</td>
<td>700</td>
<td>1127</td>
</tr>
<tr>
<td>Informant60</td>
<td>&lt;1</td>
<td>86.2%</td>
<td>13.8%</td>
<td>700</td>
<td>561</td>
</tr>
<tr>
<td>Informant61</td>
<td>&lt;1</td>
<td>70.6%</td>
<td>26.5%</td>
<td>300</td>
<td>238</td>
</tr>
<tr>
<td>Informant62</td>
<td>&lt;1</td>
<td>76.7%</td>
<td>20.0%</td>
<td>700</td>
<td>446</td>
</tr>
<tr>
<td>Informant63</td>
<td>&lt;1</td>
<td>91.3%</td>
<td>8.7%</td>
<td>300</td>
<td>162</td>
</tr>
<tr>
<td>Informant64</td>
<td>1</td>
<td>46.7%</td>
<td>50.0%</td>
<td>500</td>
<td>1388</td>
</tr>
<tr>
<td>Informant65</td>
<td>&lt;1</td>
<td>46.4%</td>
<td>42.9%</td>
<td>300</td>
<td>423</td>
</tr>
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<td>Informant66</td>
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<td>71.4%</td>
<td>200</td>
<td>173</td>
</tr>
<tr>
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<td>21.4%</td>
<td>38.1%</td>
<td>500</td>
<td>406</td>
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<tr>
<td>Informant68</td>
<td>&lt;1</td>
<td>100.0%</td>
<td>0.0%</td>
<td>300</td>
<td>486</td>
</tr>
<tr>
<td>Informant69</td>
<td>&lt;1</td>
<td>30.8%</td>
<td>69.2%</td>
<td>400</td>
<td>592</td>
</tr>
<tr>
<td>Informant70</td>
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<td>63.6%</td>
<td>36.4%</td>
<td>17 000</td>
<td>251</td>
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<tr>
<td>Informant71</td>
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<td>100.0%</td>
<td>0.0%</td>
<td>300</td>
<td>80</td>
</tr>
<tr>
<td>Informant72</td>
<td>&lt;1</td>
<td>66.7%</td>
<td>33.3%</td>
<td>900</td>
<td>1807</td>
</tr>
<tr>
<td>Informant73</td>
<td>&lt;1</td>
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<td>0.0%</td>
<td>500</td>
<td>256</td>
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<tr>
<td>Informant74</td>
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<td>10.2%</td>
<td>89.8%</td>
<td>1 800</td>
<td>1066</td>
</tr>
<tr>
<td>Informant75</td>
<td>&lt;1</td>
<td>55.6%</td>
<td>44.4%</td>
<td>3 800</td>
<td>819</td>
</tr>
<tr>
<td>Informant76</td>
<td>&lt;1</td>
<td>100.0%</td>
<td>0.0%</td>
<td>600</td>
<td>1995</td>
</tr>
<tr>
<td>Informant77</td>
<td>&lt;1</td>
<td>25.0%</td>
<td>75.0%</td>
<td>2 300</td>
<td>1031</td>
</tr>
<tr>
<td>Informant78</td>
<td>&lt;1</td>
<td>8.0%</td>
<td>92.0%</td>
<td>300</td>
<td>671</td>
</tr>
<tr>
<td>Informant79</td>
<td>&lt;1</td>
<td>18.2%</td>
<td>81.8%</td>
<td>300</td>
<td>186</td>
</tr>
<tr>
<td>Informant80</td>
<td>&lt;1</td>
<td>66.7%</td>
<td>33.3%</td>
<td>1 700</td>
<td>924</td>
</tr>
<tr>
<td>Informant81</td>
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<td>100.0%</td>
<td>0.0%</td>
<td>1 200</td>
<td>354</td>
</tr>
<tr>
<td>Informant82</td>
<td>&lt;1</td>
<td>5.3%</td>
<td>94.7%</td>
<td>500</td>
<td>281</td>
</tr>
<tr>
<td>Informant83</td>
<td>&lt;1</td>
<td>100.0%</td>
<td>0.0%</td>
<td>500</td>
<td>715</td>
</tr>
<tr>
<td>Informant84</td>
<td>&lt;1</td>
<td>100.0%</td>
<td>0.0%</td>
<td>1 900</td>
<td>2050</td>
</tr>
</tbody>
</table>
1 rounded to the nearest whole number
2 rounded to the nearest 100
Appendix D: Recruitment Blog Post

Why do you tweet about your health? [research study]

JANUARY 31, 2016

I am looking to interview people living with advanced, metastatic, stage IV or chronic cancer who use Twitter to talk, listen, learn, and/or share updates about their health. Please share a link to this post on your Twitter, Facebook, or blog accounts.

Purpose

Under the supervision of Dr. David Wiljer, this study aims to explore Twitter use among people living with metastatic, advanced, and chronic cancers, and what that means in the lives of those living with a diagnosis.

This study is being conducted by Alaina Cyr to complete a thesis as part of the requirements for earning a master’s degree in Health Services Research at the Institute for Health Policy, Management, & Evaluation at the University of Toronto.

What does participation involve?

Participation involves:

- one 25- to 40-minute interview by telephone or Skype (your choice)
- having a conversation about what role, if any, Twitter plays in helping you share your experience, make sense of your diagnosis, and define yourself

You can decide to end your participation at any time, or skip a question should you wish to do so.

Who can participate?

We are looking for volunteers who:
are living with a metastatic, stage IV, advanced, or chronic cancer diagnosis
use Twitter to talk, learn, or share updates about your health
can speak and read English
are 18 years old or over

How will my information be used?

All information collected in this study will be held in strict confidence. Your personal information will only be accessible to the investigator, Alaina Cyr. All files will be saved with code names and stored in an encrypted folder. Your identifying information will not be used in any publication or presentation. Identifying information includes things like your name and the names of other people, cities, and hospitals.

This research study is being conducted at the Institute for Health Policy, Management, and Evaluation at the University of Toronto, and is not affiliated with a cancer treatment centre. Your decision to participate or not participate will not impact your clinical care.

For more information or to volunteer:

Contact Alaina Cyr at [email address] for more information about this research study.

If you have questions about your rights as a participant, please contact the Research Oversight and Compliance Office – Human Research Ethics Program at ethics.review@utoronto.ca or 416-946-3273.

This research study was reviewed and approved by the Research Ethics Board at the University of Toronto.

To prevent disclosure of personal information, please note that comments must be approved before they appear below.
Appendix E: Sample Recruitment Tweets

1. What does all this tweeting about health really mean? Expanding our understanding of Twitter & disease [study] http://url/
2. What does all this tweeting about health really mean? [study] http://url/ Please RT
3. Expanding our understanding of Twitter & disease [study] http://url/ Please RT
5. How is “healing” experienced on Twitter? Help me find out by RT & visiting this link [study] http://url/
6. Help expand our understanding of Twitter & disease. RT & visit this link for more info [study] http://url
15. What does all this tweeting about health really mean? [study] http://url/ Help expand our understanding. Pls RT
17. Why do so many people turn to Twitter to talk about their health? Help me learn more [study] http://url/
19. Unanswered questions about Twitter & health: How does it impact life “offline”? [study] 
   http://url/

20. Unanswered questions about Twitter & health: Does it help with healing? [study] 
   http://url/


24. How do you use Twitter for your health? [study] Please RT
Appendix F: Hashtags Used for Recruitment Tweets

Where appropriate, hashtags will be added to the end of the messages to help increase visibility.

**General health hashtags:**
- #hcsmca (health care social media Canada)
- #hcsm (health communications social media)
- #hcldr (health care leaders)
- #hcsmanz (health care social media Australia/New Zealand)
- #carechat (caregiver's chat)
- #hcsmuk (health care social media United Kingdom)
- #hclitss (health communication health literacy and social sciences)

**Disease-specific hashtags:**
- #bcsmsm (breast cancer social media)
- #mayacc (metastatic adolescent young adult cancer community)
- #lcsm (lung cancer social media)
- #gyncsm (gynecologic cancer social media)
- #gwcancers (global women's cancers)
- #bccww (breast cancer chat world wide)
- #mmsm (multiple myeloma social media)
- #crcsm (colorectal cancer social media)
- #hcchat (hereditary cancer chat)
- #advancedBC (advanced breast cancer)
- #metastaticBC (metastatic breast cancer)
- #ayacsm (adolescent and young adult cancer societal movement)
Appendix G: Strategy for Recruiting Interview Participants

Process for Identifying Potential Informants

1. On one day during the data collection phase of the study, the investigator will log in to Twitter.
2. Using the search bar, the investigator will search for a relevant keyword (see list below).
3. Investigator will click on “Accounts” filter to show only user profiles using the keyword searched.
4. Investigator will record the usernames of all public accounts that do not represent an organization and save the list in an encrypted excel file.
5. Investigator will repeat steps 2-4 with the remaining keywords, adding all usernames that are not already on the list.
6. Using excel, a random number will be assigned to each username, then the list sorted by that random number to determine the order in which users will be screened and contacted.

Process for Contacting Potential Informants

1. Investigator will open the list of potential informants.
2. Investigator will view the Twitter profile of the first Twitter user on the list.
3. Investigator will screen the account for activity:
   a. If the user has posted at least one tweet or retweet in the past 30 days, they will be contacted.
   b. If the user has not posted in the last 30 days, they will be marked as ‘inactive’ and the investigator will return to Step 2 with the next username on the list.
4. Investigator will send a tweet to the Twitter user:
   “[@username] I’d like to interview you for a research study http://url_blog2/. Pls email [email address] for more info”
5. Investigator will record the date the user was contacted in the excel spreadsheet.
6. Investigator will proceed down the list of potential informants, following steps 2-5 until 10 users have been contacted.
7. Four weeks later, the contact tweet will be deleted from the investigator’s timeline, and the date the tweet was deleted will be recorded in the excel spreadsheet.

8. Steps 1-7 will be continued once a week, proceeding down the list of potential informants, until interview saturation has been reached.

   a. If all users on the potential informants list have been screened and contacted and interview saturation has not been reached, the investigator will begin the Process for Identifying Potential Informants again, adding new usernames to the excel spreadsheet, then continuing on to the Process for Contacting Potential Informants.

Keywords

Twitter is an evolving platform and new search terms or hashtags may arise throughout the duration of the study. Those currently known to be relevant to the incurable cancer population include:

- #metsMonday
- #dontIgnoreStageIV
- #mbc (for Metastatic Breast Cancer)
- #mbcaware
- #mayacc (for Metastatic Adolescent Young Adult Cancer Community)
- #bcmets
- #metastasis
- #mmsm (for Multiple Myeloma Social Media)
- #lifer
- #livingcondensed
- Metastatic
- stage 4
- incurable cancer
- cancer lifer
- multiple myeloma
- terminal cancer
Appendix H: Interview Guide

Thank you for agreeing to take part in this interview about your use of Twitter. If at any time you feel uncomfortable or do not wish to speak about a particular topic, please let me know and we will move on to another topic.

Everything we discuss today will be kept confidential. A tape-recorder will be used if you don’t mind to ensure that I have accurately captured what you have said. The tape recorder can be stopped at any time; just let me know if you'd like it to be stopped.

The purpose of our conversation today is to learn more about your experience using Twitter in relation to your disease. Have you had a chance to review the study information that I sent to your email? Do you have any questions or concerns before we start our discussion?

Informed Consent Confirmation

Before we start the interview questions, I need to confirm a few things with you.

1. Please confirm that you have received a copy of the Study Information Letter *(prompt: the PDF document that answered 11 questions about this study)*)?

2. Please confirm that you have had the opportunity to discuss this study with me, and have had all your questions answered to your satisfaction.

3. Please confirm that you consent to take part in this study, with the understanding that you can withdraw at any time without consequences.

*If interview participant had requested to be referred to by name in the publication:*

1. I understand you’d like to be referred to as [preferred name] in any quotes from this interview that are used in publications or presentations resulting from this study, is that correct?

2. And you understand and accept that there may be risks (like loss of privacy or reputation, or feeling embarrassed or upset) by disclosing your name in this study?

Sample Questions

**Use of Twitter**

1. When did you start using Twitter? ...in relation to your health?

2. How often would you say you use Twitter? … in relation to your health?
3. How has your use of Twitter changed over time? … since learning of your diagnosis?
4. What types of messages (thoughts, feelings, ideas, information) do you share on Twitter?
   a. Probe: Can you give me an example of that?
   b. Probe: What else?
5. How do you think an outside observer might describe your tweet stream?
6. In general, how do you use Twitter? In general, what role does Twitter play in your daily life? … what does using Twitter mean to you?

Impact & Experience

1. Looking back at your use of Twitter since you began using it in the context of your health, in what ways, if any, has being on Twitter affected your thoughts about your disease?
2. Would you say, in general, that using Twitter to talk about your disease has been a positive or negative experience?
   a. Probe: Can you tell me more about that?
   b. Probe: Can you tell me about a time when something (positive/negative) happened?
3. In what ways, if any, has being on Twitter changed you? … changed how you think about your disease?
4. Has using Twitter in the context of your disease changed how you see yourself since you were first diagnosed?
   a. Probe: Can you tell me more about that?
5. Looking back since you began using Twitter in the context of your health, in what ways, if any, has being on Twitter affected how you see yourself in relation to others?

Wrap-up

1. What made you want to participate in this interview?
2. Is there anything you'd like to share that I didn't ask that you think is relevant to this study?

Closing Statements

Thank you again for taking the time to talk with me today. You may find, in the days or weeks to come, that our conversation has brought up thoughts and feelings that are troubling to you. If you
find yourself in need of support, please speak to a member of your health care team like a nurse or social worker. You can also access online support from websites. [Information below will be provided based on informant’s details, as obtained during the interview, as appropriate]

- Canada: CancerChatCanada.ca has professionally-led online support groups. You can also read or sign up for the Canadian Cancer Society’s forum CancerConnection.ca to connect with others who may be in a similar situation.

- United Kingdom: Macmillan Cancer Support offers a free phone service (0808 808 0000) and also an online community. Visit macmillan.org.uk and click on the “Online Community” tab in the top navigation bar.

- United States: The Cancer Support Community at cancersupportcommunity.org has a counselor hotline (888-793-9355), an online forum, and an instant chat available.

- Australia: Cancer Council Australia offers telephone support groups and an online support community. Call them at 13 11 20, or visit cancer.org.au and click on the About Cancer tab.

- Breast Cancer: Visit the Metastatic Breast Cancer Network at mbcn.org and click on the Support Resources tab to find a list of supports specific to metastatic breast cancer.

- If none of the above are applicable: The Association of Cancer Online Resources has links to online communities for all types of cancers. You can find the list by visiting acor.org.
Appendix I: Guide for Informants in Distress (Interviews)

Let's take a break from the interview. I've turned off the tape recorder and I will not take any notes. We'll only start up again when you let me know you're ready, OK?

Other prompts, as appropriate:

- I'll stay on the phone as long as you'd like.
- We can reschedule the rest of our conversation for another time.
- I can hear that you're having a hard time right now and I want to make sure you have the appropriate clinical and professional support that you need at this time.
- Is there someone you trust there with you? Or someone nearby that you can call?
- Is there someone on your health care team that you can call, like a social worker or a psychologist?
- Would you be open to calling a distress hotline or your local emergency services?

You can find your local distress hotline by calling the operator and asking for a distress hotline.

<table>
<thead>
<tr>
<th>Common Regions</th>
<th>Emergency Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobile Phone (any)</td>
<td>911 or 112</td>
</tr>
<tr>
<td>Canada</td>
<td>911</td>
</tr>
<tr>
<td>United States</td>
<td>911</td>
</tr>
<tr>
<td>Europe</td>
<td>112 or 999</td>
</tr>
</tbody>
</table>

List of emergency telephone numbers around the world:
## Appendix J: Summary of Interviews

<table>
<thead>
<tr>
<th>Interview Participant</th>
<th>Length of Interview (mm:ss)(^5)</th>
<th>Time since first twitter use(^6)</th>
<th>Time since first advanced cancer diagnosis(^7)</th>
<th>Time since disclosing their cancer diagnosis on Twitter*</th>
<th>Delay in disclosing their status *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alex</td>
<td>37:30</td>
<td>7-8 years</td>
<td>n/a</td>
<td>n/a</td>
<td>1 year</td>
</tr>
<tr>
<td>Casey</td>
<td>34:30</td>
<td>8 years</td>
<td>6 years, 7 months</td>
<td>6 years</td>
<td>8 months</td>
</tr>
<tr>
<td>Jamie</td>
<td>38:30</td>
<td>8 years</td>
<td>2 years, 1 month</td>
<td>1.5 years</td>
<td>7 months</td>
</tr>
<tr>
<td>Kris</td>
<td>30:00</td>
<td>5 years</td>
<td>n/a</td>
<td>1.5 years</td>
<td>n/a</td>
</tr>
<tr>
<td>Lee</td>
<td>52:10</td>
<td>7 years</td>
<td>1 year, 4 months</td>
<td>1 year, 4 months</td>
<td>0 months</td>
</tr>
<tr>
<td>Morgan</td>
<td>28:40</td>
<td>4 years</td>
<td>6 years</td>
<td>4 years</td>
<td>Disclosed at sign-up</td>
</tr>
<tr>
<td>Pat</td>
<td>39:20</td>
<td>5 years</td>
<td>3 years</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Robin</td>
<td>39:40</td>
<td>7-8 years</td>
<td>1 year, 3 months</td>
<td>1 year, 2 months</td>
<td>1 month</td>
</tr>
<tr>
<td>Sam</td>
<td>34:00</td>
<td>6 years</td>
<td>8 years</td>
<td>6 years</td>
<td>Disclosed at sign-up</td>
</tr>
<tr>
<td>Yuki</td>
<td>25:10</td>
<td>2.5 years</td>
<td>n/a</td>
<td>2.5 years</td>
<td>Disclosed at sign-up</td>
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<tr>
<td><strong>AVERAGE</strong></td>
<td><strong>36:00</strong></td>
<td><strong>6 years</strong></td>
<td><strong>4 years</strong></td>
<td><strong>3.25 years</strong></td>
<td><strong>3.5 months</strong></td>
</tr>
</tbody>
</table>

\(^5\) Based on length of audio recording.

\(^6\) Any Twitter use, not necessarily their cancer-related account; value is approximate

\(^7\) Not formally part of line of inquiry. First advanced cancer diagnosis, not necessarily their first cancer diagnosis.
## Appendix K: Coding Schemas Mapped to Themes

<table>
<thead>
<tr>
<th>Theme</th>
<th>Code from Interviews</th>
<th>Code from Tweet Extracts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Constructing Identity Through Textual Selfies</strong></td>
<td>Sharing suffering</td>
<td>Strangers</td>
</tr>
<tr>
<td></td>
<td>Distress</td>
<td>Cancer experience</td>
</tr>
<tr>
<td></td>
<td>Getting thoughts out there</td>
<td>Death</td>
</tr>
<tr>
<td></td>
<td>Life changes</td>
<td>Grief</td>
</tr>
<tr>
<td></td>
<td>Processing thoughts and feelings</td>
<td>Selfie (photo)</td>
</tr>
<tr>
<td></td>
<td>Identifying with others</td>
<td>Subtweeting</td>
</tr>
<tr>
<td></td>
<td>Affirmation</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Confronting death and illness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Subtweeting</td>
<td></td>
</tr>
<tr>
<td><strong>Resisting Social Death</strong></td>
<td>Feel normal</td>
<td>Alone</td>
</tr>
<tr>
<td></td>
<td>Cancer is only part of me</td>
<td>Checking in on friend</td>
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<td></td>
<td>Social participation</td>
<td>Greeting</td>
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<td>Isolation</td>
<td>Thanking someone</td>
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<td></td>
<td>Entertainment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cooking and food</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Art</td>
</tr>
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<td></td>
<td></td>
<td>Game</td>
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<td></td>
<td></td>
<td>Humour</td>
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<td>Memes</td>
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<td></td>
<td></td>
<td>Quiz</td>
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<td></td>
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<td>Religion</td>
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<td><strong>Accounting for Time</strong></td>
<td>Time wasted</td>
<td>Time celebrated</td>
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<td></td>
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<td>Time borrowed</td>
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<tr>
<td></td>
<td>Time borrowed</td>
<td>Cancer stats</td>
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</table>

155
<table>
<thead>
<tr>
<th>Theme</th>
<th>Code from Interviews</th>
<th>Code from Tweet Extracts</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Keeping others informed of the present</td>
<td>Current events</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Personal update</td>
</tr>
<tr>
<td>Finding Freedom in Obscurity</td>
<td>Imagined audience</td>
<td>Posting anonymously</td>
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<td>Censorship and privacy</td>
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<td>Disclosure</td>
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<td>Authenticity</td>
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<td>Freedom to experiment</td>
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<td>Creating a Living Legacy</td>
<td>Being open</td>
<td>Advice for others</td>
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<td>Helping others</td>
<td>Inspiring message</td>
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<td>Selflessness</td>
<td>Supporting other cancer patients</td>
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<td>Mentoring others</td>
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<td>Insider knowledge</td>
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<td>Advice</td>
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<td>Everyone is always excited about living vicariously through me</td>
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<td>Inspiration to healthy people</td>
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<td>Questionable followers</td>
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<td>Fighting for What’s Right</td>
<td>Advocacy</td>
<td>Flame war</td>
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<td>Changing society’s understanding of cancer</td>
<td>Spamming</td>
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<td>Correcting others’ behaviour</td>
<td>Calling attention to others’ behaviour</td>
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<td>Facts</td>
<td>Call to action</td>
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<td>Influence change</td>
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<td>Make noise</td>
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### Appendix L: Themes, Aspect of Liminality, and Technological Affordances

<table>
<thead>
<tr>
<th>Technological Affordances</th>
<th>Liminality</th>
<th>How the theme ties these concepts together</th>
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<tbody>
<tr>
<td>Social norm that tweets represent in-the-moment experiences</td>
<td>Communicative alienation: feeling as though no one understands leads patients to being unable to express themselves (Little et al., 1998; Thompson, 2007; Knox et al., 2016).</td>
<td>Constructing identity through textual selfies: Posting in-the-moment experiences Textual selfies help users see themselves from an outsider’s perspective (Rutledge, 2013) Being able to share thoughts and feelings freely may help them achieve the critical distance necessary to make sense of pain (Frank, 1998)</td>
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<td>- tweets do not have to be fully-formed ideas</td>
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<td>- tweeting can be done as often or as little as one chooses; as many times in a row, or spaced out as much as one likes</td>
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<td>Raindrop in the river: feeling that tweets are lost in the flow almost as soon as they are posted</td>
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<td>Disinhibiting effect of online social spaces (Miller &amp; Horst, 2013:15)</td>
<td>Communication alienation: censoring themselves to protect the emotional wellbeing of their loved ones (Matheison &amp; Stam, 1995; McKenzie &amp; Crouch, 2004; Vilhauer, 2008; Thompson, 2007). Needing an ‘available other’ to better enable them to tell their story and make sense of their experiences (Frank, 1998; Mathieson &amp; Stam, 1995; Thompson, 2007).</td>
<td>Finding Freedom in Obscurity: Less-dense network results in freer expression of emotions (Kivran-Swaine &amp; Naaman, 2011). Using Twitter to share suffering means only those who choose to listen are exposed to their thoughts and feelings People living with advanced cancer find an ‘available other’ on Twitter, who may be unknown</td>
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<td>Asymmetrical connections mean users often follow strangers of interest (Murthy, 2012)</td>
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<td>- less social obligation to follow known users</td>
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<td>- followers are only users who are interested in what you tweet</td>
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<td>- fewer potential social consequences when followers are strangers</td>
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<td>Technological Affordances</td>
<td>Liminality</td>
<td>How the theme ties these concepts together</td>
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<td><strong>Constant prompt ‘What’s happening?’ encourages users to document their time</strong>&lt;br&gt; Tweets are one of the most accurate representation of time past:&lt;br&gt; - tweets are uneditable&lt;br&gt; - tweets are timestamped at the time of creation&lt;br&gt;Tweets are archived and searchable on Twitter and Google</td>
<td><strong>Boundedness</strong>: being aware of their limited time (Little et al., 1998; Thompson, 2007)&lt;br&gt; Having meaningful experiences is the most important part of maintaining a good quality of life when illness is no longer curable (Axelsson &amp; Sjoden, 1998; Cohen et al., 1997; Odh, Löfving &amp; Klaeson, 2016).</td>
<td><strong>Accounting for Time</strong>: Uneditable, timestamped tweet creates digital immortality by proving, unequivocally, that they existed at that particular time (Massimi &amp; Charise, 2009)&lt;br&gt; Although they may be biologically bound in time, their Twitter use creates a digital immorality that is unbound</td>
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<td><strong>Twitter users can interact with any other user in the system</strong>&lt;br&gt; Twitter’s hashtags allow users to contribute to conversations with other users who are interested in the same topic</td>
<td><strong>Boundedness</strong>: being aware of limited social power (Little et al., 1998; Thompson, 2007)&lt;br&gt; People living with advanced cancer create meaningful experiences for themselves by using their time to positively shape how others will remember them (“symbolic immortality”, Nissim et al., 2012)</td>
<td><strong>Creating a Living Legacy</strong>: People living with advanced cancer position themselves as inspiring role models or sources of hope by sharing positive talk and reassuring others (cancer patients and the general public alike) on Twitter&lt;br&gt; Through helping others, people living with advanced cancer earn a role that has meaning, value, and recognition, regardless of the value experienced by the receiver (Reissman, 1965; Nissim et al., 2012)</td>
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<td>Technological Affordances</td>
<td>Liminality</td>
<td>How the theme ties these concepts together</td>
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<td>Twitter persona represents multiple aspects of oneself through context collapse (Marwick &amp; Boyd, 2011)</td>
<td>Cancer patientness: Cancer treatment and side effects can bring about periods of time when patients find it difficult to participate in ‘regular’ daily activities, ultimately challenging one’s sense of self (Charmaz, 1983; Vilhauer, 2008; Adorno, 2015)</td>
<td>Resisting Social Death: Twitter use can give some reprieve from their cancer diagnosis because they can participate in other social activities (such as live tweeting a TV show or discussing topics of interest) Twitter use can mask or minimize the effects of cancer and its treatment while allowing users to continue some sense of normal Twitter use</td>
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<td>Users can control what aspects of their lives are represented on Twitter</td>
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<td>Low barrier to entry and use because of Twitter’s mobility and built-in brevity</td>
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<td>Able to maintain some form of social connection, regardless of what else is happening</td>
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<tr>
<td>Users can interact with any other user in the system</td>
<td>Cancer patientness: Society’s expectations that cancer patients ‘fight’ to survive and maintain hope for a cure at all costs (Adorno, 2015) are not realistic standards, particularly for those who are one “test result away from experiencing the end of [their lives]” (Thompson, 2007). Societal expectations hinder patients’ abilities to express their emotions, surrounding them in feelings of blame, regret, rejection, and being misunderstood (McKenzie &amp; Crouch, 2004; Mayer, 2010; Danesh, Belkora, Volz &amp; Rugo, 2014).</td>
<td>Fighting for What’s Right: People living with advanced cancer use Twitter to subvert expectations of what it means to be an advanced cancer patient by maintaining hope for a life with meaning and fighting against misinformation and systematic injustices. In fighting for what’s right on Twitter, people living with advanced cancer aim to improve conditions for those living with advanced cancer (including themselves) by correcting behaviours and beliefs of society at large.</td>
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<td>Activities on Twitter are exposed to others</td>
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<td>• increases the reach of messages</td>
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<td>• invites spectators to join the conversation</td>
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<td>• brings social validation when receiving positive attention from others</td>
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