



2020

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Recommended Citation

Hintermayer MA, Sorin M, Romero JM, Maritan SM, Chen OJ, Rawal S. Cancer patient perspectives during the COVID-19 pandemic: A thematic analysis of cancer blog posts. *Patient Experience Journal*. 2020; 7(3):31-43. doi: 10.35680/2372-0247.1514.

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Cover Page Footnote

Funding: The authors received no specific funding for this work. Conflicts of interest/Competing interests: The authors have no conflicts of interest to declare Author Contributions: MAH performed text and data analysis, conceived and wrote the article. MS performed blog identification, reviewed themes, conducted data analysis, conceived and wrote the article. JMR performed text analysis. SMM and OJC performed blog identification and extracted demographic information. SR conceived and edited the article. All authors contributed to study design and revision of paper. This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework. (<http://bit.ly/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

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Cancer patient perspectives during the COVID-19 pandemic: A thematic analysis of cancer blog posts

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Abstract

The content of online cancer patient blogs has previously been analyzed to inform physicians about the cancer experience and patient concerns. The coronavirus disease 2019 (COVID-19) pandemic has greatly affected cancer patients due to their vulnerable health status, as well as changes in cancer testing and treatment. We sought to qualitatively describe the concerns and experiences expressed online by cancer patients, survivors, and family members in relation to COVID-19. 152 blog posts written by cancer patients, survivors, or family members, were selected using combined Boolean searches and snowball sampling. Reviewers extracted subthemes from blog posts using line-by-line text analysis until a sufficient sample was achieved. Subthemes were hierarchically organized into major theme categories and illustrative quotations were identified. A total of 80 blog posts posted between January 20th and April 6th, 2020 were analyzed, revealing 23 subthemes. Major theme categories included: the direct and indirect impacts of COVID-19 on personal health and the health of others, comparisons between COVID-19 and the cancer experience, the impact of COVID-19 on social and psychological wellbeing, perspectives on government and the public response to COVID-19, and coping mechanisms and gratitude. COVID-19 has significantly affected cancer patients, survivors, and family members. Subthemes and quotations relating to perceived medical abandonment, patient mental health, and the impact of previous cancer trauma on the ability to cope with COVID-19 highlight the need for healthcare professionals to be cognizant of evolving patient concerns, so they may provide reassurance and appropriate care to their patients in these exceptional circumstances.

Keywords

COVID-19, SARS-CoV-2, cancer treatment, patient experience, thematic analysis, immunosuppression, cancer blogs

Introduction

The concerns, struggles, and fears of cancer patients have been exacerbated by the recent coronavirus disease 2019 (COVID-19) pandemic caused by the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2).¹ Cancer patients are at increased risk of being infected due to their immunocompromised state as a result of malignancy, chemotherapy, and other treatments.²⁻⁷ In addition, many cancer patients must visit the hospital for diagnosis, treatment, and follow-up, placing them at a greater risk of exposure and infection.^{4,8,9} As such, the COVID-19 pandemic has profound implications for the care of cancer patients, relating to the risk of SARS-CoV-2 infection and to the halting or delay of cancer diagnostic testing, follow-up and/or treatment.

Online blogs allow cancer patients to write about their illness experience and connect with other readers and

bloggers.¹⁰ The content of patient blogs has previously been evaluated in the context of women with breast cancer, relatives of cancer patients, and younger adults with cancer.¹¹⁻¹⁴ Blogs allow cancer patients or members of their support system to share relevant information and experiences, and act as a platform for emotional support. Insights obtained from the analysis of patient blogs can inform healthcare professionals about patient experiences and concerns.¹⁵⁻¹⁷

With healthcare systems currently being overwhelmed by the COVID-19 pandemic, there is uncertainty surrounding the care of cancer patients due to the delay of time-dependent treatments, the reallocation of health resources, and a lack of understanding regarding the timeline of the pandemic. Oncologists have been recommended to advise their patients on an individual basis, prioritizing those who require more urgent care, but specific guidelines vary considerably.¹⁸⁻²¹ Healthcare professionals now have the

difficult task of weighing the risks associated with delays in cancer treatment with the possibility of SARS-CoV-2 exposure in this immunocompromised group.²² Given that many cancer patients currently have less direct contact with their oncology team due to social distancing protocols and the redistribution of healthcare workers,²³ there is a need to inform healthcare professionals about the concerns and feelings of cancer patients and survivors at this time. To provide reassurance to their patients, oncologists and other health professionals require knowledge of how the cancer experience has been impacted by the COVID-19 pandemic. In the current investigation, we sought to qualitatively examine blog posts written by cancer patients, survivors, or family members to extract themes and concerns present at the intersection of COVID-19 and the cancer experience. We applied a data-driven inductive approach to our thematic analysis built on a constructivist phenomenological theoretical framework²⁴ to uncover the lived experiences of cancer patients during COVID-19 and present them to healthcare professionals.

Methodology

Ethics

Blogs were selected from open access websites for which the content posted on the websites was freely accessible to the general public. Blog authors were not contacted by our research team regarding the involvement of their blogs or content within this work. Consistent with similar investigations and guidelines,^{25–28} review by our Institutional Review Board (McGill IRB) was sought out but was ultimately determined to be unnecessary by our ethics office due to the freely accessible and public nature of blog posts.

Blog Post Identification

Inclusion criteria were personal blogs written in English by a current or previous cancer patient or someone in the immediate support network of a current or previous cancer patient concerning the cancer experience with mention of COVID-19. Exclusion criteria included blog posts that were advertisements, unrelated to human cancer, or were written from the perspectives of healthcare workers. Blog posts were identified using keyword and Boolean search parameters where applicable, followed by snowball sampling, as previously described (Supplemental Methodology).^{11,15,29,30} Searches were conducted on Google.ca, Tumblr.com, and Twitter.com. A total of 152 blog posts were identified, posted between January 20th and April 6th, 2020. Demographic information including the age, gender, and diagnosis of the author and/or patient was extracted from the blog profiles when this information was available (Table 1).

Blog Post Text Analysis and Subtheme Identification

Blog posts were randomized, and plain text extracted. Two reviewers (MAH and JMR) extracted subthemes (defined as a thought, comment, perspective, opinion, or concern expressed by an author who is or is writing about a cancer patient or survivor, that is at the intersection of the cancer experience and the COVID-19 crisis) using line-by-line text analysis (Supplemental Methodology). Consistent with a data-driven inductive approach,³¹ subthemes were not postulated *a priori* to allow for broader idea extraction from the perspectives of cancer patients, survivors, and family members. Blog posts were reviewed in groups of ten (termed a “block”) and reviewers were blinded to all author information and each other’s subtheme analyses. It was decided beforehand that a minimum of four blocks were to be reviewed in this manner. The endpoint was reached when no new subthemes were identified after reviewing two subsequent blocks, an outcome termed ‘sufficiency’.³² Interrater reliability was computed as the kappa statistic for each subtheme,³³ ranging from 0.12 to 0.90 (Supplemental Table 1; see Appendix). After sufficiency was reached, a constructivist phenomenological theoretical framework was utilized to consolidate subthemes into major theme categories so that the embodied experiences of our population could be interpreted (Figure 1).

Results

Demographic Characteristics

A total of 152 blog posts written by 72 authors were identified as meeting our inclusion and exclusion criteria. Sample sufficiency was reached after review of eight blocks (Supplemental Figure 1; see Appendix). Among the authors of the blog posts analyzed, 81.0% were female, 16.6% were male and 2.4% identified as non-binary. A total of 44 blog posts were written by the cancer patients themselves (22 authors), 22 blog posts by survivors (12 authors), and 14 blog posts by a family member of a cancer patient (8 authors) in the analyzed group. Further demographic characteristics for the authors of blog posts analyzed in our sample, as well as for those that were not analyzed, are summarized in Table 1.

Emergent Themes

Preliminary thematic analysis identified a total of 23 subthemes (A-W) expressed in blog posts by authors, defined in Supplemental Table 2. On average, 4.0 subthemes (SD=2.2) were identified per blog post analyzed. These subthemes were grouped into five major theme categories: 1) the direct and indirect impacts of COVID-19 on personal health and the health of others, 2) comparisons between COVID-19 and the cancer experience, 3) the impact of COVID-19 on social and psychological wellbeing, 4) perspectives on government and the public response to COVID-19, and 5) coping mechanisms and gratitude (see Figure 1 for the

Table 1. Demographic information for authors of blogs posts in the analyzed and not analyzed groups
Demographic characteristics collapsed between these categories are reported in the 'Total' column.

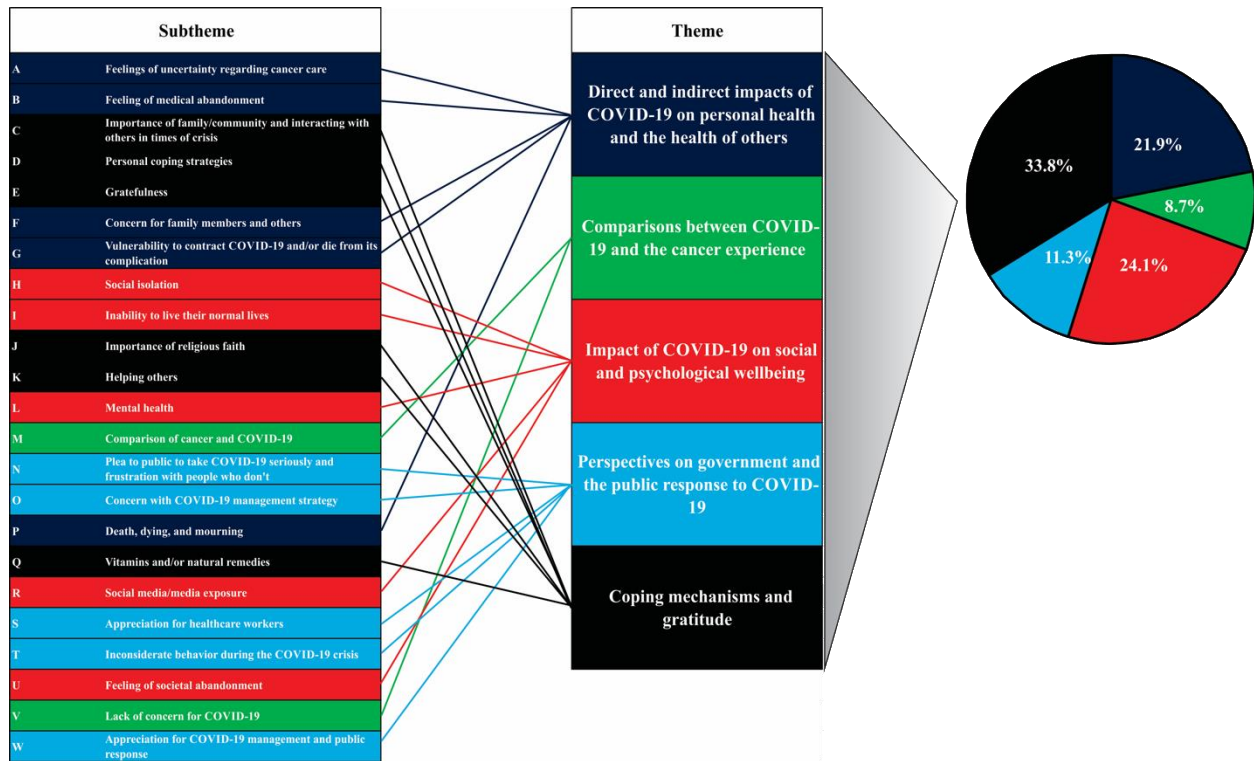
	Analysed (n=42)	Not Analyzed (n=30)	Total (n=72)
Location			
	<i>number (%)</i>		
USA	27 (64.3)	19 (63.3)	46 (63.9)
Canada	3 (7.1)	3 (10.0)	6 (8.3)
UK	9 (21.4)	2 (6.7)	11 (15.3)
Australia	1 (2.4)	4 (13.3)	5 (6.9)
Other	1 (2.4)	1 (3.3)	2 (2.8)
Not Specified	1 (2.4)	1 (3.3)	2 (2.8)
Role of Author			
Patient	22 (52.4)	15 (50.0)	37 (51.4)
Survivor	12 (28.6)	6 (20.0)	18 (25.0)
Family Member [^]	8 (19.0)	9 (30.0)	17 (23.6)
Age Range of Author (yr)			
<20	0 (0)	0 (0)	0 (0)
20-39	8 (19.0)	9 (30.0)	17 (23.6)
40-59	13 (31.0)	6 (20.0)	19 (26.4)
≥60	5 (11.9)	2 (6.7)	7 (9.7)
Not Specified	16 (38.1)	13 (43.3)	31 (40.3)
Gender of Author			
Female	34 (81.0)	27 (90.0)	63 (84.7)
Male	7 (16.6)	1 (3.3)	8 (11.1)
Non-Binary	1 (2.4)	1 (3.3)	2 (2.8)
Not Specified	0 (0.0)	1 (3.3)	1 (1.4)
Time Since First Diagnosis (yr)*			
<1	6 (14.3)	3 (10.0)	9 (12.5)
1-5	15 (35.7)	13 (43.3)	28 (38.9)
6-10	11 (26.3)	6 (20.0)	19 (23.6)
11-20	6 (14.3)	3 (10.0)	9 (12.5)
>20	3 (7.1)	1 (3.3)	4 (5.6)
Not Specified	1 (2.4)	4 (13.3)	5 (6.9)
Type of Cancer Discussed			
Breast	21 (50.0)	16 (53.3)	37 (51.4)
Colorectal	4 (9.5)	1 (3.3)	5 (6.9)
Gynecologic	3 (7.1)	2 (6.7)	5 (6.9)
Brain	0 (0.0)	4 (13.3)	4 (5.6)
Blood Cancers	3 (7.1)	1 (3.3)	4 (5.6)
Pancreatic	1 (2.4)	2 (6.7)	3 (4.2)
Bone	2 (4.8)	0 (0)	2 (2.8)
Other	5 (11.9)	0 (0)	5 (6.9)
Not Specified	3 (7.1)	4 (13.3)	7 (9.7)

[^]n=1 caregiver was included in this category

*Time since first diagnosis, if patient was diagnosed with more than one cancer

Figure 1. Subthemes identified and overarching themes

Subtheme categories (A-W) were hierarchically organized into five larger theme categories to aid qualitative analysis. The relative frequency of each theme category between all blog posts was determined by dividing the total frequency of all subthemes within a theme category by the total number of subthemes identified across all blog posts.



The incidence of subthemes identified in blog posts written by authors who are cancer patients, cancer survivors, and family members are depicted in Figure 2. Major themes and their subthemes are described in the subsequent sections and illustrative quotations have been selected.

The direct and indirect impacts of COVID-19 on personal health and the health of others

A total of five subthemes were present in cancer blog posts pertaining to the impacts of SARS-CoV-2 on the health of cancer patients and other individuals. These subthemes included: feelings of uncertainty regarding cancer care (A), feelings of medical abandonment (B), concern for the health and wellbeing of family members and others (F), vulnerability to contract COVID-19 and die from its complications (G), and the concepts of death, dying, and mourning (P).

Cancer patients, survivors, and family members expressed feelings of vulnerability or concern for the health of cancer patients during COVID-19, highlighting the subtheme of vulnerability:

“...corona virus...puts me at apparently very high risk of complications which would require significant medical intervention.”

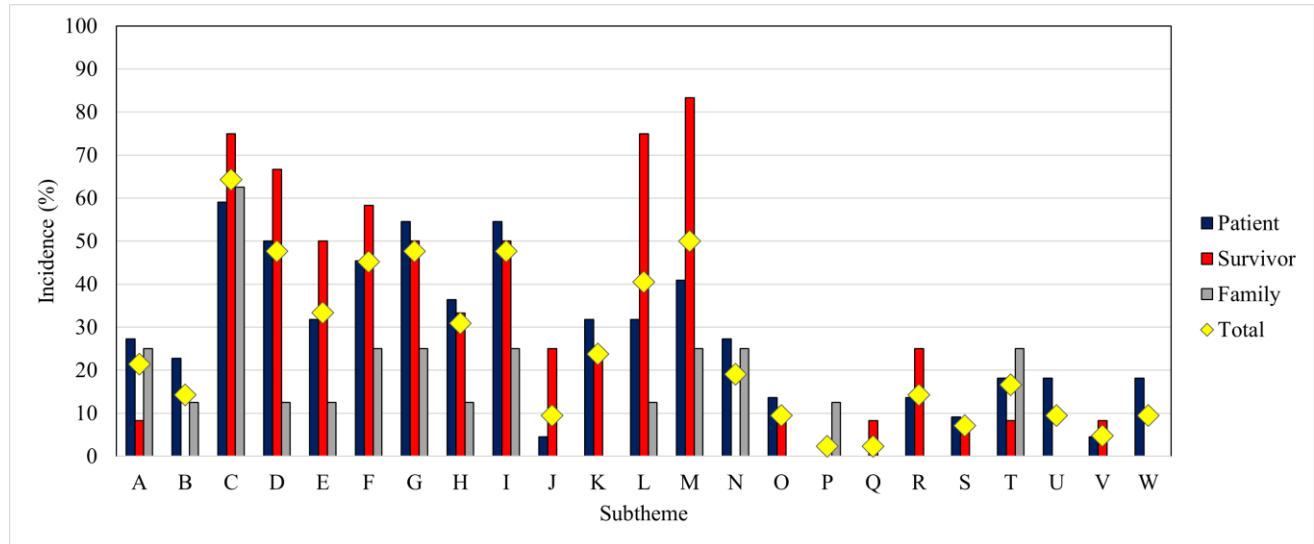
Some patients and their family members expressed concerns about patients not receiving appropriate medical attention for their cancer due to healthcare resources and attention being reallocated to managing COVID-19:

“Like oh yeah, I have a mast cell issue but no ones dealing with it. I have a heart problem. We don’t know what yet and I don’t have an appointment till June[sic].”

Expanding on this, feelings of medical abandonment were expressed by numerous cancer patients and their family members – but not by cancer survivors – and might demonstrate the perception that the COVID-19 pandemic has resulted in cancer patients being neglected by the healthcare system. Some authors also felt that hospitals were unsafe environments for cancer patients with compromised immune systems, as visits to the hospital might increase their risk of exposure to COVID-19:

Figure 2. Subtheme distribution between cancer blog authors

The distribution of subthemes (A-W – see Figure 1) identified in blogs written by cancer patients (N=22), survivors (N=12), or family members (N=8). Incidence (%) represents the percentage of blog authors that wrote about an identified subtheme in one or more blog posts. ‘Total’ represents the percentage of authors that wrote about a given subtheme across all author types.



“I’m not expendable – I’m worthwhile aren’t I? I’ll still get treated won’t I? After all I could have months or years if I find the right drug. I want to live long enough to die of breast cancer please. Please pretty please! I’ll beg!”

“...[the hospital] was the riskiest place I was required to go to in a world where I was likely to be denied a ventilator should I acquire coronavirus.”

The family members of cancer patients expressed concerns related to death and dying, due to hospital visits not being permitted. Family members also expressed that COVID-19 has impacted their ability to grieve effectively, pointing to social distancing restrictions as partly responsible:

“Today visits are strictly controlled, and families may not be with their loved ones when they die.”

“I had returned to work, met friends for coffee and walks, and had planned some weekends away. These have vanished in an instant and I now need to find new ways to work through my grief.”

Cancer patients, survivors, and family members also expressed concerns for the health and wellbeing of family members and members of their communities who may be immunocompromised due to other health conditions.

Comparisons between COVID-19 and the cancer experience

Numerous cancer bloggers made comparisons between experiences living through the COVID-19 pandemic and their cancer experience (M). Some patients expressed that their experiences combatting cancer were similar to those during the COVID-19 pandemic:

“...the fear of the unknown, the lack of control...I’ve been through this all before”

“I guess I’m used to living with a life-threatening condition and finding the energy and motivation to just keep going.” For some survivors, the COVID-19 crisis has made them feel like they were stepping back into their battle with cancer. This was the most common subtheme mentioned by cancer survivors, being expressed by 83.3% of survivors, compared to 40.9% and 25.0% of cancer patients and family members, respectively (Figure 2).

“COVID-19 has put me back in that place. Just when I thought I was really on my way back to some normalcy, this experience has hit me hard. I’m scared.”

“... it can feel like a re-inscription of our illness on our precariously held up bodies. Home is both a gift and a place we long to escape as we long to inhabit normalcy like we used to before we were diagnosed.”

A small number of cancer patients and survivors expressed that their cancer experience has made COVID-19 seem less concerning (V), expressing stoic attitudes:

“...having and “beating” cancer has made me unafraid of other health threats...I should be a little more afraid of this damn pandemic... But until I test positive for COVID-19, it’s just more of the same—fearlessly waiting around for the worst to happen.”

The impact of COVID-19 on social and psychological wellbeing

The cancer experience can take an incredible toll on patients, necessitating supports that aid their social and psychological health while they fight their cancer. However, restrictions on social gatherings and travel, and the temporary closure of many businesses and parks make coping with the cancer experience less feasible for some. Concerns related to social and psychological wellbeing included the topics of social isolation (H), the inability to live their normal life (I), impacts on mental health (L), frustrations with the media and social media (R), and feelings of societal abandonment (U).

Cancer patients expressed concerns of social isolation and the impact this had on their ability to engage with activities that helped them to cope with cancer:

“...dancing has been essential to my physical and emotional health, especially over the past year. Social distancing may cause a whole host of other problems.”

The negative impacts of media exposure were discussed by numerous authors. Specifically, some authors expressed frustration that the deaths of immunocompromised individuals from COVID-19 were being portrayed as a ‘reassurance’ to the general public, giving the impression that they were perceived as more acceptable deaths. These feelings of societal abandonment were stated to have an impact on the mental health of patients:

“Hearing that message about the dying having underlying health problems doesn’t do much for my mental health. Hearing “reassuring” briefings that they would have died soon anyway doesn’t help.”

Another variant of societal abandonment included a feeling of disregard:

“Why we don’t call [metastatic breast cancer] a pandemic I don’t know, but the risk of death is 100%.”

COVID-19 has also impacted the parents of children with cancer, specifically with their sentiments of anxiousness and vulnerability pertaining to the wellbeing of their child:

“Being scared for [our child’s] health, being on high alert for symptoms and temperatures is just a normal day for us...Coronavirus is a worry. It is truly a constant headache for us and all cancer families, an additional weight on our shoulders. It is a f**king nightmare!”

In the same post, the parent describes their feelings of how COVID-19 is affecting their child’s mental health:

“And I really worry about [our child] and his mental health. He has already said he is worried he is going to die because of Coronavirus ... what 6-year-old should have the worry of a virus on top of cancer?”

Restrictions on travel and social gatherings affect everyone in society, but for cancer patients who are impacted by a life-limiting illness, the cancellation of travel plans and social activities represents an inability to make the most of the time they have:

“I don’t have things to look forward to... I’m not coping very well. I’ve had enough.”

Perspectives on government and public responses to COVID-19

Cancer bloggers expressed opinions concerning the management of COVID-19 by the general public, community organizations, hospitals, and government systems, expressing support for some decisions and frustration with others. The subthemes identified included: pleas to the public to take COVID-19 seriously and frustration with those who don’t (N), concerns about COVID-19 management strategies (O), appreciation for healthcare workers (S), inconsiderate behaviours during COVID-19 (T), and appreciation for COVID-19 management strategy and public response (W).

Numerous cancer bloggers mentioned the direct impacts and their frustration with panic buying and other inconsiderate behaviours of the public due to COVID-19. One such patient explained how panic buying behaviour impacted their ability to manage their cancer symptoms with over-the-counter medications:

“I work full time, watch my beloved AFCRD play football and have lots of hobbies like going for walks. The humble paracetamol helps me to do that. But I’m running out and that scares me.”

Others expressed frustration at people not taking social distancing measures seriously and believe that this is putting others at risk. It was frequent for cancer patients to include pleas to their readers in their blog posts to take COVID-19 and social distancing precautions seriously:

“If you don’t kill us with your refusal to adhere to social distancing, we’ll all be hen-pecked to death by your annoying insistence on meeting up with friends. So quit it, and stay home.”

Although many patients expressed concerns pertaining to how systems of government and the general public were responding to COVID-19, some patients, but not survivors or family members, expressed satisfaction, reassurance, and understanding. This was expressed both

in terms of a general appreciation for healthcare workers, and appreciation for the efforts of specific individuals. One patient describes satisfaction when their physician acknowledged concerns regarding whether or not their cancer treatment would continue:

“... telling her that such sentiment was a source of great anxiety in my community (as if we need more to worry about). She was incredibly sympathetic and supportive and after our conversation, sent me this message . . . ‘We are doing this together, and we’ve got you’. Which is exactly what I/we need to hear.”

Coping mechanisms and gratitude

Finally, cancer bloggers described their coping mechanisms for dealing with the COVID-19 crisis. Among the subthemes most frequently encountered were acknowledging the importance of family and community in a time of crisis (C), describing personal coping strategies (D), reflecting on things to be grateful for (E), stating reassurance from religious faith (J), and speaking of helping others (K). One survivor mentioned that taking vitamins (Q) helped them to cope.

Many cancer bloggers expressed a stoic approach to COVID-19 to help them continue to move forward with their lives, demonstrating resiliency and their ability to cope in a time filled with uncertainty:

“This virus may be controlling how we live and interact right now, but it can’t control our attitude, our spirit and our hope....”

Importantly, many bloggers mentioned how technology (including video conferencing applications and phone calls) can allow people to interact with family members or members of the community. The importance of family and community in a time of crisis was frequently mentioned by all three author types but was especially evident in posts written by family members:

“With recent restrictions . . . technology is a great resource. Sending a quick text, making a phone call, or even setting an appointment to Facetime can help a person feel more connected instead of fostering feelings of isolation and aloneness.”

Discussion

During the current COVID-19 crisis, cancer patients are especially vulnerable due to their immunocompromised status and limited access to healthcare resources.²⁻⁷ Blog posts have been identified as a valuable medium to provide healthcare professionals with insights into the experiences of cancer patients, survivors, and their family members.³⁴ To the best of our knowledge, this is the first analysis of blog posts written by this population

concerning the intersection of cancer and the COVID-19 pandemic.

Utilizing a data-driven inductive approach for the generation of subthemes, we have attempted to not apply preconceived theories to subtheme identification.³¹ Through this approach, we found that some topics appeared to be emphasized specifically by cancer patients, survivors, or family members in our sample. In our study, feelings of medical abandonment (B) were emphasized by cancer patients and family members, but not survivors (Figure 2), potentially representing the direct impact of COVID-19 on present cancer treatments and management. For example, many cancer patients expressed concerns relating to their cancer care, diagnostic testing, and/or follow-up appointments not occurring. This left some patients with fears that critical advancements in their disease might not be addressed in a timely manner. Feelings of medical abandonment have previously been described as a concern by cancer patients as it related to an uncertain prognosis and to no longer being the focus of care after having received or failed aggressive therapies.^{35,36} In contrast, in the context of COVID-19, concerns regarding medical abandonment were present at the healthcare level due to what some cancer patients perceived as a shift in their medical priority relative to other patients. Some cancer patients stated that they did not believe that they would be prioritized for treatment if they were to become sick with COVID-19, alluding to policies which prioritize treatment for patients who are less likely to have a fatal SARS-CoV-2 infection. It is worth noting that treatment protocols vary between regions affected by COVID-19,¹⁸⁻²¹ and the organization of cancer care throughout the pandemic is under constant remodeling.³⁷ Therefore, this patient concern highlights the need to resolve misconceptions regarding care of cancer patients during the pandemic to reduce undue stress and anxiety related to these feelings of medical abandonment, which might be grounded in false information.

Comparisons between the cancer experience and COVID-19 were highlighted much more frequently by cancer survivors, than patients or family members. The long-term impacts of the cancer experience whereby stressful events later in life might trigger emotional responses, similar to those of a post-traumatic stress disorder (PTSD) are well-described.³⁸⁻⁴¹ Survivorship has been described in blog posts as a transition to a new normal accompanied with concerns regarding possible recurrence.^{42,43} Feelings regarding the COVID-19 pandemic might act as an additional trigger for survivors, especially given that limitations on social gatherings and activities with others might resemble experiences of isolation throughout periods of immunosuppression for some patients. The precise effect of the COVID-19 pandemic on cancer-related PTSD can only be speculated in the current

investigation, but these findings from cancer blog posts should elicit further study elucidating the psychological impacts of the COVID-19 pandemic on this patient population.

Although the content and insights obtained from cancer patient blogs are incredibly rich, there are limitations associated with the use of this media in research. Given that individuals who decide to write blog posts are likely to be systematically different from those who do not, cancer blog post authors cannot be assumed to be representative of cancer patients, survivors, or family members in general. Therefore, we are unable to comment on the relative significance of each theme or subtheme identified to cancer patients in general due to this implicated self-selection bias. Additionally, each individual author is assumed to compose blog posts with unique perspectives that are influenced by their political, geographical, and personal environments and circumstances,⁴⁴ which are more difficult to control for in blog post analysis as compared to more formal interview qualitative methodologies. We were unable to directly compare our findings with thematic analyses conducted in other investigations, since the theoretical frameworks and blog searching strategies vary considerably depending on the objectives of the different studies. Our search strategy and analysis were focused on identifying stressors that interacted with the COVID-19 pandemic explicitly. Due to its immense impact on healthcare systems, cancer patients are identifying the COVID-19 pandemic as a source of anxiety and dissatisfaction. Future investigations should be conducted to expand on the psychological impacts of the COVID-19 pandemic in this patient population using extensive surveying methodology and interviews. Finally, although blog posts were systematically identified, it is possible that those included in our study are not representative of cancer blog posts in general.

There are numerous strengths associated with the use of cancer blog posts as a data source in qualitative research of this nature. In providing a forum to express thoughts perhaps not voiced elsewhere - including to their healthcare team - the analysis of cancer blogs gives unique insights to physicians and other healthcare workers that allow for the practice of informed emotional and psychological support throughout the cancer experience. This is especially true of those survivors who may have less contact with their oncologist after treatment. Additionally, the spontaneous nature of blog post composition allows authors to expand on ideas without being affected by the biases of researchers, which is a strength in many observational studies.⁴⁵ Indeed, the blog post author has complete control over the views and perspectives that they express, and thus expansion on specific topics likely represent those most poignant to the author.⁴⁶

Future studies making use of machine learning algorithms or computer science methods might aid in providing more quantitatively valid impressions of online opinions and experiences.⁴⁷⁻⁵⁰ Follow-up of specific cancer patient concerns regarding COVID-19 can be conducted utilizing blog analysis, as conducted here, or by utilizing surveying methodologies to obtain more representative opinions and perspectives. Additionally, future investigations concerning the impacts of COVID-19 on the cancer experience might benefit from triangulating the findings of this scoping investigation with other qualitative measures. For example, we have identified a potential effect of social distancing on the re-emergence of emotions related to the cancer experience in cancer survivors. The psychological implications of COVID-19 on the mental health of cancer survivors - who might have very little contact with their primary care team - is currently unknown and should be elucidated. We have also identified feelings of medical abandonment by cancer patients, which may prompt investigations concerning how to maintain contact more appropriately with vulnerable patients in a pandemic situation. Additionally, we identified feelings of societal abandonment by cancer patients with respect to media coverage and public attitudes toward the deaths of vulnerable populations. Thus, our current investigation may inform the direction of these subsequent studies, with more specific hypotheses leading to the use of more focused interviews and/or survey methodologies. The responses of cancer bloggers to the COVID-19 pandemic are dynamic, and future studies should be conducted focusing on how patient experiences and perspectives evolve throughout the remainder of the pandemic.

Conclusion

In conclusion, we have described the views of cancer patients, survivors, and family members expressed in online blog posts in response to the COVID-19 pandemic. These perspectives may inform healthcare professionals as to the unique challenges faced by their patients. The care of patients in oncology needs to be holistic in nature, requiring that healthcare professionals be made aware of evolving patient views and concerns during the COVID-19 pandemic.

Supplemental Methodology

Blog Identification

Blog posts were located by three separate authors ('searchers'; SMM, MS, and OJC). OJC employed the following Google.ca Boolean Search: "(cancer) AND (blogger OR blogs OR blogspot OR wordpress)" and filtered results from January 20th to April 6th, 2020. SMM searched Tumblr.com using the keyword "cancer", filtered the results for text posts and sorted by publication date. Blog posts meeting the inclusion criteria were identified from the results. MS searched Twitter.com for hashtags

“cancerblog”, “cancerblogger” and “cancerblogging” and included relevant blog posts. All three searchers employed a snowball approach as previously described,^{11,15,29,30} whereby initial blog posts found through the strategies mentioned above led to the discovery of additional posts that met the inclusion criteria and were therefore included. A total of 152 blog posts were identified. All blogs were located using the above search strategies between March 29th and April 6th, 2020 to limit variability in search results due to searches being done at different times.

Demographic information including the age, gender, time since diagnosis, geographical location, and diagnosis of the author and/or patient was extracted from the blog profiles by the searchers.

Blog Post Text Analysis and Theme Identification

Blog posts were assigned an identification number, placed in a randomized order, and plain text was extracted. Two authors (MAH and JMR) acted as ‘reviewers’ and extracted themes from blog posts as per the protocol described below. Themes were defined as a thought, comment, perspective, opinion, or concern expressed by an author who is or is writing about a cancer patient or survivor that is at the intersection of the cancer experience and the COVID-19 crisis. This definition allowed flexibility in the extraction of subthemes and made it possible to assign multiple subthemes per blog post. Blog posts in randomized order were reviewed in groups of ten (‘blocks’) and were read in opposite orders by the two reviewers to limit any bias associated with priming from subthemes identified in previously read blog posts. Reviewers were blinded to any identifying or personal information about the bloggers and each other’s thematic analysis.

In order to remove bias in attribution of blog posts to preconceived subthemes, no subthemes were determined *a priori*. To determine themes to be used for categories, each block underwent two review phases: identification and categorization.⁵¹ In the identification phase, reviewers independently extracted themes they identified as being present in blog posts and submitted them to a separate author (‘rater’ MS). The rater then synthesized the subthemes identified by the reviewers to create consistent terminology between reviewers. Reviewers were consulted regarding theme equivalence and to formally define identified themes.

The final list of subthemes for each block was then returned to the reviewers, and the presence or absence of each finalized subtheme within individual blog posts was indicated by each reviewer independently. This process was repeated for each subsequent block, with new themes identified by the reviewers being subject to the same categorization described above. To determine when to stop thematic analysis of new blog posts (when sufficiency

was reached), reviewers were instructed by the rater to stop reviewing blog posts when no new themes were identified for two consecutive blocks, as conducted previously, indicating sufficiency of sample in our qualitative analysis (Supplemental Figure 1).³² It was agreed *a priori* to review a minimum of 40 blog posts regardless of whether sufficiency was reached prior to this. Interrater reliability was computed as the kappa statistic for each theme (Supplemental Table 2; see Appendix).³³ After the endpoint was achieved and inter-reviewer consistency established, reviewers engaged in a collaborative expansion on the subthemes identified in the blog posts to create the five overarching themes in Figure 1.

References

1. Chen N, Zhou M, Dong X, et al. Epidemiological and clinical characteristics of 99 cases of 2019 novel coronavirus pneumonia in Wuhan, China: a descriptive study. *The Lancet*. 2020;395(10223):507-513. doi:10.1016/S0140-6736(20)30211-7
2. Yu J, Ouyang W, Chua MLK, Xie C. SARS-CoV-2 Transmission in Patients With Cancer at a Tertiary Care Hospital in Wuhan, China. *JAMA Oncol*. Published online March 25, 2020. doi:10.1001/jamaoncol.2020.0980
3. Liang W, Guan W, Chen R, et al. Cancer patients in SARS-CoV-2 infection: a nationwide analysis in China. *The Lancet Oncology*. 2020;21(3):335-337. doi:10.1016/S1470-2045(20)30096-6
4. Zhang H-Y, Wang L-W, Chen Y-Y, et al. A Multicentre Study of 2019 Novel Coronavirus Disease Outcomes of Cancer Patients in Wuhan, China. *medRxiv*. Published online April 15, 2020:2020.03.21.20037127. doi:10.1101/2020.03.21.20037127
5. Xia Y, Jin R, Zhao J, Li W, Shen H. Risk of COVID-19 for patients with cancer. *Lancet Oncol*. 2020;21(4):e180. doi:10.1016/S1470-2045(20)30150-9
6. Sica A, Massarotti M. Myeloid suppressor cells in cancer and autoimmunity. *J Autoimmun*. 2017;85:117-125. doi:10.1016/j.jaut.2017.07.010
7. Kamboj M, Sepkowitz KA. Nosocomial infections in patients with cancer. *Lancet Oncol*. 2009;10(6):589-597. doi:10.1016/S1470-2045(09)70069-5
8. Zhang L, Zhu F, Xie L, et al. Clinical characteristics of COVID-19-infected cancer patients: A retrospective case study in three hospitals within Wuhan, China. *Annals of Oncology*. 2020;0(0). doi:10.1016/j.annonc.2020.03.296
9. Cannizzaro R, Puglisi F. Covid-19 and cancer patients: Choosing wisely is the key. *Dig Liver Dis*. Published online April 8, 2020. doi:10.1016/j.dld.2020.03.030
10. Ross E. Researching Experiences of Cancer Risk Through Online Blogs: A Reflexive Account of Working Toward Ethical Practice. *J Empir Res Hum*

- Res Ethics*. 2020;15(1-2):46-54.
doi:10.1177/1556264619867840
11. Kim B, Gillham D. Gender differences among young adult cancer patients: a study of blogs. *Comput Inform Nurs*. 2015;33(1):3-9.
doi:10.1097/CIN.0000000000000118
 12. Martino ML, Lemmo D, Gargiulo A, et al. Underfifty Women and Breast Cancer: Narrative Markers of Meaning-Making in Traumatic Experience. *Front Psychol*. 2019;10. doi:10.3389/fpsyg.2019.00618
 13. van Eenbergen MC, van Engelen H, Ezendam NPM, van de Poll-Franse LV, Tates K, Krahmer EJ. Paying attention to relatives of cancer patients: What can we learn from their online writings? *Patient Educ Couns*. 2019;102(3):404-410. doi:10.1016/j.pec.2018.11.004
 14. Coll-Planas G, Visa M. The wounded blogger: analysis of narratives by women with breast cancer. *Sociology of Health & Illness*. 2016;38(6):884-898. doi:10.1111/1467-9566.12405
 15. Baik SH, Klonoff E, Barnes LE, Schiaffino MK, Wells KJ. Mapping the online social network of cancer bloggers. *J Health Psychol*. Published online November 21, 2019;1359105319888269. doi:10.1177/1359105319888269
 16. Gualtieri L, Akhtar FY. Cancer patient blogs: How patients, clinicians, and researchers learn from rich narratives of illness. *Proceedings of the ITI 2013 35th International Conference on Information Technology Interfaces*. Published online 2013. doi:10.2498/iti.2013.0586
 17. Braun V, Clarke V. Novel insights into patients' life-worlds: the value of qualitative research. *The Lancet Psychiatry*. 2019;6(9):720-721. doi:10.1016/S2215-0366(19)30296-2
 18. Hanna TP, Evans GA, Booth CM. Cancer, COVID-19 and the precautionary principle: prioritizing treatment during a global pandemic. *Nat Rev Clin Oncol*. Published online April 2, 2020:1-3. doi:10.1038/s41571-020-0362-6
 19. COVID-19 Patient Care Information. ASCO. Published March 18, 2020. Accessed April 16, 2020. <https://www.asco.org/asco-coronavirus-information/care-individuals-cancer-during-covid-19>
 20. COVID-19 Information for health professionals in cancer care. Accessed April 16, 2020. [http://www.bccancer.bc.ca/health-professionals/clinical-resources/provincial-cancer-clinical-management-guidelines-in-pandemic-situation-\(covid-19\)](http://www.bccancer.bc.ca/health-professionals/clinical-resources/provincial-cancer-clinical-management-guidelines-in-pandemic-situation-(covid-19))
 21. Overview | COVID-19 rapid guideline: delivery of systemic anticancer treatments | Guidance | NICE. Accessed April 16, 2020. <https://www.nice.org.uk/guidance/ng161>
 22. Kutikov A, Weinberg DS, Edelman MJ, Horwitz EM, Uzzo RG, Fisher RI. A War on Two Fronts: Cancer Care in the Time of COVID-19. *Ann Intern Med*. Published online March 27, 2020. doi:10.7326/M20-1133
 23. Mayor S. COVID-19: impact on cancer workforce and delivery of care. *The Lancet Oncology*. 2020;21(5):633. doi:10.1016/S1470-2045(20)30240-0
 24. Trinidad HS Susan Brown. Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory - Helene Starks, Susan Brown Trinidad, 2007. *Qualitative Health Research*. Published online July 1, 2016. Accessed May 11, 2020. <https://journals-sagepub-com.proxy3.library.mcgill.ca/doi/10.1177/1049732307307031>
 25. Foley NM, O'Mahony M, Lehane EA, Cil T, Corrigan MA. A Qualitative Content Analysis of Breast Cancer Narratives Hosted Through the Medium of Social Media. *Journal of Advances in Medicine and Medical Research*. Published online 2015:474-483. doi:10.9734/BJMMR/2015/15309
 26. Keim-Malpass J, Baernholdt M, Erickson JM, Ropka ME, Schroen AT, Steeves RH. Blogging through cancer: young women's persistent problems shared online. *Cancer Nurs*. 2013;36(2):163-172. doi:10.1097/NCC.0b013e31824eb879
 27. Eysenbach G, Till JE. Ethical issues in qualitative research on internet communities. *BMJ*. 2001;323(7321):1103-1105. doi:10.1136/bmj.323.7321.1103
 28. Bryman A. Social Research Methods. In: *Social Research Methods*. 4th ed. Oxford University Press; 2012:202.
 29. Johnson TP. Snowball Sampling. In: *Encyclopedia of Biostatistics*. American Cancer Society; 2005. doi:10.1002/0470011815.b2a16070
 30. Buis LR, Carpenter S. Health and Medical Blog Content and Its Relationships With Blogger Credentials and Blog Host. *Health Communication*. 2009;24(8):703-710. doi:10.1080/10410230903264014
 31. Boyatzis R. *Transforming Qualitative Information: Thematic Analysis and Code Development*. Sage; 1998.
 32. Francis JJ, Johnston M, Robertson C, et al. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology & Health*. 2010;25(10):1229-1245. doi:10.1080/08870440903194015
 33. McHugh ML. Interrater reliability: the kappa statistic. *Biochem Med (Zagreb)*. 2012;22(3):276-282.
 34. Kim B, Gillham DM. The experience of young adult cancer patients described through online narratives. *Cancer Nurs*. 2013;36(5):377-384. doi:10.1097/NCC.0b013e318291b4e9
 35. Lim SM, Kim HC, Lee S. Psychosocial Impact of Cancer Patients on Their Family Members. *Cancer Res Treat*. 2013;45(3):226-233. doi:10.4143/crt.2013.45.3.226
 36. Linda Gorman. *Psychosocial Impact of Cancer on the Individual, Family, and Society*. 1st ed.; 1998.
 37. Richards M, Anderson M, Carter P, Ebert BL, Mossialos E. The impact of the COVID-19 pandemic

- on cancer care. *Nature Cancer*. Published online May 20, 2020:1-3. doi:10.1038/s43018-020-0074-y
38. Stein KD, Syrjala KL, Andrykowski MA. Physical and psychological long-term and late effects of cancer. *Cancer*. 2008;112(S11):2577-2592. doi:10.1002/cncr.23448
 39. Kangas M, Henry JL, Bryant RA. Posttraumatic stress disorder following cancer. A conceptual and empirical review. *Clin Psychol Rev*. 2002;22(4):499-524. doi:10.1016/s0272-7358(01)00118-0
 40. Leano A, Korman MB, Goldberg L, Ellis J. Are we missing PTSD in our patients with cancer? Part I. *Can Oncol Nurs J*. 2019;29(2):141-146.
 41. Kangas M, Henry JL, Bryant RA. The Relationship Between Acute Stress Disorder and Posttraumatic Stress Disorder Following Cancer. *Journal of Consulting and Clinical Psychology*. 2005;73(2):360-364. doi:10.1037/0022-006X.73.2.360
 42. Cantrell MA, Conte TM. Between being cured and being healed: the paradox of childhood cancer survivorship. *Qual Health Res*. 2009;19(3):312-322. doi:10.1177/1049732308330467
 43. Schlairet MC. Needs of older cancer survivors in a community cancer care setting. *J Gerontol Nurs*. 2011;37(1):36-41. doi:10.3928/00989134-20100730-05
 44. Hookway N. 'Entering the blogosphere': some strategies for using blogs in social research. *Qualitative Research*. Published online February 1, 2008. doi:10.1177/1468794107085298
 45. Jager KJ, Stel VS, Wanner C, Zoccali C, Dekker FW. The valuable contribution of observational studies to nephrology. *Kidney International*. 2007;72(6):671-675. doi:10.1038/sj.ki.5002397
 46. Entwistle V. Considering 'balance' in information. *Health Expectations*. 2007;10(4):307-308. doi:10.1111/j.1369-7625.2007.00469.x
 47. Xu H, Yang W, Wang J. Hierarchical emotion classification and emotion component analysis on chinese micro-blog posts. *Expert Systems with Applications*. 2015;42(22):8745-8752. doi:10.1016/j.eswa.2015.07.028
 48. Zhang S, Wei Z, Wang Y, Liao T. Sentiment analysis of Chinese micro-blog text based on extended sentiment dictionary. *Future Generation Computer Systems*. 2018;81:395-403. doi:10.1016/j.future.2017.09.048
 49. Kim J, Yun U, Pyun G, et al. A blog ranking algorithm using analysis of both blog influence and characteristics of blog posts. *Cluster Comput*. 2015;18(1):157-164. doi:10.1007/s10586-013-0337-9
 50. Raghupathi V, Zhou Y, Raghupathi W. Exploring big data analytic approaches to cancer blog text analysis. *IJHISI*. 2019;14(4). doi:10.4018/IJHISI.2019100101
 51. Kannaley K, Mehta S, Yelton B, Friedman DB. Thematic analysis of blog narratives written by people with Alzheimer's disease and other dementias and care partners. *Dementia (London)*. 2019;18(7-8):3071-3090. doi:10.1177/1471301218768162

Appendix

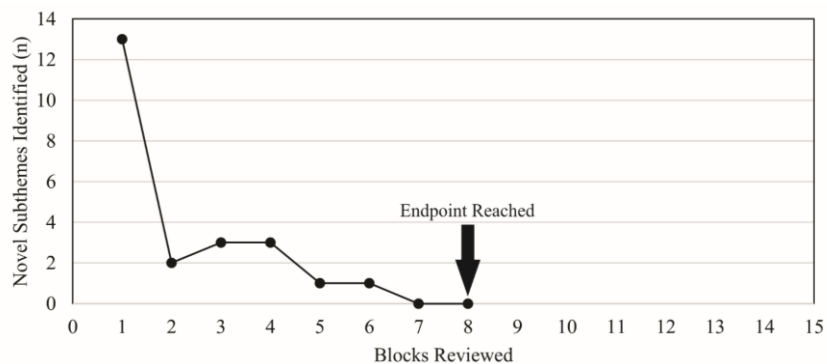
Supplemental Table 1. Kappa statistic for each subtheme identified

Kappa statistic depicting interrater reliability between reviewers was computed for each subtheme.

Theme	Kappa
A	0.625
B	0.630
C	0.570
D	0.512
E	0.432
F	0.536
G	0.695
H	0.613
I	0.222
J	0.750
K	0.128
L	0.462
M	0.735
N	0.646
O	0.902
P	0.487
Q	0.487
R	0.707
S	0.573
T	0.689
U	0.787
V	0.381
W	0.709

Supplemental Figure 1. Number of novel subthemes identified as a function of blog posts reviewed

Subthemes were identified by reviewers in blocks of ten blog posts, and the number of new (novel) subthemes identified in each block was determined. The number of novel subthemes decreased as a function of increasing blocks reviewed, as expected. Endpoint was determined *a priori* as the point at which two blocks (20 blog posts) were reviewed without any new subthemes identified. This endpoint was achieved after the review of eight blocks (80 blog posts) of the 152 posts originally identified in our search.



Supplemental Table 2. Subtheme names and definitions

Final subthemes identified are defined and are presented here in order of decreasing frequency amongst all blog posts.

ID	Subtheme	Subtheme definition (with respect to cancer patient)	Frequency
C	Importance of family/community and interacting with others in times of crisis	Talking to family or spending time with them, interacting with them.	37
D	Personal coping strategies	Anything that is helping in this context of COVID-19.	29
I	Inability to live their normal lives	Inability to live their normal lives as a result of COVID, not able to go on a vacation or see a family event, plans cancelled.	28
M	Comparison of cancer and COVID-19	Comparing their experience with cancer to COVID-19; how it can help them deal with the social ramifications of COVID-19; what they think is worse.	25
E	Gratefulness	Happy, counting blessings, positive outlook.	24
F	Concern for family members and others	Expressing concern for people who are not cancer patients; lonely or depressed in relation to COVID-19, getting infected, etc.	23
G	Vulnerability to contract COVID-19 and/or die from its complication	Vulnerability to contract COVID-19 and/or die from its complication.	23
L	Mental health	Impact on mental health or concern about it.	21
H	Social isolation	Not seeing other people is having an impact on their wellbeing (saying they're lonely, saying they're socially isolated, miss hugs).	16
K	Helping others	Desire to help others or actually helping others.	14
N	Plea to public to take COVID-19 seriously and frustration with people who don't	Asking the public to follow social distancing guidelines and frustration with people who haven't been abiding.	12
A	Feelings of uncertainty regarding cancer care	Worried about treatment, chemotherapy and diagnostic test being rescheduled due to COVID (fear of delay).	11
B	Feeling of medical abandonment	Patient feeling abandoned and sense of low medical priority/not important.	10
J	Importance of religious faith	Importance of religious faith, excluding colloquial use (i.e. "Thank God...").	9
T	Inconsiderate behavior during the COVID-19 crisis	Panic buying; selfish behavior due to COVID-19 crisis; everything except social distancing.	8
R	Social media/media exposure	Advising or mentioning to others to limit exposure to social media/media coverage of COVID-19.	6
O	Concern with COVID-19 management strategy	Concern with how the government or hospitals are handling the COVID-19 crisis or concerns with COVID-19 testing.	5
S	Appreciation for healthcare workers	Stating appreciation for a specific healthcare worker or for healthcare workers in general.	5
W	Appreciation for COVID-19 management and public response	Appreciation for how the governments are handling the crisis, healthcare organizations, researchers, communities, how the public is responding.	5
U	Feeling of societal abandonment	Feeling of no longer being relevant/important to society because attention has shifted to COVID-19 (but not in the eyes of the medical community).	4
V	Lack of concern for COVID-19	Denial that COVID-19 is a big deal; apathetic towards COVID-19; feel invincible because have been through cancer experience.	2
P	Death, dying, and mourning	Worried that COVID-19 will impact their logistical ability to be with loved ones with or without cancer when they die, or that dying and/or mourning plans for someone with/without cancer will be affected by COVID-19.	1
Q	Vitamins and/or natural remedies	Advising or mentioning the use of vitamins and/or natural remedies for prevention or management of COVID-19.	1