

Blood cancer caregiving during COVID-19: understanding caregivers' needs

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Abstract

The COVID-19 pandemic likely exacerbated caregiving challenges for caregivers of parents diagnosed with a blood cancer. Providing care during a public health crisis presents a complex web of uncertainties regarding cancer care, personal health, and COVID-19 risk. Identifying caregivers' uncertainty experiences during the COVID-19 pandemic can be a first step in learning where to direct resources or alter policies to ensure that they can not only perform their caregiver role but also cope in health-promoting ways. Using uncertainty management theory, this study explored how the pandemic has impacted adult child caregivers' experiences caring for a parent diagnosed with a blood cancer, as well as their experiences of uncertainty and uncertainty management. As part of a larger study on blood cancer caregivers' needs, a survey was administered from March 30 to June 1, 2020, to recruit caregivers through the Leukemia and Lymphoma Society. A qualitative and quantitative content analysis was conducted on open-ended responses from 84 caregivers. Caregivers described changes illustrating the complexity of providing care during a pandemic: (a) increased fears and uncertainty-related distress, (b) reduced in-person care opportunities, (c) increased isolation, and (d) enhanced family communication. Caregivers with parents diagnosed with acute blood cancers used significantly more uncertainty management strategies and had more sources of uncertainty than caregivers with parents living with chronic blood cancer types. Findings highlight the need for supportive services to help caregivers manage uncertainty and improve their capacity to provide care in an unpredictable global health crisis. Such support may reduce poor psychosocial outcomes.

Keywords

COVID-19, Caregiving, Blood cancer, Uncertainty

INTRODUCTION

The coronavirus disease 2019 (COVID-19) pandemic has presented multiple challenges for cancer patients and their caregivers. Given the emergent need for social distancing and risks associated with in-person care, clinicians have become more dependent on family caregivers to help maintain complex care within the home environment [1]. This is especially critical for those at an increased risk for COVID-19 and at heightened risk of mortality if COVID-19 is contracted, which is particularly the case for older adults with a blood cancer [2].

Implications

Practice: Findings highlight the need for supportive services in an unpredictable global health crisis to help caregivers manage uncertainty, improve their capacity to provide care, and reduce their risk of poor psychosocial outcomes.

Policy: The study results help identify directions for new resources or policy adjustments to ensure that adult child caregivers of a parent diagnosed with a blood cancer can not only perform their role as caregiver but also cope in health-promoting ways during the COVID-19 pandemic.

Research: This study helps illuminate how the COVID-19 pandemic has impacted caregivers' ability to provide care to their parent diagnosed with a blood cancer and exasperated their uncertainty and distress related to their parent's care, personal well-being, and COVID-19 risk.

Midlife adult children commonly become the primary caregiver for their parent after a blood cancer diagnosis [3]. The median age at diagnosis for the most common types of blood cancer (leukemia and non-Hodgkin lymphoma) is 67 [4, 5]. Caring for an aging parent with blood cancer can involve significant challenges, including an immediate need for treatment, life-threatening as well as lengthy treatments, extended hospitalizations, frequent and stressful emergency department visits, and complex side effects [6–11]. Given the unique challenges associated with blood cancer care, families facing this cancer type can be at a higher risk for psychological distress than those coping with other types of cancers [9, 10]. Midlife adult child caregivers report significant burden and stress with family functioning, which can be heightened when they are sandwiched between generations. Therefore, many are juggling multiple roles while being a caregiver to their parent, including demands within their own families, homes, and professional lives [3].

Maintaining critical care regimens became even more complicated as the world had to quickly shut-down in response to the pandemic, forcing patients and caregivers to shelter-in-place [1]. Clinicians in palliative, chronic care, and oncology have called for a research agenda that identifies the unique issues facing patients and their caregivers during this pandemic [12] and the need to develop a multidisciplinary approach to palliative care [12]. There is an immediate need to build resources and enact policy changes to reduce or minimize suffering [12]:

As crisis standards and protocols are redeveloped and refined during this pandemic, we must consider how decisions will affect not only the care family caregivers are able to provide but also the health and well-being of caregivers themselves. [1] p. e66

The pandemic has likely exacerbated caregiving challenges. Caregivers already experience significant psychological distress as well as social distancing, and isolation to reduce the spread of COVID-19 could further inhibit both caregivers' mental health and that of patients [1, 13]. Moreover, caregiving can involve extreme economic insecurities. This can be further amplified during a pandemic in which job or financial security is threatened [1, 13]. Caregivers also face challenges with ensuring their loved one's physical care, as their care may be uncertain or restricted during a public health crisis in which decisions might prioritize COVID-19 risk reduction and public health needs [1, 13]. The health care system needs to support "frontline family caregivers," thereby recognizing that the care of seriously ill patients has become reliant on family members faced with providing care in the midst of heightened uncertainty [1].

Uncertainty management and blood cancer caregiving during COVID-19

Providing care during a pandemic presents a complex web of uncertainties that are likely compounded by the fact that caregivers must now find a way to juggle their parent's blood cancer care needs, their own personal health, as well as their family's health and related risks of exposure within the realm of a global public health crisis. Identifying caregivers' needs is paramount, which includes understanding caregivers' needs within an extreme context of ongoing uncertainty. As Mishra et al. [13] noted:

Cancer has an unpredictable disease trajectory. Thus caregiving role for cancer patients has its own share of challenges. Pandemic and nationwide lockdown has imposed more uncertainties to that. Thus it is important to prepare the caregivers beforehand to handle a crisis situation effectively. (p. 206)

Uncertainty management theory (UMT) is a prominent framework that researchers have used to

explain the process through which individuals encounter, appraise, and cope with health-related uncertainty [14–18]. Research using this framework has helped to unveil the challenging sources of uncertainty facing patients and caregivers and how managing that uncertainty might differ based on various contextual factors (e.g., age, risk perception, family relationships, and disease type) [19–22].

According to UMT, uncertainty occurs "when details of situations are ambiguous, complex, unpredictable or probabilistic; when information is unavailable or inconsistent; and when people feel insecure in their own state of knowledge or the state of knowledge in general" [14] p. 478. A key proposition of UMT is that uncertainty may take several different forms and stem from different sources, including medical, personal, and social concerns [19, 23, 24].

When an individual encounters uncertainty, he or she assigns meaning to it through a process of appraisal. Appraisals may be positive (e.g., optimism), negative (e.g., fear or danger), neutral (e.g., inconsequential), or a mixed response [14]. Once appraised, UMT predicts that individuals may engage in a range of different behaviors in an attempt to manage uncertainty. In some circumstances, individuals may seek additional information or social support to manage uncertainty [14, 15]. In other situations, they may avoid information [25], particularly when trying to maintain hope or deniability, resist over-exposure, or when there is no action they could or should take [26].

Identifying caregivers' experiences of uncertainty management during the COVID-19 pandemic can be a first step in learning where to direct new resources or alter policies to ensure that they can not only perform their role as caregiver but can also cope in health-promoting ways during an unpredictable public health crisis. To explore this further, we posited the following research questions:

RQ1: How has the COVID-19 pandemic affected the experiences of adult children caring for their parents with a blood cancer?

RQ2: What is the relationship between the type of blood cancer of a caregiver's parent and the number of sources of uncertainty during COVID-19, number of information-seeking/avoidance strategies, types of medical uncertainty, and types of other sources of uncertainty related to COVID-19?

RQ3: What is the relationship between caregivers' demographic variables and sources of uncertainty during COVID-19, information-seeking/avoidance strategies, types of medical uncertainty, and other types of uncertainty related to COVID-19?

METHOD

Recruitment

After obtaining institutional review board approval, caregivers were recruited through The Leukemia

& Lymphoma Society (LLS) to complete an online survey for a larger study aimed at developing an intervention for adult caregivers of a parent diagnosed with a blood cancer. The survey opened March 30, 2020, and continued until June 1. The study was advertised through direct emails to the LLS's constituent database and through a post in LLS's online community site for patients and caregivers (the LLS community). Two reminders were sent after the first invitation. To be eligible, caregivers had to be: (a) at least 18 years old and (b) caring for a living parent, step-parent, or parent-in-law with a blood cancer who was still in treatment or had completed treatment not more than 1 year ago. Individuals were compensated \$25 for participation in the survey.

Measures

The survey took approximately 20 min to complete and addressed caregivers' parent-child communication and provider communication in the context of caring for a parent diagnosed with a blood cancer. Participants were also asked to answer questions to collect demographic information. Given the global public health crisis developing at the time the survey was first administered, prior to dissemination, two open-ended items were added to the survey that explored caregivers' experiences and concerns in the context of the COVID-19 pandemic: (a) How has the COVID-19 pandemic affected your experiences as a caregiver? (b) How has the COVID-19 pandemic affected your communication with your parent, family members, and health care providers?

Content analysis of survey data

We conducted a content analysis of responses to the two open-ended questions addressing the pandemic obtained in the survey [27, 28]. We employed both qualitative and quantitative analysis to provide a richer interpretation of the data. The inductive or qualitative content analysis captures themes that emerge from the data, whereas the deductive or quantitative content analysis begins with predetermined codes informed by theory and the qualitative findings [29]. In line with an exploratory sequential approach [30, 31], responses were first qualitatively analyzed for emergent themes. Those findings then informed the coding approach for the quantitative content analysis.

Qualitative analysis

To answer RQ1, a thematic analysis was conducted by two authors using the widely validated, rigorous constant comparative method (CCM) [32, 33]. From this approach, data were constantly compared for emergent themes and further analyzed to provide rich descriptions and properties

of those themes. Data were initially kept separate for each survey item; however, analyses revealed early on that participants' responses to both survey items overlapped significantly. As such, data analysis was collapsed to explore changes in caregivers' experiences due to the pandemic. Analytical steps for CCM included (a) immersing oneself in the data by constantly reading and comparing participants' responses, (b) identifying concepts and assigning codes to text in responses, (c) grouping categories of emergent themes, and (d) collapsing categories based on shared characteristics or thematic properties. Once a codebook was developed by the first author (C.F.), another author (A.K.) conducted an analysis of the full data set using the codebook to validate the themes and further ensure rigor [34]. Both coders also independently analyzed the data for severity in response to more fully appreciate that participants' experiences ranged in severity. This included searching for words indicating severity (e.g., heart-breaking, regret, panic, anxiety, and devastating) to identify which themes used such language as well as the frequency of responses within those themes that included this language.

Quantitative analysis

To further understand caregivers' experiences of uncertainty, the quantitative analysis (RQ2-3) was informed by UMT theoretical constructs. Specifically, we drew upon several typologies from the literature on UMT to develop the units of coding/codebook for the current study (see Fig. 1). The categories for sources of uncertainty during COVID-19 were derived from work by Brashers et al. [15, 17, 19]. The uncertainty management strategies category was developed using typologies from previous work [18, 26], including both information-seeking and avoidance strategies. Sources of medical uncertainty were drawn from UMT-related work by Dean and Street [35] that examined uncertainty in clinical encounters. Finally, the authors developed an "other sources of uncertainty related to COVID-19" category to code comments regarding uncertainty about the duration of the COVID-19 pandemic and caregiver/parent susceptibility to COVID-19.

Two graduate research assistants (C.H. and T.V.) were trained on the code definitions. After establishing the satisfactory pretest intercoder reliabilities, they independently coded all the answers to the two open-ended survey questions. Krippendorff's alpha was used to assess intercoder reliabilities using the macro for SPSS [36]. All variables reached acceptable levels of intercoder reliability (ranging from Krippendorff's alpha levels of 0.77 to 1.0), with the average Krippendorff's alpha = 0.84 for all comments.

Sources of Uncertainty During COVID-19

Uncertainty related to reduced caregiving opportunities—caregiver expressed uncertainty or frustration regarding inability to meet with provider face-to-face, limited in-person care available, or not being able to remember what the doctor said in previous visits, etc. due to COVID-19 restrictions.

Uncertainty related to patient's health or well-being due to COVID-19—caregiver expressed uncertainty about parent's health or well-being due to COVID-19.

Expressed frustration over not having enough information or wanting more information—caregiver expressed frustration over not having enough information or wanting more information from medical team about COVID-19 in regard to the parent's health or well-being.

Uncertainty about what their parent's care is going to look like now or in the future given the COVID-19 pandemic/shutdown—caregiver expressed uncertainty about what their parent's care will look like now or in the future given the COVID-19 pandemic/shutdown.

Uncertainty over whether treatment plan for parent will change due to social distancing restrictions—caregiver expressed uncertainty over whether treatment plan for parent will change due to social distancing restrictions.

Uncertainty Management Strategies

Information-seeking behaviors—caregiver mentioned engaging in information-seeking behaviors to reduce uncertainty (e.g., such as searching information online, calling the provider, etc.) during COVID-19.

Information avoidance behaviors—caregiver mentioned avoiding information about COVID-19 in regard to parent's health or well-being.

Accepted limits of action—caregiver mentioned not seeking information regarding their parent's health/well-being when there was no action they could or should take, if they believed they believed the information was not applicable (i.e., would not allow them to take action) to their particular case, or if time constraints limited or prevented their ability to respond.

Resisted overexposure—caregiver mentioned avoiding information about COVID-19 due to being overwhelmed by the information or tired of hearing about it.

Fig 1 | Codebook for the COVID-19 responses from caregivers.

RESULTS

Participants

The majority of survey respondents completed the survey in April 2020 when most states were under stay-at-home orders. Participants' responses ranged from 1 to 150 words per response, with an average number of 26 words per response for each question. A total of 84 individuals participated in the study. The majority of these individuals identified as White ($n = 65$, 73.9%), 8 as Black (9.1%), 10 as Asian (11.4%), 1 as Native American (1.0%), and 1 as Pacific Islanders (1.0%). Eleven individuals identified as Hispanic or Latino (12.5%). The average age of the participants was 43.88 (standard deviation

[SD] = 10.98). In terms of the participants' relationship to the parent with blood cancer, 69 (82.1%) respondents mentioned they were a daughter or daughter-in-law, while 15 (17.8%) said that they were a son or son-in-law. Thirty-six (42.8%) individuals reported that they had a graduate degree, 27 (32.1%) participants reported having a 4 year college degree, 7 (8.3%) respondents stated a 2 year degree, 7 (8.3%) individuals reported taking some college courses, and 7 (8.3%) reported having a high school diploma or equivalent. With respect to marital status, 46 (54.7%) participants were married, 23 (27.3%) were single, and 15 (17.8%) were divorced, widowed, or separated. Sixty-four (76.2%)

Types of Medical Uncertainty

Informational uncertainty—caregiver expressed uncertainty related to parent’s health/well-being due to unavailable scientific evidence/information about COVID-19.

Ambiguity uncertainty—caregiver expressed uncertainty about parent’s health/well-being and COVID-19 due to conflicting evidence or strength of evidence, missing or inconsistent data, or conflicting clinical recommendations.

Stochastic uncertainty—caregiver expressed uncertainty about future outcomes or events related to parent’s health/well-being due to COVID-19.

Disease-centered uncertainty—caregiver expressed uncertainty over scientific or data-centered information about parent, including diagnosis, prognosis, causal explanations, and treatment recommendations (e.g., risk information, estimates of outcome probability).

Practical or system-centered uncertainty—caregiver expressed uncertainty regarding the type of care the parent patient needs and/or how to get care during COVID-19.

Other Types of Uncertainty Related to COVID-19

Uncertainty about duration of COVID-19—caregiver expressed uncertainty or anxiety about the duration of COVID-19 pandemic.

Uncertainty about caregiver susceptibility of contracting COVID-19—caregiver expressed uncertainty or concern about his or her susceptibility of contracting COVID-19.

Uncertainty about parent susceptibility of contracting COVID-19—caregiver expressed uncertainty or concern about parent’s susceptibility of contracting COVID-19.

Fig 1 |Continued.

participants were currently employed, 12 (14.2%) were unemployed, and 8 (9.5%) were retired. For the quantitative analysis, we collapsed specific blood cancer types into two categories: acute blood cancers (e.g., acute myeloid leukemia) and chronic blood cancers (e.g., chronic lymphocytic leukemia and myeloma). Thirty-eight (45.2%) individuals reported having a parent with an acute blood cancer, and 41 (48.8%) had a parent with a chronic blood cancer. The average age of the caregivers’ parents was 72.45 ($SD = 11.24$). With respect to the parents’ marital status, 40 (47.6%) were married, 26 (30.9%) were widowed, 11 (13%) were divorced, and 3 (3.5%) were separated. In terms of where the parents lived in the USA, 10 (11.9%) were from the Northeast, 33 (39.2%) from the South, 16 (19%) from the Midwest, and 14 (16.6%) were from the West.

RQ1: qualitative findings

Caregivers reported four notable changes they encountered that complicated their caregiving role and illustrated the complexity of providing care during the COVID-19 pandemic. They described personally experiencing (as well as their parent

encountering) interrelated changes: (a) *increased fears and uncertainty-related distress*, (b) *reduced in-person care opportunities*, (c) *increased isolation*, and (d) *enhanced family communication*. Participants at times used language that indicated severity (e.g., heart-breaking, regret, panic, anxiety, and devastating). The majority of responses using such language (11 of 12) did so to describe the first emergent theme (*increased fears and uncertainty-related distress*) and a smaller subset described *reduced in-person care opportunities* (4) or *increased isolation* (3), which typically intersected with the distress described in the first theme. Findings are presented using the caregivers’ written words to further illustrate how these themes intersected.

Increased fears and uncertainty-related distress

Caregivers described both their parent and themselves experiencing increased distress, which varied in severity. Caregivers at times used words that illustrated the severity of distress, using phrases like “I lost faith in the healthcare system,” “insane amount of anxiety all around,” “extremely hard,” “extremely difficult emotionally and mentally,” as well as terms

like “terrified,” “heartbreaking,” “devastating,” “terrible,” and “scared.” They described an experience of “increased anxiety and panic.” Although caregivers indicated that their parent’s mental and emotional well-being was negatively impacted (saying they were more anxious, fearful, sad, or depressed), caregivers’ responses focused primarily on their own distress. Caregivers’ heightened distress was related to (a) fears or uncertainty about COVID-19 risk and (b) fears and uncertainty about their parent’s current and future care.

First, caregivers expressed fears about getting COVID-19 and how their exposure would then impact their parent. As this caregiver stated: “I am very concerned that if I get exposed I will not be able to care for my mom and there is no one else to help her.” Caregivers were fearful that they would also be the one to expose their parent to COVID-19: “My biggest fear was that I would bring something home to her.” Caregivers also expressed uncertainty about COVID-19 risk (e.g., what they could or could not do):

It sucks! [I’m] unsure how to be there for my parents. They are 82 years old. Is it safer not to visit? Is it okay to take my dad for a drive? Is it okay for my dad to go to Starbucks drive-thru and bring it home?

Second, caregivers shared fears and uncertainty about their parent’s current and future care. They were concerned about how new policies and restrictions to promote social distancing would prevent parents from getting the care they needed, as this caregiver wrote:

We have had to move his treatment from 6 to 10 weeks because he has to go to the main hospital to get a midline on the first day of treatment. He was scared to go because of all the COVID-19 patients at the hospital. He already has a low WBC count. It is probably lower now because of the delay in treatment. He has not been able to have his weekly blood draw.

Caregivers also described having uncertainty about how their own absence from their parent’s medical visits could impact their parent’s care. This caregiver explained, “I am frustrated that we now have to re-live the ‘I can’t remember what the doctor said.’ ...[ugh] I have been instantly removed as his advocate and no one else is doing it.” Fears and uncertainty about their parent’s care were tied to communication (or lack thereof) from health care providers when quarantine orders began. Some reported no communication, some described receiving little information, and another shared they “had to be very aggressive to get any answers and information was not provided to keep me informed.” This caregiver expressed: “Healthcare providers I feel are giving

more information about what cannot happen due to COVID-19 than what can happen as it relates to his condition. It is very frustrating.” Thus, care uncertainty or fear intersected with the next theme.

Reduced in-person care opportunities

With quarantine orders, changes in hospital and clinical protocols, and social distancing requirements, caregivers noted that their parent’s opportunities for in-person clinical care were reduced for a number of reasons, including “all appointments have been postponed,” “appointments were canceled as they were deemed nonessential,” and regular appointments were now less frequent (e.g., biweekly appointments became monthly). Language sometimes indicated the severity of their experiences (e.g., regret and torture). Caregivers described fewer in-person care opportunities that included (a) fewer in-person appointments for parents with providers and (b) fewer or eliminated opportunities for caregivers to provide in-person care (at home or in clinic).

First, caregivers expressed concerns that because they had fewer in-person appointments, their parent’s care could be diminished. This caregiver wrote, “There’s no physical communication. Everything is done through video. It leaves a level of concern regarding [whether] symptoms are being seen right away.” Similarly, telemedicine presented additional challenges to parents, which as this caregiver described, could exacerbate current care needs: “My mother had no idea how to video conference for her appointment. As a result, it was missed and rescheduled. This was terrible because she has some symptoms and pain.”

Second, reduced in-person care included fewer instances for caregivers to accompany their parent in the clinical settings. This seemed to prompt caregivers’ fears and uncertainty about their parent’s current and future care (the first theme), as this caregiver illustrated:

I am not allowed back to [the] lab testing room. ... I am concerned that my mom may need to be started on a new medication and I won’t be allowed in [the] office visit with her. She does not understand all the medical jargon.

Caregivers also described fewer opportunities to provide care to their parent in their home. This caregiver explained, “It has brought up an insane amount of anxiety all around, not being able to travel to my mother to take care of her like I do is extremely difficult emotionally and mentally.” Distress intersected with caregivers’ reduced in-person care opportunities, as is evident in the two emotionally demonstrative responses from participants:

This has been awful. My father moved from the hospital to a rehab center the day COVID-19 hit. We have not been able to see him during the past month. NO

ONE from the facility has reached out or helped us stay informed. This is torture!!!

It has been heartbreaking. I was not able to be with my mother for over a month due to restrictions in visitors. ... I had the option of bringing her home or let her go to a skilled nursing facility ... I decided to have her go to a skilled nursing facility, despite it not allowing visitors. I WILL REGRET THAT DECISION FOR THE REST OF MY LIFE.

Reductions in in-person care opportunities also contributed to the next theme in which caregivers described increased isolation.

Increased isolation

Caregivers explained how public health measures to reduce COVID-19 contributed to increased isolation for themselves and their parent. They shared how isolation intersected with previous themes of less in-person care and distress, with some caregivers using language to indicate severity (e.g., traumatizing, terrified, and soul crushing). Increased isolation was experienced as (a) fewer outings, (b) reduced number of visitors, and (c) decreased visits or time between caregivers and their affected parent.

First, caregivers shared how they limited outings for themselves and their parent to reduce exposure to COVID-19. As this caregiver disclosed, “I need to be more careful about my mother’s condition. That is why we [are] both staying home and limited going outside.” Some caregivers indicated that they also limited or “do not allow people to visit”:

I am extremely more careful about her exposure to people and stuff from the outside. ... The only place I have taken her is to [her] doctors. I disinfect anything that comes into our home that will be touched or used by her and also me.

Second, caregivers restricted visits with loved ones or family to reduce risk. This caregiver explained, “[It’s] made us stay separate from [my] daughter because she works at a hospital. We do not let my mom go into stores because she is 95.” Limiting visitors also meant reduced help or fewer shared caregiving responsibilities. As this caregiver stated, “We cannot rely on anyone else to assist.” Caregivers linked this increased isolation to more caregiving burden and “anxiety” because “the amount of work has increased.”

Third, some caregivers also described how they themselves had to social distance from their parent, such as this caregiver who disclosed, “I do not give her hugs anymore.” Isolation was also tied to caregivers seeing their parent less or not at all. As one caregiver noted, “My dad can’t have visitors. It’s honestly soul-crushing. Everyone should be allowed a visitor. It’s very traumatizing.” Isolation also limited caregivers’ ability to provide care (thus, intersecting with caregivers’ experiences with reduced in-person care opportunities) as well as distress (the first theme). Some described how their parent seemed very “lonely” or “depressed and sad,” and caregivers also shared personal distress tied to isolation: “It absolutely stinks not being able to go to her. I miss her very much right now.”

Enhanced family communication

Interestingly, the previous experiences (themes) centered around restricted in-person interaction as well as caregivers’ distress. However, caregivers also described how stay-at-home orders (and, thus, less in-person or face-to-face time with one another) were also associated with healthy changes in family communication and connections. They shared how their family interaction was enhanced by (a) increasing communication and (b) augmenting relational closeness.

First, caregivers described that because they (and family members) “are all homebound,” there is “more time to talk.” This included more phone conversations as well as using video functions on Facetime or Zoom to increase communication among family members. As one caregiver shared, “[I] stay in touch with them more than I normally would.” Virtual communication among multiple family members also allowed families to jointly support each other or the diagnosed parent: “We set up a group text and talk as needed to help put Mom at ease and be a sounding board for her. It’s challenging but she understands the severity and that the stakes are very high for her.”

Second, caregivers shared that having more time to communicate enhanced their relational connections. At times, this seemed tied to staying in touch more. This caregiver explained, “It’s gotten us closer, using FaceTime/Zoom more often, communicating more frequently.” Other caregivers noted that the mode of communication was important. Video communication seemed to be a key component to heightening intimacy. As this caregiver

Table 1 | Contingency table for adult caregivers’ employment status and uncertainty regarding parents’ health/well-being due to COVID-19

	Caregiver expressed uncertainty regarding parent’s health/well-being due to COVID-19	Caregiver did not express uncertainty regarding parent’s health/well-being due to COVID-19
Not employed	8	12
Employed	43	21

Table 2 | Frequency of reported uncertainty sources, uncertainty management strategies, types of medical uncertainty, and other types of uncertainty related to COVID-19 ($N = 84$)

Sources of uncertainty during COVID-19	Yes	No
Uncertainty related to reduced caregiving opportunities	24 (28.5%)	60 (71.4%)
Uncertainty related to patient's health or well-being due to COVID-19	51 (60.7%)	33 (39.2%)
Expressed frustration over not having enough information or wanting more information	7 (8.3%)	77 (91.6%)
Uncertainty about what their parent's care is going to look like now or in the future given the COVID-19 pandemic/shutdown	13 (15.4%)	71 (84.5%)
Uncertainty over whether treatment plan for parent will change due to social distancing restrictions	1 (1.1%)	83 (98.8%)
Uncertainty management strategies		
Information-seeking behaviors	7 (8.3%)	77 (91.6%)
Information avoidance behaviors	4 (4.7%)	80 (95.2%)
Accepted limits of action	4 (4.7%)	80 (95.2%)
Resisted overexposure	4 (4.7%)	80 (95.2%)
Types of medical uncertainty		
Informational uncertainty	1 (1.1%)	83 (98.8%)
Ambiguity uncertainty	1 (1.1%)	83 (98.8%)
Stochastic uncertainty	18	66
Disease-centered uncertainty	1 (1.1%)	83 (98.8%)
Practical or system-centered uncertainty	18 (21.4%)	66 (78.5%)
Other types of uncertainty related to COVID-19		
Uncertainty about duration of COVID-19	1 (1.1%)	83 (98.8%)
Uncertainty about caregiver susceptibility of contracting COVID-19	11 (13%)	73 (86.9%)
Uncertainty about parent susceptibility of contracting COVID-19	42 (50%)	42 (50%)

disclosed: “We actually communicate a bit more as a family, trying to use video tools to stay close.” Other caregivers noted that changes in how they communicated cultivated closeness (e.g., “We are open with each other.”). For instance, this caregiver reflected on this, describing more openness in their relational communication: “We’re communicating more and I’d like to think our relationships are getting closer because we’re talking about our emotions more often and more openly.”

RQ2–3: quantitative results

Quantitative results provide further interpretations about caregivers’ experience with uncertainty, a caregiver experience that emerged in the qualitative findings. RQ2 asked about the relationship between the type of blood cancer diagnosis of the caregivers’ parents and the number of sources of uncertainty during COVID-19, number of uncertainty management strategies, types of medical uncertainty, and other sources of uncertainty related to COVID-19 (see [Tables 1](#) and [2](#)). A *t*-test revealed that caregivers who had a parent with an acute blood cancer diagnosis used significantly more uncertainty management strategies ($M = 0.16$; $SD = 0.37$) than caregivers who had parents with a chronic blood cancer type ($M = 0.02$; $SD = 0.15$; $t = -2.119$, $p < .05$). In addition, a *t*-test found that caregivers who had a parent with an acute blood cancer diagnosis had significantly more sources of medical uncertainty

($M = 0.63$; $SD = 0.82$) than caregivers who had parents with a chronic blood cancer ($M = 0.29$; $SD = 0.55$; $t = 2.161$, $p < .05$).

RQ3 asked about the relationship between the participants’ demographics and sources of uncertainty during COVID-19, uncertainty management strategies, types of medical uncertainty, and other types of uncertainty related to COVID-19. A chi-square test revealed a statistically significant relationship between employment status (employed or unemployed) and caregivers’ uncertainty regarding their parent’s health and well-being in general (chi-square = 4.722, $p < .05$; see [Table 1](#)). Caregivers who were employed were more likely to report uncertainty regarding their parent’s health and well-being. Relationships between all other demographic variables and sources of uncertainty during COVID-19, uncertainty management strategies, types of medical uncertainty, and other types of uncertainty related to COVID-19 were nonsignificant.

DISCUSSION

Collectively, the results bring to the forefront the critical role of uncertainty in blood cancer caregivers’ experiences during the COVID-19 pandemic. Results demonstrate how public health mandates have changed the landscape of both clinical care and one’s home environment, thereby impacting caregivers’ ability to provide care or function in

their caregiving role. Caregivers described how new health care environment restrictions due to social distancing needs contributed to reduced in-person care opportunities in the clinical setting and increased isolation for patients, caregivers, and families. Restrictions could also contribute to fewer in-person care opportunities for caregivers themselves. As the caregivers described, these challenges intersected with their uncertainties and fears about their parent's well-being or care.

Caregivers' written narratives also at times indicated the severity of their distress using terms like "traumatizing" and "torture" in the context of uncertainty about COVID-19 risk and reduced in-person care and in response to being separated from parents. Some of their responses help illustrate that caregivers could potentially experience posttraumatic stress symptoms that can result from decision-making occurring in the context of the pandemic [37]. While great attention in the media has highlighted the significant impact on being separated from loved ones receiving care in the inpatient setting and, in most devastating cases, being separated from loved ones as those loved ones take their last breaths, data here highlight another source of potential trauma recently profiled by *The New York Times* [38]—being separated over the long term from loved ones residing in rehabilitation or nursing facilities.

The powerlessness emerging in the narratives of caregivers here, combined with their significant sense of uncertainty, particularly among caregivers of patients with acute illness trajectories, highlights the critical need for supportive services to assist caregivers in managing these difficult emotions. Sitting with uncertainty has been identified prepandemic as a key task faced by caregivers [39, 40] and providing support to caregivers reporting high levels of uncertainty could help protect them against the emergence of anxiety, depression, and posttraumatic stress disorder and poor bereavement outcomes. Some caregivers described enhanced family communication in the midst of this crisis, noting that they made more of an attempt to communicate and stay in touch, talk through things, or be more open. It is possible that for those families, those changes in communication strategies could also be helpful for managing distressing uncertainty. Yet, at the same time, caregivers are likely encountering various communication challenges not only clinically (as we saw in these findings) but also within their family systems.

The findings further reveal how caregivers' experiences of uncertainty and attempts to manage it are informed by two important factors. First, employment may inform caregivers' uncertainty needs. The finding that caregivers who were employed had more uncertainty could be due to their own employment settings, which we did not capture. A caregiver may be concerned about a heightened risk for infection/exposure if one does not have the ability to work from

home (and the possibility of transmission from caregiver to parent), thus increasing the concerns identified earlier. Caregivers who cannot work from home may also have reduced in-person care opportunities. Second, the findings showed differences in caregivers' uncertainty experiences based on their parents' blood cancer type. The finding that caregivers who had a parent with an acute blood cancer diagnosis used significantly more uncertainty management strategies and had more sources of uncertainty than caregivers with parents living with chronic blood cancer types may be due to the more urgent nature of acute blood cancer treatments and that these treatments are often, at least initially, in hospital. These caregivers and their parents may have been having more interactions with the health care system, which, particularly at the beginning of the pandemic, was wrought with confusion about what was safe and often meant that the caregiver was restricted from visiting the patient. Engaging these caregivers in supportive services can improve caregivers' capacity to provide care to their parents in the uniquely challenging setting of the COVID-19 pandemic and may help prevent poor psychosocial outcomes.

LIMITATIONS

This study's limitations should be considered in future studies to identify ways to support caregivers of cancer patients during a pandemic. First, about 75% of the participants were White women. Purposive sampling should be considered to better ensure racial, ethnic, and gender differences can be captured to identify variant supportive care needs. Second, although quantitative and qualitative analyses helped to deepen our understanding of the data, open-ended survey responses tend to be short and less descriptive, which can limit quantitative analysis. A qualitative approach involving interviews or diaries could deepen our understanding of caregivers' sources of uncertainty, communication challenges they may encounter with managing their uncertainty (both in the medical setting and with family), as well as exploring what has been helpful (or unhelpful) in helping them accept and learn to cope with uncertainty during a pandemic. Finally, caregivers opted to participate in the survey and, as such, may not represent all caregivers' experiences. Given that LLS helped with recruitment, participants may differ in terms of access to information from those not connected to LLS.

CONCLUSIONS

The findings from this study help illuminate how caregivers' experiences of uncertainty are magnified during a public health crisis. Results also indicate that caregivers' uncertainty management needs may be especially heightened when caring for a parent diagnosed with an acute blood cancer. This study

demonstrates the need for supportive resources that can attend to cancer caregivers' psychological burden. Caregiver uncertainty about a parent's blood cancer diagnosis appears to stem from many sources during the COVID-19 pandemic, including the degree to which caregivers will be able to meet with providers, changing treatment plans due to the pandemic, and frustration over limited information from providers. Moreover, caregivers appear to experience medical uncertainty, such as conflicting information or the ability to predict future medical outcomes related to their parents' blood cancer due to COVID-19. Caregivers manage their uncertainty in a variety of ways, including information-seeking behaviors as well as avoidance. Factors such as employment status appear to influence caregiver uncertainty about their parent's health and well-being.

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Compliance with Ethical Standards

Conflicts of Interest: The authors have no conflict of interests to report.

Author Contributions: C.L.F and C.L.B conceptualized the design of the study. C.L.F, C.L.B., and G.L. collected the data. C.L.F, A.K, K.B.W., C.N.H., and T.S.V. analyzed the data. C.L.F and K.B.W. drafted the initial manuscript. All authors revised the manuscript. All authors approved the final version.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals.

Informed Consent: Informed consent was obtained from study participants.

Study registration: This study was not formally registered.

Analytic plan preregistration: The analysis plan was not formally preregistered.

Data availability

Deidentified data from this study are not available in a public archive. Deidentified data can be made available (as allowable according to institutional review board standards) by emailing the corresponding author.

Analytic code availability: There is no analytic code associated with this study.

Materials availability: Materials were not published but can be made available upon request.

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