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Challenges Experienced by U.S. Cancer Patients during COVID-19: Implications for Future Public Health Emergency Preparedness

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Abstract This study aims to examine the specific health challenges experienced by cancer patients and survivors during the COVID-19 crisis. It's a descriptive mixed-methods study with 317 participants recruited from multiple sources. Participants were asked to complete an online anonymous 35-question semi-structured questionnaire. Data was analyzed both quantitatively and qualitatively. During the COVID-19 pandemic, 56% of the participants felt their medical care was disrupted or delayed. About 85% believed healthcare providers were taking the necessary measures to address COVID-19, yet, 50% of the participants felt they had received adequate information from healthcare providers. Participants had 49% satisfaction with general healthcare provided through telehealth, while only 33% were satisfied with telehealth cancer care. Common themes of challenges confronted by cancer patients during COVID-19 also include, delays in testing and treatment leading to cancer metastasis; lack of family and general support in hospitals/office visits, and feelings of isolation as a result of the quarantine; limited access to mental healthcare services; limited communication with medical personnel. There is an urgent need for medical and oncological institutions to create streamlined protocols for cancer treatment, appointments, and communication to minimize the number of challenges endured by cancer patients during a health pandemic.

Keywords COVID-19, Pandemic, Cancer, Challenges, Preparedness

1. Introduction

As of June 29th, 2021, 3,932,872 people worldwide have died of the Coronavirus disease 2019 (COVID-19) [1]. In the United States (US), 604,347 people have died of this disease thus far [1]. A recent study found that 25.6% of cancer patients who contract COVID-19 die of the disease [2]. COVID-19 has presented particular challenges for cancer patients involving healthcare. COVID-19 is a fluid situation leading to disruption of treatments [3], doctor visits [4, 5], and surgical procedures [6]. To better improve protocols found within oncological medical organizations, treatment facilities, hospitals, and doctor offices, a greater understanding of challenges faced by cancer patients is imperative to future public health emergency preparedness.

As the COVID-19 pandemic continues to affect cancer patients, multiple public health preparedness issues involve access to health care for this vulnerable population. There were some benefits to delaying treatments to keep high-risk cancer patients with co-morbidities out of hospitals and delaying treatments that weaken the immune system, however, this delay may put some cancer patients at more significant risk for cancer progression [7]. One study found

that cancer patients can safely delay their surgical treatments for up to four weeks [8]. However, guidelines differ based on the type of cancer. With patients diagnosed with prostate cancer, it was recommended that tumor boards and scheduled surgeries continue with pre-surgical COVID-19 testing and chest x-rays. For patients with colorectal cancer, it was recommended to delay surgery for up to six weeks, which is within the safe range, and prioritizing surgery to have the most severe cases treated first. Yet, if a patient has tested positive for COVID-19, their surgery must be delayed [9]. With breast cancer patients, recommendations were made for the least invasive surgical procedure with the most rapid post-surgical recovery to be used on patients triaged into groups from least aggressive to most aggressive forms of breast cancer, and reconstructive and elective surgeries postponed indefinitely [10]. Delaying radiation treatment for breast cancer patients after surgery has shown to double the risk of local reoccurrences of the disease [11]. For patients who required more complicated surgeries, a stay in the intensive care unit (ICU) is necessary during post-surgical recovery. Unfortunately, because there is a need for ICU beds and ventilators during severe COVID-19, there are minimal beds available for those non-COVID patients [12]. Additionally, surgeons did not want to put their already vulnerable patients into an ICU that shares space with COVID-19 positive patients. Therefore, they were challenged to decide if the increased risks outweigh the benefits of surgery [12].

Office visits to oncologists have evolved because of COVID-19. It was recommended that patients conduct telehealth visits with their oncologists to discuss scans and bloodwork results that do not require direct contact [13]. If a physical examination is required, temperature checks are done upon entering offices and patients must attend appointments with a limited number of people or by themselves. At the beginning of the pandemic, scans were delayed unless it was a medical emergency. Recently, scan delays have been relaxed, allowing for non-emergency scans to occur. However, the same protocols as office visits are maintained, including temperature checks, health checklists filled out 24-48 hours before the scan, and a limited number of visitors allowed to accompany the patient [14]. Telehealth visits have been an important resource for cancer patients during the COVID-19 pandemic. Unfortunately, there are challenges in this new model of health care. Using video-conferencing software programs have helped bridge the gap between face-to-face visits and complete quarantine, but feelings of loneliness and isolation still exist among cancer patients [15]. Similarly, those patients who do not have access to technology or reliable internet access may miss out on the personal contact garnered from the face-to-face contact on a videoconferencing call and be left to more impersonal phone calls. Technology has allowed office visits to continue, albeit on a different medium, but challenges in technology accessibility remain a concern [15].

Keeping oncology patients safe during office visits was another major challenge healthcare professionals had to address during the COVID-19 pandemic. In the early stages of the pandemic, cancer centers attached to hospitals that treat COVID-19 patients had to make protocol changes which included negative pressure testing rooms (i.e. treatment rooms specifically for suspected COVID-19 patients) and clean rooms, separate radiology equipment, and creating dedicated staff to treat COVID-19 suspected patients [4]. On a local oncology office level, COVID- 19 Survey Checklists for patients were completed before visits asking whether they have had contact with anyone with symptoms of COVID-19 or if they are exhibiting symptoms. Temperatures were taken before entering to determine if a fever is present [5]. Since survey answers are self-reported, accuracy is not assured. Similarly, some patients exposed to COVID-19 exhibit no symptoms but can still transmit the virus and contaminate surfaces [16, 17]. A cancer patient may not want the added risk of being in an area that has been possibly contaminated by an asymptomatic patient, therefore they may not attend their necessary appointments for fear of becoming sick.

Moreover, psychologically, a cancer diagnosis is generally difficult, but includes a global health pandemic, and it can become even more complicated. If a cancer patient experiences severe mental health issues, such as severe depression, they are more likely to die within a year compared to other patients with minimal mental health issues [18]. Fear of disease progression, anxiety, and depression is generally higher among cancer patients compared to those without cancer [19]. In addition, cancer patients have an increased prevalence of Post-Traumatic Stress Disorder (PTSD), due to COVID-19 quarantine protocol isolation [20]. Breast cancer patients with a delay of treatment of up to 12 weeks in the United Kingdom, had increased rates of psychological and social distress and an increased rate of acquiring psychological issues in the future [21].

Even without a pandemic, cancer treatment and related costs, with or without insurance, can lead to financial issues [22]. This, in turn, can decrease the quality of life in cancer patients and increase levels of stress and anxiety [22]. Countries that have enforced stay-at-home orders or long-term COVID-19 quarantine protocols have had businesses close, resulting in a loss of income and insurance coverage for cancer patients [23]. In a study of renal cell carcinoma patients, those who made less than $50,000 a year felt more anxious about financial hardships and more than 25% of the participants were worried about losing their jobs [24]. Cancer patients and survivors who are employed in jobs that do not have an option to work from home are faced with an agonizing decision to continue working with the added health risk or to quit their jobs. This is compounded by the fact that those who have a cancer diagnosis have difficulty in being hired for new jobs

[25]. The purpose of this study is to examine the specific health challenges experienced by U.S. cancer patients and survivors during the COVID-19 crisis and make recommendations for future public health emergency preparedness.

2. Materials and Methods

2.1. Subjects

Both criteria and snowball sampling were utilized to recruit participants to the study. To be included in the study, participants were between the ages of 18-89 and residing in the United States. Additionally, participants were required to have a cancer diagnosis and provide consent to participate in the study. The survey link was included within emails to oncologists residing across the county and shared to a number of survivorship and active cancer groups on social media, including sarcoma and breast cancer support groups available on Facebook. The Cancer Survivor's Network website, sponsored by the American Cancer society, disseminated the study link. G*Power was employed to estimate the necessary sample size.

2.2. Measures

The current study instrument consisted of 35 questions modified and adapted from existing surveys and based on a thorough literature review. The existing surveys were available for use, such as a COVID-19 Community Response survey, to gain a better understanding of challenges experienced by cancer patients during the COVID-19 outbreak and identify if cancer patients had to postpone appointments, or experienced treatment cancellations. They were on a 5-point Likert scale. Moreover, it provided options for cancer patients to identify the main causes of these cancellations and missed appointments [26]. Other survey questions were adapted to identify challenges for cancer patients. These questions included a 5-point Likert scale section addressing financial hardships and additional health care disruptions [27]. Furthermore, an additional open-ended question was included to allow the participants an opportunity to describe further challenges experienced during the pandemic that were not addressed in the questions included in the survey.

2.3. Procedure

This study was approved by the university's Institutional Review Board #930. The data were obtained through a descriptive and mixed methods study, using an online survey to assess the challenges of cancer patients in the U.S. during a public health crisis. The survey remained open from January 4th, 2021 until March 2nd, 2021. The purpose of the study was detailed at the survey's initiation and consent was obtained at the start of the survey. The survey took less than 15 minutes to complete.

2.4. Analysis

IBM SPSS version 26 (IBM) was used to complete descriptive statistics along with frequencies and percentages. Thematic analysis was used to analyze the qualitative data and identify common themes found in the responses from the open-ended question, "What are other challenges you have experienced related to healthcare during this pandemic?" Codes and categories emerged and organized during analysis, and common themes were identified, and responses were grouped within each of the common themes.

3. Results

Of the 317 cancer patients that were participants in the study, there was almost a evenly split with 3 out of 4 regions in the United States: Midwest (31%), South (31%), and the Western U.S. (28.3%). The smallest region, the Northeast, only contributed 9% of the participants. A total of 254 participants reported that they were diagnosed of cancer before the COVID pandemic (March 2020), and 44 participants reported that they received their diagnosis after the pandemic. Answering whether in active treatment or post treatment, 25% identified themselves being in active treatment and 75% of participants identified as post treatment cancer patients. Patients diagnosed between stages one and three made up 75% of participants, 18% were diagnosed at stage 4, and 7% were diagnosed at stage 0. The largest group of participants, approximately 38%, were breast cancer patients. The remainder, almost 62%, had a wide variety of cancer diagnosis including multiple lymphomas, skin cancer, prostate cancer, and sarcoma. Relating to the ages of participants, 47% were between the ages of 37-55. Those between 75-89 years old made up only 3% of the participants. Other demographic questions identified that 90% of the participants identified as female, 91% identified as white, and 94% as non-Hispanic or Latinx origin. A bachelor's degree and graduate school attendance was selected by 77% of participants. More than half of participants (62%) stated they were employed and the largest salary range (31%) was $60,000-99,999.

Challenges encountered by the study patients during the COVID-19 pandemic were illustrated. In deciding not to attend a general medical appointment during the pandemic, 40% of participants elected not to attend general health care appointments. However, regarding cancer care appointments, only 21% elected to not attend due to the

COVID-19 pandemic. Only 16% of participants elected to not receive care in an emergency room or urgent care center because of the COVID-19 pandemic. It was agreed by 56% that general medical care was disrupted because of the COVID-19 pandemic. Yet, only 37% felt that their cancer care and follow-ups were disrupted or delayed by COVID-19. Although participants felt that healthcare providers had taken necessary measures to address COVID-19 (85%), only 50% felt they had received adequate information on prevention from their cancer care providers. Although 33% felt they had experienced financial difficulties, and 17% expressed an inability to buy basic necessities. Thirty-three percent felt financial anxiety because of the COVID-19 pandemic, and 10% felt they could not financially support the people they typically supported as a result of the COVID-19 pandemic. Reasons for missing appointments included: having symptoms of COVID-19 (24%), cancelling their appointment to avoid others (20%), and not feeling comfortable in a medical setting (16%).

When asking survey participants if they had been involved in telehealth appointments, 24% replied no. Those who said yes: 137 had cancer care appointments via a telehealth platform and 126 participants said they had had other medical care appointments with telehealth. The number of general care appointments reported ranged from 1 appointment (n=40) to 50 appointments (n=3). For cancer care appointments responses ranged from 1 appointment (n=29), 2 appointments (n=24), to 35 appointments (n=1). For general care appointments, 49% felt satisfied with their telehealth experience. For cancer care telehealth appointments, 33% felt satisfied with their experience.

A total of 172 participants responded to the open-ended questions, "what are other challenges you have experienced related to healthcare during this pandemic?" Themes emerged from their responses include the following, (1) Delay of Treatments and Procedures Many had appointments postponed because of increased COVID-19 infections. Only lifesaving procedures were being done. Elective procedures were put on indefinite hold for several participants. Some expressed that pre-surgery appointments were kept to a minimum to minimize the risk of infection. One participant stated that office visits were "reduced in time to keep contact limited but this doesn't give me time to ask questions of the doctors and feel assured before or after surgery." Another participant was "unable to be seen to be evaluated for rare diseases and other issues at Johns Hopkins due to the pandemic." Medical tests were being delayed or almost impossible to schedule with one participant expressing "I could not get diagnosed- I had a strong feeling my cancer returned and the health system would not let me through their doors due to COVID-19; doctors wanted to run tests but could not get them scheduled." Participants expressed concern over the number of patients allowed in hospitals or other medical facilities including "it has become harder to set up scans to check on my tumor. They only want a certain amount of patients in the hospital…I've been bumped because there were too many people." One participant stated it took them nine months to receive a correct diagnosis and another stated "my diagnosis was delayed so long it spread to my lungs. I have had to travel across the country for care and have paid out of pocket for expensive care." (2) Lack of Social Support Another common theme was the lack of support. In a large number of healthcare settings, visitors were not allowed and one participant stated they were "not able to have my husband with me at appointments and was unable to have any visitors during a nine-day hospital stay." Another participant felt that "a major part of recovery is a support system…hospitals are denying this aspect of care by not allowing family members near patients…makes me very nervous." Specifically, regarding surgeries, "…not having my husband with me in pre-op/ post-op areas" was a challenge reported by cancer patients requiring surgical care. Additionally, general quarantine rules also contributed to an increase sense of isolation as participants were not able to "interact with loved ones nor were able to "help sick family members." Another participant was in an assisted living facility and had not "seen family in over a year…groceries were delivered by her daughter but kept at the front desk before being delivered to my room." (3) Mental Distress Anxiety was another common challenge found among the participants. There was general anxiety about COVID-19. One participant stated their challenge was "anxiousness-need to find new DR but afraid to go out looking." Others felt anxiety about "catching covid and losing my Medicaid." Additionally, others had the "anxiety of knowing if care is rationed and providers are forced to make decisions, as a two-time cancer survivor, I'm not going to make the cut. So, I am extremely cautious about my exposure and it impacts relationships and mental health." Others expressed they were "afraid of other people not wearing masks [properly], not following distance guidelines, and not following directions in stores." (4) Lack of Access to Mental Healthcare Services Mental health status and access to services affected many of the survey participants. One participant stated "There is virtually no access to mental health providers. I called a hotline provided by my employer for crisis with an episode of anxiety. They had me leave a message and returned my call 11 days later. The pandemic is a trigger for emotional trauma caused by isolation during cancer treatment, and I have no options for support, even with health insurance." Others stated their issues with mental support is that "everyone [is] full or expensive." (5) Lack of Communication Many participants felt that a lack of communication was one of the major challenges they had to endure during the pandemic. Many felt that the "communication of health care providers" on the procedures they needed to follow to stay safe were not

effective. One participant stated they "…had a hard time with my primary care doctor understanding my worries concerning a care plan if I were to get COVID-19 since I am a cancer survivor with type 1 diabetes I felt that a plan should have been in place [just] in case." Others felt that the government was not effective in their communication of protocols needed to be followed with one participant stating "[the] government has made it difficult for healthcare providers to enforce safety protocols." Also, "contacting insurance for questions on denied claims has been difficult." Still others blamed the lack of communication for the empty shelves at stores and the inability to purchase basic necessities because the best way to keep safe from COVID-19 was not communicated to the general population.

4. Discussion

The delay of treatment and surgical procedures was commonly reported by the participants, even to the point of having their disease metastasize because of delays in diagnostic scans and inability to acquire an appointment at a specialized care cancer center. One study discussed the importance of breast imaging at the onset of the COVID-19 pandemic, how their center coped with the pandemic, and how to prepare for future outbreaks [28]. Although breast imaging requires close contact with patients, having sufficient personal protective equipment on hand, triaging the testing of patients from necessary imaging due to suspected cancer to those with their annual imaging with nothing suspicious, and providing mental health resources was integral for their facility [28]. There are gaps in standards of care for cancer patients within cancer centers or oncological medical organizations. In an ongoing study of cancer patients diagnosed with lung cancer, currently, more patients are being diagnosed at a later stage and exhibiting respiratory symptoms indicating a poorer long-term prognosis compared than those who were diagnosed pre- COVID, showing that COVID-19 has affected the diagnosis of lung cancer patients [29]. In England, treatments have been adjusted to allow for alternative treatment protocols that allow patients to stay home for treatment and, in turn, reduce the number of in-hospital treatments and keeping vulnerable patients safer [30].

Another important finding from the current study was the lack of having family members or support at visits to their medical care providers, pre-operative meetings, and waiting during COVID-19. Even a year into the pandemic, these restrictive policies of no visitors or only one additional person are still in place at cancer centers [31]. Although these restrictive policies were necessary at the onset of the pandemic, there is still little evidence that supports the continued restrictive policies in regard to infection spread. In a study investigating sources of emotional support for cancer patients, family members and primary oncology doctors were the most important source of support from cancer patients [32]. Another study addressing the challenges of palliative care for cancer patients, identified that social isolation, while necessary to protect those cancer patients with vulnerable and weakened immune systems, was a barrier for providing the necessary support of these patients [33]. The finding of social support being a major challenge for cancer patients during COVID-19 was also reported by Chavez et al. [34], who interviewed oncology health care providers about the impact of COVID-19 on the mental health of their cancer patients.

One study discussed important priorities to protect mental health in a future pandemic that included ensuring mental healthcare access for all, protecting the mental health of young adults, and removing mental health access inequities [35], Another suggested a long-term solution for resolving mental health access during future pandemics and health crisis by encouraging mental health training for family practice residents to later fill in the gap during a crisis [36], In a free Canadian program, Text4Hope, Canadian citizens that enrolled in the program, were sent daily text messages to improve their mental health during COVID-19 [37]. After three months there was significant improvement in depression symptoms. Although the study did not focus on cancer patients, it highlighted the importance of integrating public health wellness initiatives that focused on mental health in future health pandemics [37]. An international proposal was presented at the Group of 20 (G20) meeting, stressing the importance of integrating mental health into future emergency preparedness response with a focus on remote or web-based support while people are quarantined at home, along with a strengthening of psychosocial support resources in place already [38]. The proposal also reiterated the need for communication between governments and their citizens in the following ways: using simple and easy to understand terminology, correcting misconceptions found in multiple media channels, and to show support to frontline workers and those infected with COVID-19. This can also be done during any future pandemics [38]. Even further, researchers agreed that telepsychiatry is critical during a pandemic, when those accessing the service fear contracting a contagious disease, or, in this case, COVID-19. They recommended that converting an outpatient clinic to a virtual psychiatry unit would benefit patients, allowing them access to much needed mental health resources [39].

In addition, although most study participants' households made above the average U.S. salary, there were still concerns with finances during the pandemic. This suggests a compounding need for high risk individuals to navigate pandemic protocols in a healthcare setting along with dealing with the general anxiety and

financial stress that results from a cancer diagnosis, alongside the additional stress of general financial concerns within a pandemic. Multiple participants expressed fears and concerns as they had to seek out jobs during the pandemic. Others described needing to start GoFundMe campaigns to help pay for their medical costs as they had to travel to receive cancer care. One study discussed how COVID-19 has affected the economy [39]. As a result of social-distancing protocols and quarantines, local economies have suffered greatly during the pandemic. Lower wage workers had to continue working under high stress situations, which would increase the stress and mental health of individuals during the pandemic [39]. Another study described how a third of cancer patients in their study used high risk care altering strategies, including not purchasing medications because of financial distress emanating from their cancer diagnosis [40]. Moreover, an additional study explained that many cancer patients cope with the financial burden of cancer by using all their savings, using credit-cards, and reducing spending in things that may improve their quality of life [41]. Notwithstanding the financial ramifications of a pandemic, cancer patients were concerned about employment to help pay for the treatments and this financial concern increases overall distress [42]. By encouraging cancer patients to access social workers employed at cancer centers that have available financial resources, could assist cancer patients in helping to minimize both the financial strain of cancer and decreased quality of life issues [23].

5. Conclusion

This study provided insight into the challenges experienced by U.S. cancer patients during the COVID-19 pandemic. Although it only provided an initial understanding into this specific population's experiences during the COVID-19 pandemic, the results suggest improvements that could be considered to address their challenges. There is an urgent need for medical and oncological institutions to create streamlined protocols for cancer treatment, appointments, and communication to minimize the number of challenges endured by cancer patients during a health pandemic. Additionally, understanding how to continue community and familial support safely while adhering to government pandemic protocols at healthcare institutions, is necessary for the wellbeing of cancer patients, especially those in active treatment. Finding ways to safely continue to provide support resources for cancer patients during a global pandemic should be one of the priorities for medical institutions to prepare for any future/ongoing global health crisis.

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