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Review article

Undergoing active treatment for gynecologic cancer during COVID-19: A qualitative study of the impact on healthcare and social support

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ABSTRACT

The COVID-19 pandemic poses unique challenges for oncology patients and clinicians. While guidelines for oncology care delivery during the pandemic have been established, there is a paucity of data examining patient experiences of cancer care during the COVID pandemic. This qualitative study captured the perspectives of women undergoing active treatment for gynecologic malignancy at an academic medical center. Hour-long semi-structured interviews were conducted via video-conference and transcribed verbatim. Focused coding was conducted to identify all data related to COVID-19. These data were then categorized into themes that emerged inductively. Seven women (N = 7) were interviewed. Several themes arose under two main categories: 1) Impact of COVID-19 on cancer care delivery and interactions and 2) Intersection of cancer and COVID-19 outside of the healthcare setting. Under category 1, themes included: going to treatment alone; variable access to care and information. Under category 2, themes included: unavailability of cancer-specific social support; mask wearing; COVID-19 & life outlook; adapting coping strategies. Participants' perceptions of having cancer during the COVID-19 pandemic varied and were not always negative. Healthcare systems can draw on our findings to inform interventions to ensure optimal patient care. Additionally, given our finding that noncompliance with mask wearing and physical distancing can be uniquely distressing to cancer patients, healthcare systems should prioritize clear messaging around COVID-19 precautions and ensure compliance of staff and patrons. Due to the rapidly changing nature of the pandemic, outcomes for these patients should be monitored and care guidelines should incorporate first-hand patient narratives.

1. Introduction

The COVID-19 pandemic has presented unprecedented challenges to our healthcare system and has fundamentally changed the way patients receive care. While no medical field has been spared of its impacts, oncology care providers and patients face unique challenges, as treatments have been interrupted, surgeries canceled, and regular visits with providers rescheduled (Frey and Blank, 2020). Cancer patients may also be at increased risk for complications of COVID-19. Early data from patients in China suggests that patients who had undergone surgery or chemotherapy in the last month were more likely to be admitted to the ICU for COVID-19 complications than people who were not being treated for cancer (Liang et al., 2020). For women with gynecologic

cancer, prior research has shown that patients value communication with their providers (Frey et al., 2014; Elit et al., 2003; Oskay-Ozcelik et al., 2018), and several studies indicate these patients benefit from social support (Hersch et al., 2009; Lutgendorf et al., 2002). COVID-19 may complicate both of these priorities and cause particular distress. Editorials and professional guidelines from all over the world have been published regarding gynecologic cancer care in the time of the pandemic (Ramirez et al., 2020; Akladios et al., 2020; Bogani et al., 2020; Wang et al., 2020), yet patient voices and experiences, a key piece of any successful response to this crisis, are largely absent. This exploratory study provides early qualitative insight to the experience of receiving gynecologic cancer treatment during the COVID-19 pandemic.

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2. Methods

The University of Kansas Institutional Review Board approved this qualitative study of the experiences of gynecologic cancer patients participating in a peer-to-peer mentoring program. Woman to Woman (W2W) at the University of Kansas Health System, a program of the Ovarian Cancer Research Alliance, is a peer mentorship opportunity for patients with gynecologic cancer. However, because our originally-planned study took place during the COVID-19 pandemic, prior to data collection we modified the interview guide to capture the experience of undergoing active treatment for gynecologic malignancy during the pandemic. Inclusion criteria for the original study was i) ability to read/write in English; ii) have or have had gynecologic cancer; iii) participation as a mentor or mentee in the W2W program. Exclusion criteria was a current unstable psychiatric disorder. Data collection ceased when all women who met this inclusion criteria were interviewed. For this analysis, we examined interviews for themes about the effect of COVID-19 on oncologic care from each of the seven W2W program participants who were in active treatment at time of interview. The other participants who were interviewed for the original, larger study but who were not undergoing active treatment were excluded from this analysis.

A researcher approached each participant via telephone and provided an overview of the study. Interested participants completed a video-conference interview after providing verbal consent. Demographic information was collected. Interviews followed an interview guide created by the researcher in collaboration with a senior investigator who has extensive experience in qualitative health research. Interviews were audio recorded and transcribed verbatim for analysis.

Analysis followed a qualitative descriptive design to identify and describe themes related to COVID-19 (Sandelowski, 2000). For this paper, one researcher read the transcripts multiple times, making exploratory notes. Focused coding was conducted to identify all data related specifically to COVID-19. All data pertaining to COVID-19 were combined and then categorized according to themes that emerged inductively. Preliminary themes were discussed by the entire study team until they arrived at consensus.

3. Results

Data from seven participants (N = 7) were included, and each was assigned a letter (A-G) for quote attribution. Demographics are reported in Table 1. Several themes arose, under two main categories: 1) Impact of COVID-19 on healthcare delivery and interactions and 2) Intersection of cancer and COVID-19 outside of the healthcare setting.

Table 1
Participant demographics (N = 7).

Characteristic	
Age	
Median	62 (53–73)
Race	
White	7 (100%)
Marital Status	
Married	6 (86%)
Single	1 (14%)
Cancer Type	
Ovarian	6 (86%)
Endometrial	1 (14%)
Year Diagnosed	
2017	2 (29%)
2020	5 (71%)

4. Impact of COVID-19 on healthcare delivery and interactions

4.1. Going to treatment alone

Attending treatments and appointments alone was one of the primary COVID-19 difficulties. Many employed resourceful solutions, such as recording conversations with their physician:

“...everything I did was by myself. And um, usually, either my daughter or my husband was with me before, and not to be able to come in, we would take my phone and not show the doctor but just say “I’m recording all of this so I don’t forget what you’ve told me” and they can listen to it.”-A

Two others put family members on speaker phone or video-conferenced during chemotherapy. One participant appreciated having the same nurse administer her chemotherapy, a consistent presence even if family could not be there.

For rare emergency instances during treatment, not having a support person was uniquely traumatic. When one participant found out she needed emergency surgery while alone at a radiation visit, she described the anxiety around trying to inform her husband:

“...the radiation doctor was examining me...And he said, “We gotta do emergency surgery,” and I said “When?” He goes, “Right now.” And I’m like, “Oh my gosh, we have to get ahold of my husband.” He was out, who knows where, waiting. I had radiation, 3 h of radiation to get done...At first, they said “He can’t come in.” I said, “He’s, he’s gotta come in and he’s gotta know what’s going on.” ...they let him in, they brought the gurney thing, put me on it, and took me, I mean that’s how quick.”-A

Another participant undergoing treatment for a recurrence shared that COVID-19-imposed-restrictions proved almost more difficult for people in her support system than for herself.

“It hasn’t really changed the way I’m getting treatment other than the fact that I have to do it by myself, you know, my daughter...I think that’s harder on her than it was on me, not being able to go with me.”-G

4.2. Access to care and information

Five of the seven participants were diagnosed in 2020. Three spoke of the challenges of establishing care in the middle of a pandemic, seeing their physician once or not at all in person prior to pandemic restrictions. One participant spoke of her distress in waiting for her surgery:

“I had to wait until March, March 10th for surgery just cuz they couldn’t get me in. So that was kind of a long wait. I was really hoping for the week before... I thought, “This is, I can’t wait, that’s too long to wait, who knows what’s happening in there.” -E

Two reported benefits and drawbacks of telehealth appointments. The elimination of the physical exam increased time spent communicating during appointments but also required patients to report any notable physical exam findings.

“...I will say you get to talk a lot longer. Cuz you know, [ONCOLOGIST NAME]’s like, “Let’s go let’s go let’s go,” so you have to have your questions very succinct, ready to go, whereas the, [NURSE PRACTITIONER NAME] is the one that I met with three times, and she gave me a good 30 min. And I still had stuff that I didn’t have time to ask. But there was, there was a couple points where I really wanted her to feel my scar, cuz I had a big thing in there, and you can’t do it. There’s nothing you can do, so. She just has to go by how I explain it to her.” -E

The same participant also adaptively used her in-person treatment appointments to ask her chemotherapy nurses questions that required physical co-presence:

“So chemo was, you know, you’re there...for six and a half hours, so I would ask the nurses stuff. “So, what do you think about this on my scar here?” Or um, just things like that. So that was helpful cuz you could see them in person.” -E

Repeatedly, two participants emphasized the advantages of the patient portal of the electronic medical record (EMR), which allows patients to message their treatment team at any hour. Patients indicated that rapid responses through this modality were especially helpful to assuage concerns:

“I will say, they are so good with the [EMR] thing. That probably makes a big difference, cuz if I have a question or an issue, I can call them or do a message and they are so fast. I mean, so that’s huge. So I know they’re right there. Um, if they were like, really slow and not on top of things and not paying attention, that would’ve been a different story I think, you know what I mean?”-F

4.3. Intersection of COVID-19 and cancer outside of the healthcare setting

4.3.1. Unavailability of cancer-specific social support

Regularly offered cancer support programs through Turning Point, a local resource center for patients with serious illness and their families, were canceled due to COVID-19. The W2W program still proceeded as planned, but with mentors and mentees communicating virtually instead of in-person.

The closing of Turning Point was uniquely distressing to one participant, who wanted to attend a support group. She participated in the W2W program, but preferred having multiple forms of support.

“...I thought it would be good to have a one-on-one thing, but it would also be good to have other women that have other problems... not actually problems, but other situations where they might be a lot worse, and you just get a lot of, I don’t know, I just really wanted to have that, but that’s not happening, unfortunately. And I don’t even know if there’s any other place to go to get that at this point, cuz that’s the only one that I’ve heard about, was at Turning Point. And then since they’re not even meeting by [VIDEO-CONFERENCE].”-E

COVID-19 also negatively impacted the process of connecting cancer patients to available support. One participant blamed COVID-19 for the general lack of information she was provided about resources when she was first diagnosed.

“Nobody told me anything about anything! Which is a little disappointing now that I think about it—they didn’t tell me about the Turning Point...they didn’t tell me about the Woman to Woman, you’re just sort of out there...but it could also be because of COVID. I mean I didn’t even see my doctor for, 2 and a half months”.-E

All participants turned to their W2W matches for support and information. One participant spoke of the isolation she felt while initiating treatment, which made her particularly thankful for the information-packed text messages from her mentor.

“I didn’t know what to expect. Plus, it was like, it happened so fast. It was happening so fast and the COVID was going on at the end of March, so I had to do a lot of stuff by myself. You know what I mean? So when I go get my treatments, no one can go with me. When I went and got my my port, no one could go with me, so it was a lot for me because you know, I was scared and I was freaking out. I don’t know what they’re doing and so that factual information was important... you know? Cuz it helped. Cuz I was like “I DON’T KNOW WHAT’S GOING ON!”-F

Two participants felt that the lack of in-person interactions with their W2W mentor due to COVID-19 impeded their abilities to communicate and build a relationship.

“Well, it would be way better in person, I think. I think it’s always better in person. Um, [VIDEO-CONFERENCE]’s getting kinda old, don’t you think? I feel like we’ve been [VIDEO-CONFERENCE]ing forever. And [VIDEO-CONFERENCE] is okay too, that would be alright. The talking was good for the first time, but it would be so nice if COVID was done, I’d say, “Let’s meet for coffee and talk.” I just think it’s so much better in person. But you know, we don’t have control over that.”-E

“...I’m not one that enjoys just yakking on the phone, and so, just, finding a time and pulling myself away from everyone and just picking up the phone and calling, it’s, it’s hard for me even if it was a friend and so...it’s not something that is easy, it just, it just doesn’t come easily to me.” -C

The COVID-19 pandemic also served as a topic over which one mentor and mentee connected, helping to reveal that they were aligned politically.

“... I mean, you know with the COVID stuff, and her being African American and the protests that have come up and you know, you’re just getting, she’s, we, politically are on the same page.”-D

4.3.2. Mask wearing

Four participants mentioned an awareness of their immunocompromised status as cancer patients. One participant, who felt acutely aware of her immunocompromised status in combination with other risk factors, was frustrated by the seemingly careless behaviors of others.

“With the COVID you know, I’ve got age, I’ve got obesity, I’ve got diabetes, I’ve got high blood pressure, I have cancer, I have thyroid issues, I have type A + blood, which they’re now finding is 50% more likely to get COVID...I saw that report so I had to read it...that’s another thing that people just, it’s like my friends, we don’t understand, and it’s not young people, this is, it’s, it’s all ages not wearing the flippin’ masks.”-D

Daily activities like grocery shopping became more complicated, especially when other individuals disregarded social distancing policies.

“If I can’t get groceries curbside at Walmart or um, Sam’s club, I just don’t get ‘em! And you know and I really try, every now and then there will be something I want, but I’ll hit Aldi before they open and I will be like the first one in, I make a beeline, and you know Aldi has put arrows on their aisles you know, and I have no problems speaking up and telling people, “You’re going the wrong way,” because it’s like, you keep your distance! I mean, I had—and I really do try and limit going into stores and I wear my mask—but I had one lady walk right up to me and I’m wearing a hat and like, if that ain’t telling you something—I’m like, “Can you keep your distance? I’m going through chemo.” -D

4.3.3. COVID-19 and life outlook

The intersection of two highly disruptive events—a cancer diagnosis and the COVID-19 pandemic—was perceived in different ways. One participant, who was receiving chemotherapy and already taking precautions, described how she acted as a source of support for her friends when they had to join her in isolation practices. After sharing that she tells people she “had a month’s head start on everybody else,” she continued:

“I’ve actually been pretty positive about this whole experience and I’ve been cheering up some of my friends, especially the one who was my personal trainer because you know, she’s just, she’s always

bubbly and cheerful and she's been down...[I'm] just saying, you know, "We'll get through this!" And...they've said, they're amazed at my attitude."-D

Another participant articulated that she was actually thankful that her cancer diagnosis coincided with COVID-19. The convenience and the safety of working from home enabled her to continue working while receiving treatment, because she avoided having to "fight all the traffic" as she walked "five feet" to get to her desk. She avoided the typical feeling of "missing out" on life during treatment, because everyone was under similar stay-at-home restrictions.

"If I had to get up every day and go to the office it may have been a lot harder on me, so I feel lucky in a lot of ways um, because I've gotten to do this at home...I've not missed work. I miss on my chemo days. So this has been good...So in some ways, COVID and my cancer, they happened, they started at the same time. So it was really weird, my daughter said, "It was meant for you to have this at this time." Um, because...with the COVID, nobody's out doing this or doing that. I'm not missing anything. So there's a lot of benefits honestly, um, with the COVID...in a lot of ways it was really good this coincided together for me"-F

Conversely, one participant mentioned how "disturbing" it was to not be able to do normal activities.

"So like, at first I thought, "Well this will be good. I can't go anywhere, neither can anybody else." And but then after a while, you're like "Oh my god, I'm gonna go insane" so then...it's very disturbing because you don't know what kind of time you have, so I want every day to be good. Go do stuff. And have fun and see my grandkids, and do all these things, and you can't do it."-E

Two participants mentioned how COVID-19 stole from them one of the most basic demonstrations of support from family or friends: a hug.

"You know, like I said, I have great family support, but not always because we couldn't get together and we're huggers. And it's like, "Well, you know, we can't hug, but I want to..." -A

4.3.4. Adapting coping strategies

Participants were creative in finding ways to cope with their illness even when their normal support structures or daily activities were disrupted. Going to church online, taking walks instead of going to the gym, and seeing friends in a socially-distanced manner were some ways they responded to COVID-19 restrictions.

Faith was an integral part of how one participant coped with her diagnosis. She leaned heavily on her church community for support and though she missed physically attending church, she felt connected to this community, even from home.

"I had lots of people praying for me, and it's hard to explain the elation that I felt some days. And I would tell my husband "I know there are people praying for me right now because of the, the joy that I felt right at that moment." And uh, sure enough somebody would say, "I said the rosary for you," or "My family and I, um, got on our knees and prayed for you." So you know, in that way...I leaned on my faith. But unfortunately, with the coronavirus and everything, I haven't been able to go to church or Mass yet. Um, and just watching it on TV is not quite the same. -C

Two participants mentioned how prior to COVID-19, their gym routine was an integral component of staying healthy. Now, to maintain physical distancing, walking on a home-treadmill or taking walks outdoors sufficed. Staying busy and socializing was a priority for another participant, and she managed to maintain a full social schedule even during COVID-19.

"...My husband and my friends and I try to just find stuff to do. I try to get really busy. Which is hard, now, because you can't do as much stuff...but I think just trying to plan as much as you can, just to keep yourself going and enjoying the day and talking to people. I told my husband, "I have to talk to somebody in person, other than you, every day." I have to. I can't just sit in this house. It's horrible. So. Um, and I've done a pretty darn good job of that...I count on my neighbors a lot. We sit in the driveway a lot, and like in the evening, and I drink my water and they drink wine...And it keeps me happy, if I'm socializing and being busy and doing things, and then I don't start thinking about stuff.."-E

All four participants who socialized reported being highly cautious, adhering closely to social distancing guidelines.

"I wear my mask when I go out, I mean, I've gone to a friend...and we sat out on her porch, but I wear my mask...I've had another friend that since this all started, we [VIDEO-CONFERENCE] every day, and she's like, you know, "Want me to bring lunch and we can eat together?" and I'm like, "I don't want, no." Cuz that means taking the mask off."-D

5. Discussion

This study provides the first qualitative data directly from women undergoing active treatment for gynecologic malignancy about the intersection of their cancer care and the COVID-19 pandemic. Several themes arose from direct patient narratives that may be applied to enhance the cancer care experience during COVID-19. Patients indicated the increased importance of efficient and reliable communication with the electronic patient portal messaging system, a need for ways to ease isolation during chemotherapy, a request for guidance on ways to connect with fellow patients virtually, and a desire for greater community participation in guidelines for personal and public health safety surrounding COVID-19. This study may be limited in generalizability as all participants were non-Hispanic White receiving active treatment from one academic medical center in the Midwest. Additionally, this analysis does not include perspectives from patients in the survivorship stage of their cancer process, who would have initiated and completed treatment prior to COVID-19 restrictions and may be interacting with the health-care system less frequently than those in active treatment. However, it provides actionable recommendations to incorporate patient experiences into the redesign of cancer care delivery during COVID-19.

Patients receiving a cancer diagnosis and initiating cancer care face logistical and psychological difficulties due to the strain COVID-19 has placed on the healthcare system as well as on typical mechanisms of social support and coping, findings consistent with Frey's (2020) identification of needs from this patient population, including concerns about: safety and protection, coping strategies and support programs, and treatment delays or cancellations. (Frey and Blank, 2020) Our study adds depth and context to these concerns and shows that the experience of COVID-19 for these women is not always viewed negatively.

Consistent with prior studies on the importance of patient-provider communication for symptom control and quality of life, (Donovan et al., 2005; Samuel et al., 2020) patients also emphasized the positive role of EMR patient portals for their care experiences, and healthcare systems could consider using these platforms for additional purposes, like building virtual support groups, or collecting electronic patient-reported outcomes like real-time symptoms (Zylla et al., 2020). Symptom-monitoring between visits is even more crucial now, when patients may not be going to see their general practitioner or oncology team in-person as frequently. Additionally, sending rapid responses to patients' questions via patient portals is a simple and effective way to make patients feel prioritized when physical visits are limited. It is crucial to respond to these observations by enhancing patient recruitment to EMR technologies and encouraging active staff participation in

prompt and reliable communication through these modalities of patient communication during COVID-19.

Attending appointments and treatment alone was difficult for patients in our study. While creative solutions (like using a personal device to video-conference a family member) helped, there is further opportunity to build structural supports for all patients to increase virtual presence and reduce isolation during treatment. For example, widespread access to tablets for video-conferencing and routinely assessing patient internet accessibility can help ensure that all patients have this opportunity. Additionally, because the healthcare team at the chemotherapy infusion center is often the only social interaction patients received outside of those with whom they live, every effort should be made to have the same team of nurses administer chemotherapy to facilitate continuity for patients.

Our participants noted an urgent need for new ways for cancer patients to connect with each other, whether that is virtual mentoring or a support group hosted on a video-conference platform. Web-based support is not new—online support groups for women with gynecologic and breast cancer have been extensively studied. (Wiljer et al., 2011; McCaughan et al., 2017;3:CD011652.) Online resources and decision-making tools are increasingly important as typical conduits of information dissemination may be disrupted. At minimum, frequently updated “support bundles” containing information about the hospital’s online resources, virtual support groups or online decision-making tools should be made available to patients via patient portals in the EMR.

Our findings suggest that patients with cancer experience psychosocial stress when they encounter someone who refuses to wear a mask or maintain physical distance. It is crucial for healthcare systems to acknowledge this perceived harm and to continue improving safety measures like temperature checks, designating specific entrances and exits, and requiring masking of all personnel and patrons. Healthcare systems caring for cancer patients should prioritize consistent messaging around COVID-19 precautions, and advocate on behalf of this vulnerable population in the broader community.

There is no aspect of community life that is untouched by the COVID-19 pandemic. The transformation of healthcare systems to respond to this global emergency has led to dramatic shifts in cancer care delivery. As this crisis continues, we have an opportunity to shape guidelines with research that examines not only drug delivery or surgical outcomes, but also includes patient experiences of cancer care during the pandemic. We have a chance to diminish the trauma our patients endure negotiating not one but two life threatening illnesses by listening to their voices and modifying care delivery to enhance safety, both physically and emotionally, and to improve access to care and support.

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Author contributions

HM secured funding. HM, JVB, and LS contributed to concept and

design. HM collected data. HM, JVB, LS performed analysis. HM, JVB, LS wrote the manuscript, approved the final version, and are accountable for all aspects of the work.

Declaration of Competing Interest

Dr. Spoozak reports non-financial support from Intuitive Surgical outside of the submitted work.

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