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Research Report

A qualitative study on the impact of long-distance travel for gynecologic cancer care

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A B S T R A C T

Background: Women with gynecologic malignancies experience improved clinical outcomes when they are treated by gynecologic oncologists and in high-volume cancer centers. However, geography is a major barrier to high-volume care for patients. This qualitative study was undertaken to identify facilitators and barriers to patients traveling long distances for gynecologic cancer care.

Methods: Semi-structured interviews were conducted with 19 women with gynecologic malignancies traveling >50 miles for treatment at Wake Forest Comprehensive Cancer Center. Eight interviews included caregivers. Four interview domains focused on personal challenges and coping strategies related to accessing cancer care.

Results: Mean distance traveled for care was 87 miles (range: 54–218). Most participants reported that recommendations from physicians, friends, and family motivated travel. 10/19 participants were aware of closer sites for cancer care; 5 had unfavorable experiences elsewhere. Barriers to travel included time, cost, childcare, difficulty navigating, and physical discomfort. Social support was an important facilitator of travel for care; some patients utilized loaned money or vehicles. Participants reported significant energy expenditure scheduling travel, coordinating time off work, and arranging overnight stays near the cancer center. Suggestions for care improvement included travel vouchers, transportation assistance, signage and personnel to help with navigation, and appointments later in the day. Participants supported in-person oncologist outreach to rural areas and appointments via telemedicine; few preferred the current infrastructure.

Conclusion: Patients who travel long distances for gynecologic cancer care encounter significant burdens and rely heavily on social and financial support. Interventions should be developed and evaluated to reduce the burden of long-distance travel and develop efficient methods of outreach, including telemedicine.

1. Introduction

Women with gynecologic malignancies experience improved clinical outcomes when they are treated by gynecologic oncologists and in high-volume cancer centers. However, geography is a major barrier to many women seeking to realize the benefits of high-volume care; approximately 15 million, or 9%, of women in the United States live farther than 50 miles from the closest gynecologic oncologist (Shalowitz et al., 2015). Increased distance from residence to a specialty care center may be associated with worsened survival resulting from decreased likelihood of receiving care consistent with national guidelines. This relationship appears to be particularly strong for patients with ovarian cancer (Bristow et al., 2014; Villanueva et al., 2019); however, data conflict for patients with endometrial and cervical cancers (Gunderson et al., 2013; Gunderson et al., 2013; Barrington et al., 2016; Tan et al., 2009).

Distance to care appears to play a major role in patients' selection of a site for oncologic surgery (Resio et al., 2018); additionally, 20% of patients considering surgery for ovarian cancer may not be willing to travel an additional 50 miles for a significant survival benefit (Shalowitz et al., 2017). A multi-faceted approach is required to overcome geographical disparities in gynecologic cancer care, including rational use of provider outreach, leveraging telemedicine when possible, and minimizing the burden associated with patients' travel for specialty care. Some degree of patient travel will be necessary within an optimized gynecologic cancer care delivery system, given the relative scarcity of gynecologic cancer specialists, the need for clustering of specialists to provide high-volume care, and the large geographic area of the United States. Consequently, an essential part of decreasing disparities in access to care will involve minimizing the proportion of patients who do not access high-quality gynecologic cancer care because the burdens of travel are too great. Currently, little is known about which aspects of travel patients with gynecologic cancers find most burdensome, how they manage these burdens, and which factors may facilitate

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travel to referral centers.

In this study, therefore, we utilized qualitative methods to identify and explore burdens and facilitators of travel for patients who reside more than 50 miles from their gynecologic cancer care providers. Our goal was to identify potential areas of intervention to minimize the proportion of patients who are unable to obtain high-quality care based on geographic factors.

2. Methods

Semi-structured, in-depth interviews were conducted with women receiving care at the Wake Forest Comprehensive Cancer Center (WFCCC) in Winston-Salem, NC. WFCCC serves a largely rural 30-county region of western and central North Carolina, southwestern Virginia, and eastern Tennessee. 1200–1400 unique patients are evaluated annually. Approximately 10% of patients are enrolled in Medicaid, and 8–10% are uninsured and/or receive institutional charity care.

Patients with home ZIP code >50 miles from WFCCC were screened for enrollment. Goal enrollment was 20 patients, as we anticipated thematic saturation with this number of participants. If thematic saturation was not reached, we planned to continue enrollment. We employed purposive sampling to enroll new and established patients with varying disease sites and sociodemographic characteristics. If participants desired, caregivers/travel companions were included in the interview. Interviews collected enhanced our understanding of the lived experience of patients receiving gynecologic cancer care at our institution. Written informed consent was obtained prior to beginning the interviews. Patients not comfortable speaking English were not enrolled. Participants received a $25 gift card. The study protocol was approved by the Wake Forest School of Medicine Institutional Review Board.

2.1. Qualitative interviews

Interviews were conducted between October 2018 and June 2019 by one of two study personnel trained in qualitative interview techniques (V.M., T.B.). Interviews were conducted in-person or by phone, using a semi-structured format with a guide of four domains focused on personal challenges and strategies related to accessing cancer care. The goal of the interviews was to encouraged participants to delve into their own narrative of their cancer care to the depth and extent that they were comfortable. Our primary goals were to identify (1) whether patients saw long-distance travel as required for their cancer care or elective to undergo treatment at a preferred cancer center, (2) barriers and facilitators to long-distance travel for care, and (3) potential interventions to alleviate the burdens associated with long-distance travel. Domains therefore included:

Reasons for selecting a referral center for care
Barriers to traveling for cancer care
Strategies identified to handle travel-related cancer care needs
Participant-suggested changes to improve accessibility of care

Interviews were audio-recorded and transcribed. Transcripts were compared to recordings and edited for accuracy. Initial content codes were derived from the transcribed text using the four above domains as a guide; additional codes were added as concepts and themes emerged from the data. Two members of the study team (VM, TB) coded each transcript and reviewed coding with the senior author (DS). Coding was performed in collaboration with Qualitative and Patient-Reported Outcomes (Q-PRO) staff who iteratively reviewed and summarized reports of all coded segment. Thematic analysis was performed via NViVo 12. Coded segments were summarized by their prevalence and salience in the data. Twenty patients were initially enrolled; however, one patient had benign surgical pathology and was subsequently excluded from analysis. No new themes were apparent after analysis of the 19 remaining interviews; thematic saturation was therefore judged to have been reached.

3. Results

Eight of nineteen interviews included a patient caregiver in addition to the patient, for a total of 27 individuals participating in discussion. Mean interview time was 12 min (median 18, range 2–34). The interview lasting 2 min was conducted with one patient who reported experiencing no barriers to her long-distance travel. 17 (89.4%) of patients identified as White; the plurality of patients were between 60 and 70 years old (37%). Six patients (32%) were seen for ovarian cancers, 11 (58%) for cancers of the uterine corpus, and one patient each (5%) for cancers of the uterine cervix and vulva. Patients presented for surveillance (11; 58%), chemotherapy (6; 32%), or perioperative care (2; 11%). The two patients interviewed after their first visit to WFCCC (i.e. "new patients") presented for perioperative care. Eight patients (42%) traveled between 50 and 75 miles for care, 7 (37%) traveled between 75 and 100 miles, and 4 (21%) traveled more than 100 miles. Mean distance traveled for care was 87 miles (range: 54–218). Participant described a wide spectrum of reasons for selecting WFCCC for their care, awareness of area cancer centers, barriers to traveling for care, strategies utilized to handle care needs, and suggesting improvements to care based on lived experiences.

3.1. Reasons for choosing care at a referral center

Participants cited referrals from physicians (8/19) and friends or family (8/19) as the reason they chose to seek out care at a referral center.

> *"My brother also came to [the cancer center]. He had cancer. When I found out I had it, he wanted me to come here because he'd been treated really well." (Participant 1)*
> *"Word of mouth. A friend of mine, her daughter was seeing [Dr. X] at that time, and she had had good results." (Participant 18)*

Other factors for choosing WFCCC included having a bad experience at another facility (four of 19 participants) and the reputation of the referral center (three of 19 participants).

> *"The cancer place in [X] County that I started out with, the attitude was, 'Well, gee, I don't know what we're gonna do…'" (Participant 8)*
> *"I actually tried to do a few treatment closer to my home, where I would still be a patient of [X provider], but receive a few treatments here close. Unfortunately, the level of care they provided was subpar. I decided to go back to Wake Forest and receive my treatment as well as all my care through Wake Forest. It's worth the travel." (Participant 19).*

Participant 15 believed that forming a true relationship with her cancer doctor was an important aspect of choosing a cancer care center. Being able to learn more about the gynecologic oncologists at WFCCC via their online bios made her feel more comfortable in choosing a cancer doctor.

> *"I really liked what [the gynecologic oncologist] had to say … about forming patient relationships, because that was what I didn't have at the moment. And that was very important to me. And so, it was his bio, obviously, his education, and…one of the most reputable places in the state, so I went with that." (Participant 15)*

Additionally, most participants were able to identify multiple sources of cancer care available to them. Some facilities were other National Cancer Institute designated Cancer Centers or Comprehensive Cancer Centers while others were regional or local hospitals close to participants' place of residence. Eleven of 19 participants acknowledged that they knew of several local, regional, and out of state cancer-related services within North Carolina, Virginia, and Tennessee. Three out of

19 participants were not able to identify locations for cancer care outside of WFCCC. Overall, most participants chose cancer care at WFCCC due to referral from a trusted source in their life, reputations of the physicians and hospital, and better experiences at WFCCC than other area cancer care centers.

3.2. Barriers to travel for cancer care

All participants identified at least one significant barrier to travel for gynecologic cancer care, and many participants identified multiple barriers. Challenges/barriers were classified into seven primary categories. The properties of these categories often overlapped with other categories. Barriers to travel for care included: timing of appointments and duration of the trip, securing companionship, difficulties with navigation, mode and/or cost of travel, childcare, physical discomfort of lengthy travel, and care coordination challenges.

Participant 11 cited timing of appointments along with a work schedule as a significant barrier, while participant 16 had difficulty with the duration of the trip.

"Sometimes I have to be here at, you know, nine o'clock in morning, or 10, which means I have to get up at six. Where normally I work a second shift job and so that's kind of a 'try to wake up, try to wake up,'…Time constraint is definitely an issue." (Participant 11)
"We left the house at quarter to eight this morning, and we won't get home till 6:00 or 6:30 tonight." (Participant 16)

Securing companionship was also a great barrier for six participants. Participants 3 and 6 specifically had issues with a partner being able to accompany them to appointments.

"It's hard for him (husband) to get off work. He's a plumber and electrician and he's working at least 50–60 h a week." (Participant 3)
"Nobody really had the time to spend two hours just to go back and forth and then to wait for however additional late the time…Everybody has their own schedule so it's really hard to get people to take the day off and come with me." (Participant 6)

Four participants (21%) had difficulties with finances and mode of travel.

"Financially, sometimes it's taking her last few dollars to get gas." (Participant 5's caregiver)
"Well, first, was transportation, 'cause we only had one car…I couldn't get Uber because they, I guess, they weren't family and they couldn't stay with me or something like that." (Participant 6)

Five participants (26%) cited travel time and physical discomfort associated with treatment.

"I was concerned that I would have nausea or diarrhea or somethin' during the drive either before or afterwards." (Participant 16)
"…I have a bone met in my groin area, so it's kind of painful to sit for that long.." (Participant 15)
"I guess, the distance, the length of travel…For me, I think that's the biggest challenge, is the tiredness [from traveling]." (Participant 7)

14 participants (74%) had difficulty coordinating schedules with travel companions and scheduling medical appointments, childcare, and work absences.

"My biggest concern is scheduling. I have two children, so I try to schedule around what their schedule is and when their school is, someone to take care of them. If it was closer it would be easier. I could go during the day while they were at school, but because it is a greater distance, it becomes a barrier." (Participant 19)

Participants also expressed frustration about navigating to the cancer center due to geographic, weather, and changes in traffic.

"The only thing is weather-wise, if you live far away from—I have to cross the mountain and in this wintertime there's snow." (Participant 1)
"Just the drive itself, the distance. Sometimes traffic's a pain…the road closures don't help…I have to figure out a route, and as they change the work areas and stuff, it's been a challenge." (Participant 10)

Others spoke about concerns finding their way around the hospital.

"Sometimes it's hard to find a [parking] spot, depending on what time the appointment is. If it's 9:00, 10:00, it's hard to find a parking spot." (Participant 5's caregiver).
"Here lately it's just been road construction [around the hospital]. That's the one challenge we have." (Participant 14).

Finally, one participant expressed frustration with care coordination between local hospitals and the cancer center, but overall found that her providers at WFCCC were able to speak with her doctors at another facility to ensure she received proper care.

"I would say one of the biggest problems about being away [on a trip] is that I did come down with pneumonia the week after I had one of my chemos [at WFCCC]. I was down [at the beach], so I had to go to a hospital there, although I got good care and they did talk with [X provider]." {Participant 7).

3.3. Strategies used to manage travel burdens

As most participants cited at least one challenge in traveling for their cancer care, participants and caregivers had several strategies they used to lessen their travel burdens. Some participants were able to name local resources that might help with their care and companionship including transportation through the American Cancer Society, local senior center, Social Services, and local church groups. Two participants reported borrowing vehicles to travel. In 16 interviews, participants cited a driver or travel companion as their greatest source of help in traveling.

"Well, my partner's come with me. My dad's come with me a couple times. My best friend's come with me, so I always feel comfortable if I have somebody come with me, of course." (Participant 12)
"Oh, usually my sister or my dad will come down with me. I think more because they want to be in-the-know of what's going on than anything. Yeah, usually one of them will come whether I want them here or not (laughter)." (Participant 11)

Money, either borrowed or given as a gift from local organizations or charity was evident in five interviews.

"The school that I worked at…donated the money to help with travel expenses. It does add up when we were staying overnight in Winston-Salem. Travel expenses and all those types of things." (Participant 19)

Staying overnight near the hospital before or after appointments helped participants avoid travel during adverse weather conditions and alleviated the need to travel round-trip in one day. One participant cited reimbursement of travel expenses as easing the burdens of travel:

"[The insurance company] pay[s] me to travel here each time I come… They pay for a room if I have to stay overnight. Or when I had surgery, they paid for my husband and my daughter to stay." (Participant 1)
"[Subsidized housing] was wonderful. Compared to the price we were paying at the hotel to stay overnight, so friendly, it was very, very good for us since we traveled to be able to stay there overnight when my treatments were the next day." (Participant 19)

Strategies not directly related to travel included engaging social support and faith communities.

"I was a leader in a Bible study, and so, I have about 150 ladies in this group that are constantly praying for me and encouraging me and sending

me beautiful cards. And, thank God, I'm blessed, I don't need financial assistance, and so they're just there to encourage me and pray for me." (Participant 15).

Engagement with faith communities included attending church groups, praying and worshipping individually at home, practicing meditation and spiritual care, and reaching out to local religious and spiritual communities for guidance and support through the challenges of cancer care. Other participants tried to engage in their care by using the hospital website and patient portal to speak with their providers. (Participants 1 and 19). Participant 8 used her background in nursing to help understand and guide her treatment. Participant 17′s caregiver cited: "[We] try and make sure she eats healthy and takes all her medicines." Participant 19 cited applying for disability as a financial strategy, while Participant 4 budgeted money specifically for her transportation needs. Overall, participants believed that the most important factors to lessen the burden of traveling for cancer care included: financial security and/or insurance coverage; retirement which increases flexibility in scheduling appointments and reduces the demands for child care; and staying overnight near the hospital before and/or after appointments to avoid bad weather and decreasing the fatigue of traveling in both directions in one day.

3.4. Suggested changes to infrastructure to facilitate long distance travel for care

Fifteen participants offered suggestions that included service and navigation-related changes. Service-related suggestions included providing a van or other local services to transport patients to/from remote areas, providing gynecologic oncologists to remote areas, scheduling appointments later in the day, providing gas vouchers, and creating a lounge area specifically for immunocompromised patients and their companions. Navigation-related changes included simplifying driving directions and parking.

"Sometimes it's hard to find a spot, depending on what time the appointment is." (Participant 5's caregiver)

In addition, 10 of the 19 participants cited an interest in virtual appointments with their care teams. Participant 2′s caregiver supported the idea of having the virtual appointment in a local medical facility, rather than from her home. This location would provide assistance with technical issues as well as provide human support:

"What about if people lived closer to [rural medical center]..Not everybody is Internet-versed. If they can actually go there and do the tele-thing between that facility and this facility that might help." (Participant 2's caregiver)

Participants were generally supportive both of in-person oncologist outreach to rural areas and appointments via telemedicine (Table).

"I've actually had an experience with that with urgent care…It was really neat…saves us a 3-hr trip and we'll do it." (Participant 14)

A few (5; 26%) preferred the current infrastructure given the lack of access to working computers at home, preferring face-to-face communication, and feeling they would miss the experience of coming to their appointments.

"He has so much knowledge, and it's like he can look at something, which is hard to do if you're on Skype. Sometimes some of your problems you can't see, but if he's here and he can look at you or feel it, he can take care of it." (Participant 7)

4. Discussion

This investigation represents, to our knowledge, the first qualitative exploration of the experiences of patients traveling long distances for gynecologic cancer care. Our findings can help guide improvements in current health care strategies, including development of focused interventions to reduce access barriers and interventions to reduce travel such as telehealth.

Perhaps unsurprisingly, the major barriers experienced by patients include resources related to travel, including managing the time required to receive care at a distant cancer center. Each patient included in this study was, in some way, able to overcome these barriers though utilization of multiple resources and support structures. Travel-related strategies included logistical planning (including managing work and family members' schedules), finding a travel companion, and arranging local lodging. Strategies not directly related to travel included enlisting social and financial support, and, engaging with faith communities. However the long-term impact of expenditures related to travel remain unclear and should be included in assessments of the financial toxicity of cancer care (Liang et al., 2020). Importantly, the majority of patients identified reasons that long-distance travel for care was preferred (e.g., treatment at the referral site was perceived to be of higher quality), even though there may have been cancer treatment sites closer to their homes. A patient-centered approach to gynecologic cancer care therefore will likely necessarily include long-distance travel for some individuals. The current literature on correlates of distance traveled for gynecologic cancer care is limited by the inability to determine the extent to which long-distance travel is truly "required" versus merely preferred; we were unable to directly clarify this question in the present study.

We were unable to enroll patients for whom the burdens of travel were too great to permit them to come to the referral center; however, it is reasonable to hypothesize that these patients experienced similar types of barriers. This study was also limited by the number of patients enrolled and by recruitment from a single cancer center. While it may not be possible to generalize the magnitude of barriers to care and the proportion of patients supporting virtual cancer care to other populations, we hypothesize that the types of barriers and facilitators to long-distance travel will be conserved across most patients with gynecologic cancers. Interventions designed to decrease the burdens associated with travel may therefore improve accessibility of care beyond the population of patients included in this study.

Although some interventions to facilitate long-distance travel might be initiated through use of cancer center resources, others will require engagement with patients' local community. For example, oncology practices could provide assistance with navigation, referral to discounted lodging for overnight stays, and vouchers for gas expenses. However, if patients' major barriers to travel are child- or elder care, or companionship, the highest-yield intervention will require the assistance of resources embedded in the patient's community. All of these interventions merit further study, including the benefit of outreach through cancer care navigators.

This study adds to the evidence that a multi-pronged approach will be necessary to maximize the geographic reach of high-volume gynecologic cancer centers. Although the majority were supportive of telemedicine, five of 19 patients expressed a preference for in-person care. While attitudes about telemedicine may change with education and exposure to technology, for these patients, access to gynecologic oncology care may require cancers centers to consider carefully the merits of investing in outreach care versus resources to decrease patients' burdens of traveling long distances to a central campus.

CRediT authorship contribution statement

Vaidehi Mujumdar: Conceptualization, Writing – original draft, Writing – review & editing. **Timberly R. Butler:** Conceptualization, Writing – review & editing. **David I. Shalowitz:** Conceptualization, Writing–original draft, Writing – review & editing, Funding acquisition, Project administration.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Declarations

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