Healthcare professionals' perspectives of barriers to cancer care delivery for American Indian, rural, and frontier populations

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ABSTRACT

Objective: This descriptive qualitative study sought to understand the barriers affecting cancer care delivery from the perspective of healthcare professionals (HCPs) serving American Indian (AI), rural, and frontier populations.
Methods: One-on-one, semi-structured interviews with multidisciplinary HCPs ($N = 18$) who provide cancer care to AI, rural, and frontier populations were conducted between January and April 2022. Interviews were conducted via Zoom. Data were analyzed following thematic content analysis methodologies.
Results: Thematic content analysis revealed three major themes: (a) Access, (b) Time, and (c) Isolation. The themes represent the HCP perspectives of the needs and barriers of persons with cancer to whom they provide cancer care. Furthermore, these themes also reflect the barriers HCPs experience while providing cancer care to AI, rural and frontier populations.
Conclusions: This study provides preliminary evidence for the need and strong multidisciplinary support for an early palliative care intervention in rural and frontier South Dakota (SD). This intervention could support the needs of persons with advanced cancer as well as the HCPs delivering cancer care in rural settings.
Innovation: This study is the initial step to develop the first culturally responsive, nurse-led, early palliative care intervention for AI, rural, and frontier persons with advanced cancer in SD.

1. Introduction

National cancer death rates are decreasing [1,2], yet cancer is the leading cause of death in South Dakota (SD) with 50% of persons diagnosed at advanced stages [3]. Cancer disproportionately affects American Indians (AIs) with cancer mortality rates twice as high as AIs in other areas of the United States [4] and 26.2% higher than whites in SD [3]. These racial disparities have heightened over the past decade and are worse for AIs who live in rural and frontier SD [5], indicating disparities in care that intersect culture and geography. Persons living in rural and frontier areas are plagued by persistent poverty [6,7], under-resourced healthcare facilities, [8-10] and a lack of primary and specialty healthcare professionals [11]. These factors all contribute to the grievous inequities present in cancer outcomes. These inequities are predicted to be exacerbated by the pandemic [12] which intensifies the need to identify and support AI and rural persons with advanced cancer.

Persons with cancer and their families in rural America suffer tremendous burdens [2,13-17]. Over half of the SD population resides in rural and frontier areas [1,11] where persons with cancer lack access to high quality cancer care resulting in poorer survival outcomes [18,19]. The poorer outcomes for rural persons with cancer and families are linked to multifaceted burdens such as higher costs for care, greater travel for primary and specialty care, inadequate symptom management, and poorer quality of life [1,17,20-23]. These burdens are especially devastating in rural racial/ethnic minority populations with cancer [24,25], including AIs in SD who are often diagnosed at late stages [5].

The identified disparities are exacerbated by the limited access to palliative care in SD, especially the AI population [26]. SD has the fourth highest proportion of AIs in the U.S. with 12% of the state population identifying as AI [27]. Additionally, SD has nine Tribal Nations, the most in the Great Plains region [28]. One solution toward easing advanced cancer disparities is providing nurse-led palliative care locally using interventions such as Project ENABLE (Educate, Nurture, Advise Before Life Ends) [29]. ENABLE is an evidence-based intervention developed by nurses to deliver upstream (early) palliative care in rural settings in concordance with national guidelines [29,30]. ENABLE has been culturally adapted for use in the Southern United States with majority

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Black and rural communities [31] and has expanded to interventions for family caregivers [32,33]. In both settings, ENABLE was shown to improve quality of life, decrease levels of depression, and extend survival of those with advanced cancer [29,31,33]. However, no scalable, early, nurse-led, community-based palliative care interventions have been adapted to support AI and rural persons living with advanced cancer. The purpose of this descriptive qualitative study is to understand the barriers affecting cancer care delivery in AI, rural, and frontier populations from the perspective of multidisciplinary healthcare professionals (HCPs) to guide the development of a palliative care intervention for these communities.

2. Methods

2.1. Design

This descriptive qualitative study was based on thematic content analysis as described by Anderson [34] and Sandelowski [35].

2.2. Participants and recruitment

Participants for this study included multidisciplinary HCPs that provide care for persons with cancer that serve a primarily rural and frontier demographic (N = 18). To establish baseline interest in the project, members of the research team (BV & SM) met with a small group of stakeholders at the facility (including nurse practitioners providing care to persons with cancer and the nurse manager) to describe the objectives of the project and to establish recruitment protocols. This initial meeting was significant in generating buy-in from the facility which translated to enthusiastic recruitment from HCPs.

After the initial discussion of the project, the nurse manager sent a recruitment email to all HCPs that provide services to persons with cancer. The email described the purpose of the study and was sent to eligible HCPs to obtain a convenience sample. Eligible HCPs included healthcare administrators, physicians, certified nurse practitioners, registered nurses, pharmacists, dietitians, medical social workers, radiation technicians, and chaplains. The email contained a link to a QuestionPro survey that HCPs could complete if interested in participating. The survey gathered their contact information and general availability for an interview. Upon receipt of a QuestionPro response, the research team emailed the general study information, the informed consent, and potential interview times based on their selected availability to each HCP individually.

2.3. Setting, format, and procedure

The setting for this study was a rural cancer care institute with 100% of its service area designated as rural or frontier and does not have access to palliative care services. Additionally, the cancer center is not tribally affiliated or located within a Tribal Nation but serves AIs from several Tribal Nations in the surrounding area. Recruitment and data collection took place between January and April 2022. Due to the distance between the research team and HCPs (over 170 miles one-way), individual semi-structured interviews were conducted via Zoom [36]. Each interview began with an introduction of the research team members who could attend (BV alone, SM alone, or both), an overview of the project, and a review of the informed consent. Consent was implied by participants completing the interview. No consenting participants withdrew their consent during or after the interview; all participants interviewed while alone.

The research team used an interview guide for interview consistency (questions included in Table 1). The interview guide has been successfully pilot tested by previous adapters of the early palliative care intervention [37]. Interviews ranged between 20 and 60 min, were audio recorded, and transcribed verbatim. Field notes were kept by the researchers during the interviews and referenced during the analysis to

Table 1
Interview guide.

Interview Questions
1. To begin, I would just like to hear a little bit about yourself. Tell me who you are and what you do for a living?
2. What do you think are the *greatest challenges* faced by people with advanced cancer who live in a rural area?
3. What do you think are the *biggest needs* of rural advanced cancer patients?
4. How do you think support for people who live in rural locations could be improved?
5. What healthcare decisions do people with advanced cancer need to make?
6. What things make it difficult for people to make healthcare decisions?
7. What information or assistance would be helpful to help individuals make healthcare decisions?
8. Is there anything else you wish to add that we did not already discuss?

give broader context to the interviews. Consistent themes were heard by the research team by the 12th interview, but already scheduled interviews were completed. The HCPs were not compensated for participating in this interview.

2.4. Coding and analysis

Data were analyzed for thematic content analysis as described by Anderson [34] and Sandelowski [35]. Members of the research team (BV & SM) read and reread the transcripts independently while making note of codes within the transcripts for each participant. The team met and compared the independent analyses, including a comparison of our independently generated coding system. The coding systems were then aligned for a final readthrough of the manuscripts at which, the researchers me to discuss and resolve differences in analysis until achieving consensus on the final themes that are presented in the manuscript. All coding was completed in NVivo 12 Pro [38].

2.5. Rigor

The research team maintained rigor and trustworthiness as described by Morse [39]. Additionally, the team achieved credibility through transcribing participant data verbatim following each interview, through prolonged immersion in the data, and our in-depth discussions of initial codes and final themes. We attained dependability through our frequent discussions of the independent analysis and coding of transcripts using NVivo to maintain a consistent coding structure. Transferability is achieved by detailed description of the setting, sampling procedures, data collection, and data analysis, so the study design can be replicated in other situations and settings. Each team member achieved confirmability through the process of keeping notes during the analytic and coding processes. Adherence to these criteria strengthens the relevance of the data and findings.

2.6. Research ethics and protection of human subjects

The expedited approval of this study was accepted by South Dakota State University under an Institutional Review Board (IRB) Authorization Agreement with the healthcare facility where this study was conducted. The institution providing the IRB review is not named to protect the anonymity of the participants of this rural, single site study.

3. Results

Eighteen HCPs indicated their interest in participating; 100% completed interviews. The HCPs represent ten healthcare disciplines. Demographic data are not shared to protect their anonymity since they practice in a single rural facility. Three major themes were revealed through content analysis: (a) Access, (b) Time, and (c) Isolation. These three themes represent HCP perspectives of their patient's needs and the barriers affecting cancer care delivery. Although it was not the intended

purpose of this study, it was noted these three themes are also reflective of the HCPs own needs when delivering cancer care to AI, rural, and frontier populations. To distinguish these needs and barriers, results for persons with cancer and HCPs are presented separately.

3.1. Persons with cancer

3.1.1. Access

For persons with cancer, the theme of access is multi-faceted as this area faces vast geographical distances, lack of healthcare services, healthcare workforce shortages, limited technology, and insufficient resources which may influence their decision making. This complex resource scarcity is heightened on the Tribal Lands.

1) *...when we [HCPs] try to get people [patient] their stuff, they just sometimes say, "Enough is enough. I just want to stay in my community," and tends to do more symptomatic comfort care measures versus maybe getting them [patients] the things that could help them. [HCP 12]*

Distance is a significant barrier to accessing cancer care in the area. Persons with cancer must travel 30–150 miles or more one-way for care which requires good weather, a reliable vehicle, financial means, and a person to give them a ride if needed. The Tribal Lands in the area are the furthest points in the cancer care institute's service area making distance a significant barrier for AIs living in this region. Furthermore, there is no public transportation in this area, especially no consistent transportation that can transport people extensive distances. Knowing this, the clinic tries to cluster appointments as much as possible.

1) *...scheduling appointments back-to-back [to limit] having to go back and forth so many times, [especially if needing] somebody to bring them if they're unable to get themselves here due to weakness or anything like that. [HCP 2]*

Furthermore, there is a significant lack of home health, hospice, and long-term care related to a diminishing population (especially young people) in rural and frontier areas which has caused a rural workforce shortage, leaving a higher proportion of older adults living in rural areas without healthcare services. HCPs reported that persons with cancer needed to have better access to their entire multidisciplinary care team, both within the hospital and within their homes, but the rural nature of the service area limits their reach.

2) *...the farms are very close together. Ranches aren't like that, they're far apart. So, it might take our [home health] nurse - she might be able to see two [patients] in one entire day if she's driving 50 miles one direction and then having to go the other direction. So, there are times that we have to decline those patients. [HCP 4]*

This theme also encompasses lack of technology as there are places in the facility's service area without internet access. Lack of internet access is notably worse on Tribal Lands.

1) *If they could have internet access if they don't have that. I know in some rural areas that internet is not something that they can get, and even cell phone service is a struggle for some. [HCP 9]*

Another consideration is persons with cancer who do have smart phones but may not have the ability to use a smart phone, prefer in-person visits or phone calls, or have a limited number of prepaid minutes.

2) *...especially those in the rural areas, because [patients] all have access to at least a [landline] phone. They might not have internet access and they might not have video access, but almost all of them...still have a house phone, because that's their only option. [HCP 15]*

Finally, the HCPs expressed that persons with cancer are unable to obtain several resources that would be beneficial, such as support persons, support groups, and financial resources.

1) *...having a support group would help them again make a better decision. [HCP 5]*
2) *...something that helps to get more [HCPs] into the home to help the patients, whether it's mental health or medical or financial or whatever... for patients who do not have adequate financial [resources], many of them decide even if they will take treatment or not because they say, "I can't afford it." [HCP 14]*

3.1.2. Time

Throughout the HCP interviews, time was related to giving the person receiving a cancer diagnosis enough time for decision making, including treatment decisions. HCPs reported that persons with cancer needed additional time after a cancer diagnosis due to the shock of the diagnoses and amount of information they receive.

1) *...I think you need to have multiple conversations so that people [patients] have time to think and ask questions and to get those questions answered so that they understand this, and so I think a lot of it is just multiple visits. Sometimes, everybody's in a hurry just to move on with treatments. Sometimes I think we need to take a little more time at the beginning to make sure everything is understood by all parties. [HCP 1]*
2) *...after they had time to discuss it with the family and everything, a lot of patients say, "You know what, Doc, we decided not to do anything"... [HCP 12]*

To contrast, one of the HCPs stated how rural persons with cancer may have more time for decision making when compared to their urban counterparts who live close to healthcare services. The HCP indicated that the lack of proximity to larger cancer treatment centers allows those living in rural areas more time for treatment decisions, which may include palliative care.

1) *I think sometimes in the rural communities, we don't have access to everything as quickly, makes better care in the palliative setting just because if they [patients] come into one of these big centers, they're put through machines, poked and prodded and all of this stuff.... in the big city, they'd [patients] come in on a Friday, you [HCP] get the biopsy, and then you [HCP] rush them [patients] over to urgently do - start radiation or something... [HCP 12]*

HCPs spoke about persons with cancer having limited time left due to poor prognosis and needing to decide how they want to spend precious time. HCPs voiced how it's their responsibility to keep them as comfortable as they can during that time.

1) *Being able to have that conversation in a comfortable environment, especially with those who have advanced cancer, bring that up early so that they know what their options are and how to proceed. If they want to do aggressive treatments or if it's going to help at all or if they should try to seek out palliative care instead. [HCP 17]*
2) *In the community it's like, "Look, Doc, I [patient] know what you have to offer, but you know what, I prefer doing it this way." And I think at the end of the day, that's what we're [HCPS] here for. We're here to give them the choices and let them make their own decision, the pros and cons, and support their wish, whatever they want to do...[HCP 12]*

3.1.3. Isolation

The numerous access issues lead to a population that is isolated which HCPs identified as one of the greatest challenges for persons with cancer. HCPs repeatedly mentioned that older adults live in rural areas without any reliable support structure, such as nearby friends and family, which leaves them geographically and socially isolated.

1) *I talked to a few of our rural patients and they lived far away from families and friends so they don't have that support close by…If maybe that they could have internet access it would help…I know in some rural areas that internet is not something that they can get, and even cell phone service is a struggle for some. That could be why it's such a struggle for some of them to have that contact for a support system to their families and friends, so maybe trying to open that line of communication might be beneficial to our patients. [HCP 9]*

In addition to being isolated because of physical distance to caregivers and/or family members, persons with cancer are also isolated in that they may not have a caregiver or family members at all. These realities compound the challenges of receiving cancer care in a rural area. Additionally, the HCPs identified that the general demeanor of persons living in the Midwestern US with a hesitation to put undue burden on someone else.

1) *They don't have a family member to take them to where they need. [HCP 5]*
2) *Many of them do not have a good support system. They may have lost their spouse; their children don't live here; we see that quite a bit. So, I would think the isolation both of the area; they may live a long way from some town or city. Also, probably the lack of support from family or friends. [HCP 14]*
3) *Some people, especially in the Midwest, they'd like to go in alone and not bother anybody… [HCP 10]*

3.2. HCPs

3.2.1. Access and isolation

While discussing the challenges faced by persons with cancer, HCPs unintentionally revealed their own challenges. Themes of access and isolation also emerged as being influential factors on HCPs; however, access and isolation are more integrally linked for HCPs. The HCPs discussed that their lack of access to other HCPs (including registered nurses, advanced practice providers, oncologists, and additional support staff) directly leads to feelings of further isolation. The HCPs described a lack of access to other HCPs due to staffing shortages within their rural workplace.

1) *I think it's widespread in South Dakota right now and maybe across the nation that we have a huge shortage of nurses. We have lots and lots of business if we could only fill those positions. [HCP 4]*
2) *… when you're in a bigger center, you can go walk down and talk to somebody, which is sometimes quicker than trying to call them or get them answering and push this first step. I think that probably when you go to these smaller communities, even the big cities, when they're still using this older technology, it makes it even more difficult…you just want someone's input and try [to] quickly get them [patient] to that person [HCP], but if it takes a day or two to get in touch with that person…" [HCP 12]*

HCPs also reported a need for newer technology that would be more efficient and facilitate communication of care, such as EMRs that would connect across healthcare facilities.

1) *…you would think by this day and age, with all these EMR systems that we have, that you could be able to get it [needed patient information] instantaneously at any point in time… [HCP 12]*
2) *…it's difficult especially with the patient population in our area that we're focusing on. I think I know we're getting better with technology, but sometimes it's hard to really build that relationship with people just over the phone… I think Zoom would be a nice way to be able to see each other but that kind of technology isn't always available for everybody. [HCP 8]*

3.2.2. Time

HCPs often mentioned a desire for more time with persons diagnosed

with cancer and their families for education, including diagnoses, treatments, and having goals of care conversations. HCPs also reported that persons newly diagnosed with cancer are inundated by information (tests, treatment options, etc.), much more than in the past. Therefore, HCPs may not have enough time to review all options, but must find time in order to make the most well informed and accurate prognosis.

1) *I wish we had more time to spend time on them, but we just don't as an acute oncology setting. [HCP 1]*
2) *…[medication] side effects and chemo, especially the newer immunotherapies, interactions with medications, there are bunches of it, what [patients] can expect, how they're going to feel from various cycles. [HCP 6]*
3) *To me, I feel like just talking to patient and kind of putting the medical stuff aside and just trying to get to know them, and they'll tell you what they want, and it's just sometimes though you don't have that time… [HCP 12]*

4. Discussion

The purpose of this study was met as the main needs of persons with advanced cancer and the barriers to cancer delivery were discovered from the perspective of HCPs who serve AI, rural, and frontier populations. As the HCPs described the needs and barriers of providing care for rural persons with cancer, it became evident that the themes of access, time, and isolation, also affect them.

Access is tremendously impacted by the rurality of the state. SD covers a vast geographical area with 64 of the 66 counties designated as rural or frontier (less than 6 persons per square mile) [40]. The county where the cancer care institute is located is designated as rural; however, the remainder of the counties in its service area are designated as frontier which includes the Tribal Lands. Thus, distance becomes one of the most consequential barriers to cancer care delivery as it demands resources to overcome, such as transportation, finances, and drivers [41,42]. Distance not only affects access to healthcare services, but also family, friends, and colleagues, which can lead to professional and personal isolation [43,44]. As noted in the narratives, the barrier of access can affect treatment decision making for persons with cancer as they may be forced to choose the treatment option that is available locally due to financial or other constraints. In some scenarios, there may be no treatment options locally available to them, which may mean being forced to not treat the cancer. Hence, AI, rural, and frontier people may lose the opportunity to choose between numerous treatment options, unlike what may available if they lived close to a large, urban cancer center [45].

Society, including HCPs, often looks to technology to bridge gaps in access. However, the profound lack of technological resources is another noteworthy barrier affecting this rural population. Part of this technological gap includes limitations in broadband internet availability in the home. This is especially true in Tribal Lands where as some available internet service providers (ISPs) do not provide the necessary bandwidth to support high-speed telehealth calls [46,47]. There are programs available to help cover the costs of broadband internet, such as the TRIBAL LIFELINE program that provides discounts for eligible Tribal residents for internet services through ISPs that serve the area [48]. However, the total remaining costs may still be prohibitive to many who face persistent poverty and may lack the proper technology, such as a smart phone or laptop, to connect to telehealth appointments [49]. In addition, the Infrastructure Investment and Jobs Act of 2021 [50] has dedicated funding to expanding broadband infrastructure on Tribal lands to improve access to and affordability of broadband internet in rural and Tribal communities. It remains unclear how this funding will impact internet access at the individual level.

The perception of limited time to process a diagnosis of advanced cancer or to make decisions about treatment can be quite stressful [51,52]. HCPs described their personal desire to spend more time with

the people they care for but have limitations due to the rising number of persons with cancer and reduced workforce. Persons with advanced cancer also desire to have more time not only with their HCPs to discuss options, but with their loved ones to discuss what their wishes may be for their cancer journey. This kind of conversation is well known in palliative care and is known as a goals of care conversation [53,54]. Although goals of care conversations are not specific to only palliative care, the purpose of palliative care is to revisit the goals of care frequently to ensure persons are achieving their desired quality and quantity of life [54,55]. With the current time limitations felt by HCPs, these goals of care conversations may be minimal or absent from the care routine when cancer treatments are discussed, meaning the treatment course may not align well with the person's wishes [56]. In this study's rural setting, it is unclear if goals of care conversations are occurring on a routine basis or not, but palliative care is not available at the present time.

Another urban-rural disparity in SD is the availability of palliative care services which are only available on two opposing sides of the state (approximately 400 miles apart) [57]. This leaves much of the state without access to palliative care services, including the people served at this rural cancer care institute. According to the American Society of Clinical Oncology (ASCO) guidelines, palliative care services should be integrated early into the cancer treatment for persons with advanced cancer as a standard of care [58]. These guidelines and results further support the development of this adapted intervention to bring culturally appropriate palliative care to AIs, rural, and frontier persons living with advanced cancer in SD.

The main strength of this study is the number of HCPs who were eager to participate and represent a wide variety of disciplines which provided a comprehensive and holistic view of cancer care delivery to AI, rural, and frontier persons with advanced cancer. A limitation of this study is it only reflects the perspectives of HCPs, not the persons with advanced cancer. However, the perspectives of the persons with advanced cancer have been obtained and will be published in a future manuscript.

4.1. Innovation

This study is innovative as it is the only study to explore the perspectives of HCPs serving an AI, rural, and frontier population with advanced cancer. These perspectives, in conjunction with the perspectives of persons with advanced cancer, will be key to developing the first culturally responsive, nurse-led, early palliative care intervention for this population.

4.2. Conclusion

An early palliative care intervention for this AI, rural, and frontier population in SD could address the needs and facilitate overcoming the barriers to receiving cancer care. This study provides preliminary evidence for the need and strong multidisciplinary support for such an intervention. While this intervention supports the persons with advanced cancer, it would also support the HCPs serving them.

CRediT authorship contribution statement

Brandon M. Varilek: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Writing – original draft, Writing – review & editing. **Sarah Mollman:** Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Project administration, Software, Supervision, Writing – original draft, Writing – review & editing, Formal analysis, Resources.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Sarah Mollman reports financial support was provided by The Rita & Alex Hillman Foundation. Sarah Mollman reports financial support was provided by Arthur Vining Davis Foundations. Sarah Mollman reports financial support was provided by South Dakota State University Research, Scholarship, and Creative Activity Challenge Fund.

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