

Barriers to Adherence to Standard of Care in Appalachia: A Qualitative Assessment in Gastrointestinal Cancers

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Purpose: Appalachian Kentucky, a 32-county region in the eastern part of the state, has elevated colon cancer mortality rates. While recommended as the standard of care, access to adjuvant chemotherapy treatment is limited in this region due to scarce health services and significant social and geographical barriers. The purpose of this investigation was to improve understanding of barriers that cancer patients residing in rural areas not served directly by tertiary medical systems must overcome in completing adjuvant therapy.

Methods: Participants were recruited from two medical centers: A tertiary care NCI designated Cancer Center and a regional hospital. Participants underwent a 15–20 minute interview to assess factors associated with adherence to adjuvant treatment recommendations. Grounded theory identified themes related to patient behaviors and non-adherence to standard of care recommendations.

Results: Data were collected in 45 telephone and in-person patient interviews, 26 from an NCI-designated cancer center and 19 from a rural hospital. Statistically the two groups were equivalent in terms of age, subjective health status, and medical comorbidities. Six themes were identified from analysis of the transcribed interviews including: confidence in my care provider, communication, treatment issues, distrust, faith, and barriers to obtaining healthcare. Participants completing adjuvant therapy were more likely to express trust in their provider and describe fewer barriers to obtaining healthcare than those not completing adjuvant therapy.

Conclusion: Barriers to completing adjuvant therapy may differ between rural and urban healthcare systems which may yield opportunities for targeted interventions to improve rates of completion of colon cancer adjuvant chemotherapy.

Keywords: cancer, rural, barriers to care, adjuvant therapy

Introduction

The American Cancer Society (ACS) estimates that colorectal cancer (CRC) ranks as the third most common cancer and the third most common cause of cancer death in the United States for men and women.¹ In Kentucky, CRC is a leading cause of cancer death, a statewide rate of 48.1 per 100,000, behind lung and bronchus, female breast, and prostate.² In Kentucky's Appalachian region, comprised of 32 of the 120 counties in the state, CRC has the highest mortality rate, 51.7 per 100,000.^{3–6} Compared to the US population, rural residents have limited access to healthcare in general, and to oncology services, in particular.⁷ Appalachian residents are more likely to have lower incomes, higher poverty rates, lower levels of education, higher unemployment rates, and poorer health than non-Appalachian residents. In addition, the rural Appalachian population must negotiate long distances to healthcare with very limited public transportation.⁸ Given the history of poor health outcomes in the context of numerous barriers, access to standard-of-care treatment is critically important.⁹

Despite statewide public health education and promotion efforts to improve colon cancer screening rates, at 71.3% Kentucky continues to fall below the national average of 71.9% per the 2020 Behavioral Risk Factor Surveillance System (BRFSS).⁵ Despite improved screening rates over the past decade, many rural patients continue to present with advanced disease requiring adjuvant chemotherapy following surgical resection.^{6,10–12}

Although adjuvant chemotherapy treatment is considered the standard of care for CRC, access is limited for Appalachian residents due to significant social and geographical barriers.^{3,13} Therefore, adjuvant therapy regimens may not be completed, which in turn increases the risk of poor oncologic outcomes in terms of both morbidity and mortality.^{8,14–16} Understanding factors associated with not obtaining/completing adjuvant chemotherapy is necessary to identify the next steps toward improving survival rates.

Strauss and Glaser describe Grounded theory as a qualitative research method with sufficient organization and rigor to establish a theory or model based on respondent information.¹⁷ While data are available to describe the association between completion rates of adjuvant therapy and colon cancer mortality, less is known about the circumstances and availability of adjuvant therapy to high-risk patient populations. Addressing this gap requires information collected at the individual level using qualitative methods. Based on respondent behaviors, obtained via interviews and surveys, inductive processes generate hypotheses to explain the underlying motivations for observed and reported behaviors. This qualitative public health framework is applied to cancer research to further understand patient behaviors in a time of high stress where critical decisions are made.^{17–19}

Using patient interview data, our study employed a grounded theory methodology to identify the underlying motivations and barriers to completion of adjuvant chemotherapy regimens in Appalachian patients diagnosed with colon cancer. We hypothesized themes related to patient rejection of standard of care recommendations which could yield opportunities for targeted interventions to improve colon cancer adjuvant chemotherapy compliance.

Materials and Methods

Recruitment

Participants were recruited from two medical centers representing our catchment area; an NCI-designated Cancer Center (CC) serving a large catchment area that includes urban, suburban, and rural areas, and a regional hospital (RH) serving a rural, Appalachian population. CC participants were recruited through the local CC affiliate of the Oncology Research Information Exchange Network (ORIEN).²⁰ ORIEN is a cancer precision medicine initiative developed by the Moffitt Cancer Center in Tampa, Florida. RH participants were recruited from patients who had surgical resections for colon cancer and were referred to the project by their health care provider. Eligible participants had to be age 18 and older with a diagnosis of gastrointestinal cancer, willing to participate in an anonymous 15–20 minute in-person or telephone interview, and provide permission to collect additional information, without personal identifiers, regarding their treatment status via chart review. All eligible patients were invited to participate in the study.

Ethics

This study was reviewed and approved by the Office of Research Integrity at the University of Kentucky (IRB approval # 67904). This research was conducted in accordance with the Declaration of Helsinki. The purpose and potential benefits of the study were clearly explained to participants as part of the informed consent process. Participants were assured that they could withdraw from the study at any time without discrimination and consented to the anonymous information being used for publication. All relevant identifying information about the participants was deleted after data collection was complete.

Measurement

A 10-item interview was derived from previously published literature that described barriers to completing chemotherapy.^{21,22} The interviews collected responses describing subjective health status, comorbidities, interactions between patient and physician, and factors important to the patient when participating in chemotherapy. Study participants were interviewed by a single interviewer over the phone or in person. Additionally, patients were asked open-ended questions regarding their experience and the status of their follow up care. Patient's adherence with recommended chemotherapy or treatment regimens was then assessed by chart review conducted by the lead author. Completed therapy regimens were defined as complying with the recommended standard of care. Therefore, patients with low stage cancer who did not require adjuvant therapy were considered complete if a surgical resection was performed. Patients

recommended for chemotherapy alone, without surgery, were considered to have completed therapy if they finished their chemotherapy regimens.

Data Collection

Interviewers utilized semi-structured in-person and telephone interviews to collect the data for this study. Participant interviews were conducted between July 1, 2021 and December 31, 2021. Participants were offered a \$20.00 gift card as compensation for their time. All patient interviews were conducted in a private space unless the patient desired to have a second party involved. In two phone interviews, a family member assisted a hearing-impaired patient. All 26 phone interviews and 19 in-person interviews were conducted by a single interviewer. Phone interviews were audio recorded and transcribed by one person. Interviewer notes were also maintained.

Qualitative Data Analysis

Raw verbatim interview transcripts were coded and themes distilled using both inductive and deductive approaches. Themes and codes were assigned by two coders. For quality assurance regarding comparable coding, four interviews were randomly selected for both authors to code. These codes were 95% in agreement with only 2 of the codes altering between reviewers during the initial coding process.

Themes were developed through an iterative process undergoing 3 cycles. Initial codes were distilled into 15 themes, of which 6 themes were finally identified. To assist in this process, a two-by-two table was created which cross-matched patients belonging to the CC or RH groups against patients who completed or did not complete the standard of care therapeutic regimen.

Results

Participant Demographics and Clinical Characteristics

A total of 45 interviews were performed, 26 from the CC site and 19 from the RH site. Across these participants, 34 (72%) were recommended to have adjuvant therapy, 18 (69%) from CC and 16 (84%) from RH. Statistically these patient populations were equivalent in terms of age, subjective health status, and medical comorbidities ($p>0.05$). When considering all patients who completed the standard of care, 72% of CC patients completed the recommended treatment regimen, compared to 56% of RH patients ($p=0.331$). There was no difference in the proportion of patients completing treatment by age, gender, or subjective health status ($p>0.05$).

Qualitative Analyses

Six themes were identified in the analysis of interview data from the patients recommended to have adjuvant therapy (Table 1). The six themes clustered around two descriptors: personal characteristics of patients and aspects of the healthcare system and providers. Personal characteristics themes included “confidence in my provider”, “distrust”, and “faith”. Health care system and provider themes included “communication”, “treatment” and “barriers to health care”.

Table 1 Comparison of Frequency of Theme Endorsement by Completion of Adjuvant Therapy and recruitment Site

	Cancer Center		Rural Hospital	
	Completed N=13	Did Not Complete N=5	Completed N=9	Did Not Complete N=8
Confidence in Provider	13/13	4/5	6/9	4/8
Communication	8/13	2/5	2/9	1/8
Treatment	8/13	4/5	3/9	5/8
Distrust	3/13	0/5	2/9	2/8
Barriers to healthcare	6/13	1/5	1/9	0/8
Faith	0/13	0/5	5/9	6/8

Confidence in My Provider

Patients in both groups stated that they believed that without their doctors “[they] wouldn’t be alive talking to you now”. This feeling of being cared for by a “team [that] went above and beyond” was prevalent in 100% of patients in the CC group who completed adjuvant therapy compared to 66% of patients in the RH group. Additionally, CC group patients expressed a stronger belief than RH group patients that the chemotherapy regimens their doctor prescribed was worth the adverse effects but expressed concern with “what it did to [their] body, but it has to do it” to treat their cancer. Patients in both groups felt a sense of being cared for by their treatment team. Patients were secure knowing their care team “always did follow ups and checkups” regarding their overall health status. Further, they appreciated receiving care from a CC that was always able to “make it work” regardless of scheduling or personal difficulties. Patients endorsing this theme stated that they “had the absolute best surgeon” they could have. When treating cancer “the support crew team, whatever you want to call it, is essential”.

Distrust

Patients in both groups expressed distrust in their care providers stating “they didn’t tell [them]” about aspects of their care or provide sufficient explanation of why they should undergo further therapy. Distrust of RH providers included a desire for surgeons from another medical center to “come up here to do the surgery”. Many patients in both groups reported a desire for a second opinion, with CC patients more likely than RH patients to indicate willingness to travel to alternative hospitals for a second opinion or doing extensive research on their provider prior to their appointment.

Faith

Many cancer survivors as well as those going through treatment attribute an element of fate, faith, or a higher power as having a hand in their outcome. Patients in the RH group were more likely than CC patients to report applying the theme of faith to support their treatment regimen or used it to support their decision not to complete recommended treatment. Those who did not choose to undergo adjuvant therapy said they “just have faith that [they are] not going to get it [cancer] again”. However, some used faith as a motivator to move through their therapy without getting upset “because it doesn’t help anything”.

Communication

Participants commented on the quality of communication surrounding their cancer diagnosis, noting their appreciation for a “rather lengthy conversation” in which “questions got answered”. Within the CC group, 55% felt they experienced good rapport with their provider, where only 17% of RH participants expressed such rapport. Patients rating communication with their physician highly described their interactions as “talked with [them] as long as [they] wanted to talk” with an emphasis on getting questions and concerns answered. In patients who experienced good communication, they demonstrated a deeper understanding of their diagnosis and the next steps to take. Patients in the CC group were more likely than RH group patients to voice understanding of what their physician said when discussing adjuvant therapy and the importance of completing the recommended regimen. Overall, good communication with healthcare providers was mentioned more often in the CC group than in the RH group and was associated with comprehension of the importance of therapy completion.

Treatment

Respondents in both groups frequently focused on the difficulties and benefits of adjuvant treatment. Many said that “it was by far the most difficult thing I have had to contend with my health” and many seemed skeptical about the treatment, asking frequently, “Is this going to work?”. Additionally, there was misunderstanding regarding the reasoning behind continued treatment, particularly in the RH group. Some participants understood adjuvant therapy to be “preventive” and was recommended “just to be extra safe”. Overall, most patients stated that they understood chemotherapy was intended “to prevent the possibility of the cancer recurring”.

Barriers to Healthcare

RH patients were more likely to describe practical barriers to obtaining advanced cancer treatment than their CC counterparts. RH patients cited practical difficulties such as, “my car broke down just before I started treatments”. The

cost of treatment was also a factor, with one patient remarking, “we went from two paychecks to only one”. Related to healthcare costs, both groups frequently mentioned patient billing as a barrier, with many complaining that “billing [is] very confusing... the portal would say one thing and the bill would say another”. This theme is of particular concern because it creates a further layer of distrust between the patient and healthcare system, where patients feel they are not only unable to complete therapy but are concerned about being taken advantage of from a financial perspective. However, the lack of access to transportation appeared to be the most significant barrier to completing adjuvant therapy. Across all groups, patients stated that the travel distance to the nearest facility capable of providing treatment was an important factor in their decision to complete the recommended course.

In summary, the results from qualitative analysis of the patient interviews identified several factors that differentiated between CC and RH patients as related to adherence with standard of care recommendations. The barrier of distance to care and relationships with healthcare providers including trust and communication facilitated adherence in both groups. Patients who expressed trust and satisfactory communications with their provider were likely to complete treatment if barriers could be overcome. Finally, while faith did not appear to influence adherence it did influence satisfaction with patients’ decision to complete or not to complete treatment.

Discussion

This qualitative research study identified themes regarding completion of adjuvant chemotherapy following a colon cancer diagnosis and surgical resection for patients treated at a tertiary care academic CC compared to those treated at a RH with a primarily rural and Appalachian patient population. Across treatment facilities patients experienced different stressors and motivations which impact their adjuvant therapy completion. Themes such as confidence in their provider, communication, and treatment were present throughout descriptions of patient experiences. Patients in the RH group were more likely to express distrust in their provider and were less likely to complete therapy compared to those in the CC group.

Themes related to non-adherence to adjuvant therapy have been studied in other cancer disciplines, with the most robust work involving breast cancer survivors.^{21–23} Dean et al conducted a survey study to determine the frequency of treatment discordance, the patients did not follow their surgeon’s recommendations for adjuvant therapy, and its possible association with distrust of the physician or the healthcare system. From 2754 participants they found that patients who expressed distrust of the healthcare system relayed a 22% increased risk of not completing recommended treatment, whereas trust of the individual physician was not associated with treatment compliance.²⁴

Distrust was a significant predictor of non-compliance, with a higher proportion identified in the RH group. Distrust within our study’s results was directed at both the system and individual provider, where patients desired a second opinion at another center, or felt they had to research information before or after their physician appointment. Therefore, referring patients to systems they trust and providers for whom they have confidence is critical to reducing the risk of adjuvant therapy noncompliance.

For a patient dealing with a new cancer diagnosis, communication and navigation within the healthcare system can be confusing and overwhelming. In our study, patients who completed adjuvant therapy were twice as likely to report communication as an important component of their cancer therapy compared to those who did not complete it. Further, patients in the RH group were less sanguine regarding communication with their provider than those in the CC group. A possible explanation for this phenomenon may be differences between cancer patients who live in rural Appalachian Kentucky and healthcare providers who are “outsiders”, and do not share the same cultural background. Such differences often affect communication which may influence understanding of treatment plans and confidence in their efficacy.

Literature supporting multidisciplinary cancer clinics, the use of nurse navigators, and other coordination services have long been studied and processes implemented to improve satisfaction and compliance in the healthcare system.^{25–27} In lung cancer, utilization of a navigator to ensure proper appointment scheduling, manage travel logistics, and answer patient questions resulted in an improvement in the number of patients seen within 2 weeks of diagnosis and an increase in patient satisfaction.²⁸ A similar effect was identified for 76 patients with breast cancer. Nurse navigators decreased the time from initial diagnosis to provider consultation for their older populations.²⁹ The utility of patient navigation support is widely accepted and is a required criterion for accreditation by the National

Accreditation program for Breast Cancers.³⁰ Based on the patient themes collected in this study, it is likely that navigators may improve therapy completion and outcomes.

Non-adherence with recommended adjuvant therapy in colon cancer increases risk of adverse outcomes. Wang et al identified 673 patients recommended to completed adjuvant therapy with one of two therapy regimens. Non-completers, overall, had 41% higher healthcare costs unrelated to chemotherapy when compared to those who completed the recommended adjuvant chemotherapy.³¹ Practical concerns regarding healthcare utilization, healthcare costs, and billing were shared between healthcare systems and cancer patients. Providing support to increase compliance with recommended treatment protocols will improve both patient experience and healthcare system performance.

Limitations of this study are related to the research methods employed the nature of qualitative research. While every effort was made to enroll all patients fitting eligibility criteria, some selection bias may be present. Interviews were conducted in a semi-structured manner either over the phone or in person. A consistent template and script were used for both sets of interviews to reduce data collection bias. Furthermore, qualitative interview data are subject to limitations regarding self-reported data and recall bias. This study was designed to evaluate underlying motivations to complete recommended adjuvant chemotherapy based on interactions with providers and healthcare systems and participation and interview responses may have been influenced by the prospect of receiving a \$20 gift card.

Conclusions

Future research regarding the utility of patient navigation in rural health settings to improve compliance with adjuvant therapy is needed. Quality improvement initiatives regarding this intervention may provide an avenue to improve outcomes in colon cancer for patients with poor healthcare access to subspecialty care. Specialty care such as medical oncology is concentrated in population centers and while efforts are increasing to provide oncology care close to home, distance and travel issues remain. While our study identified many themes regarding adjuvant therapy completion, additional research is needed to better define specific barriers to completion of adjuvant therapy, particularly for patients in rural area.

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Disclosure

The author(s) report no conflicts of interest in this work.

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