Published in final edited form as:

Clin Lymphoma Myeloma Leuk. 2020 January ; 20(1): 47–52.e3. doi:10.1016/j.clml.2019.09.599.

Priorities for Rural Lymphoma Survivors: A Qualitative Study

Lillian Chen, MPH¹, Jackelyn B. Payne, MPH^{1,3}, Kaylin V. Dance, MPH¹, Conner B. Imbody^{1,2}, Cathy D. Ho¹, Amy A. Ayers, MPH¹, Christopher R. Flowers, MD, MS¹

¹Department of Hematology and Medical Oncology, Emory University – Winship Cancer Institute, Atlanta, GA

²Rollins School of Public Health, Emory University, Atlanta, GA

³Department of Psychology, Stony Brook University, Stony Brook, NY

Abstract

Aims—We aimed to gather rural patient perspectives on lymphoma care and unmet needs throughout the course of treatment. This was done to better understand their attitudes towards treatment and their barriers to participating in clinical research studies.

Methods—We conducted 12 individual semi-structured phone interviews in the spring of 2018 with lymphoma survivors from rural counties in Georgia. Patients were identified by a residential address in counties classified as rural based on Rural/Urban Commuting Areas. Participants were recruited from regional patient education conferences and among current research participants at a university research hospital in Georgia. Interviews were recorded and transcribed verbatim. Thematic analysis and MAXQDA 18.0.8 were utilized to facilitate a constant-comparative coding process during theme development.

Results—The greatest barrier to care was distance. Participants described difficulty navigating between local clinics and larger cancer centers. Lack of communication between local and specialized clinics complicated the process, and participants had difficulty contacting or seeking advice from the team at larger cancer centers. Seeking treatment from specialized clinics farther away introduced additional barriers. Most participants agreed that technology was important for improved communication. Participants described lymphoma etiology, subtype-specific studies, alternative therapies, and quality of life as key research priorities.

Corresponding Author: Christopher R. Flowers, Department of Hematology and Medical Oncology, Winship Cancer Institute, 1365 Clifton Road NE, Suite B4000, Emory University, Atlanta, GA 30322, Ph: 404-778-3942, crflowe@emory.edu.

Author Contributions: C.F. conceived the presented idea, analyzed data, contributed to manuscript writing and editing, and approved the final manuscript. L.C. conducted interviews, analyzed data, transcribed interviews, contributed to manuscript writing and editing, and approved the final manuscript. J.B.P. conducted interviews and focus groups, analyzed data, contributed to manuscript writing and editing, and approved the final manuscript. K.V.D. conducted phone interviews, analyzed data, transcribed interviews, contributed to manuscript writing and editing, and approved the final manuscript. C.B.I. analyzed data, contributed to manuscript writing and editing, and approved the final manuscript. C.D.H. conducted interviews and transcribed interviews, analyzed data, contributed to manuscript writing and editing, and approved the final manuscript. A.A.A. provided help with finding eligible patients in the databases, analyzed data, contributed to manuscript writing and editing, and approved the final manuscript.

Conflicts of Interest: None

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Conclusion—These findings suggest that targeted research and interventions are necessary to address the specific needs of rural lymphoma patients and survivors. To address the disparity in health outcomes within rural populations, health care professionals and investigators can utilize these data to engage rural patients in treatment decision-making and research planning.

MicroAbstract

A qualitative study of lymphoma survivors living in rural Georgia was conducted using 12 individual semi-structured phone interviews. Distance was the greatest barrier to care, while other issues included communication and navigating between local clinics and larger cancer centers. Participants saw technology as an important solution and detailed their research priorities.

Keywords

lymphoma; rural; qualitative; survivorship; disparity

A. Introduction

Non-Hodgkin lymphoma (NHL) is the seventh most common cancer and the ninth leading cause of cancer death in the United States.¹ In 2019, 74,200 new cases of NHL are expected and the number of lymphoma survivors is estimated at over 757,000.¹ With improved lymphoma treatment, this number of survivors is expected to grow.² Given the large number of individuals undergoing treatment for blood cancers or currently in remission, evidence-based strategies promoting quality of life and supportive care have become essential.^{3–5} Cancer survivorship research encompasses the physical, emotional, social, and financial consequences of a cancer diagnosis. However, long-term health-related quality of life in lymphoma patients remains understudied,^{6–8} and more exploratory research is necessary to determine how these complex needs can be assessed.⁹

Lymphomas are associated with risk factors that more commonly affect rural individuals.^{10–13} Patients from rural populations comprise 14.9% of the United States¹⁴ and face unique healthcare concerns compared to their metropolitan peers.^{15,16} For example, in one study, lymphoma patients treated in local clinics had worse survival rates than those treated in larger university hospitals and patients in rural areas demonstrated an increased likelihood of mortality due to their disease compared to urban patients.¹⁷ Moreover, rural patients face additional obstacles regarding access to highly-specialized care and clinical trials.¹⁸ Low research recruitment rates within this population may be due to patient misconceptions regarding their eligibility to participate,¹⁹ geographical and financial burdens,²⁰ and an overall lack of awareness of available research opportunities.²¹ Patient burden due to excessive participation in additional studies, concerns regarding time commitment, mistrust of researchers, and a lack of understanding the research process are also known contributors to rural patients' high study refusal rates.²²

Rural cancer patients, including those with lymphoma, have unique barriers to care, including limited access to preventive and specialized care, decreased economic resources, and reduced proximity to supportive services.²³ Comprehensive exploratory research is required to thoroughly understand these needs and propose solutions to health outcome

disparities in these populations. Prior qualitative studies have identified barriers to care and participation in research for cancer survivors.²⁴ However, beliefs and unmet needs of rural lymphoma survivors remain unexplored. We conducted semi-structured individual telephone interviews with lymphoma survivors from rural areas of the state of Georgia in order to determine perceived unmet needs regarding lymphoma care in rural areas and to examine views, perceptions, and priorities for rural patients' participation in therapeutic and observational clinical research studies.

B. Patients and Methods

Twelve individual semi-structured phone interviews were conducted in the spring and summer of 2018 with eleven lymphoma patients and survivors and one caregivers recruited from rural counties in the state of Georgia. Rural counties were defined using Rural/Urban Commuting Areas (RUCAs), a categorization system used in the research community to classify rural and urban areas based on census tract level data.^{14,25} Participants were recruited in-person by research team members at local patient educational conferences and via telephone from the pool of current research participants in the Lymphoma Epidemiology of Outcomes Cohort Study database, state of Georgia cancer registry, the Lymphoma Research Foundation, the Leukemia and Lymphoma Society, and other patient advocacy groups in Georgia.²⁶ Eligible participants were over the age of 18, fluent in English, and lived in a RUCA code of 4 – 10 (indicating rural living) in Georgia at the time of recruitment. Two participants were over the age of 18, but did not want to disclose their exact ages. This is indicated in Tables 1 and 2 in the Appendix. Recruitment and data collection occurred simultaneously and ceased when data saturation was reached, indicated participants had begun repeating themes and ideas rather than contributing novel data.²⁷

The interview guide used for study was informed by the results of a previous study involving focus groups and interviews with lymphoma patients and caregivers, a thorough literature review focused on rural lymphoma patients, and the qualitative expertise of the research team.^{28,29} The interview guide was designed to be semi-structured, giving participants the freedom to guide the interview and allowing the interviewer to probe as needed with additional questions as topics arose. The interviews were recorded with consent and transcribed verbatim. Thematic analysis was used to identify emerging themes. MAXQDA 18.0.8 qualitative data analysis software was used to facilitate a constant-comparative coding process to identify the resulting themes.

C. Results

Demographics

Sixty-two eligible patients were selected at random from a larger pool of 541 patients enrolled in an observational longitudinal study at a university research hospital. All participants randomly selected were contacted with 6 refusing to participate. Forty-five 45 were unable to be contacted and 11 patients completed interviews. The one caregiver interviewed was nominated as a potential study participant by their spouse, who was a patient interviewed in this study. The median participant age for individual interviews was 54 (range 21–73). The participants were evenly divided by sex (n=6; 50% respectively), and

were predominantly White (n=11; 91.7%) with one Hispanic participant (n=1; 8.33%). There were 12 total interviews with 1 caregiver and 11 patients: 1 patient was in watch and wait (n=1), 8 patients were post-treatment, 1 patient was pre-treatment, and 1 was interviewed during treatment. Interviews lasted an average of 30.5 minutes (range 15 – 47). Participants in this study received local care at a variety of clinics and cancer care facilities and had experiences with large metropolitan centers and academic medical centers across the state of Georgia. Two eligible participants were recruited while living in a rural county in Georgia and were eligible for participation. While in Georgia, they lived in a rural county but moved out of state during the interview process. The rural regions of the state where interview participants lived and the major metropolitan centers in Georgia are shown in Figure 1.

Major Themes

Distance: A primary concern the participants expressed was distance to the larger clinics. Nearly all participants noted commutes of several hours to the clinic and the additional strain that this placed on their cancer care experience. One participant summarized this theme saying that each clinic visit “was six hours of my day just driving” (Male, 54, Hispanic). Other participants described the difficulties of finding travel accommodations and hotel stays for each visit, with one participant noting that his main inconvenience was “the fact that I had to be away from home for seventeen straight days” (Male, 64). This distance weighed on the participants in other ways, such as forcing them to rely more heavily on their support systems for transportation and being unable to participate in educational and support resources. A participant said that cancer support groups meet “...on a Tuesday night at 7PM and I can’t be there. I have to have a hotel room and drive that far; I just can’t be there” (Female, 72).

Diagnosis Experience: A second theme from the interviews was the stark contrast in diagnosis experience at local clinics compared to a metropolitan academic center. Participants often described a lack of specialized lymphoma care providers in their hometowns and noted how this dearth contributed to a negative diagnosis experience or, in some cases, an incorrect diagnosis. One participant recounted a harrowing misdiagnosis at her local clinic, saying of her local clinical environment “We gotta get outta here. We gotta get out of [city] and, you know, get where somebody knows” (Female, 63). When participants began treatment at the university clinic, they found clearer diagnoses and more specialists, but also discovered the complexities of navigating a larger medical system. One participant said that the whole process at the university clinic was overwhelming. “This is all brand new, seeing so many doctors...It feels like I’ve been bombarded” (Female, 42). Other participants described the lack of transparency between the university hospital departments and the patients, with one participant saying the billing department was “sneaky to hit you with things after you’ve had it done...they should just be transparent and honest with us” (Female, 42).

Patient-Provider Relationships: Another theme that emerged from the interviews were differences in patient-provider relationships experienced at local clinics compared to larger, metropolitan cancer clinics. Some participants felt that they were unable to get advice or

maintain relationships with their clinical care team at university clinics. Rural patients mentioned personality clashes and less time with their clinician as contributing factors to this issue. One participant added to this, saying that her husband's doctor at the university clinic "called me a hovering wife right there to my face and basically didn't want to hear anything I had to say, you know, and kind of ignored me" (Female, 60). The lack of consistent communication by medical staff left participants feeling unheard and unwilling to trust their clinical care team as fully as they needed to.

Use of Technology: The theme of using technology to communicate with clinical care teams emerged as a solution that was unanimously supported by the participants. The use of an electronic patient portal was considered "the best thing going" (Female, 72) and was well-liked by all participants due to the speed with which they could communicate with their clinical care team. One patient illustrated this, saying "when I required assistance through the portal... they would always respond like the next day" (Male, 54, Hispanic). Another patient said the patient portal was beneficial to her because of how far she lived from the university clinic. She "regretted that [she] hadn't learned that up front and didn't use that as a communication tool because...[she was] 150 miles away" (Female, 63). In addition to the patient portal, patients reported using text messages and email to communicate with their clinical care team. These methods were also found to be useful and effective, resulting in participants feeling more connected to and respected by their clinical care team.

Participants' Priorities for Research: Participants generally expressed a desire to not only be more aware of research results, but to participate in therapeutic and non-therapeutic studies. However, most were frustrated by the difficulty of finding opportunities to participate in trials. As for research topics, some participants expressed wanting more information about the etiology of their lymphoma, wanting a more reliable source of information rather than their personal theories such as a vaccine side effect (Male, 73) or chemical exposure during childhood (Male, 65). Others wanted more research opportunities or findings about their perceived rare form of lymphoma, feeling their unique needs are often left out of educational events and research dedication. One participant illustrated this point, saying "I wish there were newer things and more specific research done on my kind of lymphoma...it doesn't get that much attention I feel. I wish there was more research being done in that area" (Female, 72).

Finally, participants expressed a need for research regarding quality of life and symptom management, as well as alternative therapies. While most were interested in any alternative to traditional chemotherapy, some were specifically interested in "...immunotherapy and gene therapy and stuff" citing that these treatments were "the wave of the future" in cancer care (Male, 49). A compilation of relevant participant quotes can be found in Tables 1 and 2 in the Appendix.

D. Discussion

Establishing a comprehensive strategy to meet the needs of all lymphoma patients requires: detailed data on incidence rates and survival across this heterogeneous group of patients by geospatial and regional characteristics,¹ an infrastructure to support clinical and basic

research to understand factors that influence prognosis and survivorship, and a clearer understanding of the needs of this patient population. An in-depth understanding of patient priorities and survivorship needs will inform interventions and education efforts for lymphoma survivors to navigate care during and following treatment, improve quality of life, and engage in the process of recovery.

In a recent epidemiological study, rural lymphoma patients demonstrated poorer overall survival, lower socioeconomic status, and lower rates of private health insurance than metropolitan patients.²⁵ Socioeconomic and structural factors affecting the outcomes of rural lymphoma patients are deserving of in-depth exploration as well as exploratory research targeting these populations to better understand these and other barriers to care. The focus of our study was to examine the perceived unmet needs of rural lymphoma patients and to explore their beliefs and perceptions about research participation and results.

Increased participation in research, especially enrollment in clinical trials, is essential to leveling the disparity in outcomes for rural cancer patients.^{20,30} Several factors have been linked to low accrual rates of rural patients to research studies, including lack of awareness,³¹ distance from study sites,³² socioeconomic barriers,³³ and physician-patient communication.^{34,35} We found that our participants were interested in participating in research and becoming more familiar with the scientific aspects of oncology, but that they were unfamiliar with the research process and how to find information concerning ongoing studies.

Rural populations in most of the United States face increasingly burdensome travel distances. This travel burden may intensify when it involves treatment, including clinical trials, at more specialized cancer care centers.³⁶ Our participants' responses indicated that there are clear advantages of specialized care centers including clarifying complex diagnoses, providing expertise in treatment decision making, and access to clinical trials. However, these may be counterbalanced by travel burden on patients and their families, lengthier and confusing diagnostic experiences, and difficulties with long-term management upon entering survivorship.³² Prior studies suggest that rural patients may be less likely to seek specialized services due to travel time, which is not only difficult to plan for and may be impossible for patients who do not have reliable transportation.²³ Our study's results align with these findings and support the need for solutions to combat the significant issue of distance in receiving optimal cancer care. Possible solutions to address this specific barrier could be providing monetary travel reimbursement for rural patients or a transportation system overseen by the hospital that is connected to its already existing shuttle and carpool systems. This would provide reliable access to and from various central points in rural communities throughout the state. Solutions like these would eliminate the need for rural patients to figure out their own transportation to and from treatment, easing unnecessary stress on both the patient their support systems.

Physician-patient communication is essential to improving rural patients' enrollment in clinical trials.³³ Even in care settings with ample research infrastructure, the beliefs and practices of individual oncologists are linked to rates of clinical trial enrollment.^{34,35} Critically, many oncologists in such settings are unaware of research opportunities for their

patients.^{24,35} Lack of information or enthusiasm from a physician can be interpreted as disapproval if a patient inquires about opportunities.³³ Our results indicate that some participants felt disconnected from their physician or care team, which affected their overall satisfaction and cancer experience. This corresponds to prior literature reviewing patients' communication needs and satisfaction with their providers,³⁷ in particular lack of communication about emotional needs of patients.³⁸

Cultural differences may also make communication between cancer care teams and rural patients more difficult. Rural patients are less likely to seek information about research participation than urban patients³¹ and are more likely to possess negative views about medical research.³⁹ Community-based interventions to increase awareness about research opportunities and the value of clinical trial provide a valuable pathway to alleviating rural disparities in cancer care and outcomes.^{40–42}

The use of technology to improve the experience and outcomes for cancer patients has been explored in prior research as one possible solution to address the lack of awareness about research opportunities,^{43,44} the barrier of distance,^{45–47} and serve as a tool to facilitate care and education without the need to travel. The use of technology has also been applied to behavioral outcomes, such as oral medication adherence.^{48–50} Our participants were enthusiastic about the use of technology and telemedicine, such as online patient portals to communicate with their providers and the use of mobile phone apps with educational resources.

Participants emphasized that using technology to communicate had made a positive impact on their cancer experience and expressed a desire for more app-based education. Currently, there is a lack of scientifically-based educational apps.⁴³ Possible future directions in this field could include app-based patient portals that are free to access and portals that are managed by the hospital for free rather than by paying insurance companies. Future research with this population should explore the efficacy and feasibility of telemedicine interventions^{47,51} as well as the usefulness of educational applications.^{47,52}

Hematological cancer survivors, including lymphoma survivors, also have unmet emotional and supportive care needs.^{53,54} Prior qualitative research with cancer survivors has explored unmet survivorship needs. Rural survivors' unmet needs are exacerbated by travel, financial burdens,^{23,55} and cultural differences.²³ These burdens are reflected in our results, with our participants' indicating a lack of survivorship and supportive care information. Participants were unable to access the same educational events and academic activities occurring in metropolitan areas. Community-based interventions and targeted educational campaigns may be of benefit to these populations,⁵⁶ in addition to telemedicine.⁵⁷ Interestingly, one theme gleaned from our data highlighted the desire for research about alternative medicine. This may be indicative of patients' perceptions of control over their health,⁵⁸ or their need to cope with dissatisfaction of their treatment experience.⁵⁹ Future studies should explore these topics further.

There are limitations of this study which should be noted. The study participants were recruited at educational events and from other studies indicating that our participants may be

more knowledgeable about lymphoma and more willing to participate in research than the general population. These results would also not include the perspectives of patients that chose not to participate in an interview and who may express views differing from those represented in this study. However, based on the results of a previous study examining a larger sub-population from this cohort, participants indicated an interest in participating in research regardless of their diagnosis. Our participants were fluent in English, had access to a telephone, were predominantly White, and all were recruited in Georgia, limiting the generalizability of the results. Future studies should explore these topics in a variety of social contexts and with underrepresented groups of rural patients and survivors. A sub study has been initiated to examine the perceptions and priorities of African American lymphoma patients. We expect this study to similarly shed light on the research priorities and unmet needs of this underrepresented population.

E. Conclusion

The results of our study provide and illuminate several patient-oriented directions for further research including systemic and socioeconomic barriers to care that rural patients face. Our results regarding psychosocial and emotional needs as well as barriers to research participation and awareness are valuable to informing future exploratory and interventional research for these populations.

F. Clinical Practice Points

These findings suggest that targeted research and interventions are necessary to address the specific needs of rural lymphoma survivors. To address the disparity in health outcomes that exists in this population, healthcare professionals and investigators can utilize these data to engage rural survivors in their treatment decision-making. In particular, the preference in this study population for the use of technology to communicate contributes to the body of research regarding the significance technology has and can continue to have in lymphoma care.

Further research can also be done to expand on these patient perspectives within other underrepresented populations, including rural minorities, undocumented individuals, and uninsured lymphoma patients, providing a more rounded understanding of the barriers that impact various groups with lymphoma and developing interventions that suit the diverse needs of these populations.

Acknowledgments

This research is supported in part by NCI award number U01CA195568 to Drs. Cerhan and Flowers, K24CA208132 to Dr. Flowers, and P30CA138292 that provides the Intervention Development, Dissemination and Implementation shared resource and the Winship Research Informatics shared resource, cores for the Winship Cancer Institute of Emory University. The authors also thank Meghan Gutierrez for her continued support through the LRF.

Funding: NIH

Appendix

Table 1.

Rural Patient Quote Table

Theme	Quote	Participant
Distance	"And um, you know, I'd be facing a trip to Atlanta which will be three hours, you know, and it could be worse traffic wise and getting people out, you know, was, was the problems that I didn't want to do and stuff like that."	Female, 63
	"No, the only thing is I get might be that I have to go back to Atlanta for appointments and so that a six hour drive sometimes..."	Female, 63
	"Yes, every time I had to drive there. It was 6 hours of my day just driving."	Male, 54, Hispanic
	"It was, I am lucky enough to be in driving distance of Emory, but that was kind of a pain, arranging transportation to and from when you can't drive."	Male, 48
	"I had to travel. Milledgeville is about the center of Georgia and we had to travel up to Atlanta."	Male, 64
	"...there was very little inconvenience other than the fact that I had to be away from home for seventeen straight days."	Male, 64
	"Well the only thing that we tried to look to see how to deal with get help with my traveling, you know expense for traveling in places to stay or not had to go to Atlanta, and back and forth but it seemed like I just walked in the rock. All I get is so superior. And it just seemed like if you didn't get Medicaid or something like that, you didn't qualify for expense travel or anything so other than that. No. Medicare and my supplement post took care of everything."	Female
Burdening Support System	"Yeah, yeah, it was much more convenient for me. And um, you know, I spent 40 years going into Atlanta, but I won't, I won't drive there now, so to go, Clifton road had to have somebody to carry me and that gets to be a little burden, you know, my children or my friends or somebody to get me down there..."	Male, 73
	"So friends would be the main thing, or either I would change doctors and get one closer by, such Fayetteville which is 45 min to an hour away."	Female, 72
	Facilitator: "It is really wonderful. If you didn't have this cancer car service, would you rely more on friends or on family?" Respondent: "More on friends, yes. There is not much family close by that could do it. Family, my two children, live far away, so it is not easy for them to get here and do it."	Female, 72
	"...and so it my full responsibility to get us to these appointments and back home and it's getting more and more difficult and will be impossible after next Tuesday when I have that surgery so we're going to have to rely on friends more."	Female, 72
	"...luckily I had you know good family members that helped me out you know get me to where I needed to go."	Male, 39
	"It will be on a Tuesday night at 7PM and I can't be there. I have to have a hotel room and drive that far; I just can't be there."	Female, 72
	"Emory puts on a program every now and then, maybe it's not Emory that does it maybe it is Emory or the various lymphoma/leukemia societies who will have programs at Emory, and I live 2 and a half hours away."	Female, 70
Local Diagnosis Experience	"...well he was misdiagnosed in the beginning and I'm, and I feel like he could have been more aggressive about following up or challenging or getting a second opinion or any of those things. And I think my biggest fear now is that he's not going to maybe recognize or is going to poo poo any kind of symptoms that you might have if they're subtle..."	Female, 60
	"I was very surprised that I had a small lymph node in my neck that was misdiagnosed in California."	Male
	"It all got taken care of, the misdiagnosis at the front end you just have to be careful about that."	Male

Theme	Quote	Participant
<i>Lack of Knowledge at Local Clinics</i>	"And I thought, oh my God, what a dumbass we gotta get outta here. We gotta get out of Macon and, and you know, get where somebody knows."	Female, 63
	"There was a 10-day period when I was in the hospital in Macon when I thought I would be well taken care of, but it was terrible. Like they didn't know what they were doing."	Female, 63
<i>Lack of Specialized Providers</i>	"I wish we could get a different doctor but there isn't a different doctor here."	Female, 42
	"Well I started off at a university hospital. Things there were extremely nice, but then my oncologist there transferred me to a cancer center because [doctor] specializes in lymphoma."	Female, 21
<i>Navigating Complicated Systems</i>	"I don't go to the doctor hardly ever. I went when I was pregnant because you have to. This is all brand new, seeing so many doctors....It feels like I've been bombarded."	Female, 42
	"We tried our best to get in [university hospital]...it was so shockingly mismanaged that we gave up and ended up going to the local cancer place... they needed this or that kind of records. We had them sent, they never received them...we mailed it to them and they couldn't open the files. We tried to make an appointment with them and then we'd get the robo calls...it was such a mess...it's all over the place. And meanwhile the clock is ticking."	Female, 60
	"[The billing department] should never -- especially sick people because some people don't have the faculty to make those kind of decisions right up front, you know? They're so emotional. I just seems sneaky to hit you with things after you've had it done...they should just be transparent and honest with us."	Female, 42
	"I'm a little apprehensive about the new PA who happens to be a male and I have seen him some time before and I felt that he was not as concerned as my female PA had been..."	Female, 72
	"He didn't, like, he didn't discuss, you know, what they future's going to be like or anything. He just wanted to know all about your job because he was so fascinated...and we got nothing out of this."	Female, 60
	"Um his doctor here referred to me to me like in front of me as being a hovering wife when I went to the doctor's appointment with him...he called me a hovering wife and like right there to my face and basically didn't want to hear anything I had to say you know and kind of ignored me."	Female, 60
	"Besides the nausea medication, like I was taking antiviral medication, and I didn't even know what they were until I looked them up myself which was no problem but I wish they would have told me so I could have had a better understanding of what all I was taking and what was going on."	Female, 21
Technology to Communicate	"And then, um, later on when I learned about the patient portal, I really regretted that I hadn't learned that up front and didn't use that as a communication tool because when they know the, the bad part of my treatment was that I was 150 miles away."	Female, 63
	"See, when I required assistance through the portal they would always respond like the next day, it wouldn't take them long for them to either be on the portal or contact me."	Male, 54, Hispanic
	"The patient portal – that's the best thing going."	Female, 72
	"I really like the patient portal where I can ask a question if I need to...They will get back to me, or someone will, so that patient portal is wonderful."	Female, 72
	"I keep it on multiple cell phones and I am on the computer too, but the app is fantastic."	Male, Unknown Rural
	"I think with (the university hospital)... the amount of connectivity is amazing. I can look at my information online. If I have a question, I usually get a call back from an email within a matter of minutes. So it's very responsive and everyone is so incredibly friendly."	Male
	My wife just said the patient caregiver, the portal was good...with a lot of information on it for her since she was the caregiver.	Male

Table 1 Key:

BOLD - Main Theme*Italicized* - Subtheme**Table 2.**

Participant Research Priorities

Research Priority	Quote	Participant
Alternative Therapies	"Well I mean what I am more interested in would be something more with cannabis because I mean I think they need to look at that a little bit more than what they have been looking at it."	Male, 39
	"I think I am very curious about what the new possibilities for therapies, immunotherapy and gene therapy and stuff, results for treatments like that in the cancer industry is the wave of the future. So I would be curious about that."	Male, 49
	"I mean, I just hope one day they find a cure other than chemotherapy."	Female, 21
	"New treatments or revisit the two that are the most current ones that I mentioned before and really make sure they are the best treatments for this type of lymphoma."	Female, 72
	"Kaiser had great support groups if you wanted to go to those. I think they do some of that too. Make that available."	Male
Source of Lymphoma	"Well I know that when he told me that what I had, I was like you know how did I get it? Where did it come from? And they don't know you don't. So yeah, I would love any answers at any of that"	Female, 63
	"Well one thing I would like to see is somebody research the connection between a shingles vaccination and lymphoma. Yeah. I can't get anybody to listen to me, but I firmly believe that either a shingles back shingles vaccination was the cause that my lymphoma or was the trigger that sent it off. And I've mentioned that to several doctors and, you know, shrug their shoulders or sense. But, uh, uh, I'm convinced that day. So now I'd like to see somebody look into that."	Male, 73
	"I had a wild idea that maybe multiple myeloma might come from having your house being sprayed by the Orkin guy and not cleaning it properly because my mom was always having that van come in and having them spray for roaches in Mobile, Alabama and both my dad and my mom got multiple myeloma which is a very rare disease and it is normally given by blood related people and obviously my mother and father were not blood related people so the doctors always raise their eyebrows when I say that my mom and dad both died from multiple myeloma."	Male, 65
Quality of Life	"Even research on quality of life. Um. How we could deal with the tiredness and the other side effects of the lymphoma and/or the treatment."	Female, 72
	"Well like I said the first one is a cure for it and the second one is how to get quality life out of it. That's basically it."	Male, 54, Hispanic
Subtype-Specific Research	"Just more knowledge of the specific kind. I don't believe there are clinical trials for my kind of lymphoma."	Female, 72
	"What I am picturing is a conference, maybe like the one I went to by the Lymphoma and Leukemia Foundation, I went to one in Atlanta, and I would love for there to have been a little break out group or a little mini session on my kind. There was a mini session for the fatigue with lymphoma but I just want to know more about my specific kind."	Female, 72
	"I wish there were newer things and more specific research done on my kind of lymphoma. SMZL because mine is so rare it doesn't get that much attention I feel. I wish there was more research being done in that area. I am open to helping with research for that. I am ready. I want more research done."	Female, 72

H. References

1. Teras LR, DeSantis CE, Cerhan JR, Morton LM, Jemal A, Flowers CR. 2016 US lymphoid malignancy statistics by World Health Organization subtypes. *CA: a cancer journal for clinicians*. 2016;66(6):443–459. [PubMed: 27618563]

2. Key Statistics for Non-Hodgkin Lymphoma. American Cancer Society. <https://www.cancer.org/cancer/non-hodgkin-lymphoma/about/key-statistics.html>. Published 2019 Accessed February 29, 2019.
3. Davies JM, Osborne TR, Edmonds PM, et al. The Myeloma Patient Outcome Scale is the first quality of life tool developed for clinical use and validated in patients with follicular lymphoma. *Eur J Haematol*. 2017;98(5):508–516. [PubMed: 28160316]
4. Barke J Qualitative accounts of living with cutaneous T-cell lymphoma. *British Journal of Dermatology*. 2015;173(1):10–11.
5. Beynon T, Selman L, Radcliffe E, et al. ‘We had to change to single beds because I itch in the night’: a qualitative study of the experiences, attitudes and approaches to coping of patients with cutaneous T-cell lymphoma. *British Journal of Dermatology*. 2015;173(1):83–92. [PubMed: 25688924]
6. Mushtaq MUU, Mangla A, Hamad H, Khurana S, Catchatourian R. Health-related quality of life in underserved patients with hematologic malignancies. *Journal of Clinical Oncology*. 2016;34(3_suppl):238–238.
7. Holland RA, Bird BR, Cahill M, et al. Assessing the quality of life of non-Hodgkin lymphoma survivors: A population-based study. *Journal of Clinical Oncology*. 2016;34(3_suppl):227–227. [PubMed: 26573078]
8. Husson O, Prins JB, Kaal SE, et al. Adolescent and young adult (AYA) lymphoma survivors report lower health-related quality of life compared to a normative population: results from the PROFILES registry. *Acta Oncol*. 2017;56(2):288–294. [PubMed: 28077017]
9. Thompson CA, Towns JN, Dripps L, et al. Impact of lymphoma survivorship clinic visit on patient-centered outcomes. *Journal of Clinical Oncology*. 2016;34(3_suppl):64–64.
10. Morton LM, Slager SL, Cerhan JR, et al. Etiologic heterogeneity among non-Hodgkin lymphoma subtypes: the InterLymph Non-Hodgkin Lymphoma Subtypes Project. *J Natl Cancer Inst Monogr*. 2014;2014(48):130–144. [PubMed: 25174034]
11. Smedby KE, Sampson JN, Turner JJ, et al. Medical history, lifestyle, family history, and occupational risk factors for mantle cell lymphoma: the InterLymph Non-Hodgkin Lymphoma Subtypes Project. *J Natl Cancer Inst Monogr*. 2014;2014(48):76–86. [PubMed: 25174028]
12. Linet MS, Vajdic CM, Morton LM, et al. Medical history, lifestyle, family history, and occupational risk factors for follicular lymphoma: the InterLymph Non-Hodgkin Lymphoma Subtypes Project. *J Natl Cancer Inst Monogr*. 2014;2014(48):26–40. [PubMed: 25174024]
13. Cerhan JR, Krickler A, Paltiel O, et al. Medical history, lifestyle, family history, and occupational risk factors for diffuse large B-cell lymphoma: the InterLymph Non-Hodgkin Lymphoma Subtypes Project. *J Natl Cancer Inst Monogr*. 2014;2014(48):15–25. [PubMed: 25174023]
14. Parker T USDA ERS - Rural-Urban Continuum Codes. <https://www.ers.usda.gov/data-products/rural-urban-continuum-codes/>. Published 2013 Accessed December 31, 2018.
15. McNulty JA, Nail L. Cancer Survivorship in Rural and Urban Adults: A Descriptive and Mixed Methods Study. *The Journal of Rural Health*. 2015;31(3):282–291. [PubMed: 25599984]
16. Hart LG, Larson EH, Lishner DM. Rural Definitions for Health Policy and Research. *American Journal of Public Health*. 2005;95(7):1149–1155. [PubMed: 15983270]
17. Loberiza FR Jr., Cannon AJ, Weisenburger DD, et al. Survival disparities in patients with lymphoma according to place of residence and treatment provider: a population-based study. *J Clin Oncol*. 2009;27(32):5376–5382. [PubMed: 19752339]
18. Paskett ED, Cooper MR, Stark N, et al. Clinical Trial Enrollment of Rural Patients with Cancer. *Cancer Practice*. 2002;10(1):28–35. [PubMed: 11866706]
19. Seifer SD, Michaels M, Collins S. Applying community-based participatory research principles and approaches in clinical trials: forging a new model for cancer clinical research. *Prog Community Health Partnersh*. 2010;4(1):37–46. [PubMed: 20364077]
20. Unger JM, Moseley A, Symington B, Chavez-MacGregor M, Ramsey SD, Hershman DL. Geographic Distribution and Survival Outcomes for Rural Patients With Cancer Treated in Clinical Trials. *JAMA Netw Open*. 2018;1(4):e181235–e181235. [PubMed: 30646114]
21. Charlton M, Schlichting J, Chioreso C, Ward M, Vikas P. Challenges of Rural Cancer Care in the United States. *Oncology (Williston Park)*. 2015;29(9):633–640. [PubMed: 26384798]

22. Mills EJ, Seely D, Rachlis B, et al. Barriers to participation in clinical trials of cancer: a meta-analysis and systematic review of patient-reported factors. *The Lancet Oncology*. 2006;7(2):141–148. [PubMed: 16455478]
23. Butow PN, Phillips F, Schweder J, et al. Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review. *Supportive Care in Cancer*. 2012;20(1):1–22.
24. Howerton MW, Gibbons MC, Baffi CR, et al. Provider roles in the recruitment of underrepresented populations to cancer clinical trials. *Cancer*. 2007;109(3):465–476. [PubMed: 17200964]
25. Ritter AJ, Goldstein JS, Ayers AA, Flowers CR. Rural and urban patients with diffuse large B-cell and follicular lymphoma experience reduced overall survival: a National Cancer DataBase study. *Leuk Lymphoma*. 2019;60(7):1656–1667. [PubMed: 30632824]
26. Flowers CR, Link BK, Nastoupil LJ, et al. The Lymphoma Epidemiology of Outcomes (LEO) Cohort Study Reflects the Demographics and Subtypes of Patients Diagnosed with Non-Hodgkin Lymphoma in the United States. *Blood*. 2018;132(Suppl 1):1702.
27. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant*. 2018;52(4):1893–1907. [PubMed: 29937585]
28. Payne JB, Ho CD, Chen L, Dance KV, Flowers CR. Survivor and Caregiver Perceptions of Lymphoma: A Qualitative Study. *Blood*. 2018;132(Suppl 1):3561.
29. Payne JB. Survivor and caregiver perceptions of lymphoma: An exploratory study. *American Public Health Association - APHA's 2018 Annual Meeting & Expo (Nov 10 - Nov 14)*. 2018.
30. Denicoff AM, McCaskill-Stevens W, Grubbs SS, et al. The National Cancer Institute-American Society of Clinical Oncology Cancer Trial Accrual Symposium: summary and recommendations. *J Oncol Pract*. 2013;9(6):267–276. [PubMed: 24130252]
31. Vanderpool RC, Kornfeld J, Mills L, Byrne MM. Rural–urban differences in discussions of cancer treatment clinical trials. *Patient Education and Counseling*. 2011;85(2):e69–e74. [PubMed: 21458194]
32. Ambroggi M, Biasini C, Del Giovane C, Fornari F, Cavanna L. Distance as a Barrier to Cancer Diagnosis and Treatment: Review of the Literature. *Oncologist*. 2015;20(12):1378–1385. [PubMed: 26512045]
33. Virani S, Burke L, Remick SC, Abraham J. Barriers to recruitment of rural patients in cancer clinical trials. *J Oncol Pract*. 2011;7(3):172–177. [PubMed: 21886499]
34. Hudson SV, Momperousse D, Leventhal H. Physician Perspectives on Cancer Clinical Trials and Barriers to Minority Recruitment. *Cancer Control*. 2005;12(4_suppl):93–96. [PubMed: 16327757]
35. Somkin CP, Ackerson L, Husson G, et al. Effect of medical oncologists' attitudes on accrual to clinical trials in a community setting. *J Oncol Pract*. 2013;9(6):e275–e283. [PubMed: 24151327]
36. Onega T, Duell EJ, Shi X, Wang D, Demidenko E, Goodman D. Geographic access to cancer care in the U.S. *Cancer*. 2008;112(4):909–918. [PubMed: 18189295]
37. Horinuki F, Noguchi-Watanabe M, Takai Y, et al. The Experience of Persons With Hematological Malignancy When Communicating With Health Care Professionals. *Qualitative Health Research*. 2017;28(3):479–490. [PubMed: 29103363]
38. Hack TF, Degner LF, Parker PA. The communication goals and needs of cancer patients: a review. *Psychooncology*. 2005;14(10):831–845; discussion 846–837. [PubMed: 16200519]
39. Geana M, Erba J, Krebill H, et al. Searching for cures: Inner-city and rural patients' awareness and perceptions of cancer clinical trials. *Contemporary Clinical Trials Communications*. 2017;5:72–79. [PubMed: 29740623]
40. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *American journal of public health*. 2010;100 Suppl 1(Suppl 1):S40–S46. [PubMed: 20147663]
41. Israel S, Moffitt TE, Belsky DW, et al. Translating personality psychology to help personalize preventive medicine for young adult patients. *J Pers Soc Psychol*. 2014;106(3):484–498. [PubMed: 24588093]
42. Wallerstein NB, Duran B. Using Community-Based Participatory Research to Address Health Disparities. *Health Promotion Practice*. 2006;7(3):312–323. [PubMed: 16760238]

43. Pandey A, Hasan S, Dubey D, Sarangi S. Smartphone Apps as a Source of Cancer Information: Changing Trends in Health Information-Seeking Behavior. *Journal of Cancer Education*. 2013;28(1):138–142. [PubMed: 23275239]
44. Vollmer Dahlke D, Fair K, Hong YA, Beaudoin CE, Pulczynski J, Ory MG. Apps seeking theories: results of a study on the use of health behavior change theories in cancer survivorship mobile apps. *JMIR Mhealth Uhealth*. 2015;3(1):e31–e31. [PubMed: 25830810]
45. Doolittle GC, Spaulding AO. Providing Access to Oncology Care for Rural Patients via Telemedicine. *J Oncol Pract*. 2006;2(5):228–230. [PubMed: 20859340]
46. Aiello Bowles EJ, Tuzzio L, Wiese CJ, et al. Understanding high-quality cancer care. *Cancer*. 2008;112(4):934–942. [PubMed: 18181099]
47. Hersh WR, Helfand M, Wallace J, et al. Clinical outcomes resulting from telemedicine interventions: a systematic review. *BMC Med Inform Decis Mak*. 2001;1:5–5. [PubMed: 11737882]
48. Burhenn PS, Smudde J. Using tools and technology to promote education and adherence to oral agents for cancer. *Clin J Oncol Nurs*. 2015;19(3 Suppl):53–59. [PubMed: 26030395]
49. Wu YP, Linder LA, Kanokvimankul P, et al. Use of a Smartphone Application for Prompting Oral Medication Adherence Among Adolescents and Young Adults With Cancer. *Oncol Nurs Forum*. 2018;45(1):69–76. [PubMed: 29251285]
50. Crawford SY, Boyd AD, Nayak AK, et al. Patient-centered design in developing a mobile application for oral anticancer medications. *J Am Pharm Assoc* (2003). 2019;59(2s):S86–S95.e81. [PubMed: 30745188]
51. Jupp JCY, Sultani H, Cooper CA, Peterson KA, Truong TH. Evaluation of mobile phone applications to support medication adherence and symptom management in oncology patients. *Pediatric Blood & Cancer*. 2018;65(11):e27278. [PubMed: 29943893]
52. Bender JL, Yue RYK, To MJ, Deacken L, Jadad AR. A lot of action, but not in the right direction: systematic review and content analysis of smartphone applications for the prevention, detection, and management of cancer. *J Med Internet Res*. 2013;15(12):e287–e287. [PubMed: 24366061]
53. Stanton AL. What Happens Now? Psychosocial Care for Cancer Survivors After Medical Treatment Completion. *Journal of Clinical Oncology*. 2012;30(11):1215–1220. [PubMed: 22412133]
54. Parry C, Morningstar E, Kendall J, Coleman EA. Working without a net: leukemia and lymphoma survivors' perspectives on care delivery at end-of-treatment and beyond. *J Psychosoc Oncol*. 2011;29(2):175–198. [PubMed: 21391070]
55. Tzelepis F, Paul CL, Sanson-Fisher RW, et al. Unmet supportive care needs of haematological cancer survivors: rural versus urban residents. *Annals of Hematology*. 2018;97(7):1283–1292. [PubMed: 29525897]
56. Hutchison SD, Steginga SK, Dunn J. The tiered model of psychosocial intervention in cancer: a community based approach. *Psychooncology*. 2006;15(6):541–546. [PubMed: 16331595]
57. Shepherd L, Goldstein D, Olver I, Parle M. Enhancing psychosocial care for people with cancer in rural communities: what can remote counselling offer? *Australian Health Review*. 2008;32(3):423–438. [PubMed: 18666870]
58. Yates PM, Beadle G, Clavarino A, et al. Patients with terminal cancer who use alternative therapies: their beliefs and practices. *Sociology of Health & Illness*. 1993;15(2):199–216.
59. Arthur K, Belliard JC, Hardin SB, Knecht K, Chen C-S, Montgomery S. Practices, attitudes, and beliefs associated with complementary and alternative medicine (CAM) use among cancer patients. *Integr Cancer Ther*. 2012;11(3):232–242. [PubMed: 22313741]

Figure 1.
Rural Counties of Georgia and Major Metropolitan Cities