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Patient and Caregiver Perceptions of Lymphoma Care and Research Opportunities: A Qualitative Study

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Abstract

\textbf{Background:} The number of lymphoma survivors has increased, however, the needs and research priorities of survivors and their caregivers are rarely examined and addressed. Determining needs and priorities for this population requires assessment the attitudes and experiences of patients and caregivers.

\textbf{Objective:} We conducted a qualitative study with lymphoma survivors and caregivers to determine care needs and research priorities.

\textbf{Methods:} In Phase I, two semi-structured focus groups were conducted with 15 lymphoma survivors and caregivers. In Phase II, 19 individual semi-structured telephone interviews were conducted with lymphoma survivors and caregivers. In both phases, participants discussed cancer experiences and research priorities. All interviews were transcribed. MAXQDA 18.0.8 software was used for coding and identifying themes.

\textbf{Results:} Most participants felt disconnected from their clinical care team due to lack of communication. Focus group participants noted a lack of information regarding diagnoses, treatment, research, and survivorship care. Participants coped with fear through strong social support and fostering relationships with their clinical care teams. Some caregivers felt completely
ignored by clinicians. Participants expressed interest in research, but had difficulty finding relevant studies. Several interviewees wanted holistic and survivorship-oriented research and more studies about quality of life and mental health.

**Conclusion:** We identified unmet needs in clinical care and patient-oriented research including needs for focus on quality of life after treatment, communication between patients and the scientific community, and emotional well-being. Health care professionals can utilize these data to provide care delivery, supportive services, and research that meets the needs of lymphoma survivors and caregivers.

**Precis:**
Lymphoma patient and caregiver needs are rarely addressed in literature. By addressing their psychosocial needs and research priorities, clinicians can gain a more thorough understanding of their patients’ requirements and develop future research centered on these populations.

**Keywords**
lymphoma; qualitative; caregivers; patient; needs; interviews; focus group

**Background**
Lymphoma patient outcomes have improved with ten-year survival rates being >50% for most subtypes.\(^1\) As life expectancies increase, research regarding all aspects of survivorship and long-term quality-of-life becomes a priority. Survivorship is a burgeoning field for oncologists and researchers as factors determining these priorities change. Unfortunately, survivors’ emotional and psychological burdens during the cancer experience are often unaddressed as providers rarely emphasize any aspect of patient care other than the patient’s physical needs.\(^2\) Examining and addressing these unmet psychosocial needs can improve the overall well-being of patients and survivors.\(^3\)

Survivorship after the course of lymphoma treatment is an important, emerging field of cancer research, but has rarely been addressed in literature.\(^4,5\) Surprisingly little is known of the long-term physical effects of cancer treatment and even less is communicated to patients.\(^5\) Unfortunately the existing reputable information on survivorship care is fragmented and often difficult for patients to understand, and not all cancer clinics provide this information to their patients.\(^4,6\) More research is needed regarding long-term survivorship and education.

In addition, caregivers are an essential part of survivorship care management due to their invaluable role as a part of the patient’s care team. They are often present for clinical visits, capture information the patient may have missed,\(^7\) and have described the process of watching over a sick loved one as traumatic.\(^8\) Caregivers can mirror the mental health patterns of the patient as they progress through the disease,\(^9\) but their mental health and other needs are rarely addressed.

Previous qualitative studies have examined the experience of lymphoma patients and survivors,\(^10-14\) but have not examined beliefs about research participation, unmet needs of survivors, optimal survivorship education and clinical care, and the unique role of
caregivers. Given the growing need for patient-centered care and lymphoma survivorship research, we conducted an exploratory qualitative study with lymphoma survivors and caregivers consisting of two phases: 1) focus groups with survivors and caregivers and 2) semi-structured individual phone interviews with survivors and caregivers. The use of focus groups enabled us to assess group consensus regarding our general research questions. Individual interviews allowed for in-depth understanding of participant beliefs and opinions to assess unmet needs and generate ideas for further research in these populations.

Methods

After IRB approval, informed consent was obtained, and we performed semi-structured focus groups followed by a series of individual, semi-structured phone interviews.

Methodology: Phase I

Focus groups were conducted in the spring and fall of 2017, involving lymphoma survivors (n=8) and lymphoma caregivers (n=7). Participation was voluntary and participants were recruited from individuals attending a national Lymphoma Research Foundation (LRF) patient education conference in Brooklyn, New York and a regional LRF conference in Atlanta, Georgia. The study was promoted with flyer distribution during conference check-in and by in-person recruitment during the conference from research team members and conference presenters. Each focus group was conducted by two moderators and one note taker.

The semi-structured focus group guide was developed based on previous literature and the patient advocacy, clinical, and qualitative expertise of the authors. Participants discussed their lymphoma experiences, their clinical care team, priorities for future research, and suggestions for improving care. Table 1 provides example focus group questions.

Focus group discussions were transcribed verbatim by a team of graduate research assistants and uploaded into MAXQDA 18.0.8, a qualitative data analysis software, to facilitate a constant-comparative coding and analysis process. The research team met frequently to discuss coding and theme development contributing to the reliability and validity of the data analysis. A codebook was developed based on inductive and deductive codes - commonalities observed in the transcripts. Deductive codes were based on topics included in the guide. Inductive codes were developed from participant responses. Example codes included “caregiver experiences,” “diagnosis,” and “feelings about cancer.” Codes were analyzed for frequency and developed into major themes. The results and topics discussed in the focus groups were utilized to create the interview guide for Phase II of the study.

Methodology: Phase II

Individual interviews were conducted in the spring of 2018. Participants were recruited in-person by research team members at LRF and other local patient educational conferences and via telephone from a pool of current lymphoma research participants at a university research hospital in Georgia. Recruitment and data collection occurred simultaneously and ceased when theme saturation occurred. Demographic data were collected for the 19 patients/caregivers who participated in individual interviews. Questions for the individual
interview guide were based on focus group results, literature review, and the researchers’ expertise. The semi-structured guide allowed for free responses and interviewer probing as needed. As described in the methodology for Phase I, the interview recordings were transcribed and MAXQDA 18.0.8 was used to identify codes and themes.

Results

Phase I - Focus Groups

Demographics—Eight lymphoma survivors and seven caregivers participated in the focus groups. Participants were predominantly female (n=11; 73%) including respondents who self-identified as White (n=7; 46.7%) or Black/African-American (n=3; 20%). Focus group discussions lasted roughly an hour in length.

Major Themes: Phase I - Focus Groups (See Table 2)

Survivors Lack Clinical Information: Focus group participants described an overall lack of information regarding their diagnoses, research opportunities, and treatment decisions. Many participants felt that they were not given information that should have been shared with them. One participant said that “it was kind of like pulling teeth getting information about survivorship.” Another stated that “it’s hard to get that kind of thing from doctors,” adding that their single criticism of the clinic would be that “they should answer [our questions]. It’s very hard to get that information.”

Survivors Feel Disconnected from the Clinical Care Team: Feeling uninformed contributed to participants feeling disconnected from their clinical care team. Many claimed that their clinicians’ lack of clarity coupled with their often unsympathetic personalities made them feel that their humanity was not considered during visits. A participant illustrated this, saying “I feel sometimes they don’t understand that you’re talking to someone whose life has just changed for the worst and you need to be as sympathetic and kind and compassionate as you can.” Another added “they are dealing with humans, not just numbers.”

Caregivers Feel Overlooked: Another emerging theme from the focus groups was caregivers feeling overlooked and unappreciated by the clinical care team. Caregivers often described feeling as though their emotions and input were not valid during clinic visits. One caregiver summarized this feeling by saying “I think we’re forgotten about.” Another participant described his wife’s experience, contrasting how much attention he received from clinicians compared to his wife. He said he was “asked 1000 times ‘How are you doing?’… No one has ever asked her.” Participants described that the lack of recognition by clinical care teams regarding caregivers and their needs left them feeling emotionally exhausted and unimportant.

Patients and Caregivers Expressed Strong Interest in Research: A final focus group theme was the participants’ interest in research. Many participants were especially willing to participate if the studies were not invasive or time-consuming. One participant was notably eager, stating “…unless it took up 8 hours a day 5 days a week, I would do it eyes closed.”
Another said that he/she would be more inclined to participate if treatment was certain. “If they would’ve given us a choice, placebo or this…it would have been a ‘no’, I’m sorry. But if it would be giving me conventional or this new approach, then yeah I’m going to look at that.” Participants were particularly interested in studies they felt were relevant to them and wanted more studies focusing on lymphoma subtypes and across cancers. “[E]verybody’s focusing on different kinds of cancers,” one participant added, “…I think that maybe a more general trial that kind of includes a lot of different kinds of cancer. Like a lot of different kinds of cancer.” Some participants stated that they were often confused by the research process, stating that clinicians were not explicit about the process of research initiation and engagement. Participants also described difficulty finding information on research participation during clinic visits. Table 2 provides participant quotes exemplifying the aforementioned themes.

Phase II- Individual Interviews

Demographics—The median participant age for individual interviews was 63 years (range 21-80). Participants were predominantly female (n=55%), White (n=17, 89.5%), and lived in rural areas (n=62.5%), with one African-American participant and one Hispanic participant. Interviews lasted an average of 33 minutes (range 15-57).

Major Themes: Phase II - Individual Interviews (See Table 3)

Participants Desire a Holistic Focus (Quality of Life): A major theme from the individual interviews was the need for holistic cancer care. Several participants felt that their emotional needs and mental health were ignored. Some participants wanted more attention on their diet and social support, while many wanted more information regarding symptom management and improving quality of life. One participant believed that future research should focus on “how we could deal with the tiredness and the other side effects of the lymphoma and or the treatment” (Male, 49). Participants also expressed their range of emotions during their cancer journeys; “a lot of anxiety, panic attacks” (Male, 49). They voiced a need for their cancer care to address their mental health and include additional support resources and “more research dealing with the emotional” (Female, 73).

Fear of the Unknown: Individual interviews also revealed fear as a common theme. Several participants described a fear of the unknown, especially immediately after diagnosis. One participant stated “I thought I was going to die…I wondered about like, what it was going to be like…what can I do to make it fast so that my family didn’t have to suffer through it…” (Female, 63). She described that her inexperience with cancer contributed to her fear, a commonality among participants. Others experienced this fear during treatment. Visiting doctors, not understanding the progression of the disease, and waiting for cancer recurrence were all sources of anxiety for the participants. “It was scary when you don’t know what they are going to do to you,” (Male, 54) summarized one participant.

Participants engaged in a wide range of coping strategies to combat their fears. Many found solace in social supports while others used alternative therapies. “I also practice self-hypnosis, and you can do a lot of taking care of symptoms, especially under chemo,” (Male, Age Unknown). The youngest participant said “I don’t know if I am supposed to tell you
this, but the biggest help for me…is marijuana. It helped with nausea, my appetite. It made me feel a lot better” (Female, 21).

**Strengthened Relationships:** A second theme from the individual interviews was the cancer diagnosis strengthening social support networks. A participant noticed that his family rallied around him after his diagnosis. “I think because of my condition they have become closer to me…They are there for me. They support me” (Male, 54). Patients turned to their family and friends for emotional, financial, and sometimes physical care, leaning into these relationships more heavily as new needs arose. “You learn who your friends really are” (Female, 72) one participant stated, citing the strain that arises from feeling burdensome to support networks. Table 3 provides participant quotes exemplifying the aforementioned themes.

**Discussion**

These results support prior literature and provide new insights regarding gaps in care and opportunities for lymphoma patients and their caregivers. A clinical implication of these results is for clinicians to establish trusting and patient-centered relationships, a finding supported by prior studies.\(^{10}\) Improving the level of trust patients have with their physicians helps them to feel more heard and respected. This can also be achieved by oncologists incorporating social workers, psychologists, and other health care professionals into the clinical care team. Cooperative strategies for improving access to mental health resources may establish additional support. Our findings add to the existing literature regarding the emotional and psychological needs of lymphoma patients,\(^{16}\) but additional research in this area remains crucial for improved patient mental health outcomes.

Participants in this study reported a general lack of clarity in guidance or instruction regarding care plans. Other studies have also demonstrated that clinicians often lack effectiveness when communicating patient information.\(^{7}\) This is detrimental to lymphoma care because clear communication between the patient and the clinical care team can produce more favorable health outcomes.\(^{17}\) Future research should focus on clinicians improving patient outcomes by increasing clarity and patient access to information.

For hematological cancer patients, individualized health communication has been previously suggested to fill knowledge gaps and address provider dissatisfaction caused by miscommunication of patient priorities.\(^{18}\) For example, research demonstrates that cancer patients are rarely asked about their mental health,\(^{2}\) yet they consider their mental health to be in the poorest state after finishing treatment.\(^{19}\) Additional research questions raised by our study center around mental health treatment and resources impacting patient outcomes. Future research can address this question evaluating outcomes among patients with varying access to supportive resources. Interventional studies also may be used to compare the outcomes and attitudes of lymphoma participants with and without these resources during the course of treatment.

Participants in this study described their support systems as places of comfort and emotional support and additional resources for transportation and care. Ensuring strong social support
for the patient should also be a clinician priority. Relationships and the lack thereof can create lasting impact on a cancer patient’s life. Prior studies have demonstrated that patients who felt that they did not have strong social support were more likely to have negative outcomes,²⁰ and that patients with strong social support networks were more likely to have better health outcomes.²¹ Our participants described support networks as crucial to improving quality of life and easing psychological burdens associated with illness and treatment. These data suggest that future research on the impact of modifying support networks on lymphoma patients, caregivers, and patient outcomes is needed.²²

With the growing population of long-term lymphoma survivors, survivorship care warrants additional attention and research. As seen in the developed themes, many participants felt: uninformed, unprepared for survivorship, disconnected from their providers, and that their mental health needs were not adequately addressed. Our findings corroborate existing literature in this area, including patients being inadequately informed about unmentioned physical effects of treatment.⁵,²³ Studies have found that patients benefit from having “follow-up” visits and conversations with their clinicians, beyond the limited scope of the physical aspects of their cancer.¹² As is also seen in prior literature,²⁴ this study’s participants stated they would have liked formal survivorship education, such as a Survivorship Care Plan, but were not informed about it. Discussions surrounding health concerns, post-treatment care, and emotional communication are needed to make the transition from cancer patient to cancer survivor more fluid.¹² The administration of survivorship care plans to survivors is a promising initiative intended to address survivorship,²⁵ but little data demonstrate their efficacy or feasibility as a tool to be disseminated in practice.²⁴,²⁶

One guiding principle infiltrating survivorship research initiatives is the concept of patient-oriented care and research. Patient-oriented care and research is increasingly present in the growing body of survivorship guidelines for providers.²⁶-²⁷ Patient-oriented care is inclusive of patient and survivor perspectives and is crucial to improving patient care and better understanding their experiences.²⁸-³⁰ By prioritizing patients’ and survivors’ beliefs and unmet psychosocial needs, clinicians and researchers can implement patient-oriented research questions and apply these findings to intervention and policy development.

Increased caregiver support is another implication that demands immediate intervention and future research. This study contributes to this field of lymphoma caregiver support as one of the few existing qualitative studies to ask about caregiver needs and research priorities. Caregivers are an unsung hero of the clinical care team; they adjust their lifestyle while simultaneously experiencing the emotional trauma of supporting their loved one during treatment.⁸ Without caregivers performing at their best and being supported by clinicians, patient health may be at risk. To counter this, caregivers should be welcomed by clinicians and provided with supportive resources such as relevant research and emotional support groups. These would improve caregiver experience and ability.³⁰ Future research should aim to encourage caregivers to find ways to manage their individual interests in the context of longitudinal care and aim to prevent exhaustion and burnout.⁹,³¹
Increasing research engagement and opportunities for lymphoma patients is another path for future study. The findings from this study identified that participants were extremely interested in participating in research specific to their lymphoma subtype. Despite this interest, participants were confused by the process of engaging with research and finding relevant studies to participate in. With participants seeming willing and eager to take part in relevant research, it is important for clinicians and researchers to be aware of the psychological barrier to research participation. Previous findings suggest that a significant predictor of research participation is awareness of research opportunities, which our findings support. Clinicians can also provide materials that help their patients understand the research enrollment process. They can help patients enroll in studies that are applicable to their subtype, facilitating the patient’s willingness to engage in a research experience. Some studies suggest that racial and ethnic minority patients are less likely to participate in research or understand the research process. Future investigation should aim to address this disparity and find culturally appropriate ways to encourage minority patient enrollment in clinical cancer studies.

Similar to most cancers, lymphoma research funding is predominantly focused on basic science and epidemiological outcomes studies. Currently, research into effective lymphoma survivorship care and behavioral intervention is in its infancy, and little is known of the long-term physical and emotional effects of treatment. Future examination of psychosocial factors in survivor and caregiver populations is needed to create effective interventions especially within vulnerable populations. This is reflective of the overarching trend towards patient-centered care and survivorship research in oncology. The National Cancer Institute (NCI) currently is funding research initiatives relevant to this work, including the Cancer Moonshot initiatives, to address symptom management, prevention, and early detection. In addition, there are current calls for research into survivorship care planning implementation, telehealth screening for depression in cancer patients, and various calls for health disparity studies. Few funding announcements specifically target interventions for cancer caregivers to improve care management. Several opportunities exist for innovative intervention research for cancer-related health behaviors and enhancing methodology of interdisciplinary behavioral research. While this research is vital to addressing the issues raised in our study, future funding should target behavioral and psychosocial determinants of health outcomes in cancer patients as well as for their caregivers. Table 4 contains examples of research priorities provided by participants that clinicians should aim to address.

Limitations

One limitation of this study is the lack of racial and gender diversity among the study sample. The majority of participants were White and female, limiting generalizability. Self-selection bias, when participants self-elect to participate in a study, is another limitation. Having participants recruited from lymphoma conferences and current study populations could lead to a sample that was more educated about lymphoma and cancer research. Nevertheless, this group of experienced patients and caregivers still had many unmet needs in cancer care and research as described in the themes above. Finally, focus groups mixed patient subtypes and included caregiver viewpoints, which may have limited addressing
some issues. Having clearly differentiated roles and subtypes may have generated different themes and results than those presented.

Conclusions

This study contributes to the scientific literature in two important ways: 1) this is the first qualitative study to explore the unmet needs of caregivers for lymphoma patients, and 2) the findings signify the importance of integrating the perspectives of patients, survivors, and caregivers in models of care and programmatic development, including research study development. These results have significant clinical implications for how providers and educators can improve health outcomes for survivors and caregivers, and provides multiple paths for potential research development including exploratory and patient-oriented intervention research regarding survivorship and research participation for lymphoma survivors and caregivers. Programming that can be extrapolated at a population level or implemented as policy is a next step in lymphoma oncology.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments:

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Funding: NIH

References


Table 1

Interview Guide Example Questions

<table>
<thead>
<tr>
<th>Theme</th>
<th>Example Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Priorities</td>
<td>“What factors would influence your decision to decline to participate in an observational research study?”</td>
</tr>
<tr>
<td>Clinical Care Team</td>
<td>“A clinical care team is composed of physicians, mid-level providers such as nurse practitioners and physician assistants, nurses, and any other type of person who provides clinical care to you. In general, what is/was your relationship like with your clinical care team?”</td>
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<td></td>
<td>“What could your providers have done differently? How would this have affected you?”</td>
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<tr>
<td>Interest in Research</td>
<td>“Based on your interests or previous studies that you’ve came across, what topics or types of research would you like to see conducted in the future? Which types of studies would you participate in and why or why not?”</td>
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<tr>
<td></td>
<td>“Whether or not you are interested in participating in studies yourself, how interested are you in reading the about the research and the results?”</td>
</tr>
<tr>
<td>Survivorship</td>
<td>“What aspects of lymphoma treatment and supportive care do you think need more attention from health care providers? Specifically, were there aspects of your lymphoma treatment or supportive care that you think could have used more attention from your clinical care team?”</td>
</tr>
<tr>
<td>Barriers</td>
<td>“What do you think is/was the most significant barrier for you throughout your cancer journey? This can be geographical, emotional, educational, etc.”</td>
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<tr>
<td></td>
<td>“Did you ever feel like you didn’t have access to certain resources that you needed during your care?”</td>
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**Table 2**

Focus Group Quote Table

<table>
<thead>
<tr>
<th>Theme</th>
<th>Quote</th>
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</thead>
</table>
| **Lack of Information** | "And that’s the most frustrating thing is, um, it was kind of like pulling teeth getting information about survivorship in that meeting."
| | "And that – that’s the kind of thing that’s hard to get from doctors. That-that would be my one single criticism… for people who’ve done the research and have questions. They should answer them. It’s very very hard to get that information."
| | "I – I don’t like the model where you, you get these diagnostics and then it takes days for, you know, your results come back and your doctor relays those. I – I - I felt totally blindsided."
| | "I wanna know the good and the bad and the ugly, and don’t - don’t hold back information. If it’s good news I wanna know it, if it’s bad news I wanna know that too…” |
| **Disconnected from Clinical Care Team** | “…they are dealing with humans, not just numbers.”
| | “I feel sometimes they don’t understand that you’re talking to someone whose life has just changed for the worst, and you need to be as sympathetic and kind and compassionate as you can…” |
| **Caregivers - Feeling Overlooked** | “So I think caregivers are… they get a – they get sometimes the short end of the stick. We may suffer as the patient through chemo and the mental things that happen… I think the caregivers don’t get enough either. Enough information.”
| | “For caregivers what I would like to see for caregiver, is information for us.”
| | “When I was in the hospital, I was asked 1000 times how are you doing. Everyone came in the room, how are you doing. When I’d go to visits everybody asked “How are you doing.” …Not once has [she] been asked, ‘How are you doing?’ No one has ever asked her.” |
| **Interest in Research** | “If they would’ve given us a choice, placebo or this, [short pause] it would have been a no, I’m sorry, but if it would be giving me conventional or this new approach, then yeah I’m going to look at that.”
| | “I went over to [university doctor] and I said ‘Ok, what was at ASH? What do you recommend that I read?’…I’ve already started collecting the information that was published there and I’m reading through it now.” |
| **Desire for Studies Relevant to Them** | “...everybody’s focusing on different kinds of cancers… I think that maybe a more general trial that kind of includes a lot of different kinds of cancer, like a LOT of different kinds of cancer, like, EVERY kind of cancer.”
| | “I think I would like to do, umm, a - like a background research on different people and to see… what the trigger is for different people, you know, maybe something like that… you know, what were their backgrounds? What do they do for a living? You know, what were they exposed to?”

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Table 3

Individual Interview Quote Table

<table>
<thead>
<tr>
<th>Theme</th>
<th>Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unmet Emotional Needs</td>
<td>&quot;Maybe more research in dealing with the emotional.&quot;</td>
<td>Female, 73, White</td>
</tr>
<tr>
<td></td>
<td>&quot;Well… it was more of an emotional thing trying to get through it…I guess that is to be expected I think because it does play on your emotions quite a bit.&quot;</td>
<td>Male, 39, White</td>
</tr>
<tr>
<td></td>
<td>&quot;Towards the end of treatment, a lot of anxiety, panic attacks.&quot;</td>
<td>Male, 49, White</td>
</tr>
<tr>
<td>Holistic Focus (Quality of Life)</td>
<td>&quot;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.&quot;</td>
<td>Female, 72, White</td>
</tr>
<tr>
<td></td>
<td>Facilitator: What types of studies would you like to see conducted in the future? Respondent: 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.&quot;</td>
<td>Male, 54, Hispanic</td>
</tr>
<tr>
<td></td>
<td>&quot;Diet and nutrition was always something and natural treatments, whether it was food or supplements….&quot;</td>
<td>Female, 73, White</td>
</tr>
<tr>
<td>Fear of the Unknown</td>
<td>&quot;Um, I am cured? Or my cancer is gone right now, but I worry about it daily if it came back and how that would affect my future.&quot;</td>
<td>Female, 21, White</td>
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<tr>
<td></td>
<td>&quot;It was scary when you don’t know what they are going to do to you.&quot;</td>
<td>Male, 54, Hispanic</td>
</tr>
<tr>
<td></td>
<td>&quot;…I mean I thought I was going to die…And so I wondered about like, what it was going to be like because I don’t just want to lay in there for weeks and weeks to be in pain, you know…what can I do to make it fast so that my family didn’t have to suffer through it…So I guess I would say just fear of the unknown because I did not have much experience…with cancer.&quot;</td>
<td>Female, 63, White</td>
</tr>
<tr>
<td>Coping Strategies</td>
<td>&quot;She went to some counseling and women’s group for grief counseling…it’s for people that either lost people, are losing people, or might be losing people.&quot;</td>
<td>Male, White</td>
</tr>
<tr>
<td></td>
<td>&quot;I don’t know if I am supposed to tell you this, but the biggest help for me…is marijuana. It helped with nausea, my appetite. It made me feel a lot better…it would help a lot with that and my muscle aches and headaches and all of that stuff.&quot;</td>
<td>Female, 21, White</td>
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<tr>
<td></td>
<td>&quot;Well I also practice self-hypnosis, and you can do a lot of taking care of symptoms, especially under chemo because you can get really sick.&quot;</td>
<td>Male, White</td>
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### Table 4
Patient Research Priorities

<table>
<thead>
<tr>
<th>Priority</th>
<th>Quote</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthy Lifestyle/Quality of Life</td>
<td>&quot;I would like to see studies done on diet and exercise…I think perhaps if we concentrated more on that area, it could be a big help to people – diet, exercise, lifestyles.&quot;</td>
<td>Female, 80, White</td>
</tr>
<tr>
<td></td>
<td>&quot;Diet and nutrition was always something and natural treatments, whether it was food or supplements.&quot;</td>
<td>Female, 73, White</td>
</tr>
<tr>
<td>Managing Effects of Treatment</td>
<td>&quot;…He would say we didn’t really study much about the after effects of chemo. I would say somebody needs to do that because it is huge.&quot;</td>
<td>Female, 52, White</td>
</tr>
<tr>
<td></td>
<td>&quot;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.&quot;</td>
<td>Female, 72, White</td>
</tr>
<tr>
<td>Genetic Component</td>
<td>&quot;I’d like to see if there’s some genetic component. I know someone that, in the family the mother has lymphoma, the son has lymphoma, umm, the aunt has lymphoma…”</td>
<td>Focus Group Participant</td>
</tr>
<tr>
<td></td>
<td>&quot;…a way to test if its genetic, like they do for the BRCA gene.”</td>
<td>Focus Group Participant</td>
</tr>
<tr>
<td>New Therapies</td>
<td>&quot;I mean, I just hope one day they find a cure other than chemotherapy.”</td>
<td>Male, 48, White</td>
</tr>
<tr>
<td></td>
<td>&quot;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.”</td>
<td>Male, 38, White</td>
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<td>&quot;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.&quot;</td>
<td>Male, 48, White</td>
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<td>&quot;More information on immunotherapy…And drugs with fewer side effects, and if they do have side effects, knowing what they are up-front and how common they are.”</td>
<td>Female, 72, White</td>
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<td>&quot;Whatever the new and most effective things are in terms of treating and getting long-lasting results.”</td>
<td>Female, 72, White</td>
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<td>Mental Health</td>
<td>&quot;I think mental health is a very big piece for me because, um, yeah I have an anxiety depressive disorder…I just think it needs to be more integrated. Like integrated solutions with mental health and that’s often, um, it’s not addressed really at all.”</td>
<td>Focus Group Participant</td>
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<td>&quot;Kaiser had great support groups if you wanted to go to those. I think they do some of that too. Make that available.”</td>
<td>Male, 65, White</td>
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<td>“…whether it’s watch and wait for the first time or watch and wait for the third time, there’s a mental battle there. People have to figure out how to deal with that…”</td>
<td>Focus Group Participant</td>
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