



Shared Decision Making in Cancer Treatment: Findings from a Large Survey of Lymphoma Patients and Survivors

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Background

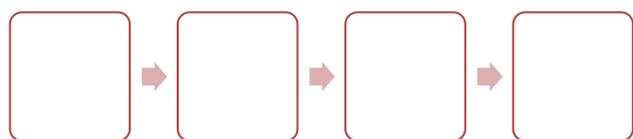
- Patients have become more involved in understanding treatment options, joining advocacy organizations, and seeking information through a multitude of venues.
- This has increased the patients voice in the treatment decision-making while the complexity of treatment options has increased, with multiple factors to consider including: various therapeutic classes, safety profile, cost, access and any potential impact on quality of life
- There is robust evidence that establishes the importance of a collaborative relationship between patients and clinicians when making treatment related decisions. The growing evidence also suggests there is an increased need for patient oriented-research, including communication between the scientific community and cancer pts. ^{1,2,3}
- However, despite the established need for shared decision making, there are discrepancies between the extent that pts prefer to be involved vs their actual involvement. Previous studies have suggested that cancer patients older than 50, patients with an education status of less than a high school degree, and female patients all respectively preferred a passive role in treatment decision making. ⁴

Objective

- To identify clinical characteristics and sociodemographic factors among lymphoma patients that are associated with patient's who do not hold their preferred role within treatment decision making. Characterizing groups that are potentially at more risk to report not being included in treatment decision can inform future shared treatment decision making approaches for lymphoma patients

Methods

- This study was reviewed and approved by the Rutgers IRB.
- This voluntary and anonymous survey was available through the online survey platform Qualtrics®, a Rutgers University approved survey platform, and was sent to 132,827 unique email addresses. Data collection and analysis was performed solely through the Qualtrics online platform with no additional patient identifiers or information collected.
- A 30 question survey was developed and sent to the Lymphoma Research Foundation (LRF) distribution list of patients and caregivers globally.
- The survey questions were designed to collect demographic information, clinical characteristics, and respondents perception of the treatment decision making paradigm. The questions of focus were (survey allowed respondents to select a combination of HCP, patient, and caregiver involvement):
 - What role do you prefer in the treatment decision-making process
 - Who was involved in your treatment decision making process
- Statistical analyses were performed using non-parametric two-sided Mann Whitney U test and Fisher exact testing. Caregivers were excluded from this analyses, as were patients & survivors that did not respond to the respective survey question



Results

Table 1: Patient Demographic (N = 878)

% based off of number of respondents to respective survey question	
Gender (n=877)	
Female	478 (54.5%)
Male	395 (45%)
Age range (n=878)	
18 - 29 years	5 (0.6%)
30 - 39 years	29 (3.3%)
40 - 49 years	57 (6.5%)
50 - 59 years	140 (15.9%)
60 - 69 years	322 (36.7%)
70 years or older	325 (37.0%)
Ethnicity (n=875)	
White	830 (94.9%)
Non-white	45 (5.1%)
Education Level (n=878)	
No College Degree	192 (21.9%)
College Degree	686 (78.1%)
Professional Status (n=877)	
Healthcare Provider	119 (13.6%)
Non-HCP	758 (86.4%)
Insurance type (n=505)	
Commercial	224 (44.4%)
Medicare	112 (22.2%)
Medicaid	14 (2.8%)
Multiple	130 (25.7%)
Watch and wait	233 (70.0%)

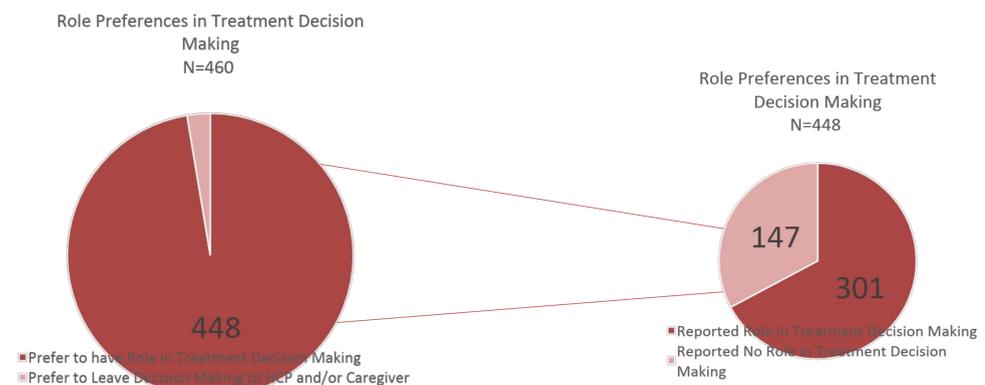
Survey takers who responded to these questions but opted not to disclose are not reported in this table

Table 2: Clinical Characteristics (N = 878)

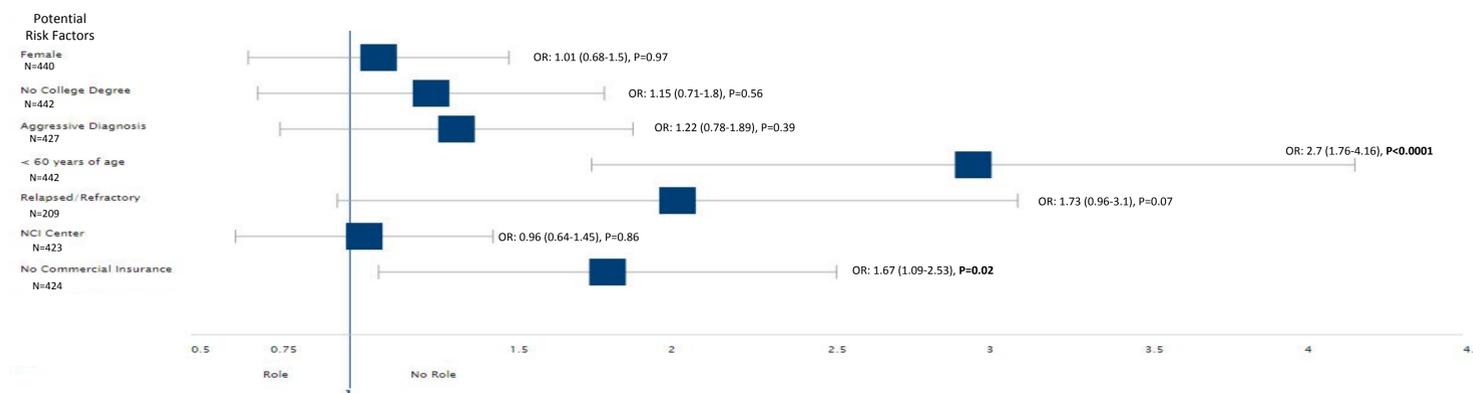
% based off of number of respondents to respective survey question	
Diagnosis (n=504)	
Non-Hodgkin:Follicular	158 (31.3%)
CLL/SLL	123 (24.4%)
Non-Hodgkin: Mantle Cell	64 (12.7%)
Waldenstrom Macroglobulinemia	51 (10.1%)
Non-Hodgkin: Diffuse Large B-Cell	42 (8.3%)
Non-Hodgkin: Marginal Zone	35 (6.9%)
Non Hodgkin: T-Cell	33 (6.5%)
Hodgkin	4 (0.8%)
Treatment (n=338)	
Chemotherapy	227 (67.1%)
Immunotherapy	255 (75.4%)
Radiation	56 (16.5%)
Surgery	33 (9.7%)
Stem cell transplant	30 (8.9%)
Investigative treatment	67 (19.8%)
Watch and wait	233 (68.9%)
Did not receive treatment	32 (9.5%)
Disease Stage (n=244)	
Newly Diagnosed	103 (42.2%)
Relapsed/Refractory	141 (57.8%)
Treatment Center (n=423)	
NCI Designated Center	194 (45.9%)
Non-NCI Designated Center	229 (54.1%)

Survey takers who responded to these questions but opted not to disclose are not reported in this table

(Figure 1) Patient and survivor reported discrepancies in preference for role in treatment decision making vs. reported role in treatment decision making



(Figure 2) Subgroup Analysis to Determine Risk of "No Role" when Preference is to be Involved in Shared Treatment Decision Making



References

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Limitations

- Our population included those currently engaged with the Lymphoma Research Foundation and are therefore more likely to be engaged in their healthcare, limiting the generalizability of this data.
- Survey participants were not required to answer questions and therefore several answers were left blank, making the number of responses in some questions less than the overall sample size.

Conclusions

- While nearly all responding patients reported they preferred to have an active role in the treatment decision making, 1/3 of those patients stated they were excluded from the decision making
- This analysis suggests that patients with no form of commercial insurance are more likely to report no role in decision making. This could be due to potential treatment selection limitations that are in place with certain health coverages (i.e. Medicare, Medicaid,) or lack of coverage all together.
- Also there was a prominent age-based discrepancy with younger lymphoma patients reporting no role in treatment decisions compared with older patients. As prior literature establishes, younger patients are less likely to prefer a passive role compared to older patients, suggesting a potential correlation.
- Despite previous literature identifying females and less educated patients to prefer more of a passive role, this analyses demonstrates that these groups are not at a lower risk to report being excluded from treatment decision-making
- Continued analyses and studies are warranted to understand this paradigm and to improve the overall decision making process for patients and providers