Hemophagocytic Lymphohistiocytosis (HLH): A Survey Study on Pharmacists' Practice Patterns and Perceptions

Ashley Teusink-Cross, PharmD, MBA, BCPS[1*,2], Christopher McPherson, PharmD[2], Astrela Moore, PharmD, BCPPS[3], Ingrid Pan, PharmD, BCPPS[4], Amod Athavale, BPharm, MS, PhD[5], Amal Gulaid, MPH[5], Bhagyashree Oak, BPharm, PhD[5], Brittany Smith, MPH, MBA[5], Abiola Oladapo, PhD[2], Matthew Wojdyla, PharmD[2], Lynes Torres Cartularo, PhD[2]

[1]Cincinnati Children's Hospital Medical Center, Cincinnati, OH| [2]Sobi, Inc., Waltham, MA| [3]Children's Hospital of Philadelphia, Philadelphia, PA| [4]Children's Hospital Colorado, Aurora, CO| [5]Trinity Life Sciences, Waltham, MA | *Affiliation during study initiation

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CONCLUSION

- A comparison of practices and perceptions across pharmacists with more extensive hemophagocytic lymphohistiocytosis (HLH) management exposure (HPVPs) to those with less exposure (LPVPs) revealed differences in pharmacist responsibilities and perceived timeliness of pharmacist involvement.
- Biomarker use in the management of HLH also differs between HPVPs and LPVPs, with LPVPs indicating lower use across most biomarkers, which may be due to limited awareness and/or access restrictions. Higher biomarker use among HPVPs was likely due to comfort level and patient volume compared to LPVPs
- Pharmacists at institutions that seldom encounter HLH patients could benefit from education to increase their awareness of and involvement in HLH management. This could be facilitated through the establishment of multidisciplinary teams (MDTs) which this study suggests are well-suited to fostering pharmacist involvement. Such efforts could improve outcomes for patients with HLH while also improving pharmacist satisfaction.

BACKGROUND

- HLH is a rare, life-threatening hyper-inflammatory syndrome characterized by overactivation of the immune system due to systemic release of proinflammatory cytokines, especially interferon gamma (IFNγ).[1]
- HLH has been historically classified as either primary, due to an inherited genetic mutation, or secondary to an inciting trigger such as an infection, malignancy, or rheumatologic disease.[1]
- The involvement of multidisciplinary teams (MDTs) has been shown to improve outcomes in patients with HLH.[2]
- While pharmacists can be involved in MDTs, the extent of their involvement is varied and underexplored, with limited published information available.

OBJECTIVES

- This study aimed to describe United States (US) pharmacists' involvement in and perception of current HLH diagnostic and management practices.

METHODS

- An IRB-exempted, cross-sectional, web-based survey was done in the US from Oct-Nov 2024 via a web-enabled case report form.
- Participants were hospital-based US pharmacists recruited via panel
- **Pharmacist Eligibility**

1. Registered pharmacist currently practicing in a US hospital, with total time practicing in a hospital setting ranging from 5-35 years
2. Cared for at least 1 HLH/Macrophage Activation Syndrome (MAS) patient in the past 12 months (Primary HLH or Secondary HLH/MAS as a complication of Still's disease
3. Access to computer and internet connectivity
4. Not currently employed by any of the following (excluding research honoraria, consultancy, speaking engagements, and advisory board participation):
   a. Pharmaceutical manufacturer or contract research organization (CRO)
   b. Medical equipment manufacturer
   c. Market research, Health Economics & Outcomes research firm or advertising firm
   d. FDA or EU equivalent
   e. Government Agency
   f. Health Insurance Companies

- Sub-analysis was performed to compare higher patient volume pharmacists (HPVPs), defined as >7 patients with HLH in the past 12 months, and lower patient volume pharmacists (LPVPs), defined as ≤7 patients.
- Descriptive analysis was conducted using Q Research Software 5.12.4.0.

RESULTS

- A total of 200 pharmacists participated in the survey. Of those who cared for patients with HLH in the past 12 months, 50.5% (101/200) were classified as LPVPs, while 49.5% (99/200) were classified as HPVPs. **(Table 1)**
- HPVPs were more likely to practice in an academic setting supporting both inpatients and outpatients and in hospitals with 500 beds or more. **(Table 1)**

Table 1: Pharmacist Demographics

		Low Patient Volume HLH Pharmacists (n=101)	High Patient Volume HLH Pharmacists (n=99)	Overall (N=200)
Number of Years as a Practicing Pharmacist (Median)		13	14	13
Number of unique patients with HLH in past 12 months (Median)		2	25	7
Primary Patient Population	Inpatient	49.5%	28.3%	39.0%
	Outpatient	4.0%	4.0%	4.0%
	Both inpatient and outpatient	46.5%	67.7%	57.0%
Current Practice Setting	Academic	55.4%	67.7%	61.5%
	Community	44.6%	32.3%	38.5%
Number of Beds at Primary Practice	Small (<100 beds)	4.0%	4.0%	4.0%
	Medium (100-499 beds)	46.5%	37.4%	42.0%
	Large (≥500 beds)	49.5%	58.6%	54.0%

HPVPs are defined as >7 patients with HLH in the past 12 months; LPVPs are defined as ≤7 patients with HLH in the past 12 months

*Primary practice location options were defined as: Urban – an area in a city or town; Suburban – an area in a smaller community or town which is close to a bigger city; Rural – an area that is not closes to a large city, typically with fewer than 2,500 residents, and open spaces/farmland

Continuous variables are presented as mean (SD). Discrete data are presented as column percents.

- Oncology and critical care were the most common specializations. **(Table 2)**
- While the two most prevalent specialties were similar between LPVPs and HPVPs, notable differences exist in specializations such as pediatrics, rheumatology, ambulatory care, and BMT.

Table 2: Pharmacist Specialties*

	Low Patient Volume HLH Pharmacists (n=101)	High Patient Volume HLH Pharmacists (n=99)	Overall (N=200)
Oncology	50.5%	62.6%	56.5%
Critical care	44.6%	39.4%	42.0%
Emergency medicine	29.7%	33.3%	31.5%
Cardiology	21.8%	29.3%	25.5%
Pediatric	20.8%	34.3%	27.5%
Rheumatology	17.8%	38.4%	28.0%
Ambulatory care	16.8%	36.4%	26.5%
Bone marrow transplant (BMT)	15.8%	29.3%	22.5%
Other	5.9%	3.0%	4.5%
None of the above	11.9%	13.1%	12.5%

*Note – This was asked as a multi-select question

- Medication therapy management and fulfillment/verification of orders were the most common responsibilities across all pharmacists. **(Table 3)**
- HPVPs were more likely to report making regular direct treatment recommendations and managing the cost and reimbursement of prescribed medications. **(Table 3)**

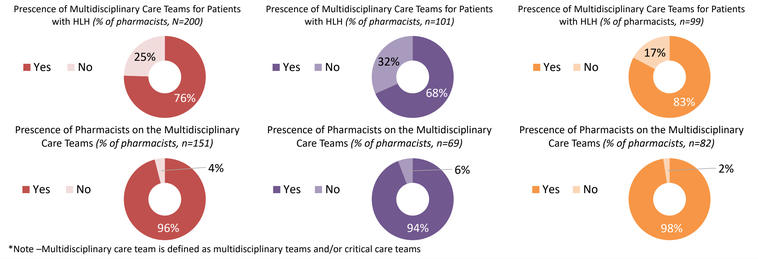
Table 3: Pharmacist Responsibilities Performed on a Regular Basis*

	Overall (N=200)	Low Patient Volume HLH Pharmacists (n=101)	High Patient Volume HLH Pharmacists (n=99)
Medication therapy management	89.5%	89.1%	80.9%
Fulfillment and verification of medication orders	81.0%	77.2%	84.8%
Compounding and dispensing of medications	76.0%	66.3%	85.9%
Participating in daily rounds/consultation with coordinated care team	71.0%	64.4%	77.8%
Procuring medications	71.0%	63.4%	78.8%
Patient education and counseling for prescribed medications	73.0%	62.4%	83.8%
Making direct treatment recommendations (e.g., adding new medications, adjusting dosages)	72.5%	62.4%	82.8%
Managing cost and reimbursement of prescribed medications	53.0%	34.7%	71.7%
Other	0.5%	0.0%	1.0%

*Note – This was asked as a multi-select question

- Overall, 76% of pharmacists worked at an institution that utilized multidisciplinary care teams, with HPVPs having a higher likelihood than LPVP counterparts. **(Figure 1)**
- For those practicing at an institution with a multidisciplinary care team, pharmacists were almost always included.

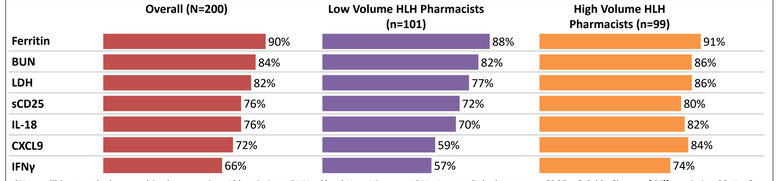
Figure 1. Availability of HLH Multidisciplinary Care Teams and Pharmacist Involvement*



*Note –Multidisciplinary care team is defined as multidisciplinary teams and/or critical care teams

- Ferritin, BUN, and LDH are the most common lab markers reportedly used by institutions for patients with HLH. **(Figure 2)**
- HPVPs are more likely to report use of IL-18, sCD25, CXCL9, and IFNγ compared to LPVPs. **(Figure 2)**

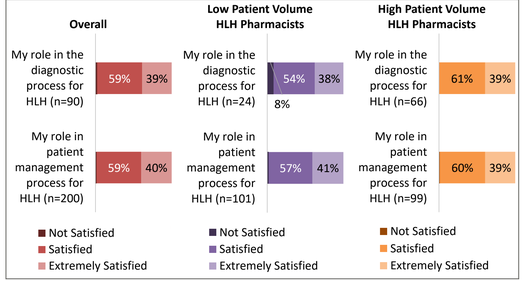
Figure 2. Lab Markers Used at Institution for Patients with HLH



*Note – This was asked as a multi-select question; Abbreviations: BUN – Blood Urea Nitrogen, LDH – Lactate Dehydrogenase, sCD25 – Soluble Cluster of Differentiation 25, IL-18 – Interleukin-18, CXCL9 – C-X-C Motif Chemokine Ligand 9

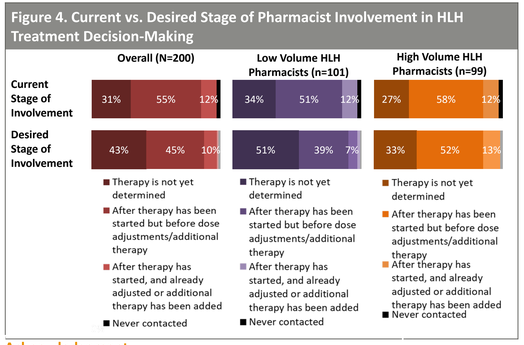
- Among all pharmacists, ~40% were highly satisfied with their role in HLH diagnosis and management. **(Figure 3)**
- LPVPs were more likely to be unsatisfied with their role in the diagnostic process.

Figure 3. Level of Satisfaction with Involvement in Diagnostic & Management Processes



- Majority of pharmacists (55%) are contacted after a therapy has been initiated but before dose adjustments or additional therapy is required. **(Figure 4)**
- Only 31% are contacted when therapy is not yet determined. However, 43% of pharmacists desire to be contacted at this early stage in treatment decision-making. **(Figure 4)**

Figure 4. Current vs. Desired Stage of Pharmacist Involvement in HLH Treatment Decision-Making



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Limitations

- Participants may be subject to recall bias. Additionally, given that the responses to this survey are from a sample of US-based hospital pharmacists, the results may not be generalizable to a different population or pharmaceutical practices.

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References

1. Konkol S, Rai M. Lymphohistiocytosis. [Updated 2023 Mar 27]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2024 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK557776
2. Taylor ML, Hoyt KJ, Han J, et al. An Evidence-Based Guideline Improves Outcomes for Patients With Hemophagocytic Lymphohistiocytosis and Macrophage Activation Syndrome. J Rheumatol. 2022;49(9):1042-1051. doi:10.3899/jrheum.211219

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