Unemployment in patients with histiocytic neoplasms is frequent and associated with clinical and treatment characteristics

Histiocytic neoplasms (HN) are comprised of Langerhans cell histiocytosis (LCH), Erdheim-Chester disease (ECD), Rosai-Dorfman disease (RDD), and juvenile / adult xanthogranuloma (JXG/AXG). The emergence and regulatory approval of targeted therapies,[1-4] and, for many patients, chronic disease suppression (rather than cure) with these agents, prompt the need to understand how patients with HN maintain function and quality of life (QoL) amid ongoing disease symptoms, treatment effects, and psychosocial challenges. Cancer broadly impacts employment with approximately one in 3 cancer survivors unemployed; additionally, patients with cancer are approximately 40% more likely to be unemployed than healthy controls.[5] We have reported that HN patients experience higher rates of anxiety and depression compared with patients with other cancers.[6] We have also demonstrated diverse symptomatology, notably fatigue and pain, and diminished QoL in patients with ECD.[7-9] Disease rarity and heterogeneity in HN contribute to diagnostic delays, which are associated with unfavorable psychosocial outcomes.[6] Financial strain, employment status, depression, and anxiety are well-recognized consequences for cancer survivors.[10] However, the interplay of these factors in relation to employment is unknown in HN. Herein, we estimated unemployment rates and identified factors associated with unemployment among patients with HN. We hypothesized that unemployment would be common in HN and associated with symptomatology and other salient challenges inherent to living with a rare cancer.

This is an institutional review board-approved, registry-based study conducted at the Memorial Sloan Kettering Cancer Center (MSKCC; clinicaltrials.gov identifier NCT03329274), enrolling participants within and outside the MSKCC. Participants providing informed consent enrolled from 2018-2025 and completed patient-reported outcomes (PRO) at the time of enrollment and at two other timepoints. PRO included employment status categorized as: full-time, part-time, unemployed, or retired. The current study included participants if they reported full-time, part-time, or unemployed status at enrollment.

Demographic and clinical variables including HN type, time from symptom onset to diagnosis (undiagnosed duration), time from diagnosis to enrollment (diagnosed duration), sites of disease, comorbidities, and treatments were ascertained as previously described.[6,8,9] HN treatment status at enrollment was categorized as conventional (chemotherapy or immunosuppression), targeted (BRAF or MEK inhibitor), or no current treatment. In addition to employment, eight other previously described[6,9] PRO were ascertained: financial burden and worry; Functional Assessment of Cancer Therapy, General (FACT-G); Functional Assessment of Cancer Therapy, Cognition (FACT-Cog); an HN symptom inventory, initially content-validated in ECD (ECD-Symptom Score; ECD-SS); Brief Fatigue Inventory (BFI); Brief Pain Inventory (BPI); Hospital Anxiety and Depression Scale (HADS); and Supportive Care Needs Survey (SCNS).

Our primary objective was to estimate unemployment rates and identify risk factors associated with unemployment at enrollment, comparing participants who reported unemployment with those reporting employment (full-time / part-time). SCNS items were dichotomized as met (no / low) or unmet (moderate / high) need. If any item within a factor was unmet, the factor was classified as unmet; the number of unmet items was also summed. Univariable associations with unemployment were modeled with logistic regression to estimate odds ratios (OR) and corresponding 95% confidence intervals (CI). Potential clinical confounders were selected a priori for adjustment in multivariable models and included: age, undiagnosed illness duration, fatigue, pain, brain involvement, number of sites of disease, and household income. In a post-hoc analysis, we formally tested whether the impact of FACT-Cog subscales on unemployment varied by brain involvement. All tests were two-sided; $P<0.05$ was considered statistically significant. Analyses were performed in SAS v9.4 (SAS Institute, Cary, NC, USA).

Two hundred enrolled patients with HN who were eligible for employment had a median age at enrollment of 51.1 years (range: 21.6-72.2) (Table 1). HN subtypes included: 99 (49.5%) with ECD, 42 (21.0%) with LCH, 26 (13.0%) with RDD, and 14 (5.5%) with AXG. The median diagnosed illness duration was 4.1 years (range: 0.2-48.1).

Fifty-one patients (25.5%) reported being unemployed at enrollment (Table 1). The unemployment rate was 24.3% at timepoint 1 (interquartile range [IQR]: 6.0-7.8 months from enrollment) and 30.9% at timepoint 2 (IQR: 12.8-16.0 months from enrollment; max: 31.7 months from enrollment). Of 140 patients reporting employment status at enrollment and timepoint 1, 120 patients (85.7%) remained in the same category (Table 2, *Online Supplementary Figure 1A*), including 32 patients (22.9%) who were unemployed at both timepoints. Similar trends were observed at timepoint 2 (Table 2, *Online Supplementary Figure 1B*).

In univariable models, risk factors for unemployment in-

Table 1. Cohort characteristics.

Variable	Category	N	%	Median	Range
Age at histiocytosis diagnosis	Continuous, years	199	99.5	46.4	0.4-69.8
Age at registry enrollment	Continuous, years	200	100	51.1	21.6-72.2
Histiocytosis diagnosis	ECD LCH RDD AXG HS Mixed ECD/LCH Mixed ECD/RDD Other	99 42 26 11 3 13 4 2	49.5 21.0 13.0 5.5 1.5 6.5 2.0 1.0	- - - - - - - -	- - - - - - - -
Histiocytosis diagnosis	ECD, mixed ECD/LCH, mixed ECD/RDD LCH RDD AXG, HS, Other	116 42 26 16	58.0 21.0 13.0 8.0	- - - -	- - - -
Registry enrollment	MSKCC Outside MSKCC	164 36	82.0 18.0	- -	- -
Sex	Male Female	104 96	52.0 48.0	- -	- -
Length of undiagnosed illness	Continuous, years	199	99.5	0.6	0-21.3
Length of diagnosed illness	Continuous, years	200	99.6	4.1	0.2-48.1
Sites of disease	Bone Neurologic Brain parenchyma Cardiovascular Pulmonary Retroperitoneum Abdomen Skin/subcutaneous Lymph node Other	146 104 80 52 34 57 28 64 29 35	73.0 52.0 40.0 26.0 17.0 28.5 14.0 32.0 14.5 17.5	- - - - - - - - - -	- - - - - - - - - -
Hypertension	No Yes	126 74	63.0 37.0	- -	- -
Diabetes	No Yes	164 36	82.0 18.0	- -	- -
Treatment at enrollment	None Conventional Targeted Unknown	106 15 78 1	53.0 7.5 39.0 0.5	- - - -	- - - -
Household annual income	$0-$25,000 $25,000-$50,000 $50,000-$75,000 $75,000-$100,000 $100,000+ Unknown or prefer not to answer	17 15 20 20 89 39	8.5 7.5 10.0 10.0 44.5 19.5	- - - - - -	- - - - - -
Highest education level	Some high school High school Undergraduate Graduate Postgraduate	3 31 73 67 26	1.5 15.5 36.5 33.5 13.0	- - - - -	- - - - -
Employment at enrollment	Part-time Full-time Unemployed	31 118 51	15.5 59.0 25.5	- - -	- - -
Employment at timepoint 1 (IQR: 6.0-7.8 months from enrollment)[a]	Part-time Full-time Unemployed Retired Unknown	21 75 34 10 60	15.0 53.6 24.3 7.1 -	- - - - -	- - - - -

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Variable	Category	N	%	Median	Range
Employment at timepoint 2 (IQR: 12.8-16.0 months from enrollment)[a]	Part-time	9	11.1	-	-
	Full-time	37	45.7	-	-
	Unemployed	25	30.9	-	-
	Retired	10	12.4	-	-
	Unknown	119	-	-	-

[a]Unknowns not included in denominator for proportions. AXG: adult xanthogranuloma; ECD: Erdheim-Chester disease; HS: histiocytic sarcoma; IQR: interquartile range; LCH: Langerhans cell histiocytosis; MSKCC: Memorial Sloan Kettering Cancer Center; N: number; RDD: Rosai-Dorfman disease.

cluded being female, ECD, longer undiagnosed HN duration, brain parenchymal involvement, and targeted treatment. Nineteen percent of patients not on treatment at enrollment reported unemployment compared to 27% undergoing conventional and 35% on targeted treatment. Unemployment was also associated with lower household income, worse general and cognitive QoL, greater symptom severity including pain and fatigue, greater unmet supportive care needs, depression, and financial burden (Table 3).

In multivariable models, risk factors for unemployment included longer undiagnosed HN duration (OR: 1.13, 95%CI: 1.03-1.25, *P*=0.01), brain parenchymal involvement (OR: 3.60, 95%CI: 1.36-9.54, *P*=0.01), targeted treatment compared with no treatment (OR: 3.78, 95%CI: 1.38-10.36, *P*=0.0096), household annual income $0-$75,000 (OR: 2.30, 95%CI: 1.00-5.30, *P*=0.0497), worse functional well-being (OR: 1.15, 95%CI: 1.05-1.25, *P*=0.002), moderate/severe depression (OR: 10.96, 95%CI: 2.84-42.24, *P*=0.0005) and greater impact of perceived cognitive impairments on QoL (OR: 1.19, 95%CI: 1.05-1.34, *P*=0.007). The impact of FACT-Cog subscales on unemployment was not heterogeneous according to brain involvement.

This is the first systematic study of employment in HN. In 200 patients, nearly one in 4 patients with HN reported unemployment at enrollment, a rate increasing to nearly one in 3 over time. Comparably, a meta-analysis of >20,000 cancer survivors reported an unemployment rate of 33.8% across a range of nine months to 15 years post diagnosis compared to 15% of healthy controls.[5] In 904 employed patients with myeloproliferative neoplasms, a first change in employment status occurred approximately two years after diagnosis with 30.2% leaving a job.[11] Our findings suggest that unemployment rates among patients with HN, with a median of five years since diagnosis, are broadly comparable to other cancers, including hematologic. However, most patients with HN have not undergone extensive surgery, radiation, intensive multi-agent chemotherapy, or transplantation, interventions common for other cancers. In our cohort, where chemotherapy administration was rare, and HN regimens are generally single-agent and less intensive than those for solid tumors or leukemias and lymphomas, unemployment rates were higher than may be expected considering the absence of these treatment-related factors. Rather, our results suggest that targeted therapy, often chronic in HN, may itself pose challenges for employment. After confounder adjustment, seven variables emerged as independently associated with unemployment: longer diagnostic delay, brain involvement, targeted therapy, lower functional well-being, lower household income, moderate / severe depression, and greater impact of perceived cognitive impairments on QoL. These findings mirror observations from the broader cancer literature where cognitive difficulties and sadness were predictors of unemployment.[12]

Table 2. Known employment distributions across time trajectories.

Enrollment employment	Employment at timepoint 1[a]	N	%
Part-time	Part-time	13	9.3
Part-time	Unemployed	2	1.4
Part-time	Retired	1	0.7
Full-time	Part-time	3	2.1
Full-time	Full-time	75	53.6
Full-time	Retired	5	3.6
Unemployed	Part-time	5	3.6
Unemployed	Unemployed	32	22.9
Unemployed	Retired	4	2.9
Enrollment employment	**Employment at timepoint 2[b]**	**N**	**%**
Part-time	Part-time	5	6.2
Part-time	Full-time	1	1.2
Part-time	Unemployed	2	2.5
Full-time	Part-time	3	3.7
Full-time	Full-time	35	43.2
Full-time	Unemployed	2	2.5
Full-time	Retired	4	4.9
Unemployed	Part-time	1	1.2
Unemployed	Full-time	1	1.2
Unemployed	Unemployed	21	25.9
Unemployed	Retired	6	7.4

[a]Interquartile range: 6.0-7.8 months from enrollment. [b]Interquartile range: 12.8-16.0 months from enrollment. N: number.

Table 3. Associations with unemployment status at enrollment versus all full-time or part-time employment (N=200).

Variable	Category	N	%	Univariable			Multivariable		
				OR	95% CI	*P*	OR[a]	95% CI[a]	*P*[a]
Age at histiocytosis diagnosis	Continuous, years	199	99.5	1.00	0.97-1.02	0.78	1.01	0.98-1.05	0.40
Age at registry enrollment	Continuous, years	200	100	0.99	0.96-1.02	0.49	1.01	0.97-1.04	0.80
Histiocytosis diagnosis (binary)	Non-ECD ECD or Mixed ECD	84 116	42.0 58.0	Ref 2.07	- 1.05-4.10	- 0.04	Ref 1.82	- 0.66-4.98	- 0.25
Sex	Male Female	104 96	52.0 48.0	Ref 2.00	- 1.05-3.83	- 0.04	Ref 1.98	- 0.96-4.74	- 0.13
Length of undiagnosed illness	Continuous, years	199	99.5	1.09	1.01-1.18	0.02	1.13	1.03-1.25	0.01
Length of diagnosed illness	Continuous, years	200	100	1.01	0.98-1.06	0.48	0.95	0.88-1.03	0.24
Sites of disease	Bone Neurologic Brain parenchyma Cardiovascular Pulmonary Retroperitoneum Abdomen Skin/subcutaneous Lymph node	146 104 80 52 34 57 28 64 29	73.0 52.0 40.0 26.0 17.0 28.5 14.0 32.0 14.5	1.41 1.41 2.22 1.40 1.47 1.03 1.17 1.05 0.71	0.66-3.00 0.74-2.69 1.17-4.25 0.69-2.82 0.66-3.28 0.51-2.08 0.48-2.85 0.54-2.07 0.27-1.85	0.38 0.30 0.02 0.35 0.35 0.93 0.73 0.88 0.48	2.36 1.50 3.60 1.74 1.27 0.85 1.09 0.94 1.33	0.71-7.80 0.59-3.83 1.36-9.54 0.64-4.74 0.44-3.65 0.33-2.19 0.33-3.56 0.35-2.55 0.39-4.53	0.16 0.39 0.01 0.28 0.66 0.73 0.89 0.90 0.65
Multisystemic	No Yes	48 151	24.0 75.5	Ref 1.04	- 0.49-2.21	- 0.91	Ref 0.49	- 0.16-1.52	- 0.22
Treatment	None Conventional Targeted	106 15 78	53.0 7.5 39.0	Ref 1.56 2.28	- 0.45-5.42 1.16-4.47	- 0.48 0.02	Ref 2.66 3.78	- 0.63-11.24 1.38-10.36	- 0.19 0.0096
Household annual income	≥$75,000 $0-$75,000	109 52	54.5 26.0	Ref 2.73	- 1.29-5.78	- 0.009	Ref 2.30	- 1.00-5.30	- 0.0497
Highest education level	<Undergraduate ≥Undergraduate	34 166	17.0 83.0	Ref 0.66	- 0.30-1.48	- 0.32	Ref 1.55	- 0.48-5.07	- 0.47
Hypertension	No Yes	74 126	37.0 63.0	Ref 0.81	- 0.41-1.58	- 0.53	Ref 1.02	- 0.42-2.45	- 0.97
Diabetes	No Yes	164 36	82.0 18.0	Ref 0.97	- 0.42-2.23	- 0.94	Ref 1.30	- 0.46-3.71	- 0.62
FACT-G physical well-being[b]	Continuous	199	99.5	0.91	0.87-0.96	0.0002	0.94	0.85-1.05	0.27
FACT-G emotional well-being[b]	Continuous	199	99.5	0.99	0.93-1.06	0.71	1.07	0.97-1.18	0.21
FACT-G social well-being[b]	Continuous	199	99.5	0.95	0.91-1.00	0.06	0.99	0.92-1.06	0.70
FACT-G functional well-being[b]	Continuous	199	99.5	0.87	0.82-0.92	<0.0001	0.87	0.80-0.95	0.002
FACT-G total score[b]	Continuous	199	99.5	0.97	0.95-0.98	0.0002	0.98	0.95-1.01	0.19
BPI severity[c]	Continuous	197	98.5	1.14	1.01-1.28	0.04	1.00	0.84-1.19	1.00
BPI interference[c]	Continuous	197	98.5	1.22	1.09-1.37	0.0004	1.17	0.995-1.37	0.06

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Variable	Category	N	%	Univariable			Multivariable		
				OR	95% CI	*P*	OR[a]	95% CI[a]	*P*[a]
BPI total[c]	Continuous	197	98.5	1.22	1.08-1.37	0.002	1.13	0.94-1.35	0.19
BFI severity[d]	Continuous	196	98.0	1.18	1.06-1.31	0.002	1.00	0.86-1.17	0.96
BFI interference[d]	Continuous	197	98.5	1.26	1.13-1.40	<0.0001	1.15	0.996-1.33	0.06
BFI total[d]	Continuous	197	98.5	1.26	1.12-1.40	<0.0001	1.12	0.96-1.30	0.17
ECDSS Top 3 Symptoms Severity[e]	Continuous	189	94.5	1.39	1.16-1.66	0.0004	1.15	0.88-1.50	0.32
ECDSS Top 5 Symptoms Severity[e]	Continuous	189	94.5	1.42	1.17-1.73	0.0004	1.12	0.83-1.51	0.47
Unmet health care service needs	No Yes	114 76	57.0 38.0	Ref 1.49	- 0.78-2.84	- 0.23	Ref 0.59	- 0.23-1.47	- 0.25
Unmet psychological/emotional needs	No Yes	86 110	43.0 55.0	Ref 1.74	- 0.89-3.40	- 0.11	Ref 2.06	- 0.76-5.56	- 0.16
Unmet physical and daily health needs	No Yes	98 98	49.0 49.0	Ref 2.26	- 1.17-4.37	- 0.02	Ref 1.57	- 0.53-4.64	- 0.41
Unmet care and support needs	No Yes	146 47	73.0 23.5	Ref 2.42	- 1.20-4.88	- 0.01	Ref 1.29	- 0.51-3.27	- 0.59
Unmet sexual needs	No Yes	152 40	76.0 20.0	Ref 2.16	- 1.03-4.57	- 0.04	Ref 1.92	- 0.74-5.04	- 0.18
N of unmet needs	Continuous	198	99.0	1.07	1.03-1.11	0.0006	1.04	0.99-1.10	0.14
Unmet needs	< 3 3+ < 5 5+ < 10 10+	81 117 102 96 140 58	40.5 58.5 51.0 48.0 70.0 29.0	Ref 2.52 Ref 2.74 Ref 2.34	- 1.24-5.11 - 1.41-5.35 - 1.20-4.57	- 0.01 - 0.003 - 0.01	Ref 1.31 Ref 2.07 Ref 1.69	- 0.48-3.55 - 0.77-5.59 - 0.66-4.28	- 0.60 - 0.15 - 0.27
Anxiety	Normal/Mild Moderate/Severe	165 35	82.5 17.5	Ref 1.43	- 0.65-3.18	- 0.38	Ref 0.67	- 0.21-2.10	- 0.49
Depression	Normal/Mild Moderate/Severe	174 26	87.0 13.0	Ref 9.61	- 3.85-23.99	- <0.0001	Ref 10.96	- 2.84-42.24	- 0.0005
Financial burden[f]	Continuous	197	98.5	1.30	1.05-1.62	0.02	1.07	0.78-1.48	0.67
FACT-Cog: perceived cognitive impairments[g]	Continuous	200	100	0.98	0.96-1.00	0.12	1.01	0.97-1.05	0.65
FACT-Cog: perceived cognitive impairments QoL[g]	Continuous	199	99.5	0.87	0.82-0.93	<0.0001	0.84	0.75-0.96	0.007
FACT-Cog: comments from others	Continuous	200	100	0.90	0.81-1.01	0.07	0.94	0.80-1.10	0.43
FACT-Cog: perceived cognitive abilities	Continuous	199	99.5	0.97	0.93-1.01	0.09	0.96	0.91-1.02	0.17

[a]Adjusted for age, length of undiagnosed histiocytosis, brain / neurologic involvement, number (N) of sites (multifocal / unifocal), household annual income, Brief Fatigue Inventory (BFI) total, and Brief Pain Inventory (BPI) total. [b]A higher Functional Assessment of Cancer Therapy, General (FACT-G) subscale or total score indicates better well-being. [c]A higher BPI subscale or total score indicates worse pain. [d]A higher BFI subscale or total score indicates worse fatigue. [e]A higher Erdheim-Chester Disease Symptom Scale (ECDSS) score indicates worse symptom severity. [f]A higher financial burden score indicates worse burden. [g]A higher Functional Assessment of Cancer Therapy, Cognition (FACT-Cog) subscale or total score indicates better cognitive functioning. CI: Confidence Interval; ECD: Erdheim-Chester Disease; OR: odds ratio; Ref: reference.

For HN, the constellation of reduced functional well-being and moderate / severe depression represents a common symptomatology cluster;[6,8,9] our current findings extend their impact to employment outcomes. The association between neurologic involvement of HN and unemployment is consistent with clinical experience that patients with brain parenchymal HN often experience functional impairments and limited treatment responses.[13] However, reverse association of more severe disease leading to both unemployment and treatment cannot be excluded. The association between unemployment and longer undiagnosed illness, frustratingly common in HN, draws attention to additional harmful consequences of delayed diagnosis.

This study raises an important question of how to mitigate the impact of HN upon employment viability. Educating employers about HN manifestations may allow for adjustments to be made to accommodate patients' needs in order to maintain employment; even perceived employer adjustments for symptoms, side effects, and follow-up visits for cancer and cancer treatment are strong predictors of a return to work, as are flexible working conditions, counseling, and job search assistance.[14] Additionally, recognizing that fatigue and pain, often elusive symptoms, are cancer-related in HN may contribute to employer adjustments. While a Cochrane review demonstrated that psycho-educational interventions alone are unlikely to improve return-to-work rates, multidisciplinary and physical interventions may have greater success, though most studies were in breast cancer.[15] For patients with HN, targeted interventions such as management of depression, optimal therapies for neurologic involvement, and reduction in diagnostic delay may improve the likelihood of sustained employment.

Our study has some limitations. As a registry-based, cross-sectional cohort, some heterogeneity is inherent by design. While there was a mixed referral base, there was a substantial representation from the MSKCC. Registry participants may be more engaged, potentially inflating unemployment rates, though estimates were comparable to those reported in the broader cancer survivorship literature. Employment status was self-reported, though this is conventional in published literature. High rates of missing employment status post enrollment limited our ability to draw longitudinal conclusions. Lack of changes in known employment distribution from enrollment to timepoint 2 precluded analyses investigating associations with change in employment status over time. Nonetheless, the finding that most patients unemployed at enrollment remained unemployed at timepoint 2 suggests that the enrollment associations likely persist over time.

Employment is a vital component of functioning and well-being in people with active cancer and in cancer survivorship, including those with HN. We demonstrated that unemployment is both common and persistent in HN, and is associated with an array of factors, some of which are modifiable. These findings present intervention opportunities through symptom management, earlier diagnosis, improved treatment of neurologic disease, and workplace adjustments that could help preserve employment and, by extension, QoL for patients with HN.

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Contributions

ASR is responsible for study conceptualization, formal statistical analysis, data interpretation, and drafting the manuscript; PHM is responsible for study conceptualization, data interpretation, and drafting the manuscript; KSP is responsible for study conceptualization, data interpretation, drafting the manuscript, and supervising the study; ELD is responsible for study conceptualization, data collection, data interpretation, drafting the manuscript, and supervising the study. All authors contributed to study conceptualization as well as reviewing and editing the final version of the manuscript and agreeing to the submission.

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Data-sharing statement

For original data, please contact the Corresponding Author at diamone1@mskcc.org.

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