

The role of illness perception in patients with cutaneous t-cell lymphoma

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Disclosures

The authors, including the presenter, have no relevant disclosures

Background

- Illness perception: beliefs about disease
 - Revised illness perception questionnaire (IPQ-R)
- Health-related quality of life (QOL): objective measure of quality of life
 - Skindex-29
- CTCL are often chronic and debilitating malignancies
 - Indolent but remitting course
- Treatment of CTCL may be burdensome
 - Wide range of therapies with varying side effects
 - Often significant disruption to normal routine
- COVID-19 pandemic significantly disrupted access to healthcare in United States
 - Unique opportunity to investigate the impact on illness perception and QOL

Background

- Illness perception
 - Internal beliefs about illness
 - Psychosocial impact
- Uses of validated scales of illness perception and QOL
 - Quantify patients' beliefs
 - Quantify specific QOL domains
 - Determine how beliefs impact patient QOL
 - Help physicians to identify and address specific issues
- Few studies investigate illness perception in Cutaneous T-Cell Lymphomas (CTCL)
 - Small sample size
 - Limited patient diversity

Background

- Primary objectives
 - Identify patients' disease understanding and interpretation
 - Identify illness perception's impact on health-related QOL
 - Determine health disparities in illness perception and QOL
- Secondary objectives
 - Investigate the impact of additional educational modalities on disease understanding
 - Investigate the impact of the COVID-19 pandemic on health-related QOL

Methods

- Inclusion criteria
 - ≥ 18 years of age
 - Diagnosed with mycosis fungoides (MF) and Sezary syndrome (SS)
 - Seen at the Johns Hopkins Dermatology Department, Baltimore Maryland United States
- Procedure
 - Participants completed an electronic survey
 - Revised Illness Perception Questionnaire (IPQ-R)
 - Skindex-29
 - Functional Assessment of Cancer Therapy – General – 7 Item Version (FACT-G7)
 - Select questions from the Household Pulse survey from the U.S. Census Bureau
 - Patients randomized to control group or to view a prerecorded educational video
 - Surveys completed at time 0, 2 months, and 6 months
- Result Analysis
 - Survey scores analyzed via descriptive statistics
 - Group differences determined via t-test or ANOVA
 - Analyzed by pairwise comparisons via Tukey's test

Patient Demographics

Total

Initial
n (%)

47 (100)

Gender

Male 24 (51)

Female 22 (47)

Other 1 (2)

Age

18-39 8 (17)

40-49 7 (15)

50-59 8 (17)

60-69 14 (30)

70-79 7 (15)

80+ 3 (6)

Race/Ethnicity

White 21 (45)

Black/African American 17 (36)

Hispanic/Latino 4 (9)

Asian 4 (9)

Other 1 (2)

Patient Demographics

Total

**Initial
n (%)**

47 (100)

Initial disease stage

Early Stage

IA 7 (15)

IB 15 (32)

IIA 4 (9)

Late Stage

IIB 4 (9)

IIIA 3 (6)

IIIB 2 (4)

IVA1 6 (13)

IVA2 1 (2)

IVB 1 (2)

Randomized group

23 (49)

Patient Demographics

		Initial cohort n (%)	NCI SEER n (%)	p-value
Total		47 (100)	3231 (100)	
Gender				
	Male	24 (51)	1866 (58)	0.45
	Female	22 (47)	1365 (42)	
Age				
	Mean	57	58	0.95
	Median	60	60	
Race/Ethnicity				
	White	21 (45)	2458 (76)	<0.01
	Black/African American	17 (36)	380 (12)	
	Asian	4 (9)	175 (5)	
	Other	5 (11)	218 (7)	
Disease stage				
	0-II	30 (64)	2253 (70)	0.03
	III-IV	13 (28)	469 (15)	

IPQ-R Scores

	Score Range	Mean $\pm$ SD
Identity	n/a	2.19 $\pm$ 2.61
Timeline – acute/chronic	6 to 30	23.26 $\pm$ 4.67
Timeline - cyclical	4 to 20	12.33 $\pm$ 3.41
Consequences	6 to 30	20.78 $\pm$ 4.60
Personal control	6 to 30	21.54 $\pm$ 3.95
Treatment control	5 to 25	18.45 $\pm$ 2.82
Illness coherence	5 to 25	16.28 $\pm$ 4.45
Emotional representations	6 to 30	17.21 $\pm$ 5.20
Most common perceived causes	Stress/worry, chance or bad luck, pollution, ageing, altered immunity	

IPQ-R Group Comparisons

Age	Mean $\pm$ SD	<i>p</i> -value
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Consequences

18-39	18.71 $\pm$ 3.50	0.08
40-49	24.50 $\pm$ 4.65	
50-59	23.00 $\pm$ 4.36	
60-69	21.00 $\pm$ 3.37	
70+	18.78 $\pm$ 5.59	

Emotional

18-39	17.75 $\pm$ 6.27	0.02
40-49	20.25 $\pm$ 3.77	
50-59	21.42 $\pm$ 5.35	
60-69	15.27 $\pm$ 3.98	
70+	14.44 $\pm$ 3.64	

Illness coherence

18-39	15.25 $\pm$ 4.40	0.96
40-49	16.25 $\pm$ 5.68	
50-59	16.57 $\pm$ 4.86	
60-69	16.23 $\pm$ 3.73	
70+	17 $\pm$ 5.32	

IPQ-R Group Comparisons

Race/Ethnicity

Mean $\pm$ SD

p-value

Consequences

White	20.24 $\pm$ 4.01	0.23
Black/African American	22.54 $\pm$ 3.84	
Hispanic/Latino	18.00 $\pm$ 8.83	
Asian/Other	20 $\pm$ 2.65	

Emotional

White	15.67 $\pm$ 5.36	0.31
Black/AA	19 $\pm$ 4.98	
Hispanic/Latino	17.25 $\pm$ 5.12	
Asian/Other	18.00 $\pm$ 5.00	

Illness coherence

White	18.22 $\pm$ 3.86	0.03
Black/African American	15 $\pm$ 4.30	
Hispanic/Latino	12.5 $\pm$ 3.11	
Asian/Other	15.67 $\pm$ 6.35	

IPQ-R Group Comparisons

Disease stage	Mean $\pm$ SD	<i>p</i> -value
Consequences		
Early-stage	19.70 $\pm$ 4.91	0.12
Late-stage	22.06 $\pm$ 3.96	
Emotional		
Early-stage	18.32 $\pm$ 5.74	0.13
Late-stage	15.76 $\pm$ 4.13	
Illness coherence		
Early-stage	15.18 $\pm$ 3.92	0.08
Late-stage	17.71 $\pm$ 4.79	

Skindex-29 Group Comparisons

	Emotions	Symptoms	Function	Total
Cutoff score	≥39	≥52	≥37	≥44
Age				
18-39	41.88	44.20	22.92	36.33
40-49	50.00	53.57	41.25	48.27
50-59	60.71	47.02	38.39	48.30
60-69	30.28	41.07	27.29	31.89
70+	28.13	38.84	24.17	30.18
<i>p</i> -value	0.06	0.70	0.60	0.26
Race/Ethnicity				
White	32.03	41.96	26.67	32.26
Black/African American	53.08	47.53	39.23	45.71
Hispanic/Latino	28.125	37.50	21.88	29.17
Asian/Other	48.125	46.43	23.44	39.33
<i>p</i> -value	0.07	0.72	0.41	0.21

Discussion

- Significant difference in race/ethnicity compared to prior studies
 - Increased representation of Black or African American patients
 - Greater ability to detect differences between demographic groups
 - Sex and age not significantly different
- Perception of CTCL to be chronic with variable course
 - Indicative of effective counseling from treatment team
 - Establishes appropriate expectations of disease course
- Perception of high treatment control
 - Indicates confidence in therapies and treatment team
- Perception of high personal control
 - Potential risk of demoralization if treatment failure

Discussion

- 40-49 and 50-59 age groups highly impacted by CTCL
 - Peak productivity years for adults in United States
 - High consequences of disease on patient and families
 - High emotional impact
- Black or African American population also highly impacted
 - Greater perception of consequences of disease
 - Difference not explained by higher initial disease stage (not presented)
- Disease understanding varies between demographic groups (illness coherence)
 - White patients had higher disease understanding
 - Black or African American and Hispanic or Latino patients had lower disease understanding
- Social determinants of health may impact illness perception
 - Relationship status, educational level, occupational status, socioeconomic status, etc.
- Additional research required to investigate disparities

Limitations

- Sample from one tertiary hospital system in the United States
- Might not be generalizable to patients living in remote or rural areas
- Limited follow-up data available at time of presentation

Future Plans

- Ongoing study
- Recruit larger number of patients
- Continue to collect follow-up data
- Additional analysis of disparities
- Analyze impact of educational modalities on illness perception and QOL
- Analyze impact of COVID-19 pandemic on illness perception and QOL

Conclusions

- Disparities exist between demographic groups of patients with CTCL
 - Disparity in illness understanding between White and Black or African American patients
 - Tailored interventions may reduce these inequities
- Patients ages 40-59 may be more emotionally and practically affected
 - Important to evaluate patients holistically when considering management options
- Patients generally have positive beliefs on personal disease control
- Patients generally have positive beliefs on treatment disease control

Thank you



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