Quality of Life in Cutaneous Lymphoma: Validation of a Novel Quality of Life Instrument

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Cutaneous Lymphoma Foundation

BACKGROUND

- Cutaneous T cell lymphoma (CTCL) has a particularly debilitating symptom burden when compared to other malignancies and skin diseases (Herbosa et. al), which has been shown to have a detrimental impact on patient quality of life (QoL) (Ottevanger et. al).
- As this disease is not curable without an allogeneic transplant, improving QoL on therapy is a key component of clinical decision-making.
- Existing QoL tools are missing critical domains important to this specific patient population (Figure 1)
- No prior surveys have focused on patients with early versus advanced stage disease.
- Robust tools would facilitate the use of QoL trial metrics as an endpoint for future prospective therapeutic studies.

OBJECTIVE

We have sought to develop a more comprehensive QoL measure for patients with CTCL, and to validate our new measure in patients with early- and advanced-stage CTCL.

METHODS

- This is a cross-sectional survey study of patients receiving treatment at the multidisciplinary CTCL clinic and dermatology clinic at Washington University in St. Louis.
- Based on prior inductive thematic analysis of semi-structured interviews of 18 patients, 54 new items were developed
- This survey was then reviewed by an internal expert panel after which 46 items remained.
- Using a cognitive interview protocol, 9 interviews were carried out using this new survey, characteristics shown in Table 1
- Qualitative feedback was elicited including views on survey length, language clarity, response options, and question structure.
- Items identified as problematic were subject to revision or removal, leaving 41 items remaining to be used to assess for convergent and discriminant validity of this survey.

RESULTS

Figure 1: Existing Surveys

	HUI3	SF-36	Skindex	DLQI	MF/SS-CTCL
Itch			x	x	
Pain	x	x	x	x	
Fatigue		x	x		x
Sleep			x		
Skin breaks					
Skin flaking					
Lack of understanding in the community					x
Concern about appearance			x	x	
Isolation	x	x	x	x	x
Otherness		x			
Depression	x	x	x		x
Hopelessness					x
Uncertainty			x		x
Treatment Burden			x	x	x

Table 1: Cognitive Interview Patient Characteristics

Characteristics		Patients (n= 9)
Stage	Early (IA – IIA)	5
	Late (IIB – IVA)	4
Age	Range 40-80 years	Average: 64 years
Gender	Female	5
	Male	4

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RESULTS

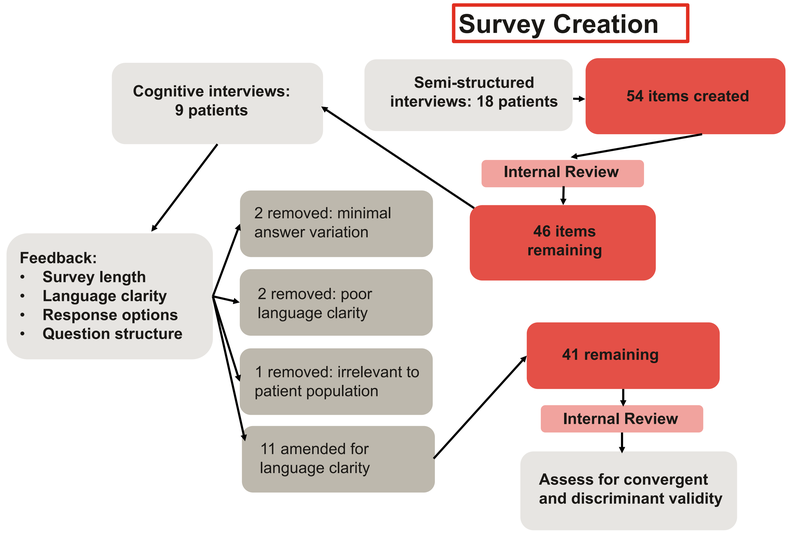


Figure 2: Overarching Critiques

Theme	Patient Responses
Cyclical Nature of Disease	"The part where it says over the past month, people would need to know what's the purpose of this because I haven't had a month the same, I would probably say it chronically and make it more general"
Difficulty Quantifying Agreement	"that's a question where what you wanna know is to what degree, sometimes you feel bad, you really do, because if you haven't gotten much rest […] I put agree on there because yes it does cause that sometimes, but to what degree it is, its not going to make you jump off a building or anything, [but] it's not something you blindly ignore the whole time"
Answering Questions That Do Not Apply	"I was a little [confused], I never have broken skin/sores or cuts, my lesions get sensitive so it's painful for my clothes to rub up against. [….] This is more n/a"
Heterogeneity of Treatment	"this was hard for me to answer because I'm not on any treatment right now" "All I do is take my Targretin, if I do have a little problem" "At times it is, both the travel time, time at the clinic, as well as the actual treatment. When on trial it is even more intensive"

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SUMMARY

- Answer variation was present in all items.
- 5 items were deleted after review of feedback, 2 were removed due to minimal answer variation, 2 were deemed to be too confusing, and one was not relevant to this patient population.
- 11 items were changed to have clearer wording.
- An important theme that came up repeatedly was the cyclical nature of CTCL symptoms, and the need to specify a specific time period in which patients can evaluate their QoL.
- This survey used the past 4 weeks as the time period the items were referring to, which was confirmed an appropriate time period based on patient feedback.
- Given there may be periods that patients are not on treatment, not applicable was added as an answer option to 4 items that asked about side effects of treatment.
- In nearly every item, patients with early stage disease had similar answers to each other, as did patients with late stage disease

CONCLUSION

Patients with CTCL have varied experiences with QoL based on their disease stage. This is important to take into account when creating a tool to evaluate quality of life in this patient population. This survey is now being validated as a clinical tool by comparing its ability to capture QoL compared to existing surveys in a prospective study funded by the Cutaneous Lymphoma Foundation.

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