ARTICLE - Quality of Life

The development and preliminary validation of the CTCL-PRO-20: a novel quality of life survey for patients with cutaneous T-cell lymphoma

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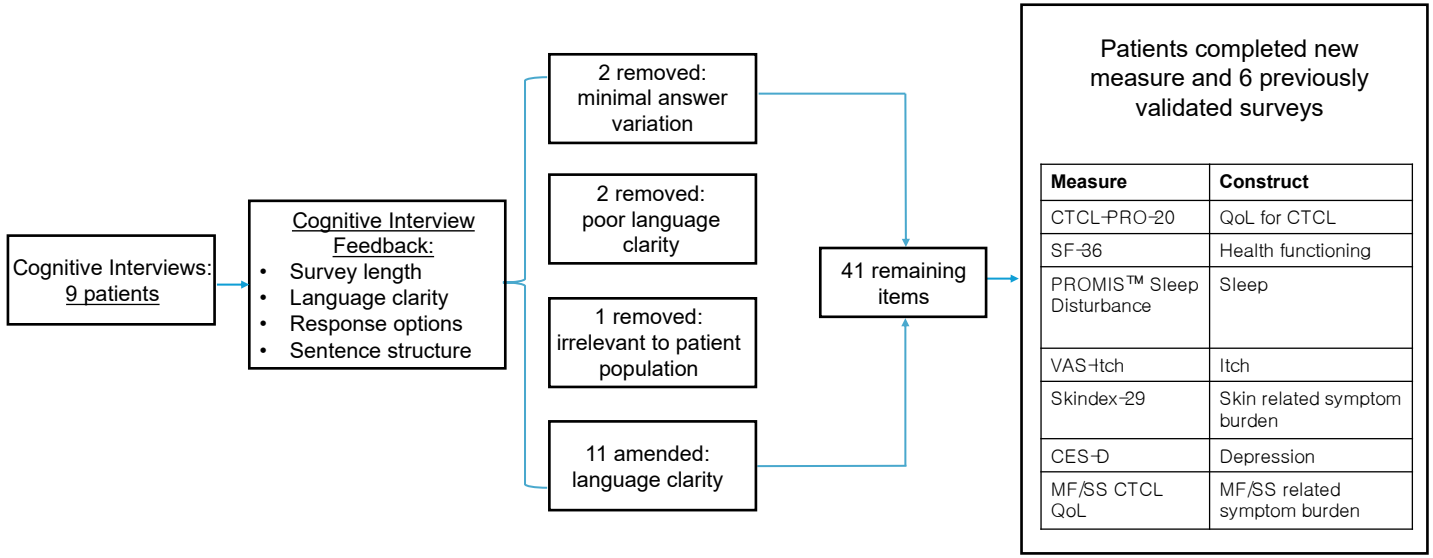
Supplemental Table 1. Domains Important to CTCL Patient Quality of Life[1] and Coverage by Existing Patient Reported Outcome (PRO) Measures.

	Skindex-29	MF/SS-CTCL	FACT-G	FACT-CTCL	CTCL-PRO-20
Itch	x			x	x
Pain	x		x	x	
Fatigue	x	x			x
Sleep	x		x	x	x
Skin breaks	x			x	x
Skin flaking				x	x
Lack of CTCL resources					x
Concern about appearance	x			x	x
Isolation	x	x			x
Otherness					x
Depression	x	x	x	x	
Hopelessness		x	x	x	
Uncertainty	x	x	x	x	
Treatment Burden	x	x	x	x	x

[1]T.S. Bhat, C.M. Herbosa, A.R. Rosenberg, O. Sogade, D.B. Jeffe, N. Mehta-Shah, Y.R. Semenov, A.C. Musiek, Current measures are not sufficient: an interview-based qualitative assessment of quality of life in cutaneous T-cell lymphoma, *British Journal of Dermatology*, Volume 184, Issue 2, 1 February 2021, Pages 310–318, https://doi.org/10.1111/bjd.19298

CTCL, Cutaneous T-cell Lymphoma; MF/SS, mycosis fungoides/Sezary syndrome, FACT-G, Functional Assessment of Cancer Therapy General

Supplemental Figure 1: Process of CTCL-PRO-20 Questionnaire Development



Supplemental Figure 2: CTCL-PRO-20
Clinical Symptoms, Side Effects, and Associated Concerns about Cutaneous T Cell Lymphoma (CTCL).

The following statements reflect concerns about how symptoms and side effects of treatment for Mycosis Fungoides or Sézary syndrome (MF/SS) might have affected aspects of your quality of life over the past month. Please indicate your response by circling your level of agreement with each statement as it relates to your experience living with MF/SS.

1. **Worrying about MF/SS prevents me from falling asleep.**

Strongly Disagree Disagree Neutral Agree Strongly Agree

2. **I refrain from going out in public because of my appearance.**

Strongly Disagree Disagree Neutral Agree Strongly Agree

3. **I am embarrassed to be with other people due to skin flaking.**

Strongly Disagree Disagree Neutral Agree Strongly Agree

4. **Symptoms of MF/SS, including itch, impact my ability to fall asleep.**

Strongly Disagree Disagree Neutral Agree Strongly Agree

5. **I have experienced broken skin (sores or cuts) due to MF/SS or its treatment.**

Strongly Disagree Disagree Neutral Agree Strongly Agree

6. **I am concerned about the sores and/or cuts on my skin.**

Strongly Disagree Disagree Neutral Agree Strongly Agree

7. **In the general population, there is a lack of understanding about MF/SS.**

Strongly Disagree Disagree Neutral Agree Strongly Agree

8. **Skin flaking due to MF/SS is bothersome.**

Strongly Disagree Disagree Neutral Agree Strongly Agree

9. **Fatigue due to MF/SS or its treatment prevents me from completing daily tasks.**

Strongly Disagree Disagree Neutral Agree Strongly Agree

10. **It is frustrating that more people do not know about MF/SS.**

Strongly Disagree Disagree Neutral Agree Strongly Agree

11. There is a lack of available resources for me to share with friends and family to help them better understand MF/SS.

Strongly Disagree Disagree Neutral Agree Strongly Agree

12. I am concerned about my appearance due to MF/SS.

Strongly Disagree Disagree Neutral Agree Strongly Agree

13. I feel self-conscious about my appearance due to MF/SS.

Strongly Disagree Disagree Neutral Agree Strongly Agree

14. My MF/SS symptoms, including itch, cause me to wake up during the night.

Strongly Disagree Disagree Neutral Agree Strongly Agree

15. I feel socially isolated because of my MF/SS.

Strongly Disagree Disagree Neutral Agree Strongly Agree

16. I am embarrassed about the way I look.

Strongly Disagree Disagree Neutral Agree Strongly Agree

17. The frequency of my treatment(s) interferes with my daily activities.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Not applicable – I have not been on treatment in the last month

18. The frequency of my treatment(s) interferes with my social life.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Not applicable – I have not been on treatment in the last month

19. The time I have spent receiving treatment for MF/SS has been a burden.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Not applicable – I have not been on treatment in the last month

20. The side effects of MF/SS treatments have been burdensome.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Not applicable – I have not been on treatment in the last month