Are existing quality-of-life instruments in cutaneous T-cell lymphoma of sufficient quality?

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Cutaneous T-cell lymphoma (CTCL) is a rare type of non-Hodgkin lymphoma. However, non-Hodgkin lymphoma is ranked as the seventh most common cancer in the USA.[1] In CTCL, mutated T cells migrate to the skin, and lesions on the skin tend to appear. Mycosis fungoides (MF) and Sézary syndrome (SS) are the most prevalent forms of CTCL.[2] Pruritus, one of the most prominent symptoms of the disease, often leads to scratching, which in turns causes painful skin and can lead to disfigurement of affected patients. This negatively impacts their quality of life (QoL).[3]

Instruments measuring QoL are of great interest as they capture the patient's perspective. Their use in clinical trials is increasingly recognized by regulatory authorities, clinicians and patients because they help to indicate whether the impact of an intervention is comprehensively assessed.[4]

In this issue of the *BJD*, Bhat *et al.*[5] use qualitative research to assess the impact of CTCL on patients' daily lives and to identify the most meaningful aspects in assessing QoL in CTCL. This is achieved by evaluating existing QoL instruments (generic, skin specific and disease specific). Generic instruments (e.g. the 36-Item Short-Form Health Survey) and skin-specific instruments (e.g. the Dermatology Life Quality Index) cannot capture CTCL-specific constructs. However, the only existing CTCL-specific measure, the MF/SS-CTCL instrument, did not include patients with advanced-stage disease in either the development or validation.[6]

In their study, Bhat *et al.* included patients at all stages of the disease. This assessment across various severity stages is novel. Eighteen semistructured interviews revealed three major themes: clinical symptoms, psychological and social functioning, and the salient treatment burden. Existing QoL instruments were screened for relevant patient concerns identified in the interviews. In particular, individual clinical symptoms, concerns about appearance and problems with sleep were not adequately represented in either generic or skin-specific instruments, or in the only existing CTCL-specific QoL measure. For this reason, there is currently no available QoL instrument of sufficient quality in CTCL.

Qualitative research involving affected patients, as performed by the authors, is the gold standard for the development of a promising patient-reported outcome measure. Without patient input, the content validity of a new instrument can be questioned. Only patients are able to judge the impact of their disease, their feelings and their treatment burden. For this reason, this study including interviews with patients with variations in severity represents an excellent starting point for the development of a new, comprehensive, disease-specific QoL instrument of sufficient quality for patients with CTCL.

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There is still a place for tumour-targeted therapies in Merkel cell carcinoma in the era of immune checkpoint inhibitors

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Merkel cell carcinoma (MCC) is a highly aggressive neuroendocrine skin cancer, which remains rare despite its increasing incidence in most Western countries. Approximately one-third of patients with MCC will develop metastases during the course of the disease. Until 2017, cytotoxic chemotherapies were the standard of care in cases of advanced disease,