SKIN CANCER (OTHER THAN MELANOMA)

THE PROCLIPI STUDY; A PROTOTYPE REGISTRY FOR RARE CANCERS WITH GLOBAL COLLABORATION FOR ESTABLISHMENT OF A PROGNOSTIC INDEX IN MYCOSIS FUNGOIDES AND SEZARY SYNDROME

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Introduction: Mycosis fungoides (MF) and Sezary syndrome (SS) are the commoner forms of primary cutaneous T-cell lymphomas, early-stage MF (IA-IIA) may have a long survival 15+years but >25% progress to advanced stage disease. 1/3 present in advanced stage with a poor outcome, median survival 1-4 years. Tests to determine which patients may have a worse prognosis are lacking.

Objectives: The PROCLIPI Study is a multi-national PROspective Cutaneous Lymphoma International Prognostic Index study to develop a prognostic index in MF/SS to select patients with a worse prognosis for more intensive therapies.

Methods: PROCLIPI launched in 2015 collecting pre-defined clinical, haematological, radiological, immunohistochemical, genotypic, quality-of-life and treatment data using a secure web-based database system. Additionally, central clinicopathological review is performed by experts to confirm diagnosis and stage.

Results: 1108 patients are registered from 46 international sites across 5 continents. 812 early-stage (IA-IIA) patients;1.64males:1female and 296 advanced-stage (IIB-IV);1.69males:1female. The median age at diagnosis of advanced disease was 65yrs

compared to 57yrs in early-stage (p<0.0001). The median time of patient reported MF-like lesions prior to diagnosis was 36 months in early and 32 months in advanced disease confirming a diagnostic delay. Raised serum lactate dehydrogenase (LDH) and large cell transformation (LCT) in skin are among the candidate prognostic factors. LCT is found in 2.4% early stage patients and in 20.1% advanced patients p<0.01. 7.8% of early stage and 36.8% advanced patients have raised serum LDH at diagnosis (p<0.01). Treatment data including responses will be measured against survival and tumour phenotype.

Conclusions: PROCLIPI has confirmed a diagnostic delay in all stages of MF/SS. There is a need to improve diagnostic techniques to quicken diagnosis. Identifying patients with a poorer prognosis should allow optimal treatments, better patient experience and improve survival. PROCLIPI is a prototype registry and this study design may benefit other cancer groups.