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Title: HOW WELL ARE OUR PATIENTS WITH CHRONIC LYMPHOCYTIC LEUKAEMIA?

Abstract Type: Poster Presentation

Topic: Chronic lymphocytic leukemia and related disorders - Clinical

Background:

Standard of care treatment for patients with chronic lymphocytic leukaemia (CLL) usually entails a period of active monitoring prior to treatment initiation. However, during this time many patients worry that their health is deteriorating and may experience symptoms of poor health. Perhaps the most frequently reported symptom is fatigue. While severe fatigue is accepted as a criterion to commence therapy, fatigue is a poorly defined entity, and the frequency and impact of fatigue may not be fully recognised by clinicians. Therefore, as part of an initiative supported by Macmillan Cancer Care we undertook a symptom screening assessment for a broad group of patients at different stages of their CLL disease to establish their fatigue symptoms and perceived quality of life (QOL), and to determine whether symptoms of fatigue were directly related to CLL disease burden.

Aims:

To quantitatively assess the frequency and severity of patient-reported symptoms of fatigue in CLL and to relate fatigue-symptoms to QOL and CLL disease burden.

Methods:

All patients undergoing active follow up for CLL at University Hospitals Plymouth NHS Trust were invited to participate. Two hospital-approved tools were selected for assessment based on prior validation and simplicity for patient self-use: The Functional Assessment of Chronic Illness Therapy-Fatigue scale (FACIT-Fatigue) and the Global QOL scale. Participation in the study required written consent and patients were offered written information (Macmillan Cancer Care Fatigue booklet) that provides strategies to manage fatigue. The responses to fatigue and QOL studies were then linked with clinical and laboratory data for each patient allowing results to be interpreted in the light of disease status.

Results:

The response rate was 66% (n=185 responses) and patients included all stages of CLL disease or treatment. Analysis showed that the mean FACIT fatigue score of this CLL patient population was 33/52, with 41% of patients fulfilling the criteria of severe fatigue (FACIT<30). This level of fatigue differs significantly from that of matched normal populations (mean 44/52) and was worse than the reported scores of patients with active cancer (mean 36/52). Surprisingly, the fatigue of our patients was only very weakly correlated with anaemia (R2<0.2, p=0.03) and showed no correlation with age (R2<0.01, p=ns) or lymphocyte count (R2<0.01, p=ns). However, fatigue was very strongly correlated with quality-of-life scores (R2=0.82, p=0.0001), with severely fatigued patients having a mean global quality of life score of 49/100, compared with the remaining patients mean score of 76/100.

Summary/Conclusion:

Patients with CLL are strongly encouraged and motivated to report symptoms related to their CLL. However, symptoms of fatigue are often not directly sought, and may be under-reported by patients. In this study we show that self-reported symptoms of significant fatigue are frequent in patients with CLL when compared with results of age-matched unaffected patients. These symptoms are not related to age, or to measures of disease stage, but have a major impact on perceived quality of life.

The causes of fatigue in CLL are poorly understood and may relate to inflammatory components of CLL disease,

and/or the greater clinical vulnerability of some patients with CLL. However, recognising and understanding this hidden problem could allow interventions that could substantially improve the quality of life for our patients.

Keywords: Fatigue, Chronic lymphocytic leukemia, Quality of life