

Fatigue, Quality of Life and Related Symptoms: Patient Reported Outcomes in Myelodysplastic Syndrome

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BACKGROUND: Fatigue is common and very distressing among patients with myelodysplastic syndrome (MDS), frequently affecting their quality of life. Often, this is combined with other symptoms such as pain, depression, anxiety, and stress. Limited data exists on the perceived level and impact of fatigue, quality of life and related symptoms in these patients. The objectives are to describe fatigue, quality of life (QOL) and related symptoms in patients with MDS by prospectively assessing these using the Functional Assessment of Cancer Therapy-Anemia (FACT-An) for fatigue and QOL (subscales within FACT- An), pain using the Brief Pain Inventory (BPI), and depression, anxiety and stress using the DASS-21, and to define management strategies routinely used.

METHODS: Surveys were administered via the Aplastic Anemia and MDS International Foundation's patient database from 10/2014 through 1/2015 via a secure internet portal associated with the Foundation's website. Descriptive statistics were utilized.

RESULTS: 145 patients with MDS responded. The mean age was 67 years with 83 (57%) female, 92 (97%) white and 30 (23%) had received a blood transfusion in the past 90 days. The mean fatigue score overall was 25 (severe level). The overall quality of life score was 69. *Please note with the FACT-An, FACT-G and FACT-F -The higher the score, the better the QOL or fatigue.* Stress was normal; pain, depression, and anxiety were mild. Most common management strategies used for fatigue in the past month were preserving energy 114 (79%); physical activity 102 (70%); naps 100 (69%) and eating healthy 97 (67%). The strategies that were helpful to extremely helpful were preserving energy 103/114 (90%), eating healthy 77/97 (79%), physical activity 81/102 (69%), and naps 65/100 (65%). Frequency of use 3 or more times/week were preserving energy 80/124 (65%), eating healthy 78/121 (64%), taking vitamins 68/116 (59%), and naps 60/121 (50%), and among those who indicated the frequency of use.

CONCLUSIONS: There are few patient reported outcomes of fatigue, QOL and related symptoms in this population of patients with MDS. Fatigue and QOL are significant challenges. In this cohort, other symptoms (stress, pain, depression and anxiety) did not have major influence on the fatigue level. Further focus on development of fatigue interventions tailored for patients with MDS may assist in decreasing the severity of fatigue with potential improvement in QOL.