

Abstract Submission

16. Myeloproliferative neoplasms - Clinical

ABSSUB-3667

BACK TO LIFE -LIVING, TREATING, MANAGING MYELOFIBROSIS: THE BURDEN OF ILLNESS FOR PATIENTS AND THEIR FAMILIES

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Please indicate your presentation preference: Oral Presentation

Background: Myelofibrosis(MF) is a chronic myeloproliferative neoplasm that affects approximately 12 individuals per 1 million people a year. The patients' survival depends on the severity and speed of progression of the disease and can vary from 2 years to more than 11 years.

Aims: The objective of the current research was to quantify the burden of illness(BoI) on patients and their families in Italy. The impact of MF on productivity and QoL, the impact of treatments with ruxolitinib or other therapies and the experience of caregivers were evaluated through written interviews consisting of a quantitative part and a narrative medicine part.

Methods: Target of research were patients affected by primary or secondary MF and unpaid caregivers. In 36 Italian haematological centers questionnaires were distributed under the supervision of ISTUD Foundation, between September 2012 and October 2013, with written consent form signed and an Ethic Committee approved protocol. For the quantification of the BoI, 287 questionnaire of patients and 98 of caregivers and , respectively, 210 and 62 their stories were collected.

Results: The patients' mean age was 65 years, 55% were men and 45% women. At the time of diagnosis, the most frequent feelings were fear(70%) and depression(28%); this affected the patients' mindset that is aimed primarily at living in the present tense(50%) or fearing no possible future(27%), as resulted from their stories.

48% of patients were forced to give up the gratifying movement activities mainly because of splenomegaly(70%) and fatigue(64%). In addition, 35% of patients failed to continue their work, with a mean loss of income of 8.065€ per year.

Further analyses showed that patients treated with ruxolitinib had a reduction of the spleen in 71% of cases, amounting to 19% if on other therapies. 92% of patients treated with ruxolitinib improved symptoms(59% if on other therapies) and pace of work in 87% of cases(44% if on other therapies).

The 98 caregivers interviewed were 41% men and 55% women with a mean age of 55 years. They declared to take care of their relatives for more than 3 hours per day in 45% of cases. As a result of the impact of MF, 87% of caregivers resulted highly stressed, as measured with the "*Caregiver self-assessment questionnaire*" of the AMA. Nevertheless, through narrative it came out that coping was present in 53% of the experience and the success factors were not only love and responsibility, but also the possibility to rely on health professionals, friend or colleagues.

In terms of lost revenue due to the care they perform, caregivers declare a quantifiable loss of 4.692€ per year, mainly because only 19% of caregivers manage to maintain their pace of work; to this productivity loss, the mean annual cost of 7.302€ for those who need family support is added.

Image/Pictures:



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Summary/Conclusion: These results suggest that MF causes a heavy loss of income for both patients and caregivers who are still in productive age, as well as high intangible costs determined by the severe limitations on the QoL of people with MF and by the high stress induced by the burden of care. Furthermore, it has been estimated that, to pay an external caregiver the average annual cost would range between 6.606 and 10.590€. Psychological burden affect both patients and caregivers. However from these data the use of ruxolitinib appears to reduce the BoI of patients with MF in terms of restarted activity, work maintenance and social and relational wellbeing. A special reward goes to the Italian hematologies, patients and their families for having participated to this project.

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