

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

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Backgrounds:

Myelofibrosis (MF) is a chronic myeloproliferative neoplasm that affects approximately 12 individuals per 1 million people a year. The patients' survival 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 quality of life (QoL), the impact of treatments with ruxolitinib or other therapies and the experience of caregivers were evaluated through written interviews consisting of a quantitative section and a narrative section.

Methods:

Between September 2012 and October 2013 in 35 Italian haematological centers questionnaires with narrative plots were administered to patients affected by primary or secondary MF and unpaid caregivers, under the supervision of ISTUD Foundation. Written consent form were collected and the project was approved by local Ethic Committee.

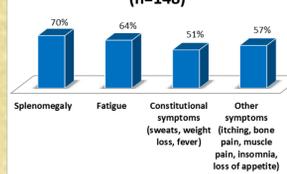
The methodology of the survey is innovative and it mixes standard quantitative questions with a qualitative approach which is based on narrative medicine declined in the context of this specific disease. In particular, a semi-structured plot led the patient or caregiver to recount his/her experience from early symptoms of the disease until the current time. For the quantification of the BoI, 287 questionnaires of patients and 98 of caregivers were collected and 210 and 62 stories were written by patients and caregivers respectively.



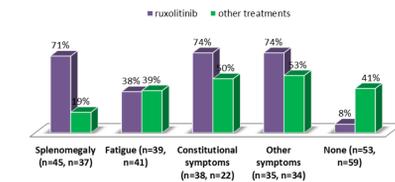
Patients' results:

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, versus 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).

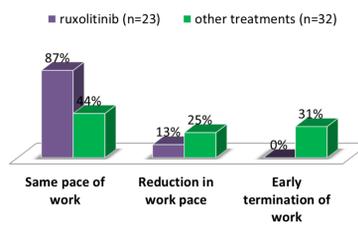
Symptoms at time of the diagnosis (n=148)



Reduction of symptoms after therapy



Work pace after therapy



The tables refer only to the project led between June 2013 to October 2013.

From some stories:

At the time of the diagnosis

"I felt destroyed, I was so young I was afraid of not seeing growing my children"-Patient
 "I felt sensations of sorrow, discomfort and fear of what I was going to face"- Caregiver
 "Distressed, anxious, because I did not know what it was, and I had never heard talking about this disease"-Patient
 "At home I could not do heavy work, or go shopping independently or get away alone without having panic attacks"-Patient

Now

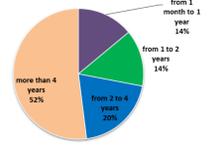
"I had a life, a family, a husband and a daughter who were wonderful and I would find the strength to adapt to this new situation" - Patient
 "I decided to be near her, to support her morally and if her illness will worsen I would have accompanied her wherever she needed to assure the best care"-Caregiver
 "at work I can remove negative thoughts and focus on something else. It's my therapy and I can't imagine not working" - Patient

"Now I feel I can do almost everything even though I'm careful not to push too hard and cuddle more often, to respect my body, which in spite of everything keeps me alive and fight with me" - Patient

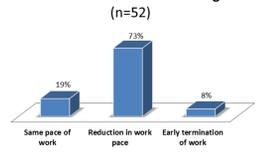
How patients felt in writing their stories

"I hope that the experience of my sickness may serve to improve the lives of us sick. Willingly and with pleasure I wrote my anxieties and fears.- Patient
 "It was very useful for me to understand some negative feelings"- Patient

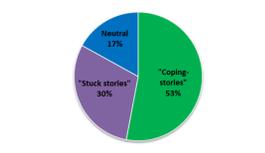
Caregiving relationship



Effects on work time of the caregivers (n=52)



analysis of caregivers' stories (n=62)



Caregivers' results:

The 98 interviewed caregivers were 41% men and 55% women (4% missing data) 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 higher than from quantitative results: in fact, 53% caregivers mastered positively their experiences and the success factors were among feelings love, among moral attitude responsibility, and the possibility to rely on health professionals and a lively network. 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; for those who need family support this productivity loss is to be added to the mean annual cost of 7.302€.

Conclusions:

Psychological burden affect both patients and caregivers. Furthermore the narrative medicine approach has demonstrated deeper power of probing the living with the disease, as shown by a better highlighting of the coping forces than that achieved only by quantitative questionnaire. 75% of patients and 74% of caregivers have given a **positive feedback to the opportunity** to share their experience with others through writing their own story of illness. They felt useful and important, appreciating in some cases the therapeutic effects of writing to retrace the steps of each own story. Moreover these results suggest that MF causes a **heavy loss of income** for both patients and caregivers who are still in productive age, and this means a loss of active role and status from the societal perspective which can endanger the identity of the persons affected by this chronic disease. In addition, the severe limitations on the QoL of people with MF yield to **high intangible costs and to high stress** induced by the burden of care of both patients and caregivers. Furthermore, the average annual cost to pay an external caregiver would range between 6.606€ and 10.590€. 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. We are now going further with the analysis to confirm the validity of this approach.

References:

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