

Sharing good practice in rare diseases: the experience of an innovative hybrid laboratory of narrative medicine and narrative psychology for patients and caregivers living with Behçet's disease

Sirs,

Behçet's disease (BD) is a challenging rare condition, characterised by a variable spectrum of disease profile, a multi-organ involvement and a relapsing course. The therapeutic management of BD is often challenging and frequently includes off-label treatments (1).

Considering the complexity of BD, patients' empowerment represents a major contribution for improving the lives of patients, caregivers and families living with the disease and it is expected to work for the optimisation of different dimensions, represented by patient-clinician communication, self-management, sharing of the therapeutic decision-making process, and patient education (2). Recently, Behçet Talk, an educational programme tailored for patients, families and caregivers living with BD, was launched in Italy (3); the initiative was promoted by the Behçet Clinic of Pisa, together with the Italian patients' association for BD (SIMBA). The main scope of Behçet Talk is to offer educational on-line webinars on different aspects of the disease, as well as support groups for patients and caregivers coordinated by a psychologist with specific expertise in BD, and to promote the awareness of the disease and improve its impact on the daily life of patients, family members and caregivers. Indeed, caregivers represent crucial figures in the lives of people with a chronic disease, especially when the disease is rare; this is the case of BD caregivers who have to deal with a rare disease. In this regard, we highlighted by means of a cross-sectional study how the caregivers perceive BD and how often caregivers are not provided with the necessary knowledge and awareness on the disease. These data suggested the need to identify areas of potential new initiatives for BD caregivers (and therefore patients) aimed at empowering them in reducing the burden of the disease in their life and family (4). Thus, following the experience of the educational programme, we launched Behçet_Lab, an innovative hybrid laboratory of narrative medicine and narrative psychology aimed at empowering BD patients and caregivers. Narrative Medicine is a medical approach that aims at integrating the stories of illness of patients in clinical management and that allows healthcare professionals to take into consideration the perspectives of patients (5, 6). Besides, narrative psychology can be described as an approach that examines and interpret human actions through the metaphors used in the narratives (7).

Behçet Lab is an interactive face-to-face workshop in which patients and caregivers share their own stories and experiences in a process guided by experts in narrative medicine and narrative psychology. The first workshop of Behçet_Lab was held in Pisa in May 2022 and it involved patients and caregivers living with BD. All participants were gathered in a plenary session dedicated to presenting the objectives and the expected outcomes of the workshop and each participant received a toolkit that contained different tools, such as an *ad hoc* workbook and numerous tools useful to work during the workshop. In particular, the workbook contained different prompts for both sessions and an illustration of the journey of the patient that included the following phases: Discovery (from the first symptoms to the diagnosis), Change (experiencing the diagnosis and treatments), Relationships (self-relationship, relationship with healthcare providers, with others), Opportunity: everyday life and lifestyle, Future: prospective and hope. The phases of the journey represented the main sections of the workbook that the participants could complete guided by the discussions held during the narrative medicine and narrative psychology. BD patients and BD caregivers were divided into groups that worked at first in a session with experts in narrative medicine and afterwards, in a session with experts in narrative psychology. Different methodological approaches were adopted during the workshop and participants had different tools available to express their feelings and tell their stories. Specifically, during the narrative medicine session, three narrative tools were proposed to the participants to write, reflect, and share their stories: Timeline, Creative Writing and Close Looking (based on a photograph of Henri Cartier Bresson). Moreover, during the session on narrative psychology, participants had the opportunity of expressing their feelings experienced during the journey by means of drawings, illustrations, creative compositions and also by sharing their stories with their fellow participants.

The workshop represented a great success for both patients and caregivers, as shared during the final plenary session in which the results of the workshops were discussed with the participants. Several topics were highlighted during the plenary discussion with a particular focus on identifying the specific resources that were adopted by the participants in the different phases of their journey, which were also visible in the workbooks. Notably, the discovery of the BD diagnosis was perceived often as a "relieve", rather than as a negative moment, as providing a name for the symptoms the patient was living with opened a new scenario that could then be faced with more awareness. Having the opportunity of sharing their stories, adopting a hybrid approach that combines narrative medicine and narrative psychology, allows patients and car-

egivers to share their experiences and their journey, improving their awareness not only of the disease but also of how to use personal resources to empower themselves. The combination of both approaches was particularly appreciated by the participants, that confirmed that, under the guidance of experts in this approach, they were able to bring home useful and ready to use psychological resources and expressed the need to make available this approach to BD, other patients and caregivers.

D. MARINELLO¹

A. MANZO²

I. PALLA³

A. DEL BIANCO⁴,

M. MOSCA¹, MD, PhD

D. TARUSCIO⁵, MD, PhD

S. POLVANI⁶

R. TALARICO¹, MD, PhD

¹Rheumatology Unit, Azienda Ospedaliero Universitaria Pisana, Pisa;

²Psychologist, Psychotherapist, Translational Analyst, Rome;

³Institute of Management, Scuola Superiore Sant'Anna, Pisa;

⁴Associazione S.I.M.B.A. (Associazione Italiana

Sindrome e Malattia di Behçet), Pontedera;

⁵National Centre for Rare Diseases, Istituto Superiore di Sanità, Rome;

⁶President of the Italian Association for Narrative Medicine, SIMEN, Italy.

Please address correspondence to:

Rosaria Talarico,

UO di Rheumatologia,

Azienda Ospedaliero Universitaria Pisana,

Via Roma 67,

56126 Pisa, Italy.

E-mail: sara.talarico76@gmail.com

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