

# Promoting patients' empowerment in rheumatic diseases: the perspective of the International Society of Behçet's Disease Working Group on Patient Empowerment, Adherence to Therapy and Patients' Education

F. Di Cianni<sup>1,2</sup>, D. Marinello<sup>1</sup>, A. Altenburg<sup>3</sup>, U. Karacayli<sup>4</sup>, G. Emmi<sup>5,6</sup>, M. Schirmer<sup>7</sup>, G. Mumcu<sup>8</sup>, F. Fortune<sup>9</sup>, R. Talarico<sup>1</sup> on behalf of the International Society of Behçet's Disease (ISBD) Working Group on Patients Empowerment, Adherence to Therapy and Patients' Education

<sup>1</sup>Rheumatology Unit, Azienda Ospedaliero-Universitaria Pisana, Pisa, Italy; <sup>2</sup>Department of Medical Biotechnologies, University of Siena, Italy; <sup>3</sup>Departments of Dermatology, Venereology, Allergology and Immunology, Brandenburg Medical School Theodor Fontane, Dessau, Germany; <sup>4</sup>Department of Oral and Maxillofacial Surgery, Gulhane Faculty of Dentistry, University of Health Sciences, Ankara, Turkey; <sup>5</sup>Department of Medical, Surgery and Health Sciences, University of Trieste, and Clinical Medicine and Rheumatology Unit, Cattinara University Hospital, Trieste, Italy; <sup>6</sup>Centre for Inflammatory Diseases, Monash University Department of Medicine, Monash Medical Centre, Melbourne, Australia; <sup>7</sup>Department of Internal Medicine, Medical University of Innsbruck, Austria; <sup>8</sup>Department of Dentomaxillofacial Radiology, Dental School, Istanbul Okan University, Istanbul, Turkey; <sup>9</sup>The National Behçet's Syndrome Centre of Excellence, Royal London Hospital, Whitechapel, London, UK.

Federica Di Cianni, MD  
Diana Marinello  
Andreas Altenburg, MD  
Umit Karacayli, MD  
Giacomo Emmi, MD, PhD  
Michael Schirmer, MD  
Gonca Mumcu, Dt, PhD  
Farida Fortune, PhD  
Rosaria Talarico, MD, PhD

Please address correspondence to:

Dr. Rosaria Talarico  
Rheumatology Unit,  
Azienda Ospedaliero Universitaria Pisana,  
Via Roma 67, 56126 Pisa, Italy.  
E-mail: sara.talarico76@gmail.com

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## ABSTRACT

Behçet's disease (BD) is a rare multi-systemic vasculitis that significantly impacts patients' quality of life. Effective management of BD requires a patient-centred approach that empowers individuals to actively participate in their care. This work explores the importance of patient empowerment, adherence to treatment, and patient education in BD. The impact of BD on quality of life (QOL) is significant, affecting both physical and psychological well-being. QOL measures are essential in capturing the full burden of the disease from the patient's perspective, helping guide interventions that can improve disease management. Moreover, treatment adherence remains a major challenge due to various factors, including medication complexity, fear of side effects, and patient perceptions of their health status. Empowerment strategies, including education and emotional support, are crucial to improving adherence and reducing healthcare costs. Empowering BD patients involves fostering a collaborative relationship between healthcare providers and patients, promoting shared decision-making and enhancing patients' knowledge and skills to manage their condition. Patient education plays a crucial role in empowering patients by providing them with accurate information about the disease, treatment options, and self-management strategies. The International Society of Behçet's Disease Working Group on Patient Empowerment, Adherence

to Therapy, and Patient Education aims to address these issues by developing global strategies to empower BD patients, caregivers and healthcare providers. This initiative promotes collaboration across the BD community, ultimately leading to better patient outcomes and serving as a model for similar efforts in other disease areas.

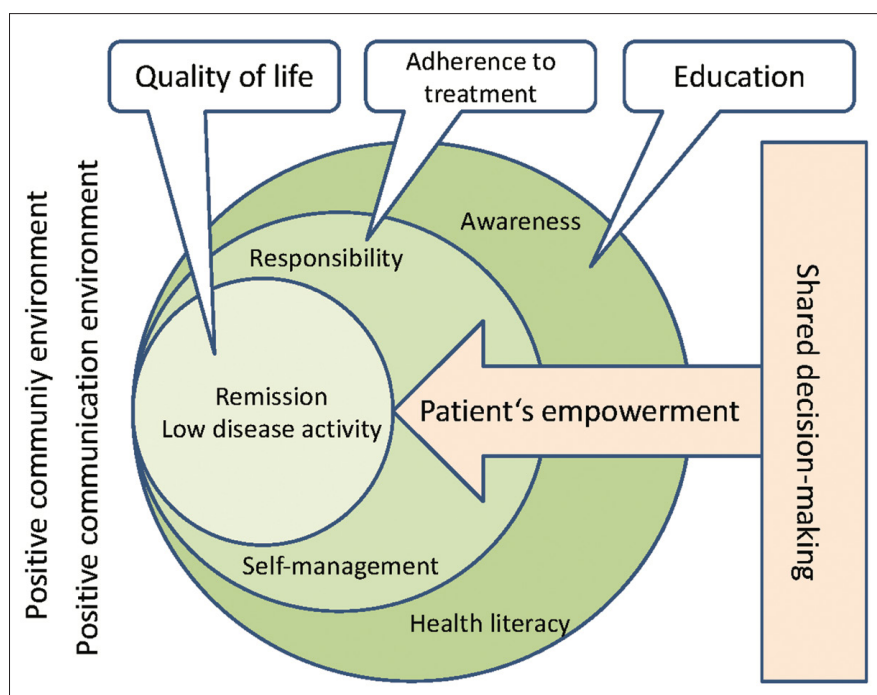
## Introduction

Behçet's disease (BD) is a rare multi-systemic vasculitis characterised by a relapsing-remitting course. Oral and genital aphthosis are the clinical hallmarks of the disease, but the major causes of mortality result from vascular and neurological involvement (1, 2). The burden of disease is typically higher in the early years post-onset, while disease activity decreases over time. One of the peculiarities of BD is that clinical manifestations vary in prevalence and severity according to ethnicity, gender, and age at onset (3). Additionally, patients may present with different overlapping manifestations throughout the course of the disease, resulting in a heterogeneous clinical spectrum within a single patient's history and among different patients (4). Such epidemiological and clinical features, along with the rarity of the condition, make the management of BD particularly challenging for clinicians. Furthermore, the chronic nature of the disease negatively impacts on patient's daily activities and psychological status (5). In this context, the participation of BD patients in the decision-making

process is essential to ensure a stable control of disease, and empowerment is increasingly recognised as a crucial aspect of healthcare. The purpose of the present work is to provide a perspective on the variables and the benefits of a patient-oriented approach in BD healthcare process. This approach is designed to fully address patient's need for effective empowerment and its main dimensions (Fig. 1), with the ultimate goals of improving quality of life, enhancing treatment adherence, and increasing satisfaction from a personal, relational, and professional point of view.

### Patient empowerment

In contrast to the provider-centric model of the past, the current patient-oriented model of care has been recently introduced for chronic rheumatic and non-rheumatic conditions (6-8). Empowerment is referred to as “the process through which people gain confidence and power over decisions and actions affecting their own health” (9). Although a precise definition of empowerment is still lacking, the World Health Organization (WHO) has described empowerment as a “prerequisite for health”, and defined four key components of the empowerment process: participation, knowledge, skills, and the creation of a facilitating environment (10, 11). Facilitating environment implies that clinicians should be able to listen to and understand patients' concerns and needs, fostering the creation of a partnership in the healthcare plan, with equally shared responsibilities between the parts (12). Moreover, the communication between health professionals (HPs) and patients has progressively evolved into an open dialogue, thus patients are no longer regarded as passive recipients of information but rather as active participants in the decision-making process (7). An interactive communication between patients and HPs may contribute to co-identify the unmet needs in illness management and facilitate shared decision-making on necessary interventions and medications, based on an accurate risk/benefit assessment. A positive communication environment was found to be



**Fig. 1.** Main aspects of patients' empowerment from the patients' (green), physicians' (red) and community's perspectives.

related to patients' active participation during consultations, resulting in better understanding of their condition, higher self-management ability, higher compliance levels and, finally, better disease outcomes (13-15). Moreover, it should be highlighted that the HP involved in the patient empowerment process include not only physicians, but also nurses, psychologists, occupational therapists, and other healthcare workers. For example, mental health support at the Behçet's Centre of Excellence played a critical role in patient empowerment in COVID-19 pandemic (16).

The concept of empowerment includes two dimensions: individual patient's empowerment and community empowerment. The former involves the process which creates the opportunities for the patients to exert control over their lives through participation in the care decision-making process and contributing to the care organisation with their personal experience. The latter involves a process based on interactions initiated by organisations, such as patients' associations and their representatives, aimed at collectively defining goals and effecting changes within a broader social system. For empow-

erment processes to be effective, they should address both the individual and the community levels (14).

### Patient education

The empowerment process cannot be separated from education and health literacy. The concept of patient education (PE) is very rapidly evolving to a much wider concept that changed from a passive model, where the patients “receive” information on how to better manage their disease, to a more dynamic and interactive process, in which patients and HPs learn from each other. On one side, patients learn new knowledge on the disease and develop new skills that enable them to actively participate in the care decision-making process and manage their condition more effectively. On the other hand, HPs gain insights into the impact that the disease has on the patient's actual daily life, in order to provide the patient with a personalised holistic care pathway. In fact, the change in education prospective can have a tangible impact on both the patient and the HP, resulting in an empowerment of both. At that point, official government and Behçet's Corporate Health web pages are essential information sources for

empowering patients with BD (16).

The agenda of the educational program includes medication compliance, techniques to overcome distress and improve coping in daily life. The program also provides educational materials about the illness, available treatment, and the location of knowledgeable clinicians. Patient educational programs should reinforce the guidance obtained from within consultations by putting the advices into a wider context. This approach helps patients to process and comprehend health information and the services necessary to make appropriate health-related decisions (11, 15, 17, 18).

However, it is crucial to ensure that BD-related educational programs are designed together with BD patients and are accessible also to caregivers and family members. The programs currently available in BD, such as BehçetTalk (19) and BehçetLab (20), were developed following this approach and confirmed the role that PE can have in promoting patient empowerment. BehçetTalk was launched in Italy in 2022 by the Behçet Clinic of Pisa and the National Association of Behçet disease and Behçet-like-Odv (SIMBA). It offers online educational webinars on different aspects of the disease. It also provides parallel support groups for patients and caregivers, coordinated by a psychologist with specific expertise in BD. BehçetLab is a hybrid laboratory combining narrative medicine and narrative psychology, which foresees interactive face-to-face workshops for patients and caregivers to share their own experiences in a process guided by experts.

This approach can be better understood by providing a tangible case of one BD patient who participated in these programs and for telling her real experience we will use a fictional name.

Eleonora, a 35-year-old mechanical engineer, has been living with BD since 2005. She is married and has been receiving care in the Behçet Clinic of Pisa since 2015, due to previous vascular involvement. Once her disease was under control, a comprehensive assessment of Eleonora's unmet needs was performed together with her and her

caregiver. This assessment led to the development of a detailed educational program which included her enrolment in the BehçetTalk educational program and in the BehçetLab narrative medicine laboratory. Eleonora requested the involvement of her caregiver in the program, resulting in participation of Eleonora and her caregiver in 19 webinars provided by BehçetTalk and they also participated in the support groups organised by the psychologist. They also participated in the BehçetLab laboratory, in which two sessions were separately organised, one for the patients and one for caregivers, while a third joint plenary session was finally held with the participation of both together. After participating in the program, Eleonora reported that she perceived a lot of new knowledge about her disease, especially in the self-management and in the recognition of symptoms related to BD. She also noted that the participation of her caregiver to the programme helped tremendously also in raising his awareness of the illness and its impact on her life. During the BehçetLab laboratory, Eleonora declared that she learned numerous new coping skills through direct interaction with other BD patients, while her caregiver felt that, thanks to the Lab, for the very first time he was able to speak openly and without the fear of being judged, of his experience and challenges of living with a person with BD. Eleonora also reported that she felt more understood by those around her. From a clinical point of view, this resulted in her improved ability to self-manage her disease and symptoms. She was much more actively involved in the healthcare shared decision-making process, and her adherence to treatment improved. Ultimately, Eleonora felt the need to share her stories with other people living with BD, as she wanted other patients to experience the program and feel more empowered as she and her caregiver did.

The case of Eleonora clearly underscores the concept that patient education has important potentials in improving outcomes of care, including treatment adherence.

#### **Quality of life**

Given the chronic and recurrent natural history of the disease and the possibility of organ-threatening manifestations, BD strikingly affects patients' quality of life (QOL) (21). The global health status impairment in BD does not only concern the physical limitations in daily activities, but also the psychosocial and emotional domains. Indeed, high rates of mood disorders, anxiety, fatigue, and sleep disorders were found in BD patients in relation to a poor QOL (22-24).

In this regard, patient-reported outcome measures (PROMs), such as QOL assessment tools, are fundamental in the healthcare decision-making process since the patient perspective may capture the global impact of the illness on all health-related domains, and helps to define which interventions are needed to improve them. Patients' perspectives became a key outcome in chronic disease management. However, it must be noted that any patient's point of view is influenced by mental and emotional representations of the illness, which in turn varies according to disease severity and gender. For instance, BD patients, particularly females, seem to perceive more symptoms and negative opinions when musculoskeletal and ocular involvement are present (25, 26). On the other hand, it appears that accepting the disease and being in contact with patients' organisations may help positively influence disease perception (27). Moreover, patient's judgement on disease activity does not consistently align with their physician's assessment, as emerged from a study in a multi-centre BD cohort in which patients mostly rated disease severity higher compared to physicians, especially in case of currently active disease (28). The mental and the physical domains of SF-36 were identified as the major determinants of the discordance in disease evaluation (28). This implies that individual perspectives, rather than the mere presence of symptoms, significantly influence patients' perceptions of illness activity and severity (28).

In the past, several studies evaluated QOL in BD patients according to one particular organ-involvement. However, generic health-related QOL meas-



ures are preferable as they take into account multiple health-related domains and offer valuable insights regarding the burden of cumulative symptoms in terms of impact on QOL (29). Besides, disease-specific QOL measures should be used, in order to successfully capture the complexity of the disease influence from the patient's perspective, and to serve as reliable disease-specific outcome measures. Conversely, today non-BD-specific QOL measures are also used to assess the overall impact of the disease, despite the availability of a tool specifically designed for BD, namely the BD-QOL (21, 30).

Several authors previously adopted generic QOL tools to evaluate the influence of multiple clinical manifestations on QOL. They observed that specific organ-involvements may independently influence multiple domains of patients' well-being. Above all, articular and neurological involvement showed the highest impact on QOL, followed by muco-cutaneous and ocular lesions (29, 31-33).

Floris *et al.* assessed QOL in relation to damage accrual in a multicentre BD cohort over a 2-year follow-up period (34). They utilised the SF-36 questionnaire for this purpose. The findings revealed that damage accrual is associated with the impairment of numerous physical and, with a greater impact, of mental domains of SF-36, particularly among female patients with higher disease activity and fibromyalgia.

Recently, the influence of lifestyle and social status of BD patients on their QOL have been studied. For instance, Senusi *et al.* observed that being married and having a lower education level negatively influenced QOL in a BD cohort from the UK (33). Additionally, smoking tobacco was associated with a negative impact on QOL. The regular use of mouthwashes was reported to effectively treat oral ulcerations and improve oral health-related QOL (OHRQOL), as well as overall QOL (33, 35). Moreover, a comparative study evaluating OHRQOL in UK and Turkish BD populations revealed that the lack of tooth brushing and a lower utilisation of dental services in Turkish patients were associated with

a poorer OHRQOL (36). Notably, a retrospective study conducted at a UK Behçet Clinic indicated that the severity of oral ulcers might contribute to the degree of overall disease activity. Thus, assuming the existence of a relationship between oral health and systemic disease activity, the regular use of mouthwashes and topical therapy for oral ulcers is encouraged in BD patients, since a proper oral hygiene education and preventive strategies might hopefully minimize the recurrence of systemic disease (37). According to Decision Tree Analysis, better oral hygiene habits are considered an important component of patient empowerment strategies for BD (18).

Similarly, the oral phosphodiesterase-4 inhibitor apremilast, which has been approved for the treatment of oral ulcers in BD, showed significant improvements in the physical, mental, and physical-functioning domains of the SF-36 questionnaire (38). Such findings concerning topical and systemic treatments suggest that supporting patients with appropriate interventions and medications improve disease control, fostering the development of the skills needed to cope effectively with the disease.

Coping and self-management skills are necessary also in the work setting, as work limitations and patients' loss of productivity due to BD are important concerns for patients, significantly affecting their QOL (39, 40). A survey conducted among a cohort of British BD patients from Senusi *et al.* showed that individuals who had quit their job because of the disease burden and those claiming benefits had significantly poorer QOL compared to others (33). Similar findings were later corroborated in another survey by the same research group (32). Additionally, a multinational study showed that a small number of BD patients were unemployed due to health issues, mainly major organ involvement of disease. Accordingly, the assessment of the relationship between productivity loss, impairment in daily activities and disease burden may serve as an important outcome measure in BD (39, 41). Musculoskeletal involvement and mucosal

ulcerations were reported to negatively influence work ability and productivity of BD patients. However, major organ involvements were associated with the decrease in working hours, higher rates of unemployment and increased work-day loss (39, 41, 42).

### Adherence to treatment

The WHO defined treatment adherence as the extent to which a person, taking medication, following a diet, or executing lifestyle changes, follows agreed-upon recommendations from a health-care provider. Adherence constitutes a fundamental component of treatment effectiveness, and poses a challenging issue in chronic conditions, including rheumatic diseases, due to their complexity, commonly in addition to rarity, usually necessitating prolonged periods of multiple medications to achieve a stable disease control. Nonetheless, low adherence rates have been reported in various rheumatic diseases, ranging from 20 to 90%, resulting in a significant increase in unnecessary healthcare visits, hospitalisations, and associated costs (43-45). Factors contributing to non-adherence to treatment can be categorised as patient-related, disease-related, therapy-related and health system-related. Patient-related factors encompass gender, age, education, marital and employment status, disease knowledge, and self-management skills, while disease-related factors include disease activity, disease duration and recurrency. Treatment complexity, including frequency and route of administration, as well as medication side effects also significantly influence adherence. Lastly, health system-related factors conducive to good adherence to treatment comprise effective patient-physician communication and utilization of health services (43-46).

Since medication non-adherence is a complex phenomenon, researchers and other HPs need to select the most appropriate measurements to understand and address the underlying mechanisms of this issue. Indirect measurements such as questionnaires and self-reported assessments are commonly used to assess the lack of adherence in BD patients. Regardless of the assess-

ment tool, studies have consistently reported that the high cost of therapy, the fear of side effects or of non-effectiveness, and the high frequency of medication intake were the most common factors related to non-adherence of BD patients (43-45). Besides, lower adherence rates have been observed in BD patients with oral ulcers, especially females with mild disease, in comparison to those with ocular disease (45). Most of all, adherence is heavily influenced by the patients' subjective assessments about their health status, the disease, and the medications (27, 44). Additionally, the self-reported questionnaires used to assess patients' adherence often come along with a social desirability bias linked to the patients' fear to be judged by the HPs in case of non-adherence (47, 48). Once again, it becomes evident that addressing patient awareness and empowerment, and the psychological status related to the burden of the disease is fundamental to understand and deal with the lack of adherence to treatment. Indeed, the results of an ad-hoc questionnaire co-designed with BD patients revealed that the less-adherent BD patient profile was related to the poor perception of their health status and the shame of being affected by BD, along with other factors like being in the third decade of life and having a long history of disease (27, 49, 50).

### ISBD perspective on patient empowerment

Recognising a significant unmet need within the BD community, the International Society of Behçet's Disease (ISBD) established the ISBD Working Group on Patient Empowerment, Adherence to Therapy, and Patient Education. This initiative aims to develop global strategies that empower BD patients, caregivers, and families by enhancing their understanding of the disease and treatment options. By focusing on patient-centred healthcare, the BD community seeks to foster collaboration among healthcare professionals, researchers, patient advocates, caregivers, and policymakers. This collaborative effort will enable the BD community to equip BD patients with

the knowledge and resources needed to make informed decisions and actively participate in their care. Ultimately, the efforts of this Working Group will contribute to improved health outcomes, more efficient healthcare costs, and enhanced patient satisfaction within the global BD community, serving as a potential model for similar approaches in other disease areas.

### Conclusions

Patients' empowerment represents a multifaceted, patient-oriented approach promoted by both individual patients and the community, with the aim to further increase patients' QOL. Evidence suggests that this concept holds true also for BD, despite it is a rare disease. Among other issues, there is a definite need for extensive patients' education, focusing on both specific BD-related problems and general items like medication adherence. By performing these strategies, empowered patients would gain a deeper understanding of their health condition, become more informed about their treatment options and reduce unplanned healthcare visits related to BD.

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