

Patients and doctors group meetings: an innovative way to explore severe asthma backstage

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ABSTRACT

Severe asthma patients' life is heavily influenced by the disease, which has impact on personal and professional choices or general lifestyle. Despite the available tools to help physicians investigating the patient-reported outcomes there is a need for a more standardised and structured approach to include the evaluation of quality of life together with the emotions of patients into the routine clinical interaction. We hereby report the use of an active listening and insight approach to understand the emotions of patients with severe asthma through dedicated in-person meetings involving a group of patients with their doctors, caregivers and an external moderator. The initiative "Patients insight meeting" was organized within 17 specialist referral centres for severe asthma in Italy in 2019 and involved 149 patients. Insights related to 4 different items were collected and a task force composed by the external moderators produced a general report including the suggestions from the participating centres. This experience of group-meetings involving both patients and doctors together represents an innovative way to investigate real life experience and the emotions of asthmatic patients, highlighting unmet needs related to patient's experience of his/her disease that need to be included in severe asthmatics' management strategy.

Key words: Severe asthma; biologics; patient reported outcomes; patient's perspective; group meeting.

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Introduction

Severe asthma heavily influences many aspects of patients' life [1,2]. A number of standardized tools help physicians investigate the patient-reported outcomes (PROs) [3]. However, none of the available PROs specifically addresses the quality of life together with the emotions of patients with severe asthma, including to what extent severe asthma has affected their choices regarding personal, professional or general lifestyle. Furthermore, these considerations are rarely addressed as topics in a routine clinical interaction. An attempt has been made 30 years ago to explore - through Narrative-based Medicine (NBM) - the experiences of patients beyond the formal borders of clinical history [4-6]. NBM is essentially based on a one-to-one interaction between a physician and a patient who is requested to provide a sort of written summary of his/her history and then to read it. In this way the physician is able to get a deeper knowledge of the patient's emotions and experiences [7-9].

Despite being relevant, there is a need for a more standardised and structured approach, with standardised protocols, in order for this to be adopted and systematically contribute to standards of care. In addition, a review of the scientific literature reveals that NBM is almost completely neglected in the field of severe asthma.

We hereby report the use of an active listening and insight approach, which derives from the NBM approach with the aim to specifically address and understand the patients' personal emotions and experience of illness, but with a different methodological and analytical perspective. In fact, our approach was based on dedicated in-person meetings involving a group of severe asthma patients with their doctors, caregivers and an external moderator. Furthermore, each individual experience is analysed together with the others in an aggregate way.

Methods

The term "insight" refers to a learning process that is different from the traditional gradual associative flow: the insight suddenly restructures the cognitive field, through the discovery of new relationships within the prior knowledge and of new meaning. The insight refers to the inner motivations, because it is based on subjective internal representation of a fact/situation [10].

With regard to the methodology used, insights' analysis consists of analytical phase and synthesis phase. In the analytical phase, information and opinions coming from patients are reported in the most faithful way. Then, reports are analysed into their essential components or concept, which are stratified (tabulated) through grids. Secondly, the synthesis phase includes creation of a diagram of all insights, with relative numerical percentages and related moods; attribution of a general mood of the total insight collected; and finally, synthesis, in a synoptic view, of the most appreciated topics (TOP insight), doubts and obstacles, information gaps, and expectations.

The initiative labelled "Patients insight meeting" was a qualitative focus group organized as a collaboration project between GSK and a number of specialists working in referral centres for severe asthma in Italy in 2019. At each of the participating Centres, a meeting was arranged with severe asthmatic patients undergoing biologic treatment after obtaining their informed consent to the activity. The external moderator, a trained expert in focus group meetings, conducted the group-interview around four macro-areas, which were the same for all the different Centres, in order to have

a standardized approach. The first item investigated on the patient's journey, from symptoms onset to the "right" treatment. The second item explored to what extent severe asthma had conditioned the patients' choices in their personal, professional and general lifestyle. The third item dealt with the subjective experience with the ongoing pharmacological treatment, and with biologic therapy in particular. The fourth item asked suggestions about the contribution from a pharmaceutical company to improve, optimize or implement the response to severe asthmatic patients' needs. A task force composed by the external moderators produced a general report, including the suggestions from each one of the participating centres.

The initiative was approved by the local Ethics Committees of the participating Centres (Verona University Hospital, Florence University Hospital, Humanitas University Hospital, Ancona Hospital, Modena University Hospital, Catania University Hospital, Treviso Hospital, Naples University Hospital, Palermo University Hospital, Maugeri University Hospital, Cagliari University Hospital) and conducted according to the guidelines outlined in the Declaration of Helsinki.

Results

Overall, 17 Referral Centres participated to the initiative (5 Centres in the North of Italy, 6 in the Centre and 6 in the South), and 145 patients (90 females and 55 males; age range: 20-75) were involved. The terminology recurrently used by patients has been reported below in quotes (Figure 1).

Regarding the patient's journey towards the "right" treatment, most of the subjects (140 out of 145) reported a long and difficult route, lasting many years before reaching a Referral Centre. The way they finally met experienced specialists was mainly by chance, or thanks to personal research and through the contact with patient networks. About the second item, all the patients declared that before initiating a biologic treatment, their whole lifestyle was heavily conditioned by the disease. The "dark shadow" of severe asthma dominated their daily activities, at home, at work, with their partner, with friends. The fear of oral steroid treatment side effects and, on the other hand, the awareness of being affected by a steroid-dependent disease, represented an underlying "nightmare". Physical limitations and psychological burden represented the two sides of the same coin, their interaction generating anxiety, depression, fear, distress, loneliness, discouragement, and frustration. When asked about the personal experience with the ongoing pharmacological treatment, focusing on biologic therapy in particular, the prevalent feeling was of big gratitude and satisfaction. Although the issue was not specifically addressed, none of the patients reported drug-related adverse effects. In addition, a strong willingness to share such experience with other patients, in order to facilitate and implement the opportunity for all the severe asthmatics to be evaluated for the biologic therapies has been highlighted. The beginning of the biologic treatment was depicted by all the patients as the "dawn of a new life" without the disease-related limitations and without steroid-dependency. As far as the fourth item is concerned, all the patients suggested that pharmaceutical companies should support awareness campaigns for patients and doctors, by increasing the overall knowledge about the disease and the innovative available treatments in order to simplify and shorten the asthmatic patients' journey. Most of the subjects also asked the company to continue the scientific research in order to explore new treatments and easier formulations, but at the same time to keep securing the currently available drugs.

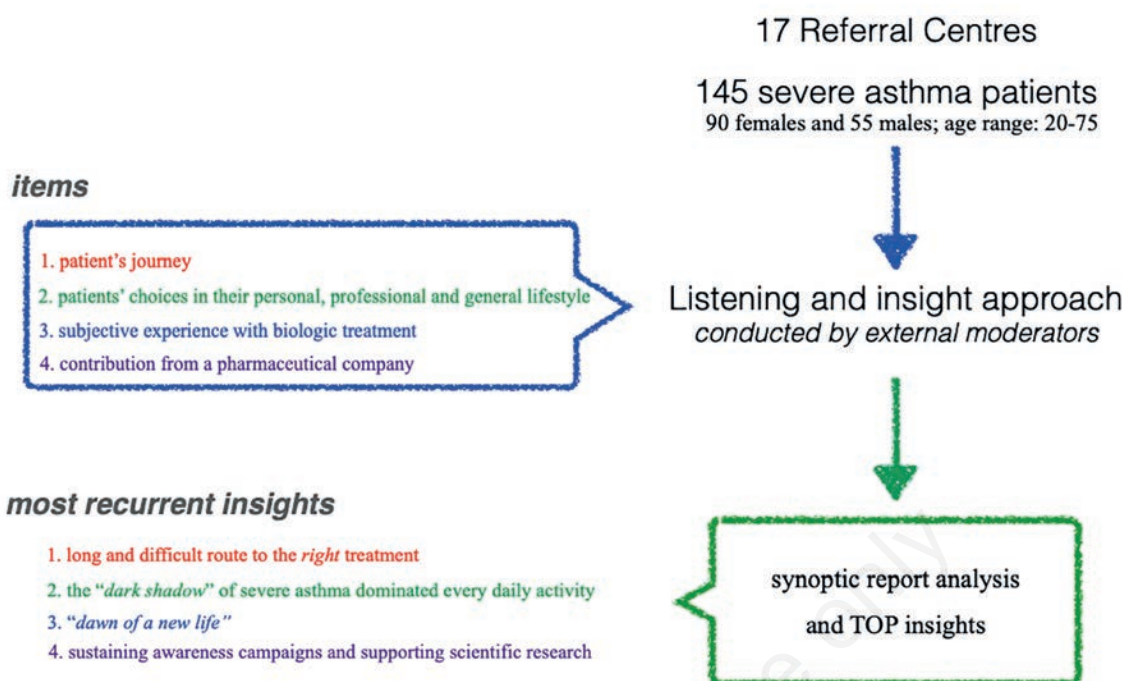


Figure 1. Overview of study methodology and main outcomes.

Discussion and Conclusion

This reported experience represents an innovative way to investigate real life experience and the emotions of asthmatic patients; in fact, to our knowledge in person group-meetings involving both patients and doctors together have never been reported so far. Despite the friendly atmosphere of each meeting and the surprising ease of communication among adult patients with a very different education and emotions, the approach is not free of bias at the moment. Standardisation is needed both in data collection and interpretation, and a systematic follow up should be planned in order for such information to contribute to individual therapeutic strategy. It is quite apparent that a number of aspects, deeply linked to the patient's experience of his/her disease and currently not specifically addressed, need to be included in severe asthmatics' management strategy, and their relevance and their contribution to the disease severity itself deserve to be taken highly into consideration. Although collecting that information and measuring its relevance in the context of the disease burden is not easy to standardise, the periodical organization of patient-physician group meeting based on the active listening and insight approach we have reported may provide an opportunity. That kind of experience may provide the background for the development of standardised PROs tools addressing more specifically than the available ones the quality of life and the emotional dimension of severe asthma patients.

Another issue suggested by the focus group meetings that needs to be prioritized is related to the patient's journey. Besides targeted drugs, representing in Italy a relatively recent treatment option, it is well known that the management of severe asthma requires a specific expertise and the availability of dedicated resources. Most of patients reported a long and difficult journey,

characterized mainly by personal research, before reaching a Referral Center. In order to limit the burden of the disease, including the treatment-induced comorbidities, and its negative impact on the overall patients' quality of life, the accessibility to the Referral Centres should be improved and implemented and much as possible. Under this perspective, the severe asthma Networks established in Italy in the last 5 years and connecting most of severe asthma clinics across the country [11,12] may increase health care professionals and patients' associations awareness, as well as facilitate the patients' referral.

Abbreviations

PROs: patient reported outcomes.

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