

“Living under the sword of Damocles”: a psychological support project for patients with immune thrombocytopenia and their caregivers

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ABSTRACT

Immune thrombocytopenia (ITP) is an autoimmune disease that causes a drop in platelet count $<100 \times 10^9/L$ and it is associated to bleeding symptoms and psychological distress. It is a non-oncological hematological disease; however, research indicate that it significantly affects patients' psychological well-being, yet psychological support is often excluded from standard care. The “Living under the Sword of Damocles” project offers support to patients and caregivers while raising awareness among healthcare providers about ITP's psychological impact. Developed by psychologists, hematologists, and patient advocates, the project provides a safe environment for discussing multiple issues and perspectives. It includes online and in-person group meetings and individual support, with the primary goal of helping participants recognize and manage ITP-related anxiety, offering new strategies to improve quality of life. Here we present the objectives of the project and the preliminary results achieved during the first year, with a psychological analysis of the three groups and possible future outcomes.

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Introduction

Immune thrombocytopenia (ITP) is a rare autoimmune disease defined by a platelet count $<100 \times 10^9/L$ without any other cause and an increased bleeding risk.^{1,2} The variety of ITP treatments enables the patient to be an active part of the therapeutic iter, as the International Guidelines themselves suggest.^{3,4} The ‘i-WISH’ survey showed that fatigue is a severe symptom that remains even after ITP remission and bleeding disappearance.⁵

The causes of this symptom are likely multifactorial: psychological stress of the onset, hospitalization, fear of bleeding or relapse and steroids may all contribute to the reported fatigue.

In other autoimmune diseases, such as psoriasis, it is known how stressogenic events can trigger the immune disease through hyper-activation of the cytokine cascade and thus of antigen-presenting cells, lymphocytes, and NK-cells.⁶ In ITP, a role of inflammation in the pathogenesis has been demonstrated; however, it is not shown whether a stressful event is the cause of the onset/relapse.⁷ Moreover, increased cytokine activity can induce depressive symptoms.⁸ It is not surprising that up to 50% of patients with autoimmune diseases present with this type of symptom.⁹ The i-WISH showed that depression do not improve in about 20% and fatigue in about 60% of ITP patients despite improvement in other symptoms.⁵ The Italian cohort of the TRAPeZe study reported anxiety related to platelet count in 53% of cases. This symptom negatively affects quality of life in 12% of patients.¹⁰

Fatigue is commonly associated with rare diseases,¹¹ and non-pharmacological approaches, such as psychological therapy, can play a role in addressing it. Indeed, ITP patients express the need for support from different sources, especially at the time of diagnosis/relapse, from not only physicians, family and friends, but from other patients, emphasizing the important role of patient associations.^{9,12}

Another important aspect concerns communication between physician and patient. The i-WISH study showed that physicians have markedly different perceptions of ITP patients' symptoms.

Specifically, fatigue is reported by physicians as a symptom in only 31% of patients, which is half the rate reported by patients themselves. Moreover, while fatigue is perceived by patients as a significant burden, physicians consider it to be a severe symptom in only 46% of cases.⁵

Robert Arnold and colleagues on the topic of “shared communication” in medicine, have demonstrated that perceptions of adverse events and care outcomes differ significantly between physicians and patients.¹³ Patients often perceive adverse events more intensely or emotionally than physicians do.

This disconnect is particularly evident in areas such as pain management and the perception of adverse events. Specifically, pain is a subjective experience, and physicians, often, may not fully understand the pain intensity experienced by the patient. Adverse events resulting from treatments are often perceived more dramatically by patients, given their direct experiences and the emotions involved, while physicians tend to view these events as temporary or unavoidable consequences, focusing primarily on the technical aspect of management.

ITP patients live constantly with “a sword of Damocles” over one’s head. This “sword” is characterized, in particular, by the presence of anxiety (e.g., about the platelet count), depression and difficulties in adapting, which have negative influences on a patient’s health and Quality of Life.

“Living under the Sword of Damocles” is a project developed in collaboration with hematologist, patient and psychologist to meet these needs. The project aims to improve the anxious-depressive symptoms of ITP patients, support patients’ caregivers, and raise awareness among hematologists about the psychological burden for their patients.

Materials and Methods

The “Living under the Sword of Damocles” project aimed at three types of users: patients with ITP, their caregivers, and physicians who treat ITP patients.

The tool of the *group* was chosen because it provides a fundamental relational space for the personal individual growth, allows their structuring in terms of personality, guarantees a sphere of meaningful relationships, and therefore, of support and care.¹⁴ Indeed, the group promotes personal individualization. It is an indispensable step, especially if one wants to address issues related to existential limitations caused by both personal behavior and the disease itself. The *group* process is considered an elective intervention that enables individuals to reach a deeper level of maturity by confronting issues related to fears of others’ reactions and judgments. Through this, they discover the infinite resource that other represents. The group process supports a greater ability to be in the world and with the world.¹⁵⁻¹⁷

The three groups meet separately online each month from January 2024 with the presence of psychologist and the patient representative. A hematologist was also present at the patients and caregivers’ meetings at the half of the meetings to answer any clinical questions regarding the disease. Project included two in-person meetings involving all participants. Sharing experiences among different groups added new point of view at participants personal journey. The groups are open, and all participants are free to attend one or more meetings.

In addition to groups, an opportunity for *psychological talk and counseling* was offered. Individual counseling is an intervention of choice for empowerment, reorganization, and coping with

non-psychiatric crises whether developmental or incidental (or the integration of both), due to one’s own disease or of a family member.¹⁸

The psychologist’s task was to guide the person to draw on his/hers own inner resources to find autonomous solutions.¹⁹ Thus, it is not to give more or less directive advice or directions, but to bring out individual potential and ideas. The psychologist acts as an auxiliary for the individual by enacting, through listening and empathy, interventions such as clarification, reflection, verbalization of affects, explanation, *etc.*, that allow the person to get in touch with the aspects of self that are a source of distress and reorganize them.²⁰

The psychologist used a holistic approach as she considers the person in the totality of body, mind, emotions and thoughts, and this fostered bodily and emotional awareness as well as cognitive and decision-making awareness as it stimulated the emergence of all resources, internal and external, available to the subject.²¹

At the beginning of the project patients and caregivers were offered the MOS 36-item short form health survey (SF-36)²² to assess their quality of life (*Appendix A*). Patients and caregivers responded anonymously to generate an assessment summary of the two groups.

As suggested by RAND, scores were assigned to each question. The higher score indicates the higher quality of life level (maximum score 3600). Emphasis was placed on questions investigating energy/fatigue (questions 23, 27, 29, 31, and a maximum score of 400) and emotional well-being (questions 24, 25, 26, 28, 30, and a maximum score of 500).²²

In addition, a second questionnaire, designed by one of the authors (LR), was administered to explore aspects related to anxiety among patients and caregivers. Patients and caregivers responded using a Likert scale with scores assigned to each response. As with the SF-36 a higher the score indicated a better quality of life (maximum score 52) (*Appendix B*).

Approximately 10 months after the baseline assessment, the two questionnaires were administered, again anonymously, to evaluate whether the group as a whole had a benefit in terms of quality of life.

Results

Regardless of the groups, we report the following benefits for the project participants:

- i. Feeling safe: relaxed and friendly atmosphere was a key element for participants to feel safe. Each participant was given an opportunity to express themselves only if willing and ready to do so.
- ii. Feeling of belonging: with time the sense of mutual trust and intimacy have created the *Wé*, which allowed participants to get in touch with their own and others’ vulnerability.
- iii. Feeling equal: the conductor was very careful to make groups boundaries respected and acted as the voice of the group, interpreting processes and providing insights at participants contributions to the benefit of the entire group.
- iv. Feeling valued: The conductor assured non-judgmental environment is created fostering mutual support, cooperation, and the sense of value of each participant.
- v. Feeling mirror: Active listening of other participants stories, acted as mirror for own personal difficulties and adopted solutions provided food for thoughts outside the group.

Patients group

Twenty patients attended the group, with an average attendance at each online meeting of 10. The median age was 52 years. The participants were predominantly women (90%); 50% of the participants were steady attendees (attendance at more than half of the meetings); 30% attended more than one meeting, but not more than half; and 20% attended only one online meeting.

Regarding the patients' group, we found the following qualitative outcomes:

- i. normalize the disease, finding a renewed balance and ability to integrate the ITP into daily life;
 - ii. a better understanding of what the disease looks like in their bodies and a significant improvement in managing anticipatory anxiety;
 - iii. feeling more supported and understood by those around them (doctors, family members, friends)
 - iv. being able to share with those who have the same experience, reducing the feeling of loneliness (independently of gender, age, ITP phase);
 - v. applying learned tools to divert daily or obsessive attention away from the platelet count and the fear of the relapses.
- With regard to individual talks, we detected:
- i. decrease of the manifestations of attack/escape response, typical of anxiety disorder;
 - ii. replacement of the reading of own ITP as a "misfortune" or "punishment" to a reading as an occurrence;
 - iii. development of ability to recognize own anxiety and how it is used to cover up certain emotions and thoughts;
 - iv. identification of inner "saboteur" and some limiting beliefs;
 - v. having given themselves an opportunity to introduce habits and "virtuous circles" that promote well-being.

Caregivers group

Eleven caregivers attended the group, with an average attendance at each online meeting of 7. The median age was 46 years. The group consisted of parents of children with ITP (64%), spouse (18%) and sons/daughters (18%); 70% of the participants were steady attendees; 30% attended more than one meeting, but not more than half.

In the caregiver group, we noted:

- i. appreciation of dedicated social space where they could find care and support that respects their emotions;
- ii. learning and sharing of new coping strategies, adopting a set of behaviors enacted to try to control and/or minimize conflicts and stressful situations;
- iii. identification of alternative forms of social support, voicing a sense of threat and instability;
- iv. learning new ways of intra-family sharing of emotional experiences related to ITP;
- v. for parents of young patients, the ability to create a network around their loved ones to have support from the outside as well (teachers, sports instructors, etc.);
- vi. for the spouses, it was crucial to confront the fatigue of the emotional regression of their ill spouse.

With regard to individual talks, was observed that for young patients' mothers it was important to:

- i. learn to be with their children and not with their illness;
- ii. face the fear of not knowing how to cope getting in touch with the need to "tame the sword";

- iii. find new strategies to cope with the social withdrawal of sick adolescents;
 - iv. share the difficulty of building social connections with other parents who do not understand the limitations and resources of ITP and exclude their children in collective/social activities;
 - v. cope with anxiety and fear of checkups and bad news.
- Also, for other caregivers during the interviews, was observed the importance of:
- i. recognizing and governing anxiety related to the ITP history;
 - ii. investigating some alternatives to dysfunctional behaviors, and thinking patterns.

Physicians group

Ten people attended the physicians' group, with an average attendance at each online meeting of 4; 30% of the participants were steady attendees; 50% attended more than one meeting, but not more than half; and 20% attended only one online meeting. The hematologists benefited only from the group experience from which it emerged the following awareness:

- i. the importance of having psychological support as they work alongside patients and their caregivers through the various stages of disease and, especially, chronicity;
- ii. recognize their own emotions and use them as a personal resource, for the teams, and patients;
- iii. share strategies for dealing with patients' anger and aggression;
- iv. optimize follow up visits for more constructive limited available time
- v. awareness to seek new approaches to guide patients to embrace the care of the entire team and not turn exclusively to the referring hematologist.

Questionnaires

At baseline, the median energy/fatigue score evaluated using SF-36 was 230 over a maximum score of 900, for patients (range 140-340) while for emotional well-being it was 350 for patients (range 160-460) and 330 for caregivers (range 160-460).

At month 10 the median energy/fatigue score was 200 for patients range (140-260) while for emotional well-being it was 360 for patients (range 280-440) and 330 for caregivers (range 280-400).

At baseline the median score, evaluated using our questionnaire was 32 over a maximum score of 52 for patients (range 27-42) and 33 for caregivers (range 27-41).

At month 10 the median score, evaluated using our questionnaire, was 34 for patients (range 25-43) and 32.5 for caregivers (range 23-44).

Discussion

In every target group, the meetings allowed for both individual and collective help. The reciprocity, exchangeability and peer-to-peer sharing have led to the therapeutic and curative outcome, and participants could create "another view" ("unaltravisione") for themselves.²³

Indeed, the group is both a complex of individualities distinct from each other and a unique "organism" that facilitates and sup-

ports processes of change and evolution. This is possible because each member of the group is simultaneously an actor in his own and others' learning process. The group leader stimulates attention to communication and the group process, focusing on the *here-and-now* and the *there-and-then*.^{24,25}

The groups, especially patients and caregivers ones, although composed of different people, had common characteristic: having sought help for a problem concerning ITP. Each member was therefore able to see reflected in all the other members a double difficulty: the personal one and in living with this difficulty, especially at the time of disease diagnosis and relapse.

Seeing that one person in the group finds a way to overcome the difficulty, spontaneously generates a chain reaction whereby every other member, in his/her own time and psychological means, finds a way to take that same step.

The counseling and psychological interviews were aimed at helping the person to find other ways of acting, other options, possibilities, ideas to overcome the critical period caused by the illness.

In-person meetings allowed an exchange of points of view between physicians and patients.

One of the approaches suggested by Arnold is the use of shared communication, which involves not only the transmission of information, but also an active dialogue in which the physician: i) listens with empathy to the patient's concerns and experiences; ii) acknowledges and validates the patient's perceptions about his or her health; and iii) involves the patient in the decision-making process, explaining treatment options in a way that is understandable and tailored to the patient's preferences.¹³

A key factor in reducing the perceived gap between physicians and patients is education and active listening. When patients feel understood and supported their perception of adverse events or negative outcomes may be less anxious or hopeless. Moreover, when physicians gain insight into how patients experience treat-

ment, they can adapt their approach to better address both the emotional and physical aspects of care.

Finally, the questionnaires were used as tools to analyze the needs of the groups, without any research purpose. Responses were collected anonymously and the questionnaire designed by LR, while not a validated test, provided useful insights. After 10 months, both the SF-36 and our questionnaire showed a stable score. The short observation period could impact the results; additionally, they are not adjusted for meeting attendance.

These preliminary data provide a foundation for designing a clinical trial to study the psycho-physical benefit of psychological support.

Conclusions

Often the emotional burden of ITP is underestimated, as it is a benign condition; however, both patients and physicians are aware of the daily challenges associated with it.

We believe that the positive feedback and enthusiasm from participants, in addition to the above analysis, provide a strong motivation to continue and expand this project (e.g., with specific training groups for physicians or teachers/trainers of children/adolescents).

Furthermore, we see the project's potential in enhancing physicians' ability to manage both their own emotions and those of their patients. Physicians' emotional well-being remains an unmet need that deserves attention. Finally, the online format of the meetings provides the opportunity to reach patients from across Italy (Figure 1). This is particularly crucial in the context of a rare disease like ITP.

Decision-making in medicine must actively involve patients, considering their perceptions, emotions and preferences. Indeed, the strength of the project lies in the close collaboration between

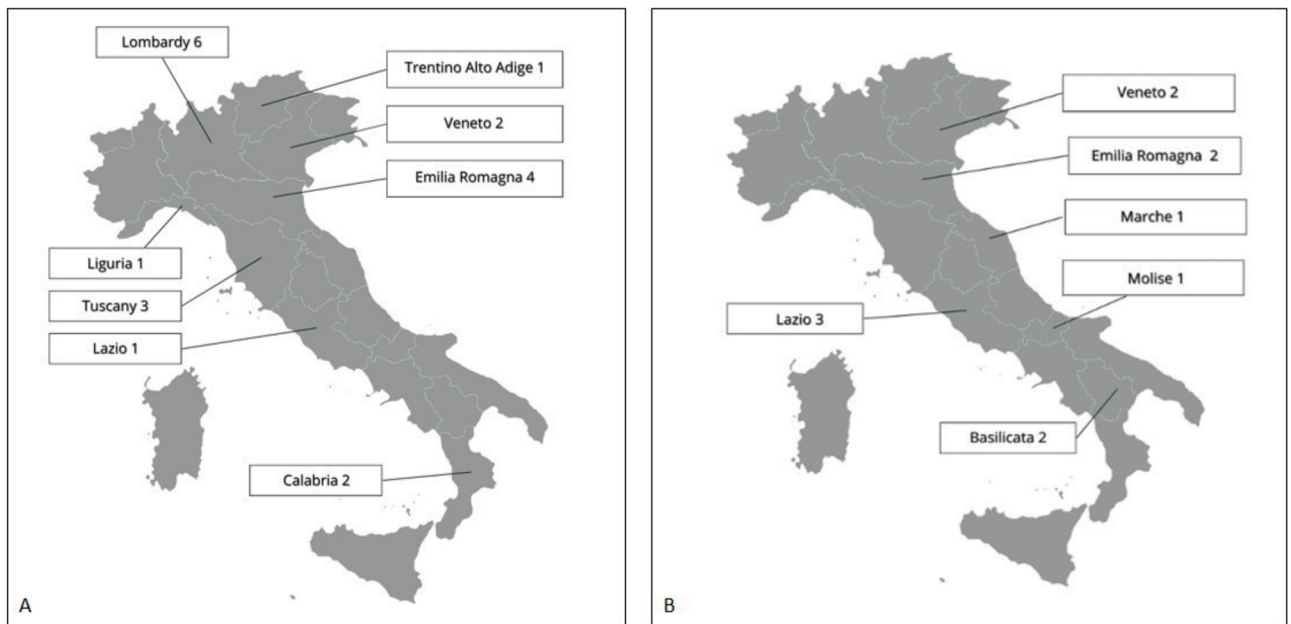


Figure 1. A) Origin of patient group participants. B) Origin of caregivers group participants.

the patients' association, physicians who treat ITP, and experts in the psychological management of chronic conditions. We believe that this model can be successfully replicated in other countries, with appropriate adjustments to account specific socio-cultural differences.

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Online supplementary material:

Appendix A. RAND 36-item health survey.

Appendix B. Anxiety self-assessment test (Italian and English).