

The Role of Patients' Associations in Educational Programs and Doctor-Patient Relationships

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The communication between physicians and patients is necessary in the decision-making process both in diagnosis and treatment in medicine. During the present Covid-19 pandemic several authors [1,2] pointed out the key role that could be played from patient Associations in providing the right information to their Associates to enhance the adhesion rate to therapies and the correct behaviours about Covid-19 infection and vaccination.

During our daily clinical practice however the educational role played from patient Associations seemed to be highly to improve through new methodologies of communication.

Starting in 2018, working in close relation with a local patients' Association on IBD in north western Italy enrolling over 1600 volunteers, we used Patients Reported Outcomes (PROs) open to free comments in the educational activity. During the development of "IBD-passport" project in 2019 [3], regular "frontal lesson meetings" held from Turin University teachers were compared to "clinical case discussions with experts" to explore whether a new method of communication could better fulfil the expectations of patients in getting informations about their diseases and raise clinical discussions from the audience. Advertising the project through personal invitation we observed a general satisfaction in the audience and a higher appreciation for the "clinical case discussions with experts", but the overall participation to meetings, held on Saturday morning to avoid a low participation rate, was only 7% of the Associates (21 out 275 advertised).

Furthermore, in September 2020 the results of the "IBD-passport" project, already published, were shared to all the Associates with explanations and in Italian language on the pages of the Association bulletin regularly posted. Only 33 Associates out of 225 Associates personally invited (14,66%) read the article. Twenty-five of them (10,22%) were also interested in participating to a new edition of the project to be held 2021 but only 17 (7%) were able to participate in video conference, since the present COVID-19 outbreak.

Moreover in 2020 a selected group of patients participating to the "IBD passport" study, highly concerned in directive roles of the Association and with a quiescent disease, were involved on the basis of the information they acquired during the meetings organized from the Association, in a survey about the use of probiotics during the quiescent phase of their diseases. The end point of the survey was to compare and discuss how different are AGA and ECCO guidelines about probiotic use in maintaining therapy in IBD. In this case the adhesion rate to the survey was higher, near 70% (9 out of 13), all of them in quiescent phase of the disease and in elderly age, but we had to consider the bias on an highly selected group of patients since we involved thirteen patients on the twenty-one already participating to "IBD passport" project.

Recently we read on the pages of an outstanding Gastroenterology Journal the Editorial on the role of patient reported experience measures (PREMs) [4] and the experience of the Italian group in Milan [5] suggesting the We-Care IBD score in the evaluation of a large

group of 1176 IBD patients. The high number of patients enrolled in the study in an area very near to the one in which we work and with a similar socio-cultural condition, surprised us since nevertheless our efforts we never reached an adhesion rate to our programs higher than 15% of Associates both in pre-COVID-19 period as during pandemic.

On our opinion it's therefore mandatory to understand how to involve an higher rate of people in educational programs, satisfying their needs to be involved in the decision-making process. The adhesion rate is in fact strictly related with the personal feelings of patients toward their illnesses, with the phase of the disease and with their involvement in the Association.

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