

# Letter to the Editor: Support Through Social Networks of e-Health in Adults with Primary Immunodeficiencies During COVID-19 Pandemic

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Dear Editor

**I**N A RECENT communication to this journal, Ahn et al. indicated how individual or organizational users differently use their Twitter<sup>®</sup> (Twitter, Inc., San Francisco, CA) accounts.<sup>1</sup> We believe that these differences may also be influenced according to the type of patient group and the circumstances of the study period.

Primary immunodeficiency disorders (PIDDs) are a wide group of diseases that are classified as rare diseases in Europe and characterized by poor or absent function in one or more components of the immune system that predisposes affected individuals to increased frequency and severity of infection. This increased vulnerability to infection may include repeated infections, infections that will not resolve, and sometimes severe or fatal infections.

At the start of the SARS-Cov-2 pandemic, recommendations by the panel of medical advisers of the Spanish Association of Primary Immune Deficits (AEDIP) were issued.<sup>2</sup> The coordination of the recently created primary immunodeficiency (PID) study group of our hospital<sup>3</sup> decided that all adult patients of the PID module were contacted at least once by telephone,<sup>4</sup> although few of them were contacted by other means (e-mail or WhatsApp<sup>®</sup> [WhatsApp Inc., Menlo Park, CA]). Of the 170 adult patients who until then had been assessed in the module, the clinical histories of 127 susceptible patients to close monitoring were evaluated. All of them were informed to follow the recommendations for confinement issued by the health authorities. Of these 127 patients, 62 patients were considered especially sensitive/critical, either due to their diagnosis of PID, mainly with immunoglobulin (Ig) deficit such as common variable immunodeficiency (CVID), specific antibody deficit, X-linked agammaglobulinemia, symptomatic selective IgA deficit, subclasses IgG deficit, or some of them with secondary ID—

not HIV—or their inconclusive diagnosis but with figures IgG <450 mg/dL.

Nine patients who continue treatment with intravenous Igs in the Daycare Hospital were given specific instructions and they were evaluated in each session. Fifty-one other patients who were (1) undergoing treatment with subcutaneous immune globulins at home or (2) with antibiotic treatment, or (3) without treatment but with an expectant attitude were provided with a direct communication media with the PID module and follow-up by phone at least every second week.

More than 100 communications through telephone were made during those first weeks. In total, 141 interactions were made through Facebook<sup>®</sup> (Facebook, Inc., Menlo Park, CA), 337 interactions through Twitter, 24 by e-mail, or 131 interactions through WhatsApp were made. During these 98 days of alarm in Spain, all planned ongoing studies were not postponed, as they could be quoted electronically. A new patient was diagnosed with CVID with a diagnosis made in record time for our usual standards. Only two patients with PID had mild symptoms that could be compatible with SARS-Cov2 infection, but were negative.

In the COVID-19 era, e-health has had a great impulse trying to avoid face-to-face assistance without having to reduce its attendance and quality.<sup>5</sup> For adult patients with PID, initial follow-up consultations during this time have been made by telephone by their usual physician. As in other rare diseases, many patients have taken years to get a correct diagnosis and have gone through multiple doctors. Thus, we considered critical to hear the voice of their regular doctor in this time of uncertainty—COVID-19. We have made our patient social networks (website, Facebook, Twitter, and WhatsApp) available to them, and a specific e-mail account was previously created.<sup>6</sup> These networks help to generate confidence from this kind of patients, who could hardly accept treatment and standards if they did not have trust in the professional group that cares for them. However, the initiatives have all come up individually by the responsible doctors. It would have been good to have a strategy at the hospital level or at the regional health service level instead of decisions by the hospital services or consultations.<sup>1</sup> In the near future, and for the next waves of this COVID-19

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pandemic, health services should have innovation units with a rapid capacity to respond to exceptional situations.

The special susceptibility of these patients and the initial lack of knowledge about COVID-19 made us take these actions before the declaration of alarm. There were some initial drawbacks (wrong phone numbers, location outside the usual territory, etc.) that made the approach somewhat complicated. One of the causes of these problems has been the existing fragmentation of the territory of our Atlantic islands, separated from the European continent and that depend on air, sea, and land means for the transport of patients and also of materials. But information through alternative information channels adequately complemented these initial doubts. The public utility of social media stands out particularly in crisis. In our small population with rare diseases such as PIDDs, those media particularly Facebook and Twitter have been of mutual help.

Now, 14 weeks later, we have opted to continue with conventional follow-ups. However, the possibility of a new wave of COVID-19 in next months, especially next autumn, makes us have new challenges to develop, such as optimizing communication channels and designing “free assistance circuits,” on different days of consultation with little influx of patients, and perhaps, create an innovative, permanent, and reliable structure for alternative communication with patients according to the standards of the 21st century.

### Disclosure Statement

No competing financial interests exist.

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