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Letter to the Editor

Long COVID: A patient perspective



Even though in this [1,2] and other journals [3–5] a number of articles described the long-term consequences of COVID-19 in patients who recovered from the acute illness, most reports mainly dealt with cases who had more severe clinical manifestations and needed hospital admission. However, relatively little information is available on the long-term state of cases attended at home during their illness. In particular, we know little pertaining not only to their current health state but also on the patterns of their post-illness living behavior and on the social and family impact. To contribute to fill these gaps of knowledge and with the background that Italy has been the first European country to be severely hit by COVID-19 with a very high morbidity and mortality (more than 130,000 fatalities), our research hospitals enlisted the collaboration of the largest Italian daily newspaper (Corriere della Sera), together with the non-profit healthcare organization Peripato. We chose as tool an online questionnaire survey promoted and released by the newspaper, of which the homepage is daily visited by an average of 819,000 people and the website by nearly 4 millions. Participation was voluntary, anonymous, free of charge and response was considered a proxy for informed consent. Access to the survey, related questions and ensuing responses was done through the web site of the newspaper but also the main social networks (Facebook, Instagram, LinkedIn). The questionnaire was developed using as models those employed in the Netherlands by Gertz et al. [6] in order to evaluate the pattern of long COVID symptoms and in the frame of the Newcastle post-COVID syndrome follow-up (www.postcovidsyndromesol.nhs.uk). The number of responders to the survey was 3125 persons who had recovered from COVID-19 and responded to multiple choice queries pertaining to their perception of the illness, its acute course and the broad consequences thereof. The main questionnaire domains were on demographics, pre-COVID health state, documentation of COVID-19 diagnosis, sites of disease management, clinical features during acute illness but mainly on the health and behavioral state at the time of the survey, that was carried out during the whole month of June 2021 through a special link and QR code after advertising it in the pages of printed and online versions of the newspaper.

The majority of responders were from the Northwestern regions of Italy, that is, those mainly and most heavily affected by COVID-19 in terms of number of cases, morbidity and mortality. The median age of responders, nearly equally split between men and women, was 60 years for those who had developed the disease confirmed by PCR in the first wave (March–May 2020), 50 years in the second (October 2020–January 2021) and 49 in the third (March–May 2021). These ages correspond to those recorded nationwide during the pandemic by the Italian Health Service. Of 3125 responders, 400 (13%) had been admitted to hospitals, but the vast majority (2725, 87%) were attended at home. The two subpopulations of hospitalized and home-treated patients were different for several features at the time of disease onset in terms of symptoms and

comorbidities. The former frequently included older, hypertensive, overweight, diabetic and cardiac cases, mainly presenting with such symptoms as high fever and severe breathlessness with chest tightness, whereas anosmia, ageusia, headache, cough and muscle pain were with fever the most reported symptoms in cases treated at home (data not shown).

Pertaining to the post COVID-19 data analyzed according to questionnaire answers, it is striking that only 38% of home-treated and 23% of hospitalized cases declared to be completely free of symptoms after recovery from their acute illness (Figure). Among the 400 hospitalized cases sustained fatigue, breathlessness and muscle weakness were the most frequent complaints (Figure), whereas among those home-treated ($n = 2725$) fatigue, breathlessness with chest tightness, anosmia and cognitive symptoms such memory and attention impairment were the most frequent (Figure). Moreover, 49% in the former and 66% in latter subgroups reported the novel onset of symptoms not present before COVID, mainly pertaining to the lung and heart but also to the gastrointestinal tract, central nervous system and mood domain, such as anxiety, depression and often both (Figure). Pertaining to the course of these symptoms, breathlessness did improve along with the lengthening of the post-COVID period, as indicated by the fact that 30% of the cases who had become ill in Spring 2020 stated to be still symptomatic in June 2021, in contrast with 49% of those who became ill in Spring 2021, i.e. closer to the June survey. On the other hand, anosmia was poorly influenced by the time elapsed since acute illness, because 25% of the responders were still suffering from it irrespective of the elapsed time. Regarding drug intake, 33% of hospitalized cases had started afresh pharmacological therapies not taken before illness (15% of those attended at home).

The behavioral questions regarding the activities of daily living and family relationships showed a post-COVID negative effect on working capacity, reported by 52% of hospitalized and 37% of non-hospitalized cases. Moreover, 20% of those hospitalized reported a deterioration of the pattern of their family life, whereas among the cases handled at home these was deterioration in 24%. Spouses, sons but also more distant relatives and neighbours were felt to be helpful and supportive during and after the illness, plus the hospital personnel at large. In the older respondents the most helpful and supportive were sons, whereas for younger patients the most supportive persons were identified among hospital personnel, spouses and neighbours.

There were differences between hospitalized and home treated cases regarding their self-evaluation of the care received during the illness. Hospital care was judged excellent, with a score of 10/10 recorded by 45% of hospitalized cases and a score between 8 and 10 by 86% of them. On the other hand, home care by general practitioners or specialized home teams was judged less favorably, the top score of 10 being awarded by only 23% of the responders, 52% of them giving scores ranging

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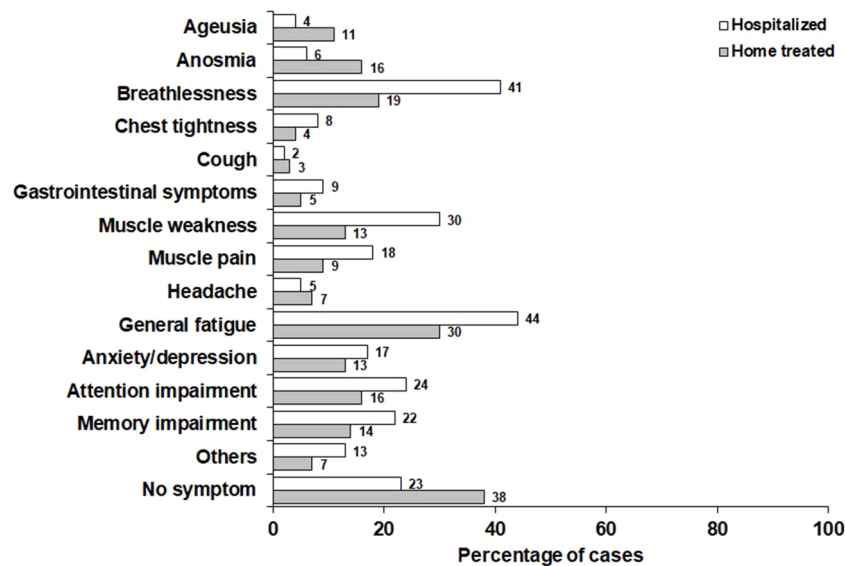


Fig. 1. Percentage rate of post-COVID symptoms at the survey time (June 2021), split by hospitalized and home treated patients.

between 8 and 10.

In conclusion, this survey on post COVID has all the inherent limitations of those based upon responses to a questionnaire. However, its value is the involvement of the first daily newspaper in Italy, that contributed by means of its widespread distribution to acquire directly from the affected people knowledge on the open issue of long COVID. This experiment of collaboration was successful if one considers the large number of responses, the quality of questionnaire answers as well as the fact that the general features of the case sample indicate that it is representative of the pandemic situation in the country, thereby providing a real life snapshot of the post-COVID picture. Moreover, we managed to enlist responses from a large segment of the population of ill cases handled at home, that would otherwise be of difficult reach in terms of high numbers and real-life representation. Finally, this report witnesses the unusual collaboration between two research hospitals and a daily newspaper, who accepted to run with us this survey (Fig. 1).

Conflict of interest

The authors declare no conflicts of interest.

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