

## Analyzing patient stories to better understand Long-COVID; learning from those who have gone the road before

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*Do you know, [name national expert], what it feels like to not being taken seriously, especially when you don't have the strength to talk back, people at their most vulnerable are not being taken seriously only because you cannot explain what **is** the matter with them, because you cannot explain the suffering of all those people like me who are lying in bed angry and frustrated? Who are angry, also because science is not equipped to handle diseases such as these? [1, p.63].*

The important role patients played in gaining recognition for and knowledge about Long-COVID by sharing their experiences on little understood and long-term symptoms after an infection, is an interesting example of citizen science. The disease is still little understood by medical science. By consequence, it is argued that this citizen science effort should continue to better understand the disease in terms of medical complaints and treatments, the social aspects of living with it and the experience of being ill. Ireson et al. (2022) for example make a strong plea in this journal to recognize the vital importance of patient testimonies about the physical as well as epistemic challenges patients encounter for research into Long-COVID. In this letter we subscribe to this view and make a plea to extent this endeavor to include stories of patients who have had similar experiences in the past. Examples include experiences of patients with other little understood conditions such as ME/CFS or Q-fever or of patients using similar types of care such as physical therapy. This way we can built on and explore the existing knowledge base of patients, which can contribute to the field of Patient Sciences. In this contribution we want to explore the added value of this endeavor.

There are many patients who share stories on their experiences, for example in books or blogs [2, 3]. An important advantage of these stories is that they offer insight into the different aspects of living with a condition. Analyzing these stories is thus an important way of uncovering the experiential knowledge of patients. This knowledge can be used by other patients to learn how to live with their condition, by professionals and managers to improve their services and by

policy makers to adjust their policies to better attune to the needs and wishes of patients. These stories can also be used in education to sensitize future professionals, managers and policy makers to the importance of this additional knowledge base.

Part of this research should focus on learning about patient experiences across conditions. This can uncover knowledge about what experiences are disease-specific and what are more general lessons that can be learned from patients' experiences. In the case of new diseases like Long-COVID this has the added value of not having to begin from scratch but build on the insights from patients who have gone a similar road before them.

For example, as the research of Ireson et al. (2022) and the quote of a patient we started our contribution with show, Long-COVID patients must deal with a lack of recognition and a lot of misunderstanding. They argue that current medical science is not equipped to understand this type of disease. This argument is not new and can also be found in stories of patients with other little understood conditions such as ME/VCS and Q-fever. Their stories provide insight into the damaging effects of not being taken seriously and having to fight for the recognition of their complaints.

*There are few ME patients who confidently go to their GP when they have certain complaints. Still some doctors deny the existence of ME, as if the patient complaints are solved by ignoring the disease. [4, p.108]*

The stories of these patients who have been struggling with this situation for longer periods of time than their long-COVID counterparts, highlight the impact of having to struggle for recognition over time. They also show the struggles patients encounter in other parts of life and using different public services. This goes for example for applying for social benefits and the impact of having to quit your job and the need to explore alternatives that fit the individual person. It also goes for the focus on cognitive therapy and self-management to treat their conditions, which do, in the experience of patients, not always do justice to the daily struggles in their social lives [5].

There is much variation in the long-term complaints and the care provided between long-COVID patients. Patients who have been in the ICU might experience less misunderstanding but might need long-term recovery therapy. Also, in this case we can learn from the experiences of patients who have used these types of services before. For example, from their

stories we can learn that the rules patients are subjected to can have a suffocating effect. Limited space to attune care to what is needed according to patients themselves can cause a lot of frustration.

*I could, had to even, say in the six-weekly meeting what I wanted to accomplish the next week, but I especially remembered that a lot was not possible. I wanted to swim twice a week instead of once. Was not allowed. I wanted more therapy, could not happen. It was too expensive, I was not eligible for one reason or the other, there was no point to this or that. [6]p.110)*

From the stories of patients using this type of care we can also learn what can be the added value of professionals who think outside the box and attune their care to what matters to the individual patient in front of them [7].

Taking the stories of patients with Long-COVID seriously is important to learn more about the disease, in terms of medical complaints and treatments, the social aspects of living with it and the experience of being ill. In this contribution we argue that in addition the stories of other patient groups are important to take on board in this research. They can provide lessons for how care and support can be improved and contribute to a strong knowledge base on patient experiences.

## References

1. Bleeker, B., *Het leven moet maar even wachten: Wat ik leerde van long covid*. 2022, Amsterdam/Antwerpen: Uitgeverij Atlas/ Contact.
2. Ireson, J., et al., *Exploring invisibility and epistemic injustice in Long Covid-A citizen science qualitative analysis of patient stories from an online Covid community*. Health Expect, 2022.
3. Van de Bovenkamp, H.M., C. Platenkamp, and R. Bal, *Understanding patient experiences: The powerful source of written patient stories*. Health Expectations, 2020. **23**: p. 717–718.
4. Schonckert, M., *Meer dan moe. Een andere visie op ME/CVS*. 2006, Antwerpen/ Amsterdam: Uitgeverij Houtekiet.
5. Risør, M.B. and K. Lillevoll, *Caught up in Care: Crafting Moral Subjects of Chronic Fatigue*. Medical Anthropology, 2021. **40**(5): p. 432-445.
6. Mújde, F., *Niemand weet meer waar ik vandaan kom (sinds ik in een rolstoel zit)*. 2016, Amsterdam: Jurgen Maas.
7. Platenkamp, C. *Opknappen of afknappen: leren van revalideren en revalidanten 2020*; Available from: <https://www.patiëntervaringsverhalen.nl/collectie/opknappen-of-afknappen-leren-van-revalideren-en-revalidanten/>.