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People With COVID-19 Unite to Document Recovery

Four key findings mined from patient-led research by the Body Politic COVID-19 Support Group

May 14, 2020 By Trent Straube

When several leaders of the queer feminist collective Body Politic contracted COVID-19 in March—including founder and editor-in-chief Fiona Lowenstein, who was hospitalized for breathing trouble—they quickly realized that both knowledge and community around this disease were lacking. So they created the Body Politic COVID-19 Support Group. The support network is hosted on the online communications platform Slack and has over 4,000 members.

On May 11, the group published a report titled What Does COVID-19 Recovery Actually Look Like? An Analysis of the Prolonged COVID-19 Symptoms Survey by Patient-Led Research Team. The findings were based on survey responses from 640 people, and the report was created by volunteers from the support group. (One of the authors is well-known HIV advocate JD Davids. In fact, the empowering “take charge of your own health” narrative behind this report should sound familiar to anyone versed in HIV history.)

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It’s been said that coronavirus does not discriminate. And while it’s true that there is no age, race, amount of money, or level of “health” that can guarantee you won’t become infected, these are still determining factors in many ways. Social distancing is possible and easier for the wealthy. BIPOC communities are being disproportionately affected by this virus - 70% of people killed by COVID-19 in Chicago have been Black. Medical bias exists, has existed, and will continue to affect treatment of PoC, LGBTQ+ populations, women, plus sized and fat folks, and those with disabilities. Don’t even get me started on how access to medical insurance will affect people’s ability to be treated for, and recover from this illness. It’s worth noting that my story went viral in part because it scared people in my demographic who may have previously felt invincible - the young, certainly, but also white people, “healthy” people, thin people, and other groups that benefit from certain privileges. I’ve said this numerous times but I’ll say it again: individual action and responsibility shouldn’t be dependent on the realization that you yourself could become infected or die. We should act first and foremost to help our most vulnerable communities. I am very glad my story changed some minds and provoked action, but also aware that in many ways that is due to the way I look, and the fact that I’m wearing a “Yale” sweatshirt in some of my photos.

A post shared by Fiona Lowenstein (@fi_lowenstein) on Apr 9, 2020 at 1:47pm PDT

While most of the medical and media focus of recent months remains on critical COVID-19 cases, the Body Politic report underscores the fact that many people with the illness experience prolonged symptoms ranging from mild to moderate.

According to an executive summary of the report, four key findings from their data include:

- Symptoms are not limited to cough, fever and shortness of breath: Other widely reported symptoms span neurological, gastrointestinal, cardiovascular, and other systems and include fatigue (reported by 81.3% of respondents), chills/sweats (75.9%), body aches (73.9%), headache (72.2%), brain fog and concentration issues (68.6%), gastrointestinal issues (66.9%), trouble sleeping (66.1%), and dizziness (60.6%). An elevated temperature under 100.1°F was reported by 72.2% of respondents while a fever over 100.1°F was reported by only 47.8% of respondents.

- Recovery is volatile, includes relapses, and can take six or more weeks: At the time respondents took the survey, 90.6% reported not being recovered and were, on average, on day 40 of experiencing symptoms. 89% of respondents said that their symptoms fluctuated in intensity and frequency, and 70% reported new symptoms appearing at different stages of their illness. Based on textual responses and anecdotes from the support group, patients may feel better for days or weeks only to relapse into old or new symptoms soon after.

- Early testing is crucial, and questions remain around test accuracy: Despite all respondents showing COVID-19 symptoms, 47.8% were either denied testing or not tested for another reason. The main difference between respondents who tested positive and those who tested negative was how early in their illness they were tested (on average day 10 for those testing positive, and day 16 for those testing negative). Furthermore, the only difference in symptoms between these groups is that those who tested positive reported loss of smell and loss of taste more often, even when controlling for testing time. This could indicate that current tests are not picking up on a subset of COVID-19 patients, and further investigation into whether tests are accurately capturing the presence of the virus is encouraged.

- Stigma and lack of understanding compromise access to health care and quality of support: 50% of respondents felt only somewhat supported by medical staff, and many respondents reported receiving conflicting advice from different health care professionals on testing eligibility, symptom severity, and when to cease self-isolation. Furthermore, patients experienced a wide range of social stigmas. Both systemic and internalized stigma impact patients’ ability and willingness to seek care, self-isolate, and recover with adequate medical and social support

“While we acknowledge that this analysis pertains to a biased sample of patients with higher recovery times than typically reported,” the authors write, “we hope the report will inform public health professionals, inspire future research, and give family, friends, employers, and the general public deeper insight into the range of experiences of people living with COVID-19.”

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Thank you @glaad and @vonkenny for this profile! Link in bio to read more on @rabbisabbi and my experiences and how @wearebodypolitic is shifting to support COVIID-19 survivors.

A post shared by Fiona Lowenstein (@fi_lowenstein) on Apr 15, 2020 at 9:41am PDT

Body Politic launched in 2018, with a goal to “change the face of wellness, and create programming that acknowledged the intersections of wellness, politics and personal identity [and] to redefine connection in an increasingly isolated age,” wrote founder and editor Lowenstein and creative director Sabrina Bleich in a letter to the community on WeAreBodyPolitic.com. “We believe the most important wellness practice is the practice of tapping into and building community—especially for those of us who live in marginalized bodies.”

Lowenstein penned two pieces for the New York Times opinion page about her experiences with COVID-19: “We Need to Talk About What Coronavirus Recoveries Look Like” and “I’m 26. Coronavirus Sent Me to the Hospital.”

And Clare Kenny, the director of youth engagement at LGBTQ media advocacy group GLAAD, interviewed both Lowenstein and Bleich (who happens to be Kenny’s girlfriend). For that story, read “Two Queer Millennials With COVID-19 Speak Out on Their Experiences.”

In related news, keep in mind that novel coronavirus guidance and concerns for unique populations may vary. For example, see “3 Reasons COVID-19 Poses a Higher Risk for the LGBTQ Population,” “UPDATED: What People With Liver Disease Need to Know About the New Coronavirus” and similar articles regarding people with HIV and people with cancer.
