**Title:**

Physical well-being and burden of care in adults on modulator therapy: A mixed methods study of patient-reported experiences from the Well-ME survey

**Lay Title:**

Understanding Changes in Physical Health and Care of People with CF on Modulator Therapy

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**What was your research question?**

This analysis was designed to better understand how adults with CF on modulator therapy feel their health and care needs have changed since starting modulator therapy. We considered different aspects of physical well-being and care burden to see what improved, what worsened and what different groups might have in common.

**Why is this important?**

While clinical trials and related studies have reported on improvements in lung function, sweat chloride and exacerbations, this research helps us understanding the role modulators play in how people feel and are able to engage in their daily lives outside of these areas. We hope this research can help direct research priorities and improve care for people with underdiagnosed or previously unrecognized symptoms.

**What did you do?**

We used data from the Well-ME study to look at how people with CF feel their health has changed since starting modulator therapy. Individuals were asked to report improvement or worsening across a variety of symptoms ranging from lung health to fatigue and gut health. We also asked individuals to report any improvements or worsening in care delivery such as time spent on treatments, number of medications taken, and time spent in the hospital (among others). This allowed us to look for differences in those who reported their health was poor compared to those who reported good or excellent health.

**What did you find?**

Even though most people taking the modulators elexacaftor/tezacaftor/ivacaftor or ivacaftor had improvements in physical symptoms and the time they spent on their care, a small group still feels like their health is poor. Often people in this group identify struggles with symptoms beyond lung function, such as gut or sinus issues, pain, or fatigue as not improving on modulator therapy. In addition, the group reporting poor health did not experience improvements in care delivery such as time spent on daily treatments.

**What does this mean and reasons for caution?**

There are still important research questions that need to be answered to best help all people with CF. By better understanding less common CF symptoms that have a large impact on some people’s lives, we can better address them and support a better quality of life for all people with CF.

**What’s next?**

The results of this study can serve as a reminder that symptoms beyond the lung can and do play a large role in the overall health of a person. By considering all aspects of physical health, it may be possible to improve well-being for all people with CF.

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