Introducing ‘energy limiting conditions’: the emergence and evolution of a new impairment concept

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In this paper we say that the terms Energy-Limiting Conditions (ELC) and energy impairment are a helpful way for some people with chronic illness to describe how their conditions or impairments affect them. We describe how people with chronic illness chose these terms when they took part in a research project, the Chronic Illness Inclusion Project (CIIP). We understand that some disabled people don’t want impairment labels, so we explain why people with chronic illness felt these terms were important and useful when asking for adjustments and support. We do this by exploring ideas about chronic illness and impairment in Disability Studies and society.

The CIIP research project had two parts. One was a focus group for 20 people with different chronic illnesses. They connected with each other online over eight weeks. They answered researchers’ questions and talked to each other about what they had in common and what changes could improve their lives. The second part was an online survey of over 2,000 people. This research was inspired by the social model of disability - disabled people coming together to identify and overcome socially created barriers. CIIP researchers and the authors of this article all live with chronic illness and are disabled themselves.

Some disability scholars and activists think that disabled people shouldn’t talk publicly about how chronic illness or impairment affects us. Instead, we should concentrate on challenging how society creates disability through barriers that exclude people with impairments. But people with chronic illness have said we need to talk about the experience of our bodies, otherwise people don’t understand the barriers we face and won’t support us.

This is why we first explore other research about fatigue and chronic illness. We know that fatigue affects many disabled people. But fatigue is a problem for scientists and doctors because they can’t see or measure it easily in our bodies, so they often dismiss or ignore it. This problem affects us beyond the healthcare system. For example, the UK government’s Work Capability Assessment also ignores the effects of fatigue. This means people with chronic illness struggle to prove they are disabled or need support and can’t get benefits. It also means that we get left out of plans and policies to improve our lives because the government doesn’t understand or accept fatigue as a type of disability.

In the focus group, participants said that fatigue is the worst of all their symptoms because it stops them doing everyday tasks. Fatigue from chronic illness limits both physical activity, and mental activity. But many people don’t think fatigue is a real disability because they think it is the same as everyday tiredness that affects everyone. Because of this, participants often didn’t know if they were allowed to say that they are

disabled. They were fearful of how other people might respond if they ask for help or support, because sometimes other people think they are lying about their disability. They said being disbelieved makes you feel bad and lose confidence in yourself. Some participants said it's so hard to ask for support and adjustments that it stops them going out or joining in with things.

We think this shows how people with chronic illness are disabled by society. But the barrier we face is other people's disbelief, because if people don't believe us they won't support us.

The survey we created after the focus group showed that these experiences and feelings were shared by many other people with chronic illness.

Participants did not like the word 'fatigue' because other people don't think it's serious or real. So they wanted a better word or label that helps other people understand their experience. It was difficult to find a word or phrase that describes everyone's experience. But out of the options we gave, most people preferred 'energy-limiting chronic illness' (ELCI) and 'energy impairment'. The change from ELCI to ELC happened after the research, because many disabled people found it more inclusive.

Participants wanted the CIIP to continue so they could have a voice and advocate for the inclusion of people with ELC in society and in the government's plans. We are asking that policy makers, researchers and Disabled People's Organisations include ELC in their work on disability.

The terms ELC and energy impairment have many implications.

Implications for Disability Studies. We believe that having a label to describe our impairments is important when it reflects our lived experience and helps other people understand our needs. By coming together to choose our own language of impairment, the CIIP helped to challenge the barrier of disbelief.

The CIIP followed a main principle of the social model of disability, that is "Nothing About Us Without Us". This is important because some people with chronic illness think the social model doesn't work for them and feel excluded by it. The CIIP shows that we can be disabled by society as well as by our bodies. And we can fight for social change as well as better medical treatment.

Implications for Policy and Practice: people with chronic illness are often left out of plans for supporting disabled people. We think this is partly because fatigue isn't seen as a real disability. But the government's own research shows that 1 in every 3 disabled people has an ELC. So we should be listened to and included in all plans relating to disability, for example around benefits and work.

The CIIP research happened in 2018. It was led by researchers who live with chronic illness and were not based in universities: Catherine Hale, Jenny Lyus and Stef Benstead. The CIIP was part of the DRILL programme of research by, and for, disabled

people. It was funded by the National Lottery Community Fund. It was hosted by the Centre for Welfare Reform.

This article discusses one part of the CIIP research: the reasons why participants chose the terms ELC and energy impairment. The full report about the CIIP is at: https://osf.io/preprints/osf/xwjuh_v1
and the Easy Read version is at: https://citizen-network.org/library/energy-impairment-easy-read.html