



PATIENT EMPOWERMENT

Recognising lived experience is essential to empowering disabled patients

Peer networks are essential to support people with disability to live happy, autonomous lives, writes
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Disability is not rare: 15% of the world's population—more than a billion people—are affected by disability, according to the World Health Organization.¹

I have been researching, campaigning about, and living with disability for my whole life. A person who is born blind, develops autism or schizophrenia in youth, or becomes paralysed in mid-life probably experiences that difference evermore. They get to know their difference and what difference it makes to other people, and encounter barriers and discrimination in daily life. They become “experts by experience” and often activists for a world in which they fit better.

Disability usually presents a continuous series of small hurdles, whether bodily or social in nature. Disability is “adversity inoculation,” as psychologists put it. Day by day, we have to surmount difficulties, whether it is falling out of your wheelchair, dropping something, finding your way, or persuading someone to provide you with what you need.

Adversity makes you strong

Adversity is a bore. It grinds you down. But the experience of surmounting difficulties, and of succeeding against the odds, can be powerful.² It shows what you can achieve and can make you strong. Of course, in some cases, a person can be defeated: the difficulties are too great, the environment too hostile, the impairment too extensive. But people can survive and thrive—and report a high quality of life.³

Patient empowerment can have a powerful effect on this experience of disability. Here I am talking in the broadest sense, about feeling good about yourself and having control over your life. Empowerment works best in groups. Coming together to help each other, to be inspired by what people with disabilities can achieve, to witness each other's stories of hurdles overcome, is the best way. In-person is preferable, but even virtual groups can make a huge difference, whether through Zoom or an email discussion list.

I have seen this time and again in groups that I have belonged to—groups of people with dwarfism⁴ and groups of people with spinal cord injury.⁵ I learnt the most important lessons about daily life from other people who shared my condition, such as how to manage catheterization or how to put my wheelchair into a car. I have also seen this in groups I research with: groups of people with dementia, such as the

DEEP (Dementia Engagement and Empowerment Project) network,⁶ and people with disabilities in Africa.⁷ People feel they still have something to contribute despite a diagnosis that at first felt like a death sentence. Life goes on.

Evidence and clinical practice

This doesn't mean that doctors and other professionals are no longer needed: far from it. “Experts by training” know far more than I do about skeletal dysplasia, orthopaedics, or psychiatry. I turn to them to get answers which help me live my life with my disabilities better. They know the evidence and the clinical practice to help me manage my conditions.

My experience is always n=1. It is my experience, which makes it powerful, but also limited.

I see professionals for limited periods, maybe as little as 10 minutes. But I know whether I have a bladder infection long before the sample is tested because I know exactly how it feels. Moreover, I have a pretty good idea about how assistive technology or other fixes will work in practice. I want a partnership with my clinicians, collaborating on a better life for me and my peers.

A great doctor once said to me that she knew all about the neuromuscular genetic conditions in which she specialised. But she did not know all about the schools or welfare benefits or assistive technologies, which were of a greater importance to her patients. Living disability means living disability lifelong; it also means living every part of life with disability, in housing, education, employment, welfare, faith groups, and family life.

Empowerment is beautiful

When it comes to disability, patient empowerment can be beautiful. I notice how people sit differently after I explain to them that many of their problems are down to social barriers, not the disability itself. They leave the room differently from how they entered because of the power of this understanding of disability.⁸ But we need to make sure that support groups achieve their constructive and problem solving potential, not lapse into criticism and moaning.

In many parts of Africa and in other low and middle income countries, disability can result in children being excluded from school and in family poverty. But I have also worked with many proud, self-reliant,

and strong people with disabilities throughout the continent. They have had to rely on themselves and their networks because the state offers minimal help. Of course, we need better provision and services for everyone. But we also need to recognise that people can be successful despite disability. Nobody should be written off by their families, communities, or professionals.

People with disabilities need to access different ways of thinking, peer support groups, and that little bit of assistance to overcome their barriers. Professionals can help, by directing people towards good support groups and recognising lived expertise. The goal is for empowered individuals to lead better lives, supported by professionals.

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