



Stephanie T. Machell, PsyD

Promoting Positive Solutions

QUESTION: *I read the article in my local paper by syndicated columnist Dr. Donohue about having had polio. Who would ever be proud that they had polio? I wish it had never been published.*

Dr. Stephanie T. Machell is a psychologist in independent practice in the Greater Boston area and consultant to the International Rehabilitation Center for Polio, Spaulding-Framingham Outpatient Center, Framingham, Massachusetts. Her father was a polio survivor.

Response from Stephanie T. Machell, PsyD:

It sounds like that column brought up a lot of feelings for you. Many polio survivors do feel shame about having had polio. Polio was a shameful disease and those who had it (and their families) were often shunned, even after there was no possibility of contagion.

Those who had it as very young children often didn't understand what was happening to them or why their parents had left them sick and miserable in the care of strangers. Young children believe they cause things to happen and so might be left with a sense that they had done something very bad indeed. That polio was often not discussed when they came home added to the sense that something very shameful had happened.

There are three basic models for how we make sense out of disability. Broadly stated and with apologies to my co-columnist (who explains them in far more detail in her writings) the moral model implies that if bad things happen to us we somehow deserve them.

The medical model says that disability is a medical condition and therefore value-neutral. In both of these models being proud of having a disability makes no sense.

In the minority model, it makes complete sense. In this model, people with disabilities are part of a minority.

It is the largest minority and the only one we are all eligible to join at any time. Having a disability is part of the person's identity. In this model being proud of being disabled would be the same as being proud of being a woman, or African American, or gay – all attributes that majority culture might consider unlikely reasons for pride.

What is your model of disability? Those who had polio and couldn't pass as nondisabled were the pioneers of the disability rights movement. They struggled with society's perceptions of themselves and with the ways they had internalized those beliefs, coming to a place of recognition that part of their identity was that of being a person with a disability. Those who were able to pass never had to identify themselves as having a disability. When these "passers" developed PPS, their identity was called into question.

The "Encyclopedia of Disability" defines disability pride as follows:

Disability Pride represents a rejection of the notion that our physical, sensory, mental and cognitive differences from the non-disabled standard are wrong or bad in any way, and is a statement of our self-acceptance, dignity and pride. It is a public expression of our belief that our disabilities are a natural part of human diversity, a celebration of our heritage and culture and a validation of our experience.

Please send questions for Drs. Machell and Olkin to info@post-polio.org.



Rhoda Olkin, PhD

Can you as a polio survivor relate to this? If not, perhaps you can feel proud that you did survive polio. If you still feel only shame about having had polio, it would be helpful for you to address this in some way. Shame takes up energy that you as a polio survivor can't afford to waste.

Response from Rhoda Olkin, PhD:

I can understand not being proud of having polio – it was a random event for which one can take neither credit nor blame. But I do think it is possible to be proud of being a polio survivor.

There are many possible psychological and emotional responses to having a disability such as polio. One can be depressed, angry, blaming and bitter, or determined, persevering, optimistic, even grateful. And these responses are not random events, but daily choices one makes over and over, in all the little things we do.

If life had shown me a menu of health options and offered me an array of choices, I don't imagine that I (or anyone) would choose polio over not-polio. But none of us get that menu. We only get to decide how to live with the menu item given to us.

Polio brings with it a lot of baggage. There is the diminishment of mobility that many of us experience, the attitudes of other people, the inaccessibility of many public arenas, the fatigue that limits activities, the aches and pains and swelling and so on.

Again, I wasn't given a menu from which to choose. And do those things sometimes get me down? Absolutely! But all any of us can do is take what we are handed, and make the best of it. And if we do make the best of it, that is something of which we can be proud.

I don't mean to imply that polio survivors have to be cheerful and peppy all the time. Making the best of it doesn't mean ignoring the real disadvantages that disability incurs. But it does mean not letting polio ruin the rest of our lives.

The same things that make everyone happy apply to polio survivors as well: family and friendships, meaning, love, purpose, nature. Some people get to pursue these goals with able bodies and excellent health. Others have to pursue these goals with disadvantages.

Be proud of how you have circumvented the disadvantages to attain your goals in life. When I hear people say they are proud of having had polio, what I hear is, "I am proud of what I have done, given the plate that was handed to me." It may not be the menu item you would have chosen, but still, you gotta eat. ▲

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.