Identification with "your" Illness

find it and go beyond!

Stark raving mad

No doubt, the organ on which any chronic illness will have the most impact is the human mind, which is a function of the brain. The mind is the self-created illusory structure from which we derive a sense of identity, a sense of "I am", which is a process of separation that happens in almost every human being early in life. In fact, this identification with "me, the separate person" could very well be considered a sort of psychosis, but it is generally accepted as being normal because the entire species seems to have fallen victim to it. It is called "the human condition", but I like to call it madness. We are all stark raving mad. Now we have this out of the way, we can start to look at "being ill". What does it mean?

"I, Patient"

In most people who suffer from a chronic illness, another layer of identity will form on top of this "normal-but-mad" identity of "being a person of some kind", giving the person the story of "me, the diseased, the (proud or sorry) patient". Mostly, the mind embraces this extra identity with a lot of attention.

This can be overcome only by realizing it has happened, sincerely wanting not to believe this story and going back to the "normal" situation of "just me". It will also happen if the entire personality-story collapses and liberation takes place. Both identities, the one of "me, the patient" and the one of "me, someone separate" will then vanish at the same stroke. But this is a rare phenomenon (sometimes called enlightenment or awakening). So, most patients can only hope to get rid of the patient-story and return to the relative normality of common human madness. That is, if they can and want to. Not all of them do.

Making the story

The patient must realize that and how the disease has created a story in his mind and how he actively and passively supports and believes in this story. And that this process of identification with the disease costs a lot of time, energy, impedes on his innate happiness and makes the disease infinitely more burdensome for him and his loved ones. Most patients will never come to this insight because first of all, it is difficult to go beyond the mind, and secondly in a way, they (that is: their minds) own and embrace every story, including and sometimes especially the disease-story. They hate the disease, but - given that it is uncurable anyway - they can't help but support the identity, specialness and the attention and distraction it provides. They start investing in the story: "I am not just some person; I am a special (sorry or proud) person because I have such-and-such disease". So some form of identification will arise from this. Often, especially in the more broad-spectrum chronic diseases like Cystic Fibrosis can be, this takes the form of "engulfment", where the patient defines his entire personality as a function of the disease. It presents for instance as reading and talking incessantly about the disease, complaining about, attracting attention and competing with the symptoms etc. Discussions are engaged with subjects such as: "Who has had the most operations", "How many organs are removed", "Which organ hurts the most", "How many scars do you have", "How do you want to be called by the non-diseased people", "How many different pills do you take", "What would my life have looked like if only I didn't have this disease" etc. Patients can take a lot of pride and/or pity in their disease, its symptoms and scars and consider themselves in war with their disease, in which victories get epic proportions and defeats are extensively mourned. A large part of their perspective on life will (mostly unknowingly to them) be dominated by their illness. All these are signs of a strong identification having taken place.

Good and bad stories

Other ways of identification with the illness are also possible. Patients can for instance more or less deny that they have the disease, which is the opposite of engulfment and will often result in bad outcomes because of a lack of adherence and worse self-management of the disease. A more preferable form of identification is "acceptance" of the disease, in which the patient acknowledges having the disease and has managed to integrate it with all the other identifications that his complex life revolves around (family, relation, work, education, profession, possession etc.). The competition between these identifications provides the patient with some feeling of (delicate) balance. Finally there can be a form of identification called "enrichment", in which the patient can mention all kinds of good things coming from the disease, like more appreciation for the beauty of life as such, gaining of wisdom and resilience and a feeling of pride about his handling of the disease. In reality, these sorts of identifications may very well happen together: a patient may feel engulfed in one symptom or side of the disease, while denying other symptoms, and having accepted or feel enriched by yet other aspects of his disease. Identifications may also shift in time from one set of symptoms to another, or in intensity.

While of course the latter forms of identification (acceptance and enrichment) are more preferable than the former (engulfment and denial), all identifications are in fact a limitation of the patients innermost and pure self, they are conceptualizations of reality as it is, take a lot of energy to maintain and can (and will) easily go wrong. An identification for instance in which the patient is proud of his fight with the disease and his accomplishments in spite of it, needs to be defended and constantly updated and balanced in view of the current state and progression of the disease. Further defeats may easily upset this balance and turn the patients pride into disappointment, denial, fear or depression. Every self-image is a burden; when it is negative it is a burden by itself, and when it is positive it is burdensome by the very fact that nothing in life is permanent and the end of all self-stories is implied with the unavoidable demise and the end of the bodily life.

Dissolving the stories

But there is no need for the patient to wait until the end of physical life; the sooner he gets rid of any identification with the disease, be it engulfment, denial, acceptance or even enrichment, the better off he is.

As soon as the patient takes a really close look at himself – which involves going beyond the mind – and realizes that any form of identification has indeed taken place, and if he sincerely wants to get rid of this, he can stop believing in the story and start acting normally again, picking up a more normal life in which the disease only plays the most minimal role possible. He will then have to face the reality that he is nothing special because of his disease, but an average (and wonderful) Jill or Joe with some extra physical requirements. After a while of practicing this, the mind will become quiet and will part with the story of "me, the patient". Then the former-patient is back to a more fulfilling and less dramatic life in which the disease is more or less absent as a story, and is reduced to the apparent plain symptoms that need to be taken care of as a matter of fact, like the body takes care of hunger, thirst and fatigue also by eating, drinking and sleeping, without our mind's "help". Even acceptance is no longer needed and enrichment does not need to be defended anymore: there is nothing to be accepted or feel enriched by; things are as they are, where nothing is lacking and nothing is in excess, without

any effort or doing by the body. In a way, both the "patient" and the "disease" have disappeared from the mind's focus and life becomes easy and natural again.

Dissolving the "I"

Under the heading of Illness Identity there are quite a lot of medical, psychological and sociological publications to be found on the problem of identification with disease in chronically ill patients, but they all focus on what kind of identification is going on, in stead of pointing to the possibility of going beyond the identifications altogether. Only when one recognizes identification with an illness as a disease in and of itself, a special variant of the "normal" human identification with "me, the person" in general, one can start to see the mechanism, as well as the escape. However, because traditional Western psychology and sociology consider this general process of identification not only as normal, but also as healthy and desirable ("one should form a so called `healthy personality', shouldn't one?"), no hope for a cure of the special disease-identification (like acceptance and enrichment) with the disease is a good thing, because it shows and improves commitment of the patient with the treatment (so called adherence and compliance) and stimulates a good doctor-patient relationship. Of course these are good things indeed, but they can happen equally well (or better) without identifications at all, because only then the patient has a clear, undistorted and healthy view of his true needs and knows what is good for his entire being, not only for the imaginary patient-part of it.

Ancient Wisdom

Sadly, this wisdom has mostly been lost in contemporary societies. One has to consult perennial philosophies like Hindu, Buddhist or early Christian philosophy to uncover this "disease of identification in general" and find the real cure: going beyond the person, the mind and the disease called thinking and identifying all together. Not many are prepared to go this journey of awakening, in fear of losing themselves. But those who are, will find themselves beyond the person/disease, lose fear and gain reality.

It's my experience that having a chronic illness is a perfect incentive to start dismantling the personality. In going beyond the illness and all its complex identifications, one has a good chance to find freedom from the entire human condition(ing) and see through the human madness once and for all.

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