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Illness as transformative experience

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Imagine that you need to decide whether to adopt a child or not. It's the only avenue to parenthood that is open to you. If you adopt a child, you will become a parent. You will experience the (currently unknown) highs and lows of being a parent. If you decide not to adopt, you will never know what being a parent is like. The decision you are asked to make is doubly risky.

This problem has been discussed recently by philosopher L.A. Paul in her book *Transformative Experience*. Paul suggests that experiences such as becoming a parent (or, more fancifully, a vampire!) are doubly transformative. First, they are epistemically transformative: you can only learn what it is like to be a parent by becoming one. There is no other way to learn what it would be like for you. You might ask other people, read parenting blogs, look after a friend's children, or work as a childcarer. However, Paul claims, none of these experiences can tell you what it will be like for you to be a parent. Of course she sets the bar for knowledge rather high, but let's set that aside for now.

Second, experiences such as becoming a parent are existentially transformative: you don't know how such an experience will change you and your preferences. People who become parents change in many ways—their values and identity often change in deep ways, and not always the ways they expected. Many people express this transformation when they say that their priorities changed completely when they became a parent. What seemed important before seems less so now; what excited little interest in the past can take on enormous value when you are a parent.

When we make a decision rationally, we base it on what we believe and what we value. My belief it is going to rain, alongside my valuing being dry more than being unencumbered by an umbrella, leads me to choose to take an umbrella when I go outside. But when you are deciding whether or not to adopt a child, you don't know how much you value that

experience now (because you don't have the knowledge of what it is like); and you don't know how much you'll value it when you become a parent (because you don't know how you will be changed by the experience). So, according to Paul, it is impossible for you to make the choice to adopt rationally.

Of course, people do make the decision to adopt, or to become parents, all the time. But what Paul's idea of transformative experience captures is how deeply life events can change us and how little we may know about particular experiences when we decide to have them. Calling an experience transformative means that having the experience will teach us something new that we could not have known otherwise, and that the experience will deeply change us.

We suggest that serious illness is a transformative experience and that Paul's framework usefully characterises central aspects of it. First, illness is epistemically transformative: it teaches the ill person what it is like to receive a diagnosis; what it is like to experience new symptoms. It teaches the ill person what it is like to cope with severe ill health and life-limiting symptoms, or to undergo medical procedures, such as general anaesthetic and surgery. It can also reveal to the ill person, if the prognosis is poor, what it is like to be confronted with one's death in an immediate and pressing manner.

In all of these ways illness is epistemically transformative. It gives us experiences that we would not otherwise have had and that we cannot know what it is like to have until we undergo them - knowledge that cannot otherwise be acquired. You might watch someone faint, or know someone who suffers from, say, chronic pain, but that would not give you the same knowledge as having these experiences yourself. For example, many health professionals who become ill say that nothing in their professional life prepared them for the experience of being patients. No matter how extensive their training or clinical experience, nothing gives them knowledge of what it is like to be patients themselves, a theme of Robert Klitzman's book, *When Doctors Become Patients*.

Of course, we engage with illness through others' experience of it, in our role as carers, say. The second- person perspective can compensate for lack of a first-person perspective. To deeply care for and mourn an ill person's losses and suffering and be intimately acquainted with their anguish, needs, and hardship can teach us much about illness. Moreover, reading accounts of illness can both edify and inform non-patients about the experience of illness,

revealing what it is like to live “at the will of the body”, as Arthur Frank puts it. But to know, fully and first-hand, what it is like to have a serious illness, to experience bodily failure, vulnerability, and anxiety about one’s body and one’s life, one needs to have the experience itself. Illness, then, is epistemically transformative.

But is illness also existentially transformative? Here, too, we answer in the affirmative. We know from literature in health economics, health psychology, and qualitative health research that people rate health states differently depending on whether they are in them or not. People with serious health conditions, ranging from paraplegia to renal failure and cancer, consistently rank their wellbeing higher than healthy controls asked to imagine what living in a particular health state would be like and to provide a ranking for that state. So sighted people think that living with blindness is worse than blind people think it is. People without diabetes think that living with diabetes is worse than people with diabetes say it actually is, and so on. This empirical evidence supports our claim that illness is doubly transformative: we don’t know what it would be like to live with a particular illness and we don’t know how we will change in the process.

People living with ill health do not average as high scores of wellbeing as healthy people, but slightly lower. This may lead us to think that ill people are not entirely unaffected by their health condition, but have learned to live with it. Although not oblivious to their losses or struggles, they nonetheless learned to live well within the confines of their illness. Around the time of diagnosis or symptom appearance people experience a substantial reduction in wellbeing, but return to slightly below baseline levels within a year or two. This adaptation explains why what seems to the outside observer like a terrible catastrophe is manageable and, moreover, something to which the person with the illness adapts. We also, therefore, suggest that this process of adaptation captures the existential transformation people undergo when they fall ill. The adaptation process takes time, during which wellbeing levels drop; but when complete, the ill person recovers her sense of wholeness and wellness, having adapted to her condition. She has been transformed by the process in ways that are surprising, informative, and potentially instructive for health professionals.

In what ways does illness transform people? We know that people experience a dramatic shift in their identity; for example, patients with cancer who recover view themselves as “survivors”. Many pathographies detail how people have changed when they emerge from an

illness episode, sometimes dramatically. The values and desires of ill people can alter. They may slow down or speed up, reconsider their career, or want to spend more time with their family; they might find new meaning in work or as a volunteer, and they may value time and simply living in the present more highly. Goals and ambitions are often updated, taking into account the limitations and opportunities brought about by illness, perhaps becoming more focused on what is still possible. Their world-view may change deeply. They may become depressed, or more religious, or happier. And, of course, they may not change at all. There is simply no telling how illness may change a person, which is precisely Paul's point.

So, how does this change our view of informed consent, risk assessment, advance directives, and other decision-making junctures in a patient's health-care journey? How do you discuss possible future outcomes for a current patient, knowing full well that she may be quite a different person by the time these outcomes unfold? How can we ask a patient to choose a course of action in the present when we know that the future patient will be transformed by their illness experience in unanticipated ways? And how do prevailing conceptions of the nature of illness affect how a person is transformed - for instance, if a suffusing ideology of "positive thinking" presents only the positively transforming effects of illness, and obscures more negative possibilities, as critics like Barbara Ehrenreich worry?

Our suggestion is that, first, we should appreciate the transformative nature of illness and introduce this element of increased uncertainty when discussing options and future scenarios with patients. Second, the notion of adaptation can be used to alleviate concerns about a life with a disability or long-term illness. We can share with patients the evidence showing that most people living with a chronic condition adapt to it and continue to live meaningful and (mostly) happy lives with it, even if they are unwilling to believe this at the time of diagnosis. Third, the notion of transformative experience can be used as a springboard for discussions about putative futures - reducing the certainty opens the door to more uncertainty, but also to the possibility of imagining a fulfilling life which is not socially scripted or the life the patient has wanted, but could nonetheless be a rich and satisfying life.

Further reading

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