
Amputating Healthy Limbs

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Should people with body identity integrity disorder be allowed to amputate a healthy limb?

Jill has two normal legs, but she wants one of them chopped off.

Otherwise, Jill (not her real name) is perfectly normal. She is 48 and a married mother of two. She is a business woman and successfully manages three city gift shops. In her spare time, she is manager of her 10-year-old's soccer team.

Jill's only complaint is her left leg. Specifically, it is her foot and shin up to exactly 4 cm below her left knee. She can draw a line around her leg at the exact point. Above that line, her leg is perfectly normal.

"Below the line," says Jill, "my leg still feels normal, but it also feels like it shouldn't be there. I know, of course, that it is there. It works perfectly well. It is just like my right leg in most ways, but it doesn't belong. It is attached to me, but it should not be."

For as long as Jill can remember, at least as far back as her early teens, she has wanted to have that section of her lower leg removed. "I just hate it being there. It makes me so unhappy."

Jill has body integrity identity disorder (BIID). People with BIID are normal individuals who have always felt that some part of them is not truly their own. Usually it is a leg, but sometimes it's an arm. They feel wrong with their unwanted limb and are usually desperate to become amputees. Occasionally, the feeling of wrongness seems to involve the whole lower body, and in those cases sufferers want to become paraplegics.

BIID is very rare, but the condition hit the headlines in 2000 when it became known that Scottish surgeon Robert Smith had twice amputated a healthy leg from two people with BIID. The surgeon's hospital banned any future operations, a member of the Scottish parliament called for a law to make such operations illegal,

and leading medical ethicists were quoted as saying these operations were obviously wrong.

"It is not that I want someone to amputate it," Jill pleads. "I need someone to amputate it. It is the only way I can truly be myself."

Is it ethically permissible for a doctor to amputate the healthy limb of someone with BIID? I will argue here that it is. If you are like almost everyone else, including me, your first reaction would have been that it is not. Stick with me and see what you think by the end.

This Is Just Crazy

Margot is another patient who wants her left leg amputated. She is also normal, or was until she became extremely depressed a month ago. Now she is so depressed that she has come to believe that her left leg is "sinister"; that it is possessed by the devil and that it wants to kill her.

No one thinks that we should amputate Margot's leg. Margot just needs her depression treated so her desire for amputation will go away.

Margot, though, is very different from Jill. Jill is upset about her leg, but she is not depressed in a medical sense. Margot's belief about her leg is a delusion – a fixed false belief due to a mental illness. Jill is not deluded. She knows that she has a leg; it is just that it doesn't feel like hers. It doesn't match her body image. She feels, and has always felt, like an amputee.

There is an obvious parallel here to gender identity disorder (GID). People with GID feel they are trapped in a body of the wrong sex. A sufferer may have been born with a man's anatomy, but will feel that she is actually a woman. Although GID was controversial when it was first recognised in the 1970s, these days it is an

accepted diagnosis, and sufferers are often offered sexual reassignment surgery so that their anatomy will match their internal view of themselves.

No one knows what causes GID and no one knows what causes BIID, but early research seems to suggest that in BIID there may be an abnormality in the area of the brain that forms our body image. We know that if this area of the brain is damaged in a stroke, people may come to believe that their leg is no longer their own.

Brain scans of some BIID sufferers suggest that they may have been born with a similar abnormality. If this ends up being true, then BIID will be better seen as a neurological disorder than a psychiatric disorder.

There Must Be Another Way

Amputating a healthy leg seems such a big step. How do we know it will even help? Surely there are alternatives.

BIID is so rare and so new that there isn't much research on it, so we don't know the answer to those questions. The research that has been done does not hold out much hope of alternatives at this stage. Sufferers have usually undergone some sort of psychotherapy, but there are no reports that psychotherapy can do more than provide some relief of the distress associated with the condition. Similarly, most sufferers have received a range of medications and so far none has been reported as providing much help.

There are no studies of the outcomes of amputation either, but here the anecdotal evidence is far more positive. The majority of BIID sufferers who have eventually had their limb removed say they have no regrets about their loss, and most say that they have never felt better. However, anecdotal reports are not the same as proper studies, and there is no way of being certain that someone like Jill would feel better if they had the amputation they wanted.

Medications and psychotherapy are reversible. Amputation is not. At this point it would be hard to argue that it would not be wise to at least try some alternative to amputation before surgery is be considered.

But what if the alternatives don't work and the person is still suffering? Shouldn't we try amputation then?

Arguments Against Amputation

There are three basic arguments against amputation when other measures have failed. None of them are very strong when examined closely.

The first is that doctors should "do no harm", and that amputating a healthy limb is obviously causing someone harm. The problem with this argument is that it involves a very narrow definition of harm. Removing a healthy limb would be causing harm in most circumstances, but this is not most circumstances.

People with BIID say that the continued presence of their limb is causing them harm in the form of mental anguish. They can also see that losing their limb will cause them some harm, but this is a price they are more than prepared to pay. Having lost their own leg, sufferers are happy to use artificial limbs to minimise the impact of the loss of their offending limb.

A second argument suggests that doctors should not be allowed to remove healthy tissue, but this argument also fails quickly on examination. There are already numerous examples where healthy tissue is removed for perceived benefit. The most obvious example is the gender reassignment surgery of GID, but there are plenty of others. Women at high risk of breast cancer regularly undergo removal of their healthy breasts or ovaries to lessen that risk and to reduce the anxiety associated with living with the risk. Living organ donors give up their healthy kidneys to benefit others.

A third argument suggests that we should not be performing this sort of surgery when we know so little about its likelihood of success. Surely we should wait until we know whether amputation is likely to help. Perhaps if we wait, something better will come along. Perhaps it will, but perhaps it won't. We just don't know.

Moreover, if no one can have it we'll never know if amputation will be helpful. Patients who request amputation should know that we cannot be sure that the operation will help, but we routinely give people experimental treatments without knowing for sure that the treatment will help. We don't withhold the new treatment. We just make sure that the person who is getting the treatment knows the risks involved and that we monitor whether it works or not.

Arguments for Amputation

Two arguments support the idea of amputation for sufferers of BIID.

The first is an argument based on autonomy. Autonomy is the notion that people should be allowed to chart their own course in life and make their own decisions so long as those decisions don't harm others. Autonomy is a strong ethical concept. It is respect for autonomy that compels doctors to seek a patient's consent prior to any operation. Respect for autonomy is behind the argument that people can refuse even life-saving procedures if that is what they want to do. Respect for autonomy alone does not compel a doctor to remove a patient's healthy limb, but it should mean that we should have excellent reasons for not helping a BIID sufferer maximise their autonomy.

The other argument in support of amputation is one of harm minimisation. Present sufferers of BIID have no clear pathway to follow to find medical assistance for their suffering. This lack of clarity means that they frequently rely on the internet for help. Some internet sites contain poor information and suggest that "at present elective surgery is not an option in the West and that true sufferers can only achieve their requirements by self-injury".

If sufferers believe that there is nothing medicine can do to help them, some will inevitably take matters into their own hands. I know several sufferers who have been driven to place their legs in dry ice in order to force their amputation. At least one person has died after a botched amputation in Central America. In modern hospitals amputations are generally safe procedures with only minimal risk.

Although we should not be offering people amputation if it is the wrong thing to do, if it is not obviously wrong then we should have good reasons for having a system that forces some sufferers to go to such extreme lengths.

Feeling What It's Like

I hope I have dismissed any initial reactions that people with BIID are crazy. I have shown that the arguments against amputation in BIID are poor and the arguments that support it, when other things have been tried, are strong.

Nonetheless, most people still find the notion

of cutting off a healthy limb hard to truly accept. I believe this non-acceptance is due mostly to our inability to empathise with the plight of the BIID sufferer. There is nothing they want more than to have their limb removed; others can imagine few things worse. No amount of rational argument can close this empathy gap and we are still left feeling "this must be wrong".

I do not think it is possible for the rest of us to truly understand what it must be like to have BIID. Our feelings about the importance of maintaining our own body integrity are just too strong. However, it may be possible to get close to approach it by trying the following thought experiment.

Imagine that you have an extra finger. Look down at your left hand now and try to imagine that the back of your left hand is a little wider, and that a second little finger protrudes from it parallel to your existing digits. Imagine that you were born with this extra finger. Imagine it works and feels just like your other fingers, and that few people ever notice it, so that it has not you caused you much embarrassment, even as child.

This is not a particularly farfetched notion. About one in 500 people are born with an extra digit.

Spend a moment now trying to imagine that you are one of those people. Try to image you have that extra finger. With a bit of effort I can almost convince myself that I can sort of feel it there.

Now imagine that although it has always been there, and although it works perfectly normally, you nonetheless do not feel it is part of you. No one else seems to notice it, but you certainly do. Every time you see it, it causes you pain, because it just feels foreign, it is not supposed to be there, and yet it is there, attached and staring up at you.

Finally, imagine that you go to a surgeon to ask her to remove it because it makes you so unhappy. Wouldn't you think that she should do that for you?

That is, I suspect, how Jill feels about her leg. I think we should probably help her out.

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