# BODY INTEGRITY IDENTITY DISORDER AND THE ETHICS OF MUTILATION

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#### Introduction

Christian theology teaches the goodness of the material world, a goodness that was declared in creation, vindicated in the resurrection, and will be fulfilled in the world's redemption. The material world includes the human body, and acceptance of the body as the gift of a good Creator, as something neither to be worshipped nor to be escaped, lies at the heart of Christian thinking about the practice of medicine. It has also grounded a critique of those technological modes of thought characteristic of the modern world that explicitly or implicitly suggest the desirability of disembodiment and celebrate the freedom of the self to live unencumbered by the fatedness of gross matter.

The critique of the technological mind-set is extremely attractive, and has rightly received much attention.<sup>1</sup> Nevertheless in its outworking in relation to modern medicine, it runs certain dangers, particularly when it treats of certain experiences, standardly treated as psychiatric disorders, in which people find themselves in some sense alienated from and in conflict with their bodies. The most obvious example of this is the experience of transsexualism, where a person finds himself or herself feeling at odds with his or her anatomical sex. The affirmation of the goodness of the body might suggest that the clinical response must be psychotherapeutic in nature, and must eschew sexual reassignment surgery.<sup>2</sup> Yet the case may not be so straightforward. I will explore this, not through a study of transsexualism, which involves broader questions of sexuality and gender, but through the much more unusual situation in which individuals desire the amputation of a healthy body part. By considering the appropriateness of a surgical remedy for psychological distress in this situation, we may be able

<sup>&</sup>lt;sup>1</sup> For an eloquent recent example, see Brian Brock, *Christian Ethics in a Technological Age* (Grand Rapids, Mi.: Eerdmans, 2010).

<sup>&</sup>lt;sup>2</sup> See for example, Oliver O'Donovan, Transsexualism: Issues and Argument (Cambridge: Grove Books, 1982).

to shed some light on the proper role of medicine in a world which, though fallen, remains good.

# The making of a new diagnostic category

Some years ago Robert Smith, a consultant surgeon at the Falkirk and District Royal Infirmary in Scotland, defied received medical wisdom by performing an above-knee amputation of the perfectly healthy leg of a man who was evidently in great psychological distress and who was convinced that he would continue in this state until his leg was removed. A couple of years later Smith carried out a similar operation on a second person, but in response to hostile newspaper reports was subsequently prevented by his NHS hospital's ethics committee from performing a third.<sup>3</sup> He reported that the patients on whom he had operated apparently felt 'incomplete' with four limbs, but believed that they would feel 'complete' if a limb was surgically removed. The results of the operations appear to have been remarkable: in both cases minimal post-operative analgesia was required, and the patients, whose lives and careers had previously been blighted by frequent depressive episodes, found themselves transformed and without any subsequent need for psychiatric treatment.<sup>4</sup>

The numbers of people who are gripped by the desire for the kind of radical surgery undertaken by Smith are exceptionally small, unsurprisingly, and until the advent of the internet were largely invisible to each other, to the medical world, and perhaps, in a sense, to themselves. Nevertheless there is now enough evidence to suggest a number of commonalities amongst them.<sup>5</sup> The most commonly desired impairment is amputation, of one or more arms, legs, fingers or toes, though some wish to be blind, others to be paraplegic, others to wear plaster casts or orthopaedic braces. Many have lived with these desires since childhood, and for some the experience is related to an early memory of seeing an amputee or a person using crutches or the like. Those in this situation will often go to exceptional lengths to fulfil their desires, not only pretending to be disabled through the use of wheelchairs or opaque contact lenses or plaster casts, but in some cases endangering their own lives in a bid to be free of unwanted limbs. To take one example, the manager of an ice works was found by the police early one morning with

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<sup>&</sup>lt;sup>3</sup> Clare Dyer, 'Surgeon Amputated Healthy Legs', *British Medical Journal* 320 (2000), 332. The patients had received psychiatric assessment, and the procedure had been discussed in advance with the ethics committee of the General Medical Council.

<sup>&</sup>lt;sup>4</sup> Robert C. Smith, 'Body Integrity Identity Disorder: The Surgeon's Perspective', in Aglaja Stirn, Aylin Thiel, Silvia Oddo (eds.), *Body Integrity Identity Disorder: Psychological, Neurobiological, Ethical and Legal Aspects* (Lengerich: Pabst Science Publishers, 2009), 41-8.

<sup>&</sup>lt;sup>5</sup> The largest surveys to date are reported in Michael B. First, 'Desire for Amputation of a Limb: Paraphilia, Psychosis, or a New Type of Identity Disorder', *Psychological Medicine* 35 (2005), 919-28 (52 participants); and Rianne M. Blom, Raoul C. Hennekam and Damiaan Denys, 'Body Integrity Identity Disorder', *PLoS ONE* 7 (4) (2012), e34702. doi:10.1371/journal.pone.0034702 (accessed 13 March, 2013) (54 participants). Valuable web resources can be found at <u>transabled.org</u> and <u>biid-info.org</u>.

his legs crushed by an Archimedean screw, but holding a walking stick which he 'happened' to have with him and with which he had switched off the machinery. Both his legs were amputated, and he returned to work a mere three weeks later, using a wheelchair and apparently a happy man. Others are reported as having resorted to immersing their legs in dry ice, using chain saws on themselves, laying their legs on railway lines, shooting themselves in the leg, refusing treatment to reattach limbs, and so on. Just as intense as the psychological suffering can be from the unresolved tension of feeling incomplete ('Can one's head explode from BIID pain?'), so can the relief and lack of regret after having had an amputation similarly be profoundly felt. There are several reports of complete resolution by surgery; and there is some evidence that this is not regretted into old age – witness the statement of one 76-year old woman who had had a leg amputated at the age of 23: 'living with an amputation is nothing compared with a lifetime of mental torment.'

This phenomenon was first brought to the attention of modern medicine by the psychologist John Money in 1977,<sup>10</sup> although evidence of someone wanting to have his leg amputated has been unearthed from the late eighteenth century.<sup>11</sup> On the basis of two case histories Money, who was primarily a sexologist, deduced a connection between a desire to have one's leg amputated and an erotic attraction towards amputees. The former he named 'apotemnophilia' (literally, 'love of amputation'), intending with this designation to categorize it as a paraphilia, an erotic obsession with becoming an amputee. As it happens, while Money was right to note the connections between amputation and sexual arousal for many of those affected, later work surveying larger numbers has suggested that the erotic aspect is not universal, and that even for those for whom it is present, in only a minority of cases is it the predominant motivation for seeking amputation.<sup>12</sup>

Other psychologists, noting that it is typically first experienced in childhood and that

<sup>&</sup>lt;sup>6</sup> Gregg M. Furth and Robert Smith, Amputee Identity Disorder: Information, Questions, Answers, and Recommendations about Self-Demand Amputation (Bloomington, Ind.: 1stBooks, 2002), 41-7; Robert Smith, 'Less Is More: Body Integrity Identity Disorder', in Stephen W. Smith and Ronan Deazley (eds.), The Legal, Medical and Cultural Regulation of the Body: Transformation and Transgression (Farnham: Ashgate, 2009), 147-57, at 148-50.

<sup>&</sup>lt;sup>7</sup> http://twitter.com/wylz/statuses/8442830218 (accessed 13 March 2013).

<sup>&</sup>lt;sup>8</sup> For a case history see Arjan W. Braam and Nicole de Boer-Kreeft, 'Case Report – The Ultimate Relief; Resolution of the Apotemnophilia Syndrome', in Stirn et al. (eds.), *Body Integrity Identity Disorder*, 70-6; and for a first-hand account, see Andrew Becker, 'Body Integrity Identity Disorder (BIID) and Me', in ibid., 103-6.

<sup>9</sup> Smith, 'Less Is More', 155.

<sup>&</sup>lt;sup>10</sup> John Money, Russell Jobaris and Gregg Furth, 'Apotemnophilia: Two Cases of Self-Demand Amputation as a Paraphilia', *Journal of Sex Research* 13 (1977), 115-25.

<sup>&</sup>lt;sup>11</sup> See Carl Elliott, Better Than Well: American Medicine Meets the American Dream (New York: Norton, 2003), 214, citing Jean-Joseph Sue, Anecdotes Historiques, Littérraires et Critiques, sur la Médicine, la Chirurgerie, et la Pharmacie (Paris: Chez La Bocher, 1785).

<sup>&</sup>lt;sup>12</sup> First, 'Desire for Amputation of a Limb'. The case for understanding it as a paraphilia continues to be argued by Anne A. Lawrence ('Parallels between Gender Identity Disorder and Body Integrity Identity Disorder: A Review and Update', in Stirn et al. (eds.), *Body Integrity Identity Disorder*, 154-72).

some sufferers report the coldness and asexuality of their upbringing, have suggested that it might be a form of attention-seeking, deriving from a desire to receive the sympathy in their identity as disabled that was lacking to them in their early years. But these have not been found widely persuasive, partly because the desire to be impaired appears in many cases to be extremely stable and largely recalcitrant to any kind of psychotherapeutic intervention, but also because people typically keep these desires secret and will frequently spend many years at home pretending in the desired body shape long before venturing out into the open. Others still have tried to understand it as a body dysmorphic disorder, a preoccupation with a particular bodily feature such as the nose, hair or skin which the person perceives as being ugly or unattractive and which causes distress or loss of self-esteem of a magnitude sufficient to demand clinical attention. But again the disparallels are substantial, amongst them that those desiring amputations rarely see the body part as ugly, and are motivated not by the desire to be more socially acceptable or attractive but by the felt need to be more personally complete or authentic.<sup>13</sup>

The seeming failure of psychological explanations and the typical absence of other psychiatric symptoms (apart from depression, which is very likely better understood as a consequence of these experiences than a cause of them) has prompted a drift towards a neurological account. On this view the disjunction between the body and the experienced body image is the result of physical damage to the part of the cerebral cortex which correlates to the conscious representation in one's mind of the shape of one's body. This part of the brain is situated in the right hemisphere, which would make some sense of the observation that there is a disproportionate desire for amputations on the left side of the body. The desire for amputation would be the inverse of the phenomenon of the phantom limb, where a person experiences a missing or severed limb as somehow still present. On this account it is taken to be the result of a developmental neurological anomaly, which creates an internal mismatch and a consequent acute sense of inner tension that requires resolution, one that is felt to be most easily addressed through removal of the affected limb.<sup>14</sup>

There may well of course be multiple aetiologies of broadly the same set of symptoms, and it may be that an approach which integrates neurological and psychological perspectives will finally prove to be more plausible. However none of these capture another feature of the phenomenon, namely its effect on the individual's sense of self. For most people the loss of a

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<sup>&</sup>lt;sup>13</sup> See further Smith, 'Less Is More', 150-2.

<sup>&</sup>lt;sup>14</sup> Paul D. McGeoch, David J. Brang and V. S. Ramachandran, 'A New Right Parietal Lobe Syndrome?', in Stirn et al. (eds.,), *Body Integrity Identity Disorder*, 225-37. Ramachandran sets this in a broader account of brain-body relations in *The Tell-Tale Brain: A Neuroscientist's Quest for What Makes Us Human* (New York: Norton, 2011), 255-8.

limb is experienced as a catastrophe, whereas for those who yearn for amputation the same event is the object of intense longing. Because they have never known a time when they experienced the limb as their own, they do not regard the losing of a limb as adventitious or disastrous, but as an integral constituent in their sense of themselves. For this reason, the psychiatrist Michael First has proposed that it be regarded as an identity disorder; noting several parallels with Gender Identity Disorder, including discomfort with the anatomical identity, the frequency of role-playing in the desired identity, and the success of surgery as a treatment in many cases, he suggests that it be designated Body Integrity Identity Disorder.<sup>15</sup>

The name has many attractions. In contrast with apotemnophilia, it suggests that it is not universally or primarily experienced as related to sexual desire. In contrast with amputee identity disorder, it indicates that amputation is not the only kind of desired impairment. As an 'identity disorder', it at least clarifies that it is not a psychosis and is not ordinarily accompanied by other psychiatric signs or symptoms. Yet it also carries its own problems. By being discussed and categorized within the disciplines of psychology, neurology and psychiatry, it also locates the problem within the body and mind of the deviant individual, and fails to ask the relation between the individual body and the social body. That is, it fails to question how the cultural context in which and by which individuals are significantly constituted itself has effects on the experienced reality of this kind of estrangement from one's body. And by adopting the language of 'identity disorder', it suggests that there is a secure psychiatric understanding of identity, of what a well-ordered identity might be, and therefore what might constitute a disordered identity.

#### The bioethical discussion: respect for autonomy

For the majority of philosophical bioethicists who have addressed the questions surrounding the moral legitimacy of a surgical response to BIID, unquestionably the central

<sup>&</sup>lt;sup>15</sup> First, 'Desire for Amputation of a Limb', 926-7. First considers here the possibility that BIID be included in future editions of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, an eventuality that is likely to be precluded more by its statistical rarity than the imprecision of the diagnostic category.

<sup>&</sup>lt;sup>16</sup> The same criticism could be made of the recently proposed 'xenomelia' (i.e. having an 'alien limb'), the repugnant sound of which is scarcely calculated to ease the sense of shame and social isolation BIID sufferers already feel.

point of concern has been that of respect for autonomy.<sup>17</sup> Of course other arguments have been canvassed. Sabine Müller, for example, employs the principlism of Tom Beauchamp and James Childress to argue a case against surgery for BIID.<sup>18</sup> On her interpretation of their principles, the principle of nonmaleficence allows an amputation to be carried out only if it is medically indicated, which is prima facie unlikely since amputation is permanent and is in response to no unambiguous medical need; the principle of beneficence requires that the benefit of the treatment outweighs the harm, but here she finds the alleged examples of patients who have benefited too few in number to be a reliable basis for surgical intervention (though she grants that this might be justified under the principle of beneficence in order to prevent potentially lethal attempts at self-mutilation); and the principle of justice would prevent public funding of elective amputations on the grounds of the costs of treatment, of lost income and tax, and the consequent financial implications for health and welfare provision.

These are all relevant considerations which would have to be taken into account in an overall assessment of the ethics of elective surgery for a person with BIID. However it is the question of whether BIID patients have autonomy which has excited most attention. Müller herself argues that they do not on the grounds that they lack substantial autonomy. Just as we would not accede to the demand for removal of the leg of a schizophrenic patient who was under the delusion that he was acting on the instruction of visiting aliens, so '[i]n all cases of BIID that have been investigated by psychiatrists, the diagnosis states that the amputation is obsessive or results from a monothematic delusion, comparable to anorexia, Capgras syndrome, or anankastic counting'. However her argument is not wholly persuasive. Of course each case must be considered individually, as in all assessments of capacity, and in every case the possibility of delusional or other psychiatric grounds for lack of capacity must be acknowledged. But the lack of correlation of BIID with other psychiatric disorders also needs to be noted. It is not clear that the desire to have a limb amputated is delusional: unlike those who suffer from

<sup>&</sup>lt;sup>17</sup> In addition to the articles by Müller and Savulescu discussed below, see for example: Annemarie Bridy, 'Confounding Extremities: Surgery at the Medico-Ethical Limits of Self-Modification', *Journal of Law, Medicine and Ethics* 32 (2004), 148-58; Tim Bayne and Neil Levy, 'Amputees by Choice: Body Integrity Identity Disorder and the Ethics of Amputation', *Journal of Applied Philosophy* 22 (2005), 75-86; the articles collected in *American Journal of Bioethics* 9, no. 1 (2009); D. Patrone, 'Disfigured Anatomies and Imperfect Analogies: Body Integrity Identity Disorder and the Supposed Right to Self-Demanded Amputation of Healthy Body Parts', *JME* 35 (2009), 541-5; and Christopher James Ryan, Tarra Shaw and Anthony W. F. Harris, 'Body Integrity Identity Disorder: Response to Patrone', *JME* 36 (2010), 189-90.

<sup>&</sup>lt;sup>18</sup> Sabine Müller, 'Body Integrity Identity Disorder (BIID) – Is the Amputation of Healthy Limbs Ethically Justified?', *American Journal of Bioethics* 9 (2009), 36-43. Cf Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, seventh edition (New York: Oxford University Press, 2013).

<sup>&</sup>lt;sup>19</sup> Müller, 'Body Integrity Identity Disorder', 40.

<sup>&</sup>lt;sup>20</sup> Michael B. First, 'Origin and Evolution of the Concept of Body Integrity Identity Disorder', in Stirn et al. (eds.), *Body Integrity Identity Disorder*, 49-57, commenting on his own interview study: 'apart from the desire for amputation this was a psychiatrically healthy sample' (53).

somatoparaphrenia, who do not recognize one of their limbs as their own and maintain that it belongs to someone else, people with BIID fully accept that the limb is theirs.<sup>21</sup> Nor is the desire necessarily clinically obsessive: at all events, obsessive desires that are of psychiatric significance need to be distinguished from mere persistent wishes, which need not as such indicate a lack of autonomy.

Even if those with BIID are otherwise psychiatrically healthy and do have substantial autonomy in at least some cases, does their autonomous desire to have an amputation create an obligation on medical professionals to supply what they demand? The case for respecting patient autonomy, even in controversial choices such as the elective amputation of healthy limbs, is made by Julian Savulescu.<sup>22</sup> Appealing to both Kant and Mill, he argues that we should respect people's autonomous decisions rather than refuse them on paternalistic grounds, even when these encompass such contentious behaviours as sado-masochism, requests for futile treatment or extreme body modification. This does not permit anybody to choose anything they like: people have an obligation to make rational choices, but those who disagree with them should seek to argue with them and encourage them to make more rational choices, rather than impose decisions on them. Thus, 'whether an individual's decision is ultimately respected (by doctors, family and friends) turns on whether that individual is competent or incompetent, not on whether the decision is rational or irrational'.<sup>23</sup> There are constraints on whether an individual's wishes should be finally decisive, but these centre on distributive justice, harm to others, and in some circumstances the public interest, not on whether others regard their choices as rational or desirable.

### The moral theological discussion: the goodness of the body

Savulescu's argument represents a liberal autonomism of a particularly pure variety, and is one that is found widely attractive in contemporary bioethics. While others may calibrate the balancing considerations slightly differently from him (interpreting harm to others or the requirements of justice in more exacting ways, for example), the principle of respect for autonomy is pivotal – and indeed is becoming increasingly pre-eminent in many interpretations of bioethical principlism.

Yet the appeal to autonomy as the central axis of an ethic of body modification faces a

<sup>&</sup>lt;sup>21</sup> Bayne and Levy, 'Amputees by Choice', 81.

<sup>&</sup>lt;sup>22</sup> Julian Savulescu, 'Autonomy, the Good Life, and Controversial Choices', in Rosamond Rhodes, Leslie P. Francis and Anita Silvers, *The Blackwell Guide to Medical Ethics* (New York: Wiley-Blackwell, 2006), 17-37.

<sup>23</sup> Ibid., 27.

fundamental problem. In relation to body integrity identity disorder, it ironically is unable to make intelligible any conception of the integrity of the body. Whether the idea of autonomy is interpreted by reference to the clinically-determined possession of capacity or in terms of one or another philosophical account of rational self-direction, it does not possess of itself the resources to enable an exploration of the question whether the body has any intrinsic intelligibility, and if so, what the moral implications of that might be. As a consequence, because of the final refusal of any constraints outside of the choosing will, constraints which this mode of thought can only construe as paternalism, the danger is constantly courted of degeneration towards a narcissistic or consumerist attitude towards the body. The body, instead of being in some sense integral with the self, is prone to becoming externalised, alienated and mobilised to serve the projects of the self. Such an understanding is incapable of capturing any sense of the goodness of the body beyond that which we contingently decide to award to it.

By contrast, in the Christian tradition the goodness of the body is declared to belong to its participation in the created order, a participation which entails that the body may never be volatilised into mere formless extension. Creation, as Oliver O'Donovan puts it, must be understood 'not merely as the raw material out of which the world as we know it is composed, but as the order and coherence *in* which it is composed'.<sup>24</sup> Creation has form and is *in*-formed: it has an intrinsic intelligibility that is in principle capable of being recognized and is not merely a projection of the active, knowing self. Creation is the gift of a good God to which human beings belong, which they are to love, and in which they are to live: the good is to be found in and through creation and its fulfilment, not in escape from it or denial of it. For O'Donovan this licences a recovery of the notion of the 'natural', which can to some extent be discerned without resort to revelation: according to this, there is point to saying that it is natural for children to be brought up by human beings and not by chimpanzees, and natural for babies to be born by natural birth rather than by Caesarean section, and natural for people to prefer pleasure to pain, health to disease, or life to death.<sup>25</sup>

This does not imply any quick or crude naturalistic ethics, nor any blithe or unhermeneutical assumptions about the body's legibility, but rather that human beings are called to recognize that the body is in-formed, and are to seek to bear witness to that in-forming in their actions and dispositions. Thus in relation to medicine, however we finally decide to intervene or operate on our bodies, we may never treat them as so much matter, mere ingredients out of which we may form whatever strange devices might emerge from our fevered

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<sup>&</sup>lt;sup>24</sup> Oliver O'Donovan, Resurrection and Moral Order: An Outline for Evangelical Ethics (Leicester: Inter-Varsity Press, 1986), 31.

<sup>&</sup>lt;sup>25</sup> Cf O'Donovan, A Conversation Waiting to Begin: The Churches and the Gay Controversy (London: SCM Press, 2009), 90.

imaginations. We may not distance ourselves from them in such a way that we are freed to exercise an unfettered *dominium* over them that pays no attention to their formed nature, but rather we are to nourish and cherish them (Eph. 5.29).

Nor does this care for our bodies or recognition of the good that they express preclude any intervention at all in them. The invocation of the category of the natural may not be taken to be a means of short-circuiting the task of moral discernment. That we may properly talk of natural birth by contrast with Caesarean sections does not imply that Caesareans are never medically appropriate. The pangs of childbirth have been greatly increased because of the first sin (Gen. 3.16), and at times they may increase to the point at which surgical delivery is medically justified. The practice of medicine (and within that, of surgery) is precisely one of the ways in which we exercise responsibility towards our bodies in a world that is still groaning for its redemption. But this gives rise to the question: how are we to discern what kinds of surgical intervention might be a sign of responsive care, and what kinds might be a sign of an untrammelled technological manipulation of the body? Must we interpret the elective amputation of a healthy limb as an implicitly docetic denial of the goodness inherent in the body? Or in a fallen world might it be a medically justified response to the facticity of a mismatched mind and body?

# The ethics of mutilation

Within the tradition of moral theology these questions have been treated under the heading of the ethics of mutilation. Taking its bearings from Thomas Aquinas's account in the *Summa Theologiae*, the discussion of the moral legitimacy of mutilation has sought to interpret the meaning of the given form of the body in the context of particular circumstances. The question we have to ask of it is whether it can furnish us with appropriate analogies which could help us with the detailed moral discernment that is required in the case of BIID.

Aquinas's investigation appears in *ST* II-ii.65.1, and forms part of his exploration of the vices of injustice and within these, of injuries to the person. He appears to have had in mind at least three different kinds of situation: the use of amputation as a punishment by a public authority, the ascetic practice of those who have made themselves eunuchs for the sake of the kingdom of heaven, and the surgical removal of gangrenous limbs in order to save a patient's life. Each of these is addressed through the application of a basic principle:

A limb is part of the whole body and it therefore exists for the sake of that whole, as the imperfect for the sake of the perfect. The individual limb must therefore be dealt with in

According to this principle, which was subsequently termed the 'principle of totality', if a particular part of the body is detrimental to the good of the whole body, then it may be removed for the sake of the body as a whole. And conversely, 'if a limb is healthy and working in accord with its natural function, it cannot be removed without detriment to the whole body'. Applied in the penal context, Aquinas argues that this implies that just a person may be deprived of their life for major crimes, so they may be deprived of a limb for lesser crimes, since the whole human being is ordained to the whole community of which they are a part. Applied in the case of the ascetic, it implies that self-castration can never be justified, since the sin which self-castration is intended to guard against is grounded in the exercise of the will, and spiritual wellbeing can be ensured without need to resort to physical means of this kind. Applied in the medical case, it indicates that an individual may legitimately consent to the amputation of a limb that may potentially poison the body as a whole, and do so without reference to anybody else, since the health of each person is the responsibility of that person.

Aquinas did not of course have BIID in mind when he composed this article. When he writes of amputation of a healthy member, he is thinking of those driven by sexual urges to compromise their chastity. By contrast those who suffer from BIID are not spiritual giants giving up all for the sake of the kingdom of heaven, but ordinary people seeking some modicum of psychological resolution. Therefore despite his injunction that 'in any other case [than those he explicitly accepts] it is quite wrong to mutilate another', 28 it would be wise not to strain his teaching beyond the natural arc of cases he might have anticipated.

In response to new circumstances since his time, there has inevitably been evolution in the tradition of moral theological reflection on the subject, and we need to investigate this to see whether it might illuminate the problem of surgical intervention in BIID cases. One major period when close attention was paid to the topic was during the middle decades of the twentieth century when novel questions were raised by techniques of organ transplantation. Much of the discussion was given over to establishing the validity of mutilation of a person for the good of a neighbour. Such operations might be needed, not only in minor cases such as would be required in the course of blood transfusion, medical experimentation, and the like, but were also used to argue for organ transplantations, so long as they were not disproportionately burdensome to the

<sup>&</sup>lt;sup>26</sup> 'Dicendum quod cum membrum aliquod sit pars totius humani corporis, est propter totum, sicut imperfectum propter perfectum. Unde disponendum est de membro humani corporis secundum quod expedit toti.' (*ST* II-2.65.1).

<sup>&</sup>lt;sup>27</sup> Ibid. (my translation).

<sup>&</sup>lt;sup>28</sup> Ibid.

donor. These could not be justified by appeal to the principle of totality, it was persuasively argued in an influential article by Gerald Kelly, SJ, since this was a principle of subordination of part to the whole which could only be justified in relation to the physical body: it could not be applied to the body politic – evidently departing at this point from Thomas, who had justified the death penalty on this basis, as we have just seen – nor to the Mystical Body of Christ. Instead organ transplantation should be allowed as an exceptional case under the law of charity for the benefit of the neighbour.<sup>29</sup>

Mutilation of the body for the sake of the neighbour is not the salient issue in relation to BIID, but in the course of his discussion Kelly comments on a number of principles and cases which had been discussed by the manualists and which are of greater relevance to our concerns.<sup>30</sup> I will comment on a number of these under five points.

First, the general principle of totality is that mutilation of the body for one's own good is permitted 'when it is proportionately necessary or useful for the good of the whole (i.e. the person)'. Kelly's gloss on 'the whole' as 'the person' might be taken here to affirm that mutilations can be performed for the sake of the whole individual, body and soul, which would of course be central to a discussion of surgery for BIID. That is, if amputation of a limb were being undertaken for the good of the whole person, rather than just as a physical response to a clearly physical malady, it might then be justified under this principle. However, given the context of Kelly's general polemic against justifying organ transplantation by reference to the principle of totality, it may be safer to infer that 'person' here is being contrasted with 'social whole' rather than with 'physical body'.

Second, following on some teaching of Pius XII that mutilations are permissible in order to avoid serious and lasting damage, Kelly infers that purely prophylactic surgical removals might be permissible, even of healthy limbs or organs: this might include the incidental removal of a uterus, for example, in the course of the resection of cancerous ovaries, if this were medically justified to prevent possible later complications. However, although we now have an explicit

<sup>&</sup>lt;sup>29</sup> Gerald Kelly, S.J., 'The Morality of Mutilation: Towards a Revision of the Treatise', *Theological Studies* 17 (1956), 322-44. Cf. Albert R. Jonsen, 'From Mutilation to Donation: The Evolution of Catholic Moral Theology regarding Organ Transplantation', Catholic Social Concerns Lecture Series (University of San Francisco: Lane Center for Catholic Studies and Social Thought', 2005). The reference to the Mystical Body of Christ refers to an effort from the 1940s to develop a version of ecclesial ethics which would justify organ transplantation between members of the Church, and therefore between all human beings, on the grounds that all members of the human race have been redeemed (Jonsen, 4-5).

<sup>&</sup>lt;sup>30</sup> It should be noted that my use of Kelly in the present context is intended as a way of accessing some of the moral discriminations discussed in the tradition that might illuminate the case of BIID through providing relevant analogies. In doing so, I do wish to affirm the continuing significance of casuistry for moral theology, but do not thereby mean to endorse in detail Kelly's method or conclusions, nor to take sides in the controversies of midtwentieth century Roman Catholic moral theology.

<sup>&</sup>lt;sup>31</sup> Kelly, 'The Morality of Mutilation', 331.

example of amputation of a healthy body part, it is clear that he envisages unambiguously medical indications as justifying it: the self-report of the BIID sufferer, even when taken with their evident distress, would not obviously provide the same quality of evidential warrant.

A particular case, third, which involves amputating a healthy limb but does not assume a medical context or the exercise of clinical judgement, is the probably fictive example discussed by the manualists of the tyrant who offers to an unfortunate individual the choice either to cut off his own hand or to be put to death. Selly affirms the broad consensus of the tradition that amputation in this context would be justified, suggesting also that this shows that it is at least solidly probable, if not certain that there need be no intrinsic connection between the mutilation and the saving of one's life; that is, the necessity which connects electing to lose a limb with saving one's life need not be the medical need of the physical body, but could be external (in this case, the will of the tyrant). While this may bring us a little closer to BIID, however, the difference still remains that in the one case we have the implacable will of the tyrant, a necessity external to the person whose limb will be severed, in the other we have an individual's psychological condition which is likely to struggle to generate the same degree of necessity as a gangrenous or necrotizing leg on the one hand or a pitiless despot on the other.

More relevant still, fourth, might be the case of castration for abnormal sexual urges.<sup>33</sup> While this is similar to the situation discussed by Aquinas, the presentation in Kelly is secularized and medicalized, and refers not to self-sacrificial mutilation in the pursuit of spiritual goods, but to psychiatrically-assessed sexual disorder. Clearly his response here would be of great interest for our concerns; but unfortunately he does not stoop to pronounce explicitly on the principle, no doubt because of its connection with sterilization, and resorts instead to the observation that doctors are unconvinced of the effectiveness of the resort to anatomical castration.

Fifth, of all the cases Kelly considers, that which parallels the situation raised by BIID most closely is lobotomy, a surgical intervention for severe psychiatric conditions that became popular in the mid-twentieth century in preference to even more extreme procedures, and remained widely used, if of course controversial, until the arrival of modern antipsychotic drugs. Kelly quotes with approval an instruction to Catholic hospitals:

Lobotomy and similar operations are morally justifiable when medically indicated as the proper treatment of serious mental illness or intractable pain. In each case the welfare of the patient himself, considered as a person, must be the determining factor. These operations are not justifiable when less extreme remedies are reasonably available or in cases where the probability of harm to the patient outweighs the hope of benefit to him.<sup>34</sup>

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<sup>&</sup>lt;sup>32</sup> Ibid., 336.

<sup>&</sup>lt;sup>33</sup> Ibid., 337-8.

<sup>&</sup>lt;sup>34</sup> No. 44 of the revised edition of Ethical and Religious Directives for Catholic Hospitals, quoted by Kelly, 340.

Here we do finally have a situation in which casuistry addresses and approves a surgical remedy for psychological distress. Shrewdly Kelly recognized that medical progress might soon make lobotomies more or less obsolete, and that the technique was anyway questionable, but the affirmation in principle is clear.

## Surgical interventions for psychiatric disorders

Is this the analogy with BIID which we are after? The parallels are clear. There is a clear surgical intervention intended as a treatment for a psychiatric problem, which does not take the form of an amputation, to be sure, but does equally have major, irreversible consequences for the patient. In both cases surgery may only be performed after a full psychiatric assessment. In both cases surgery should be undertaken only as a last resort, if there are no lesser therapies available, and if the probability of harm should not be greater than the hope of success. If there is a difference it is that some of the conditions for which lobotomies were performed are more serious than BIID: schizophrenias and other psychotic and delusional disorders are typically considerably more debilitating and detrimental to everyday functioning. Yet even here the differences should not be exaggerated: on the one hand BIID is also very frequently accompanied by depression serious enough to give rise to suicidal thoughts, and in many cases leads people to undertake actions with an extremely high risk of incidental death; and on the other, lobotomies were frequently performed (and frequently had relatively better outcomes) in cases of affective disorders, obsessive-compulsive disorders, anxiety disorders, and a variety of other conditions of arguably broadly similar severity to BIID.

On the face of it, therefore, if the objection to surgery in the case of BIID is that it uses a surgical solution to address a psychiatric need, then the same objection ought to obtain in the case of the lobotomies that were endorsed for use in Catholic hospitals. And conversely: if lobotomies were at least on some occasions morally and medically justified, then so too should surgery for BIID be.<sup>35</sup>

This conclusion may seem counter-intuitive, or at the very least unexpected. Our instinctive, pre-reflective responses to each case may well differ quite considerably. On the one hand the instruction to the Catholic hospitals seems reasonable: at any rate if we regard

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<sup>&</sup>lt;sup>35</sup> A defence of surgery for BIID by reference to the practice of lobotomy might not appear the most appealing of argumentative routes, given the reputation it gained (it was banned in the Soviet Union in 1950 on the grounds that it was inhumane). But this is not really relevant to the point of principle which we are concerned with, namely the moral legitimacy of surgery for mental disorders.

lobotomy techniques as problematic, we are likely to do so because of the variable levels of their success, or their side-effects, or the enforcement of medical power over patients which they represented, but not on grounds of the principle that they are a surgical response to a psychiatric problem. By contrast, many people's initial response to surgery for BIID is questioning, if not downright hostile.

There are, I suggest two different reasons why the two situations intuitively may feel very different. The first is that they occupy places in two different cultural narratives. Lobotomies on the one hand, for all the ways they now seem repellent and violent, still represented an effort to find some form of alleviation of suffering for patients whose symptoms had resisted all previous efforts – it was intended as a more tolerable alternative to leaving those patients either wholly untreated and forgotten in asylums, or treated with only partial effectiveness with a variety of shock therapies and the like. Their therapeutic motivation seems evident. By contrast BIID lends itself to being represented as occupying a place in a cultural narrative about the growth of autonomy within bioethics, in which therapy is being gradually supplanted - or at least complemented – by consumerist attitudes towards medicine. As an example of this, one might consider Carl Elliott's inclusion of BIID in Better than Well, a book on the intersection of medicine and American aspirations for self-improvement, amidst chapters on cosmetic surgery, Prozac, performance-enhancing drugs, and other enhancement technologies. The demand for surgery for BIID could be presented as another site where the anxious pursuit of authenticity amongst modern Westerners takes the form of bodily enhancement and the subjugation of the body to the socially-mediated quest for competitive self-fulfilment.<sup>36</sup>

A second reason why lobotomy procedures and surgery for BIID might be thought different is that while lobotomies are surgery on the brain for psychiatric disorders, amputation of a limb is surgery on another part of the body. Of course both are surgical interventions to deal with problems which present psychiatrically, and both are radical and perhaps irreversible, but there is still some difference between neural surgery and the destruction of the function of a limb. Neurosurgery is at least surgery on the diseased organ, one might say, whereas there is no obviously diseased body part in the case of BIID. The problem, on this view, could be argued not to be psychiatry through surgery as such, but psychiatry through *this* surgery.

<sup>&</sup>lt;sup>36</sup> Elliott, *Better than Well*, 208-36. Elliott concedes that his attitudes to a surgical response to BIID have shifted since meeting people wanting elective amputation. Contrast Wesley J. Smith's less sympathetic views, commenting on Bayne and Levy's 2005 article: 'If you want to see why Western culture is going badly off the rails, just read the drivel that passes for learned discourse in many of our professional journals ... That this kind of article is published in a respectable philosophical journal tells us how very radical and pathologically non judgmental the bioethics movement is becoming' ('Should Doctors Amputate Healthy Limbs?', <a href="http://www.cbc-network.org/2006/11/should-doctors-amputate-healthy-limbs/">http://www.cbc-network.org/2006/11/should-doctors-amputate-healthy-limbs/</a> (accessed 12 March 2013).

To take this second claim first, it is surely at least as easy to argue that they are not so far apart in moral significance. Both kinds of surgery have significant adverse consequences, and it is not obvious that one is proportionately worse than the other relative to the seriousness of the conditions they are each addressing. The most one could concede to the point is that if a resolution of the psychological distress of BIID could be found by operating on the brain rather than amputating a limb, this would be medically indicated. But the detailed neurological knowledge needed for this is precisely what is not currently available; the question we are faced with now is how to act in our current, limited state of knowledge.

More importantly, we should observe that if BIID is the result of some specifically neurological malformation or anomaly, that is, some unambiguously physical cause, we cannot interpret surgery for BIID as simply refusing to accept the preferred status of the biological, or as a wilful disregard of the structures of the body in pursuit of cultural or psychological fantasies. Rather it looks more like intervention in a body that is at war with itself, where one organ is in conflict with another, the head saying to the feet, 'I have no need of you' (1 Cor. 12.21). The body does not here point unequivocally to the goodness of creation, but has in its divided nature also become a sign of the fallen creation, a fall which may have originated in the disobedience of the will but which in the increased pains of childbirth is shown also to have bodily consequences. In a case such as this, it is much less clear what the practice of healing, as a sign both of the restoration of the creation and the fulfilment of the kingdom, might look like. Of course it is proper medical practice that all less radical alternatives should be pursued first - psychiatric, pharmaceutical, non-impairing. But in our current, limited state of knowledge, it is not evident that it must necessarily preclude the possibility of amputation in some occasional cases. As in the instruction to Catholic hospitals about lobotomy, the determining factor would be the welfare of the patient himself or herself, considered as a person; the totality which the mutilation would serve would be the whole person, body and soul.

#### Surgical interventions for identity disorders?

This might provide a limited justification for surgical therapy for BIID. But an anxiety still remains. Even if such surgery were on occasions defensible in principle, might it not yet be doubtful because of the circumstances in which it would be practiced? This returns us to the question of the cultural narrative within which BIID is set. One of the concerns behind affirming that psychological suffering could warrant drastic surgery lies in the perception that this would represent a further step in the direction of the instrumentalisation and

consumerisation of the body. Once we accept the principle that we may provide surgical solutions to emotional distress, what other practices might we also find ourselves legitimating? How are we to prevent the ever increasing medical colonisation of our cultural imagination, driven (it should be noted) not so much by the calculated expansion of medical power as by the impatient expectations of the patient-consumer? This trend is amplified and given philosophical voice in those conceptions of autonomy, such as those of Savulescu, which not only defend the capacity for informed consent, but also make claims on medicine to supply whatever individuals may demand. On such accounts, surgery for BIID is folded into the category of consumer choice, as a lifestyle preference or a form of self-realization, even if no doubt an extreme and rare one.

The concern is compounded by the proposed categorization of the desire for elective impairment as an 'identity disorder'. The notion of one's 'identity' is remarkably fluid, and is perhaps peculiar to the modern West; it is arguably little surprise, and it says little about its usefulness as a cross-cultural psychological or psychiatric classification, that people in modern English-speaking cultures resort to the language of identity and identity disorder, since this is precisely the language that we habitually reach for when handling this kind of issue. The danger with novel categories of psychiatric diagnosis is that under the guise of supposed scientific impartiality they may impose on others patterns of behaviour, of perception and feeling, which are the local products of specific historical and cultural conditions. And because of the reciprocal, reflexive nature of the relation between people's self-interpretations and the diagnostic categories available to them, especially when mediated through support groups, internet blogs, information sites, and the like, such classifications may end up structuring the ways in which people perform their mental torment in ways that preclude alternative interpretations. Indeed in general, as might be surmised from studies of other arguably transient psychiatric phenomena, our understanding of the significance of cultural context for the structure of experience is inchoate in the extreme.<sup>37</sup>

There are also particular reasons for unease here in relation to BIID. Not only are there significant unclarified issues in the choice of classification.<sup>38</sup> The potential for abuse and for a

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<sup>&</sup>lt;sup>37</sup> See Ian Hacking's discussion of fugue states in nineteenth-century France and multiple personality disorder in late twentieth-century America in *Mad Travellers: Reflections on the Reality of Mental Illnesses* (London: Free Association Books, 1999) and *Rewriting the Soul: Multiple Personality and the Sciences of Memory* (Princeton, NJ: Princeton University Press, 1995). These are discussed in relation to BIID by Elliott, *Better than Well*, 227-34.

<sup>&</sup>lt;sup>38</sup> Here it is striking that the current fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders*, the standard psychiatric classificatory instrument in use in the United States, defines two different kinds of identity disorder, Dissociative Identity Disorder (formerly Multiple Personality Disorder) and Gender Identity Disorder, but does not define 'identity disorder' as such (*Diagnostic and Statistical Manual of Mental Disorders: DSM-IV* (Washington, DC: American Psychiatric Association, 1994)). It is perhaps even more striking that the WHO's classificatory system, which is more widely used internationally, does not contain the category of identity disorder (see *The ICD-10* 

consumerisation of surgery is also magnified by a significant number of 'wannabes' who are unresolved about precisely which amputation they are seeking, and therefore might end up having several physically successful but psychologically unfulfilling amputations;<sup>39</sup> as well as by the possibility some might choose to downplay or deny a sexual dimension of their feelings in order to secure the desired surgery. Perhaps most importantly, the adoption of an official psychiatric classification might end up essentializing the experience, ossifying in some people a quasi-positivist self-understanding that precluded the possibility of any alternative accounts of their situation. It might leave them grasping onto their identity as sufferers from BIID as the deepest truth about themselves, clinging to the possibility of surgical intervention as their sole hope of salvation, and unable to ask even in principle whether there were any alternatives.

All of these are real reasons for concern, and would have to be taken into account before any settled understanding of the phenomenon or final reckoning of the morality of elective amputation were reached. The historical trajectory to which a technological and autonomist culture seems irrevocably committed is one about which anyone concerned with humane values should entertain suspicion. Nevertheless the spacious panorama which the grand historical narrative opens up should not eclipse the views afforded by the petits récits. The lived realities of those people whose autobiographies have been marked by the intense desire to be rid of a healthy body part deserve to be considered in their own terms, rather than being assumed to play a mere bit part in a wider story, and a questionable one at that. They need not be interpreted as lending themselves, whether intentionally or inadvertently, to endless vistas of arbitrary bodily reinvention or florid fantasies about perpetual self-creation.

However if it is the case that such surgery need not be co-opted into a narrative of technological annihilation of the body, if it is possible to bear witness to the fundamental goodness of the body even as one entertains seriously the possibility of eliminating a healthy body part, then those considering such an action need to recognize certain constraints. Rejection of an expansionist philosophy of autonomy does suggest certain ways of performing desire. Those who live with these desires would need to be open to the possibility of other ways of having their desires resolved than that of surgery. They would need to be willing to interrogate their desires, knowing that desires can be deceptive and that the literal fulfilment of desire might

Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines (Geneva: World Health Organization, 1992)). Nor did Michael First offer any views on the matter in proposing the term 'Body Integrity Identity Disorder' (First, 'Desire for Amputation of a Limb'). For a defence of the language of identity disorder here, see Avi Craimer, 'The Relevance of Identity in Responding to BIID and the Misuse of Causal Explanation', American Journal of Bioethics 9 (2009), 53-5.

<sup>&</sup>lt;sup>39</sup> Erich Kasten, 'Body Integrity Identity Disorder (BIID): Befragung von Betroffenen und Erklärungsansätze', Fortschritte der Neurologie Psychiatrie 77 (2009), 16-24, who on the grounds of the roving target of amputation within some individuals finds reason for questioning the neurological account of BIID.

not be identical with the true fulfilment of desire. They would need to refuse the fatalism of assuming that the only solution to the desire to have the limb amputated is to have the limb amputated. They would need to wary of tying themselves to a particular identity if that identification reified their predicament and made intelligible only one solution. If – hypothetically – the option were available, they would need to be open to the possibility of losing the desire for surgery rather than losing part of their body.

Of course for many the option of losing the desire for surgery, however theoretically attractive it might be, remains consistently alien to their experience. They may have lived with their feelings for as long as they can remember, and may not know what it would be like to experience life without them. They may well know the emotional cost of failed efforts to distance themselves from their feelings and the seeming impossibility of doing so, and thence the attraction of seeking surgery. For them, if they were finally to request surgery, recognition of the integrity of the body would also evoke appropriate attitudes. They would not assume that amputation would be a genuine and final 'cure', rather than just a treatment of their symptoms which will likely bring other problems in train. They would not hope that a diagnosis and surgery would provide a final solution of all their life's concerns, but would merely provide the basis for a liveable way forward, a modicum of peace.

# Body integrity and the body of Christ

I emphasize the element of choice in performing one's desires in order to avoid the danger of essentializing the experience, a danger which may intensify when the dominant available categorizations use the language of identity. Not all ways of responding to an experience are equal, and some may be genuinely less enclosed, less fatalistic, more self-aware, more liberating than others. Moreover, whether wittingly or not, some may reflect better than others the final truth of human identity as it is displayed in baptism into Christ. For baptism does not confirm us in our identities but is the crisis of all human identities; baptism reveals the reality of a human identity disorder of a depth inaccessible to any diagnostic manual or psychiatric assessment; it directs us to follow one who did not lay claim to his identity as something to be clung on to; and it promises us new life as the bearers of his identity and members together of a liberated and complete body.

Would surgery for BIID be justified? No doubt we are not yet in a position to reach a mature conclusion on this. The church would certainly not be free if it were not free to make the judgement, No. But equally, I submit, it would not be free if it were not free to make the

judgement, Yes. And this, not as a concession to pastoral 'necessity', nor out of a misplaced emphasis on compassion as the sole ground of discernment. Nor, as I have suggested, need it derive from giving any ground to an autonomy-centred philosophy. Rather it would be based on a serious, principled attention to the welfare of the patient, considered as a person, which is not the same as a descent into a gnosticizing, historicizing rejection of the goodness of the body. There is a difference between an argument that we should allow surgery for BIID since we allow consumer demands over the body such as cosmetic surgery, and the recognition that we are here dealing with a genuine problem which may have no obvious organic cause and which is only accessible through people's self-description, but for which surgery under certain circumstances might be a remedy. And the person who made that judgement out of responsibility towards their own health need not do so as someone appealing to their secure and self-dependent status as an autonomous individual, but might also do so as someone called to be an integral part of the body of Christ.<sup>40</sup>

<sup>&</sup>lt;sup>40</sup> I am grateful to Chris Cook, Gerard Loughlin, Susan Parsons, Jean Porter, Helen Savage, Brent Waters and Vanessa Williams for their comments on the themes of this paper.