

Feminism, Disability and

by Susan

En général, les notions de transcendance du corps sont rejetées par les féministes, en partie parce que les théories sur le corps n'ont pas encore vraiment confronté la souffrance physique. À partir des expériences personnelles de l'auteure et des écrits d'autres personnes atteintes d'un handicap, cet article discute des stratégies qu'une personne développe pour vivre avec la douleur, la maladie et les limitations physiques. L'auteure soutient qu'une compréhension féministe plus approfondie du corps pourrait inclure quelques notions de transcendance.

Ideas of transcending the body have generally been rejected by feminists, including feminist theologians, because they are seen to originate from philosophies and/or religions which de-value the body (especially women's bodies) and bodily experience. For example, Naomi Goldenberg describes the notion of transcendence in traditional theology as "a wish for something beyond body, beyond time, and beyond specific relationships to life" and "a notion of perfect safety...probably motivated by a characteristically (but not exclusively) male fear of being merged with matter" (Goldenberg, 211).

Feminist theorists have criticized the mind-body dichotomy and the intellectual denigration of the body, both of which make important contributions to motivations for transcending the body, and both of which are prevalent in the history of Western thought. We can see their philosophical roots in such ancient ideas as those of Plato and Aristotle, where abstract forms are superior to material things, and reason is superior to the appetites which originate in the body. Feminists have also argued that the dominant forms of Christian theology strengthened these ancient views by representing the body as a major source of the desires and weaknesses that lead to sin, and seeing transcendence of the body as an essential ingredient in moral perfection.

Yet feminist theory has so far failed to appreciate the strength of another motive for wanting to transcend the body. We need to recognize that much of the appeal of philosophies of life which recommend some form of transcendence of the body lies, not in elevation of the mind and denigration of the body, but in the desire to make one's happiness, or at least one's sense of self, independent of illness, pain, weakness, exhaustion, and accident. We have not recognized this because feminist

writing about the body has not fully confronted experience of the negative body.¹ This is partly because feminism's primary concern has always been to identify and change social arrangements that cause preventable suffering, and we have applied this approach to the body. But it is also because we have focussed the rest of our attention on *alienation* from the body and on bodily *differences* between women and men. These emphases have not been conducive to developing a feminist understanding of bodily suffering.

One of the central concerns of feminism has been men's control of women's bodies, especially women's sexuality and reproductive processes, through violence and coercion, law, economic relations, religion, custom, and institutionalized medicine. Outrage over the injustice of this control and the many ways it hurts women led to the long-established movement to increase women's own control of their sexuality, reproductive lives, and health care. Because this movement has always sought to increase women's power to make decisions about their own bodies and to prevent or reduce their bodily suffering, and because there is still so much that needs to be done toward both these goals, it does not foster discussion of experiences of bodily suffering that cannot be controlled or prevented.

Another direction of feminist discussion of the body has been particularly concerned with how men's and women's alienation from their bodies contributes to women's oppression, and how women are alienated from their bodies by male-dominated society. Understandably, alienation from the body is a very negative concept in these discussions; it is something to be overcome by re-uniting culture and people with bodily experience.

Dorothy Dinnerstein and Susan Griffin are the major developers of the view that

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alienation from the body contributes to women's oppression. Both focus upon the desire to escape the vulnerability of the body, especially its vulnerability to unfulfilled need, which is experienced by infants in relation to their mothers. They argue that this desire is a primary motive for creating/maintaining cultures and ideologies which objectify, rage against, and attempt to control women. Because Dinnerstein and Griffin want us to see the pathology of cultures which are pitted against the bodily experiences of men and women, it makes sense that both discuss only the experiences of healthy bodies in relatively favourable physical circumstances. However, for those of us who find their theories persuasive (as I do), there is a potential difficulty that arises from ignoring negative adult experiences of the body: we may come to believe that all will be well between us and our bodies if we can overcome cultural alienation from them.

Other feminist discussions of the body have explicitly focussed on overcoming women's social and cultural alienation from our bodies. A major concern of feminists has been the re-description, by women, of bodily experiences unique to women. Because the Western tradition particularly de-valued women's bodies and appropriated the authority to describe bodily experiences unique to women, feminist writings about experiences of the body tend to focus on sexuality (heterosexual, lesbian, and bi-sexual), the changes of monthly cycles, pregnancy, birth, and mothering. Also in reaction to this tradition and its consequences, feminists have celebrated the body, emphasizing aspects of bodily experience that are sources of pleasure, satisfaction, and feelings of connection. These two understandable and valuable reactions, however, have led feminists to overlook or underestimate

the fact that the body is also a source of frustration, suffering, and even torment. One consequence is that women with disabilities may feel that feminists have an ideal of the female body or of female bodily experience in which they cannot participate any more than they can in the idealized images of sexist society, and that their experiences cannot be included in feminist understandings of the body.

Nevertheless, although feminists have often ignored the suffering body in their theorizing, they have not ignored other aspects of the negative or rejected body. They have always drawn attention to and criticized body image ideals that alienate women from our own bodies and function as instruments of social control. There have been feminist critiques of fashions in body type and clothing, of the cult of youth, of the tyranny of slimness, of standards of femininity that require restricted movement, extensive grooming and use of makeup, and of growing cultural pressures on women in wealthy countries to alter their bodies by "cosmetic" surgery, to name but a few. Traditionally, these critiques have encouraged women to cultivate more positive and realistic body images in resistance to the idealizations with which they are pressured, and to reduce their alienation from their bodies by focussing on bodily experience and competence rather than appearance. (For more discussion of these issues, see Bartky). These are important aims for women with disabilities as well as for women without them. But, as in the other feminist treatments of alienation, there is little room to examine bodily suffering when the goal is to restore women's appreciation of embodiment. Recent work along these lines has taken another direction, urging women to adopt a playful, mocking stance toward standards of beauty and femininity, using their own bodies to

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body....When the body, like my body, is no longer consistent over time...when something that meant one thing in April may have an entirely different meaning in May, then it is hard to rely on the stability—and therefore the truth—of the body (Butler and Rosenblum, 136-137)

Chronic pain creates a similar (but more limited) crisis of meaning, since, to a healthy person, pain means that something is wrong that should be acted upon. With chronic pain, I must remind myself over and over again that the pain is meaningless, that there is nothing to fear or resist, that resistance only creates tension, which makes it worse. When I simply notice and accept the pain, my mind is often freed to pay attention to something else. This is not the same as ignoring my body, which would be dangerous, since not resting when I need to rest can cause extreme symptoms or a relapse into illness that would require several days of bedrest. I think of it as a re-interpretation of bodily sensations so as not to be overwhelmed or victimized by them. This process has affected profoundly my whole relationship to my body, since fatigue, nausea, dizziness, lack of appetite, and even depression are all caused by my disease from time to time, and thus all have changed their meanings. It is usually, though not always, inappropriate now to interpret them as indications of my relationship to the external world or of the need to take action. Unfortunately, it is often much easier to recognize that something is inappropriate than to refrain from doing it.

For this reason, I have found it important to cultivate an "observer's" attitude to many bodily sensations and even depressive moods caused by my illness. With this attitude, I observe what is happening as a phenomenon, attend to it, tolerate the strangeness of, for example, feeling depressed or nauseated when there is nothing obviously depressing or disgusting going on, accommodate to it as best I can, and wait for it to pass. This is very different from the reactions that come most easily to me, which have to do with finding the causes of these feelings and acting on them. I find it hardest to adopt an observer's attitude toward depression, since although in the past I had brief

illnesses that caused the other symptoms, I had never experienced severe depression without something to be depressed about. Thus, my first, easiest response to depression was to search my life for something that might be depressing me. Since my world (like virtually everyone's) is full of things that, if focussed upon, might cause depression, I increased and prolonged my depressions with this habitual response. Learning to regard severe depression (by this I mean, not the lows of everyday living, but the sorts of feelings that make you wish you were dead) as a physical phenomenon to be endured until it is over and not taken seriously, has greatly reduced my suffering from it and may have saved my life. Register de-

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scribes a similar strategy used by a man who suffers from recurring depressive illness (280).

In general, being able to say (usually to myself): "My body is painful (or nauseated, exhausted, etc.), but I'm happy," can be very encouraging and lift my spirits, because it asserts that the way my body feels is not the totality of my experience, that my mind and feelings can wander beyond the painful messages of my body, and that my state of mind is not completely dependent on the state of my body. Even being able to say: "My brain is badly affected right now, so I'm depressed, but I'm fine and my life is going well," is a way of asserting that the quality of my life is not completely dependent on the state

of my body, that projects can still be imagined and accomplished, and that the present is not all there is. In short, I am learning not to identify myself with my body, and this helps me to live a good life with a debilitating chronic illness.

I know that many people will suspect this attitude of being psychologically or spiritually naive. They will insist that the sufferings of the body have psychological and/or spiritual meanings, and that I should be searching for them in order to heal myself (Wilber). This is a widespread belief, not only in North America but in many parts of the world, and I have discussed some of its consequences for people with disabilities and/or terminal illnesses elsewhere (Wendell). I do not reject it entirely. I too believe that, if my stomach tightens every time a particular person enters the room, it is an important sign of how I feel about him/her, and I may feel better physically if I avoid or change my relationship to that person. But, having experienced a crisis of meaning in my body, I can no longer assume that even powerful bodily experiences are psychologically or spiritually meaningful. To do so seems to me to give the body too little importance as a *cause* in psychological and spiritual life. It reduces the body to a mere reflector of other processes, and implicitly rejects the idea that the body may have a complex life of its own, much of which we cannot interpret.

When I look back on the beginning of my illness, I still think of it, as I did then, as an involuntary violation of my body. But now I feel that such violations are sometimes the beginnings of growth, in that they force the self to expand or be destroyed. Illness has forced me to change in ways that I am grateful for, and so, although I would joyfully accept a cure if it were offered me, I do not regret having become ill. Yet I do not believe that I became ill *because* I needed to learn what illness has taught me, nor that I will get well when I have learned everything I need to know from it. We learn from many things that do not happen to us because we need to learn from them (to regard the death of a loved one, for example, as primarily a lesson for oneself, is hideously narcissistic), and many people who could benefit from learning the same things never have the experiences which would teach them.

When I began to accept and give in to my symptoms, when I stopped searching for medical, psychological or spiritual cures, when I began to develop the ability to observe my symptoms and reduced my identification with the transient miseries of my body, I was able to re-construct my life. The state of my body limited the possibilities in new ways, but it also presented new kinds of understanding, new interests, new passions and projects. In this sense, my experience of illness has been profoundly meaningful, but only because I accepted my body as a cause. If I had insisted on seeing it primarily as reflecting psychological or spiritual problems, and devoted my energy to uncovering the “meanings” of my symptoms, I would still be completely absorbed in being ill. As it is, my body has led me to a changed identity, to a very different sense of myself, even as I have come to identify myself less with what is occurring in my body.

People with disabilities often describe advantages of not identifying the self with the body. For those who are ill, the difficulty of living moment-to-moment with unpredictable, debilitating symptoms can be alleviated by having a strong sense of self which negotiates its ability to carry out its projects with the sick body (Register, Chapter 9). This sense of self and its projects provides continuity in lives which would be chaotic if those who led them were highly identified with their bodies. The anthropologist Robert Murphy, who is quadriplegic and has been studying the lives of people with paralysis, describes another motive for disembodiment: “The paralytic becomes accustomed to being lifted, rolled, pushed, pulled, and twisted, and he survives this treatment by putting emotional distance between himself and his body” (100-101).

In addition, people with disabilities often express a strong desire not to be identified with their bodily weaknesses, inabilities or illnesses. This is why the phrase “people with disabilities” has come to be preferred over “disabled people.” When the world sees a whole person as disabled, the person’s *abilities* are overlooked or discounted. It is easy to slip into believing other people’s perceptions of oneself, and this can take a great toll on the self-esteem of a person with a disability. Those people with disabilities who still have impressive

and reliable physical abilities can counteract people’s misperceptions by asserting those abilities. For those of us whose remaining physical abilities are unimpressive or unreliable, not to identify ourselves with our bodies may be the best defense. It is good psychological strategy to base our sense of ourselves, and therefore our self-esteem, on our intellectual and/or emotional experiences, activities, and connections to others.

Robert Murphy, whose paralysis is steadily increasing as a tumor in his spinal column slowly grows, writes eloquently about the consequences of losing the ability to move. He says of himself: “My thoughts and sense of being alive have been driven back into my brain, where I

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now reside” (102), and: “Like all quadriplegics, I have a great fear of being left stranded and helpless, but my sense of self is otherwise shrunken to the confines of my head” (193). Although Murphy does not shrink from recognizing what he has lost by this, he describes vividly what he has gained:

I have become a receptor in physical things, and I must continually fight the tendency for this growing passivity to overcome my thoughts. But there is a certain security and comfort in returning to my little cocoon every night, enswathed in a warm electric blanket, settled into a micro-environment consisting of one’s essentials. It

is a breach of communication with the toils of social ties and obligations, a retreat into a private cerebral world. And it is at these times that my mind wanders furthest afield. In such deep quietude, one indeed finds a perverse freedom (193-194).

I do not want to give an exaggerated impression of the degree to which people with disabilities rely upon strategies of disembodiment. For all the advantages that some degree of disembodiment may have in coping with illness or disability, the process of coming to identify with a sick or disabled body can play an important part in adjusting to it. For many of us who have become ill or disabled as adults, reconstructing our lives depends upon forging a new identity. An important aspect of this process is what Register calls “acceptance: ability to regard the illness [or, I would add disability] as your normal state of being” (31). This could also be described as learning to identify with a new body, as well as, for most of us, a new social role. For me, this had many advantages: I stopped expecting to recover and postponing my life until I was well, I sought help and invented strategies for living with my sick body, I changed my projects and my working life to accommodate my physical limitations, and, perhaps most important, I began to identify with other people with disabilities and to learn from them. Thus, I do identify with my sick body to a significant degree, but I also believe that my thoughts and feelings are more independent from my experiences of it than they ever were from my experiences of my well body.

What has all this to do with transcendence of the body? That, of course, depends on what we have in mind when we speak of transcendence. The forms of independence from the body’s sufferings that I have described are partial and mundane. They are strategies of daily living, not grand spiritual victories. Perhaps some people might even regard them as forms of alienation from physical experience. I think that would be a mistake. Alienation, as we usually understand it, reduces freedom, because it constricts the possibilities of experience. If we spoke of being alienated from suffering, I think we would mean being *unable* to face up to and undergo some necessary, perhaps pur-

poseful, pain. To choose to exercise some habits of mind which distance oneself from chronic, often meaningless physical suffering increases freedom, because it expands the possibilities of experience beyond the miseries and limitations of the body.

It is because they increase the freedom of consciousness that I am drawn to calling these strategies forms of transcendence. It is because we are led to adopt them by the body's pain, discomfort or difficulty, and because they are ways of interpreting and dealing with bodily experience, that I call them transcendences of the body. I do not think that we need to subscribe to some kind of mind-body dualism to recognize that there are degrees to which consciousness and the sense of self may be tied to bodily sensations and limitations, or to see the value of practices, available to some people in some circumstances, which loosen the connection. Nor do I think we need to de-value the body or bodily experience to value the ability to gain some emotional and cognitive distance from them. On the contrary, to de-value the body for this reason would be foolish, since it is bodily changes and conditions which lead us to discover these strategies. The onset of illness, disability or pain forces us to find conscious responses to new, often acute, awareness of our bodies. Thus, the body itself takes us into and then beyond its sufferings and limitations.

In conclusion, by defending some notion of transcendence of the body I do not mean to suggest that strategies of disembodiment should be adopted by people without disabilities. Instead, I want to demonstrate how important it is to consider the experiences of people with disabilities when theorizing about the relationship of consciousness to the body. One thing is clear: we cannot speak only of reducing our alienation from our bodies, becoming more aware of them, and celebrating their strengths and pleasures; we must also talk about how to live with the suffering body, with that which cannot be noticed without pain, and that which cannot be celebrated without ambivalence. We may find then that there is a place in our discussion of the body for some concept of transcendence.

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¹I use the terms "negative body" and "rejected body" to refer to those aspects of bodily reality (such as illness, disability, weakness, and death), bodily appearance (usually deviations from the cultural ideal of the body), and bodily experience (including most forms of bodily suffering) which are feared, ignored, despised, and/or rejected in a culture and society.

²M.E. stands for myalgic encephalomyelitis, which is a debilitating illness that affects the muscles and nervous system. Its cause is still unknown, but it usually begins with a severe viral infection like influenza.

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