

Dementia, Autonomy, and Unexpected Happiness

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May 15, 2016

According to the Alzheimer's Association, approximately 5.3 million Americans had Alzheimer's disease in 2015 ("2015 Alzheimer's Disease Facts and Figures"). For each person with Alzheimer's and other forms of dementia, many family members and friends are plagued by troubling ethical questions about how to make decisions with and for a loved one whose memory and judgment are becoming increasingly impaired, someone whose very self may have changed drastically. In *Life's Dominion*, Ronald Dworkin addresses the question of what to do if someone, when competent, said that she did not wish to receive treatment for life-threatening medical conditions if she were to develop Alzheimer's but who, when experiencing dementia, seems content to live. After summarizing Dworkin's framework and his solution to this question, I provide an alternate solution that emphasizes the changeability of the self and the extenuating circumstances provided by unexpected happiness.

Dworkin's View

To set up his argument, Dworkin describes the case of Margo: "the apartment had many locks to keep Margo from slipping out at night... Margo said she knew who [the doctor] was each time he arrived, but she never used his name, and he suspected that this was just politeness" (220). In contrast to some dementia patients, however, Margo seems content. Her doctor writes, "in spite of her illness, or maybe somehow because of it, Margo is undeniably one of the happiest people I have ever known" (221). Dworkin turns Margo's case into a thought experiment, introducing a catch: when competent, Margo expressed that "in [the event that she got Alzheimer's] she should not receive treatment for any other serious, life-threatening disease she might contract" (226). Dworkin's central argument states that if Margo were to get a life-threatening but treatable disease, her advance directive should be followed and she should be allowed to die as a way of respecting her autonomy. Respecting her autonomy, in turn, would be in Margo's best interests. Thus, Dworkin asserts that there is no conflict between respecting Margo's autonomy and following her best interests.

Dworkin then turns to the question of *why* we should follow Margo's autonomy. He views autonomy as a means to the end of integrity: "the value of autonomy, on this view, derives from the value it protects: the capacity to express one's own character"(224). This view of autonomy also focuses on the importance that a coherent life trajectory has to the fundamental integrity of a person: "a competent person making a living will providing for his treatment if he becomes demented is making exactly the kind of judgment that autonomy, on the integrity view, most respects: a judgment about the overall shape of the kind of life he wants to have led"(226). Thus, in Dworkin's view, Margo's family members should promote her autonomy, integrity, and best interests by following her advance directive in order to help her life conform to the trajectory she wanted it to have when competent.

To fortify his argument, Dworkin draws on the concepts of critical interests and experiential interests, which he sees as partly constitutive of one's unique character (224). Regarding experiential interests, Dworkin says, "we all do things because we like the experience of doing them... Pleasures like these are essential to a good life... But the value of these experiences, judged one by one,

depends precisely on the fact that we do find them pleasurable or exciting *as experiences*" (201). In other words, experiential interests are those interests that are only (or are at least primarily) valuable because they are experienced. Dworkin also argues that "people who do not enjoy an activity I do... are not making a mistake; their lives are not worse for not sharing my taste" (201). Expressed differently, experiential interests are not central to the worth of a life; a life would not be significantly worsened if it lacked a particular experiential interest. Critical interests, by contrast, tend to be based on values; they are "interests that it does make [a person's] life genuinely better to satisfy, interests they would be mistaken, and genuinely worse off, if they did not recognize"(201-202). Under this view, one's fundamental critical interest might still be satisfied even if one does not consciously experience the fulfillment of that interest. For example, a parent's critical interest in a child's health would still be satisfied even if the parent did not know that the child was healthy.¹

Dworkin draws on the idea that the fulfillment of critical interests is still in a person's best interests even if the person would reap no experiential reward from it to argue in favor of upholding Margo's advance directive. In other words, critical interests (like autonomy) trump experiential interests, even when following experiential interests brings enjoyment, and following critical interests does not. As Dworkin writes:

Of course, there is a conflict between Margo's precedent autonomy and her contemporary experiential interests if she is still enjoying her life, but there is no conflict with her critical interests as she herself conceived them when she was competent to do so... Once we accept that we must judge Margo's critical interests as she herself did so when competent—then the conflict between autonomy and beneficence seems to disappear. If Margo had asked not to be given medical care for life-threatening illnesses contracted after she had become demented, neither her right to autonomy nor her right to beneficence would give us grounds for denying that request, even if the demented Margo is enjoying her life. (231-232).

However, I disagree with Dworkin. To solve Margo's case, we must release ourselves from Dworkin's rather draconian view of what would be good for Margo and make a decision that causes her present self the least harm possible. This is especially true because—due to the self's changeability and the particular kinds of disconnect between past and present selves caused by memory loss—*past* Margo's critical interests are not as important to her best interests now as Dworkin would like to believe. I argue that we must disentangle autonomy from best interests and justify overturning a patient's past self's autonomy under rare extenuating circumstances when a patient's present self finds unexpected happiness.

An Alternative Inspired by Hawkins

To begin, Jennifer Hawkins' nonalienness principle might point us to a more promising view of what is good for Margo. In Hawkins' words, "a person's good must enter her experience, if it does, in a positive way"(536). Thus, if something is truly good for Margo, it must either enter her experience in a positive way or be such that if it *were* to enter her experience, it would do so in a positive way. This requirement is particularly important in Margo's case: since her life is now likely to be based quite centrally around experiential interests, to devalue the experiential consequences of the decision for Margo is to devalue much of Margo, herself.

The question now becomes: which decision would enter into Margo's experience in a more positive way: following her past critical interests as expressed in her advance directive and letting her die, or following her current experiential interests and letting her live? While there is a certain

¹This example was suggested by Daniel Groll.

valiance to upholding the advance directive and so affirming her past autonomy, it is also hard to deny that on a very basic level, her own death would enter her experience in a negative way by preventing her from pursuing experiential interests that give her joy. Thus, if we accept Hawkins' maxim about the good, death is not good for Margo. It seems to follow quite naturally that if death is not good for Margo, then it is in her best interests to be treated.

Next, we must respond to Dworkin's claims about the relative value of critical and experiential interests. Regarding the value of interests, Dworkin's argument is based on the idea that it is higher level, complex critical interests that give our lives value. Expressed more strongly, Dworkin could be saying that if something gives our lives fundamental value, then it is a critical interest—a category he defines largely via examples. However, his argument may not adequately account for the many varied and subtle ways that human beings find value, especially when their mental faculties or their life circumstances have been affected such that deriving more value from critical interests than from experiential interests makes little sense. Such conditions are often true for moderate to severe dementia patients, whose ability to form critical interests or to consciously hold past critical interests have often been seriously compromised by disease. In other words, if something gives value to a person's life, it could easily be an experiential interest, not a critical interest, due to a life circumstance such as dementia. Thus, in such cases, we must look more to the patient's current experiential interests than to what echoes of past critical interests she may hold to explain the value of her life and to help guide our actions. This guideline, combined with Hawkins' claim about positive experiences and the good, seems to provide a compelling case for acting to fulfill Margo's experiential interests, which are quite certain to require that Margo be alive to experience them.

I suspect that Dworkin might respond to my Hawkins-inspired arguments by saying that many events do not enter a person's experience in a positive way but are still good for them, especially if such events fulfill their critical interests. For example, the experience of getting a shot does not enter a person's experience in a positive way, but in the end, it will likely be good for the person since it may further their critical interest in long-term health. He would then use these examples to say that while death would not enter Margo's experience in a positive way, it would be good for her in an abstract sense, for it would respect her autonomy and fulfill her critical interest in integrity.

I would respond to him by questioning his idea of a unitary Margo and emphasizing the issue of present obligation. As I have alluded, it seems that we are dealing with two entities: past Margo, who exists abstractly in documents and memories, and current Margo, who exists concretely and is alive and joyful. Though the two are deeply tied together, only one of those entities is currently a human being—current Margo—and only one of those entities will actually feel the harm of death—current Margo. We must respond to the self we are presented with *now*, and in the present moment, under the present circumstances, what is most clearly good for current Margo is to continue to live and to find happiness in her experiential interests: her only other viable option is to suffer the harm of death. Crucially, the ties between current human Margo and a past self that held the abstract non-experiential critical interest in ending treatment are weaker than they would be for competent patients *since current Margo has, to a certain degree, forgotten her old self*. Thus, even if, in theory, fulfilling critical interests could be good for a person without it entering her experience in a positive way, such things have little bearing on current Margo, who is now particularly disconnected from her pertinent past critical interest in terminating treatment. Similarly, while it may appear that upholding the advance directive upholds Margo's autonomy, closer inspection reveals that we are only upholding the autonomy of a vanished past self, one who is disconnected from a present human being whose needs and best interests have changed.

We are also justified in overruling Margo's advance directive because past Margo's decision to forego treatment in the case of Alzheimer's was not fully informed: she lacked the foresight to see how happy current Margo is and how death would harm her. Her case differs from that of many vegetative patients in the sense that their lives are not happy in the same way Margo's is, and the patients, when competent, were likely to anticipate that. Thus, by overruling past

Margo's autonomy, I have not disavowed the process of advance directives or negated the practice of respecting autonomy in general. I just wish to override certain kinds of past exercises of autonomy in cases when a patient presently lives a life of unexpected happiness.

While I do believe that autonomy is a good, is an important value in life, and is a right that should not be abrogated lightly, my remarks on happiness indicate that Dworkin clings to it to the unjustifiable exclusion of other values, such as happiness and existence. Intuitively, I suspect that the practice of autonomy is, or should be, valued for a large part because of the end to which it often points: a happy existence, not only one with integrity. By clinging to autonomy in Margo's case, Dworkin eliminates a central reason for valuing autonomy, since clinging to autonomy and letting her die eliminates the possibility of current Margo continuing to have a happy existence. Dworkin, therefore, has found himself in a self-defeating position: by valuing autonomy very highly in Margo's case, he has eliminated the possibility of fulfilling what may be one of autonomy's central purposes.

Conclusion

In short, Dworkin's solution may respect past Margo's autonomy, but it does not recognize that we need to detach ourselves from the autonomy principle at times, especially when following it would only follow the autonomy of a past self now gone and/or extinguish the existence of an unexpectedly happy person. When the cost of tying past and present Margo more firmly together is the death of the unexpectedly happy present Margo, that cost is too high to be paid, even if it is paid with the intent of increasing the integrity of Margo's life trajectory. Thus, in this case, we must remember that our obligations are to Margo's current self, even if she only holds experiential interests, and provide her with appropriate treatment to avoid the harm of death.

Bibliography

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