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## DID YOU THINK ABOUT BUYING HER A CAT? SOME REFLECTIONS ON THE CONCEPT OF AUTONOMY

*Bernadette Tobin\**

The Dutch Medical Law Association recently invited Margaret Somerville, whose opposition to the legalization of euthanasia is well-known, to give the address to mark its twenty-fifth anniversary. In a conversation with a doctor at a cocktail party following that address, Margaret expressed her surprise at the Dutch willingness to engage in euthanasia by lethal injection on such a wide scale. The doctor replied, "Look, I will give you a case of euthanasia with which I am sure you will agree." At this point, Margaret expected to hear about someone suffering from something like Lou Gehrig's disease, a degenerative neuromuscular condition which affects physiological functions, including breathing and swallowing. She expected to be told of a case in which her intuitions would be pulled in the same direction as that expressed in the desire of the person requesting euthanasia. Instead, the doctor told her the story of an eighty-three-year-old, highly-educated woman who had become progressively lonely after the death of her diplomat husband, an intellectual with whom she had lived a marvelous life in different parts of the world. The woman claimed that she had nothing to live for; her husband, the center of her life, had died. All her friends had died. She had no family. Her only source of companionship was her doctor, who visited every week; and to whom, every week, out of her loneliness, the woman would request, "Please give me a lethal injection." After about three months, the doctor finally agreed. At the end of the doctor's story, Margaret paused for a moment, and then respectfully asked, "Did you think about buying her a cat?" With complete seriousness, the doctor looked at Margaret and said, "What a good idea!"<sup>1</sup>

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1. Margaret Somerville, Address at the First National Conference on Death, Dying,

I recently heard Margaret retelling this story on the radio one evening. My attention was first caught by Margaret's voice, which conveys her courteous desire to contribute to public debate about the ethical aspects of health cases. She told the story to illustrate one of the themes of her discussion: the wide variety of interpretations about the Dutch position on euthanasia. It is necessary to relay the story because it captures Margaret's intellectual and personal *joie de vivre*.<sup>2</sup> The story also clarifies what is wrong with the contemporary idea that respect for personal autonomy is the primary moral value at stake in health care.

Following the contemporary model of personal autonomy in health care, the most obvious way for the Dutch doctor to justify her decision to administer a lethal injection to the woman (had the conversation taken that turn) would have been for the doctor to say that, through administering the lethal injection, the doctor was respecting the woman's autonomy. Each week the woman said, "Please give me a lethal injection," and after three months, the doctor did what the woman wanted. Even those persons who believe that the capacity to live autonomously is the crucial mark of moral maturity and, therefore, believe that respect for the autonomous individual signifies respect for that person as a human being, are likely to be troubled by the conduct and the thinking of the Dutch doctor. Similarly, those who believe that respect for personal autonomy is an essential moral requirement to any professional-client relationship where there is an inherent imbalance of power, such as that between a physician and her patient, cannot help but feel uncomfortable. That is why the last part of the exchange between Margaret and the doctor, when Margaret gently suggested buying a cat for the woman, is both ironic and poignant. It is ironic because the suggestion is an obvious and simple way the woman could have been helped through her loneliness, and poignant because it came too late to be practicable.

If the premises are correct that, first, the most obvious way for the Dutch doctor to justify her conduct was to say that administering the lethal injection was done out of respect for the woman's personal autonomy, and that, second, there is something very troubling about the doctor's treatment of the old woman and response to Margaret's suggestion, there is the suggestion that there is something wrong with the con-

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and Euthanasia held at St. John's College, the University of Queensland (Sept. 20-23, 1993).

2. Margaret's story also aided the author in determining the subject matter for her contribution to this volume of *The Journal of Contemporary Health Law and Policy* dedicated in honor of Margaret Somerville.

temporary tendency to hallow respect for personal autonomy. By explicating some facets of the concept of autonomy as we employ it in our moral thinking and practices,<sup>3</sup> I hope to show that the doctor's conduct, and other similar decisions made out of respect for personal autonomy, rely on a distortion of the concept of autonomy. In essence, I attempt to clarify some aspects of what might be called the "grammar" of our concept of autonomy.

Some of the most noted works in bioethics today come from writers such as Edmund Pellegrino and David Thomasma. Each argues that respect for patient autonomy ought to be thought of as an ineliminable aspect of acting beneficently toward the patient, not as an obligation independent of the obligation to act in the patient's best interests.<sup>4</sup> It follows then that there are limits to what ought to be done as a matter of respecting patient autonomy; limits set by the obligation to act beneficently. In general, this Article accepts such a level of respect for autonomy as incorporated in the obligations of a physician toward a patient. However, I think that the better we appreciate the grammar of the concepts in the light of which we think of these responsibilities and obligations, in particular the better we appreciate the interdependencies between the concepts in our moral vocabulary (for instance between the concept of respect for autonomy and the concept of human individuality) and the conceptual stage-setting that gives them their point, the deeper will be our understanding and our acceptance of them.

There are two common distortions of the grammar of the concept of respect for personal autonomy. Two recent Australian publications best illustrate these distortions: Max Charlesworth's *Bioethics in a Liberal Society*<sup>5</sup> and Helga Kuhse's *Willing to Listen, Wanting to Die*.<sup>6</sup> In discussing what these two books have to say about "medical end-of-life" decisions, my aim is to demonstrate how some aspects of our shared conception of autonomy are misunderstood.

In *Bioethics in a Liberal Society*, Charlesworth, a genuinely public philosopher in Australia, sets out what he takes to be the implications of respect for personal autonomy in the context of a series of ethical issues

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3. In explaining a similar use of "we," Bernard Williams claims that it operates through invitation. "It is not a matter of 'I' telling 'you' what I and others think, but of my asking you to consider to what extent you and I think some things and perhaps need to think others." BERNARD WILLIAMS, *SHAME AND NECESSITY* 171 (1993).

4. See, e.g., EDMUND D. PELLEGRINO & DAVID C. THOMASMA, *FOR THE PATIENT'S GOOD* (1988).

5. MAX CHARLESWORTH, *BIOETHICS IN A LIBERAL SOCIETY* (1993).

6. *WILLING TO LISTEN, WANTING TO DIE* (Helga Kuhse ed., 1994).

that have arisen in health care: termination of human life, assisted reproduction and family formation, and distribution of health care resources. Charlesworth's philosophical origins and commitment to personal autonomy as the primary moral value come from John Stuart Mill's *On Liberty*. As Charlesworth states, "[i]n a liberal society personal autonomy, the right to choose one's own way of life for oneself, is the supreme value."<sup>7</sup>

In what follows, I deliberately set to one side any discussion of whether a commitment to political liberalism requires a conception of autonomy as overriding other moral considerations. A discussion of that question would need to consider whether individuals in a genuinely democratic community have (and need to have) more in common than respect for each other's freedom, together with an agreement not to harm one another. The question also needs to distinguish a consenting acceptance of political authority from a servile compliance with that authority. These questions are beyond the scope of this discussion, which is limited to demonstrating what is wrong, *in itself*, where autonomy is conceptually treated as the primary moral value. Charlesworth's expression captures the current paradigm of treating autonomy as the primary moral value. He thinks that the idea of autonomy is "blindingly" obvious.

It simply means that if I am to act in an ethical or moral way I must choose for myself what I am going to do. I may of course take advice from others and I may be subject to persuasion and pressure from external sources, but when the chips are down I must decide and choose for myself. Only then is what I have done imputable to me so that it is *my* act, and only then am I responsible for it and praiseworthy or blameworthy for it.<sup>8</sup>

Charlesworth spells out autonomy's conceptual connections with the concept of "individuality:"

[i]n one sense [individuality] is identical with the idea of autonomy, the capacity of each person to pursue her or his life in an original and spontaneous way as an independent and self-determining moral agent . . . . The liberty to decide and choose for oneself is, however, only part of what Mill means by "individuality." He also means the right to be different. Though this might be superficially interpreted as a plea for bohemianism or mere eccentricity, Mill is getting at something important here, namely that each person has his or her own moral style of life or

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7. CHARLESWORTH, *supra* note 5, at 1.

8. *Id.* at 10 (emphasis in original).

“vocation.”<sup>9</sup>

Helga Kuhse’s book, *Willing to Listen, Wanting to Die*, has three parts. The first is a collection of pieces by people who have wanted either assistance in committing suicide or legal protection from committing euthanasia. The second is a set of commentaries by people who have cared for the ill and the dying as part of their professional responsibilities. The third part consists of reflections by various social commentators who discuss their views about how society should deal with requests from people who wish to die. Although one of the contributors is opposed to the legalization of euthanasia (in the sense of the intentional hastening of a person’s death out of concern for that person’s suffering) and another does not show his hand on that question, the book nonetheless may be represented as a sustained plea for the legalization of euthanasia. Kuhse expresses a main theme of the book in the following way, “[a]utonomy—the capacity to think for ourselves, to form, revise and pursue our own plans for life—is basic to our understanding of ethics, and to our self-understanding as persons.”<sup>10</sup>

Two criticisms need to be made of the conception of the primacy of autonomy Charlesworth and Kuhse employ in their works. First, some of the situations which advocates of the supremacy of autonomy analyze in terms of the concept of autonomy are situations the moral dimensions of which are not structured by that concept. That is to say, what is morally salient in them is not (or not primarily) a matter of respect for personal autonomy. To analyze them only in terms of that concept is to distort what *is* morally salient in them. Second, in abstracting autonomy from all the concepts which give it its relevance and importance, and in making secondary all other aspects of interrelations between people, the advocates of the supremacy of autonomy obscure the concepts that are really at work in our thinking.

After discussing the ethics of suicide, the moral right to die, the decriminalization of suicide, and multicultural attitudes toward death and dying, Charlesworth turns to the topic of “choosing for those who cannot choose for themselves” in his chapter entitled “Ending Life.” He takes on the most difficult kind of case in which decisions have to be made involving severely disabled newborn infants. He notes that, “[t]he principle of autonomy . . . has . . . to be found a place here, but it is not obvious

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9. *Id.* at 19-20.

10. WILLING TO LISTEN, WANTING TO DIE, *supra* note 6, at 250.

how this might be done.”<sup>11</sup> Charlesworth sees himself as addressing the task of finding some way to close the gap between the actual practices of pediatricians in Australia and Canada, the vast majority of whom do not think that everything possible must be done to prolong an infant’s life, and the attitude of the law in most countries (at least until recent times) which requires physicians to use all available means to save an infant’s life. In the course of a discussion in which he distinguishes between various senses of the term “quality of life” and, incidentally, puts to rest the utilitarian idea that we can quantify, compare, and rank the “quality of life” of different individuals, Charlesworth considers some of the problems inherent in making decisions about what is in the “best interests” of an infant. He concludes:

[a]nd in the case of newborn infants, who are incapable of any perception or judgment about the human worth of their lives, the only thing we can do is to put ourselves in their place and *impute* such a perception and judgment to them *as though* they were autonomous moral agents. The test here must be: would the infant wish to lead such a life if it had the capacity of choosing for itself? The right we accord to adult competent patients, as autonomous moral agents, to refuse medical treatment they judge to be humanly pointless, should be extended to disabled newborns even though this right can only be exercised, in their case, through a proxy acting on their behalf and imputing a decision to them.<sup>12</sup>

I do not quarrel with the principal idea that the decision as to whether to intervene to prolong such an infant’s life necessarily involves more than medical factors. Considerations about the future quality of life made possible by such interventions must also enter into the decision. Charlesworth is right to insist that the focus of the decision should be on whether the proposed intervention can be judged to be worthwhile for the child (and not, as some would have it, whether the parents—or even the wider society—would *want* to look after such an infant).

Nonetheless, Charlesworth’s analysis of these decisions is distorted by his commitment to the supremacy of autonomy. He thinks that the decision must be made by someone “standing in the shoes” of the infant. But given that our respect for autonomy derives from our belief in the individuality of human beings, that is, from our belief that human beings are capable of shaping their own selves by the autonomous choices that they

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11. CHARLESWORTH, *supra* note 5, at 45.

12. *Id.* at 51-52 (emphasis in original).

make, then the very possibility of making such a judgment on the behalf of the infant, *subjectively* on its behalf rather than *objectively* about it, is a figment of the imagination.<sup>13</sup> We cannot make the judgment for this individual child *on its behalf*. The notion of substitute decisionmaking, which has its point with respect to treatment decisions on behalf of an incompetent individual by someone who knew the individual when he or she was once competent, idles here. There is no content to the thought, "what would this individual, who has never been competent, think if he or she were competent?" Therefore, because this infant does not have the competence to choose for itself, those who have to make the decisions—the parents in consultation with the doctors—ought to be helped to acknowledge that the decision truly concerns whether the burdens and the indignities of the necessary treatments are such as not to be compensated for by the kind of life the infant is likely to live in the future.

In one sense then, it is right to say that the principle of autonomy has a place here: for the infant about whom the decision has to be made belongs to the kind of being which has the capacity to be more or less an autonomous agent. In making a decision, the parents have to take into consideration the extent to which, and at what cost, treatment will enable the infant to live autonomously. But in another sense, reference to the principle of autonomy distorts what is morally salient here. It fosters the notion that one can make a decision on behalf of the child. That this is not possible is a reality with which parents must live. In making their decision, they have to decide what they think will be in the best interest of another individual. In that, they must do the best they can. However, they cannot, in truth, explain their decision to themselves or to others as their best attempt to respect the infant's autonomy—to capture what the infant would have wanted for itself.<sup>14</sup>

Wise decisions about the care and treatment of severely disabled newborns involve the appreciation of their being individuals with the capacity to be self-directed and whose well-being requires realization of that capacity. Nonetheless, the moral dimensions of those decisions are not to be found in the concept of respect for personal autonomy or at least not primarily in that concept. To think of them as structured by that concept is to distort what *is* morally salient in the situation. Charles-

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13. This is surprising coming from someone so aware of the conceptual connections between respect for autonomy and the notion of human individuality. *Id.* at 19-20.

14. See John Quilter, *The Babies Doe: Sanctity or Quality of Life*, 3 *BIOETHICS OUTLOOK* 4-7 n.5 (1992).



worth's analysis of the treatment decisions which have to be made concerning disabled newborn infants is distorted in just this way.

In addition, when autonomy *is* morally salient, the advocates of its supremacy often fail to see what underlies its relevance and importance. Thus, they make the mistake of thinking that because personal autonomy is internal to the kind of respect owed to human beings, it follows that respect for them as individuals must be respect *for* their autonomous nature *extracted from the rest of what makes them worthy of respect*.<sup>15</sup>

But think of how we bring up children. Amongst the many hopes we have for them and for the kind of people they will be as adults, we want them to become morally responsible. When you analyse this hope, you see that it involves the hope that they will acquire (a) the virtues (the dispositions to feel and to act in certain ways) together with that searchingly-particular judgment that is a part of practical wisdom and (b) their own independent sense of what constitutes acting well in particular situations and in general in life, and of why acting well matters. These two aspects of a good education are not separate acquisitions: rather they are two aspects of a single achievement. The way in which we value independence of mind and heart are interdependent with expressions of that independence in patterns of feeling and acting. We do not cherish this autonomy in isolation from all the other things that it enables in children.

We cherish autonomy's expression in affection and love, in courage and perseverance, in the pursuit of knowledge, and in the creation of literature and art. But we do not value the expression of autonomy in lack of sympathy or brutality, in ways of feeling and acting that are unfaithful, unjust, greedy, or self-indulgent. In fact, we judge these character traits more harshly when we think that they are the expressions of a person's autonomy than when we think they can be excused in the light of common human obstacles: ignorance, passion, poverty, illiteracy, circumstantial constraints, etc. And we continue to treat an individual as "one of us" (that is, as belonging to the kind of being who in the normal course of things expresses her autonomy in all these ways) even when she can no longer express her autonomy in any way at all or can do so only in very diminished ways. Because we deplore some manifestations of autonomy and value all those individuals who have either never had the opportunity to be autonomous or have long since lost the capacity to be autonomous, it cannot be the concept of autonomy which illuminates our sense of the

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15. Raimond Gaita makes a similar point about respect for human beings as rational beings. RAIMOND GAITA, *GOOD AND EVIL: AN ABSOLUTE CONCEPTION* 27-28 (1992).

preciousness<sup>16</sup> of a human being.

A second criticism of the current paradigm of respecting autonomy in health care is that in giving autonomy a moral primacy, the advocates for the supremacy of autonomy obscure the concepts that are really at work in our thinking about many aspects of health care, such as organ donation, euthanasia, and assisted suicide. Obscuring the concepts runs the risk of degrading our thinking and, therefore, our acting.

In Helga Kuhse's *Willing to Listen, Wanting to Die*, an emphasis on the terrible facts of terminal illness, such as severe and unrelievable pain, is commonplace throughout the book. Of course, even the best and most experienced palliative care physician cannot always relieve the pain associated with terminal illness—or at least not by direct analgesic means. Moreover, even today many people spend the last part of their lives suffering from symptoms of their illnesses which, though relievable, are not in fact relieved. But as specialists in palliative care know, physical pain is *generally* neither an inevitable nor an unrelievable part of terminal illness. For example, physical pain from end-stage cancer can be relieved either by analgesics or by non-drug measures, such as withholding or withdrawing overly burdensome treatment, reinforcing support systems, and clarifying the goals of treatment. If none of these measures is successful, others are available. For example, it is possible to lightly sedate a patient so that he or she sleeps through the last stage of life and is conscious only when it is desirable.

The issue then is why are the generally-relievable aspects of serious illnesses treated *as though they are generally unrelievable*. There are various possible reasons. Perhaps the contributors to *Willing to Listen, Wanting to Die* do not know any better, in which case, they need to be better informed so to have their expectations of palliative care raised. Perhaps they are describing someone's actual experience, in which case we must conclude with regret that the individual concerned received second-rate palliative care. One suspects another idea is at work in the minds of most of the contributors. They judge that the life of the person whose death they wish intentionally to hasten (their own or that of someone else) really is no longer worth living, and this is a judgment which *they invite us to share*. What is basic in their thinking is not the concept of respect for personal autonomy, but the concept of a life so diminished as to be not

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16. Indeed, one part of the idea that human beings are precious or "intrinsically valuable" is that we cannot account for their preciousness in terms of anything *about* them: their rationality, self-consciousness, autonomy, etc.

worth living. We are invited to agree with the soundness of that judgment. What parades as an argument in favor of legalizing euthanasia and assisted suicide based on respect for personal autonomy in fact gets its persuasive power from the idea that a life so reduced by pain and other symptoms of illness really is a life not worth living.

Those who argue for the legalization of euthanasia and assisted suicide on the grounds of respect for autonomy rely on a distinctive and challenging claim: respect for autonomy is *enough* to justify those practices and the individual's subjective valuation of his or her life may justify bringing about its end. In laying such emphasis on "quality of life" considerations, on the "unrelievable" pain of terminal illness, the contributors to *Willing to Listen, Wanting to Die* tug our intuitions in the same direction as the autonomous choice they wish to see legalized. Respect for autonomy emerges as insufficient on its own to justify the intentional hastening of death; it needs buttressing by our agreement with the soundness of a judgment that a person's life is not worth living. The contributors do not base their case for the legalization of euthanasia solely on respect for personal autonomy. Rather, they invite us substantively to agree with them about the correctness of an individual's judgment about the quality (in the sense of value) of his or her life.<sup>17</sup>

Of course, some people do believe that some lives are not worth living, that chronic suffering or lack of intelligent self-awareness or evil done or even a certain racial inheritance, etc., deprives a life of its value. The truth or falsity of that belief is not at issue here. What is important to notice here about the concept of a "life not worth living" is that it is radically inconsistent with the very concept which gives respect for personal autonomy its significance: that is, the concept of human life as intrinsically valuable or precious or "sacred." For it is an implication of the concept of the "sanctity of life" that nothing can diminish the value of a human life: not loss of the capacity for autonomous action, not loss of consciousness, not physical suffering, not even evil done.<sup>18</sup>

Those who know Margaret Somerville's writing will not be surprised by her part in the story: her expectation that she was about to hear of someone suffering from a deeply distressing and unrelievable illness, her shock on being told instead of a lonely old lady, her suggestion that it may have been more apt to respond directly to the old lady's loneliness than to

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17. No wonder it is often argued that the legalization of voluntary euthanasia inevitably will encourage the widespread practice of non-voluntary euthanasia.

18. Of course, it does not follow from this, and it is not true, that human life must always be prolonged.

have taken her request at face value, her suggestion of a cat, etc. The doctor's response, "What a good idea!" is revealing. It seems that the doctor did not really believe that respect for autonomy was enough to justify euthanasia. The doctor's own thinking about the woman's request for euthanasia reveals two ideas: respect for the woman's desire to end her life and agreement with the woman's own judgment about the worth of her life. Those who reveal themselves to be committed to the view that respect for autonomy is *not* enough on its own to justify euthanasia and assisted suicide must be clearer in their own thinking about how the concept of autonomy works than was the Dutch doctor.

Some people are genuinely committed to the view that respect for autonomy in itself is enough to justify legalizing euthanasia. Without arguing against that view, I have tried to demonstrate that sometimes our thinking about "medical end-of-life" decisions in general, and the legalization of euthanasia and assisted suicide in particular, is degraded by a distorted sense of what is meant by the concept of "respect for autonomy." For very often what is said in the name of respect for personal autonomy is motivated by another, utterly different concept, that a life so diminished—specifically by pain and suffering—is not worth living.

Someone who thinks that respect for autonomy is alone sufficient to justify euthanasia and assisted suicide, and who wants to recommend these practices to others solely on the grounds of respect for autonomy, should try to avoid using cases in which our intuitions pull in the same direction as that expressed in the autonomous choice of the person requesting euthanasia. If that is hard to do, then there is a lesson to be learned.

As pointed out earlier, someone who, like the Dutch doctor in Margaret Somerville's story, reveals herself committed to the view that respect for autonomy is *not* enough on its own to justify euthanasia or assisted suicide, needs to clarify how the concept of autonomy works in her own thinking. This need for clarification speaks to those who view the concept of "respect for autonomy" as one that derives its force from a substantive agreement with the subjective judgment of the patient about the worth of his or her life which he or she wants to end.

Respect for a person's autonomy is a relatively recent and wonderfully suggestive development of a very old but central idea in our moral thinking. It is the idea which Aristotle expressed when he pointed out that we are "part causes" of our own selves.

I have tried to show how some aspects of the current paradigm of re-

spect for autonomy, in particular the tendency to abstract it from all the concepts with which it is interdependent, distort the grammar of that concept and degrade our thinking about the moral dimension of health care. I can think of a no more telling story to illustrate my theme than Margaret Somerville's anecdote about the old lady, the doctor, and the cat.