Physician-assisted Dying in Canada; Where Do We Go From Here?

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The Supreme Court of Canada decision in *Carter v Canada* has begun the process of making physician-assisted dying (PAD) legally available in Canada, but it has not ended it. Much remains to be done in establishing an appropriate regulatory regime for this practice. In what follows I offer recommendations on some of the principal issues yet to be resolved.

1. Who is to be eligible for PAD?

The Court has mandated that PAD be available to 'competent adult persons'. The appropriate standard of competence, or decisional capacity, is the patient's ability to make reasoned decisions *about this kind of treatment--i.e.*, treatment that will hasten death. That capacity will include the patient's ability to understand their current diagnosis and prognosis, the available options for treating their condition (if any), the risks and benefits of each of these, the other available options for palliative treatment, and the implications of choosing assisted death. Because of the finality of this choice, there is a case here for setting a high standard of decisional capacity. However, there is no reason for it to be higher than the standard for other comparable

end-of-life decisions, such as refusing life-sustaining treatment or requesting terminal sedation. The stakes are just as high for these conventionally accepted measures. For adults (eighteen years of age or over), decisional capacity should be the default presumption, which can be overturned only by evidence of impaired cognitive functioning. If some such impairment is suspected, whether due to depression or some other cause, then a qualified neutral party should assess the patient's decisional capacity.

The Court did not restrict eligibility for PAD to competent adults only and there is no justification for doing so. Some provision must also be made for decision-making by 'mature minors' (between the ages of twelve and eighteen). In this case, however, it may be best to reverse the presumption of capacity, so that adolescents will need to demonstrate that they have the maturity to handle a decision of this magnitude. If so, then the decision should be left in their hands, though (especially in the case of younger adolescents) consultation with parents or legal guardians may be mandated; the rule of thumb should be that if a minor is deemed to be competent to refuse life-sustaining treatment then he or she is also competent to request life-shortening treatment. If not, then the decision must be made by the minor's legal representatives, based both on the patient's wishes and on his or her best interest.

There is also no justification for restricting PAD to competent patients only, whether they be adults or minors, and the Court did not mandate doing so. Among those who lack contemporaneous decisional capacity (e.g., through dementia or permanent unconsciousness) some will have been able to register their wishes in advance, whether in a written instrument or by more informal means. A legal policy should allow for 'euthanasia directives', which should be accorded the same weight as advance refusals of life-sustaining treatment. In cases where the patient's prior wishes are in doubt, the treatment decision should be based on the patient's best interest. The best interest standard will be the only one applicable to patients, such as infants, who have never had decisional capacity. Again the rule of thumb must be that if withholding or withdrawing life-sustaining treatment is justified in these cases then so is PAD.

2. To what forms of PAD must eligible patients have access?

On this question the Court was quite clear. PAD includes both physician-assisted suicide and physician-administered euthanasia. Since the Court struck down the laws prohibiting both forms of PAD, both must be available to patients who request them and are eligible for them. A policy which provides only for assisted suicide but not for euthanasia will be discriminatory, since it will make assisted death unavailable to any patient whose condition prevents him or her from self-administering an oral dose of lethal medication.

3. By what criteria should requests by patients be evaluated?

The Court has stipulated two criteria: (1) the patient must have a 'grievous and irremediable medical condition (including an illness, disease or disability', and (2) this condition must cause the patient 'enduring suffering that is intolerable to the individual in the circumstances of his or her condition'.

Access to PAD must be responsive above all to suffering. In order to qualify for an assisted death, therefore, a patient must be afflicted by a kind and degree of suffering that surpasses their limits of toleration. Where those limits lie must be ultimately up to the patient to determine; this will be a personal and individual decision. The suffering in question may, but need not, result from such physical symptoms as pain, nausea, dizziness, shortness of breath, etc. and it may, but need not, result from a physical illness. The illness may be psychological rather than physical and the suffering may be psychosocial, including such familiar forms of distress as depression, loss of dignity, loss of independence, loss of the ability to do what makes life worth living, etc.

The common denominator for all these forms of suffering is that they must be the product of some diagnosable medical condition (an illness, disease, or disability). It is not enough to be simply 'tired of life'; PAD is a form of medical treatment and, as such, should be reserved for the relief of suffering due to a medical condition. Those who are simply fed up with living may seek such relief as they can find on their own, but they have no right to request the assistance of a

medical practitioner. A practitioner, therefore, has the right to exercise professional judgement in determining whether a patient's request conforms to the stated criteria; there is no obligation to respond affirmatively to requests deemed to be groundless or frivolous.

While PAD is a legitimate end-of-life option, because of its finality it should be considered a palliative last resort. A policy cannot require that a patient's suffering be intractable--that is, untreatable by any other palliative measure--since the patient has the right to refuse these other measures. But it can, and should, require that the underlying illness or disability be untreatable by any means acceptable to the patient, that the suffering be permanent (thus in need of relief by some palliative means), and that the patient be fully briefed on other ways of dealing with her symptoms and urged to try them before requesting assisted death. Additionally, because of the finality of an assisted death, it would be sound practice to require an independent medical opinion on the patient's diagnosis and prognosis. In cases in which there is reason to doubt the patient's decisional capacity, expert opinion on that question should be sought as well.

The suffering requirement may seem to rule out euthanasia for some noncompetent patients: for instance, those who are permanently unconscious and therefore (we assume) incapable of experiencing any form of distress. But a person in this condition can declare in advance that she regards continued life in this condition as intolerable; in that case, she can still be considered to be suffering from her condition.

Finally, no mention has been made here of the requirement that the patient be in a terminal condition. In the broadest sense, virtually all patients who satisfy the suffering requirement will be afflicted with some condition which will (sooner or later) be fatal. In this sense, therefore, a requirement of a terminal diagnosis would be redundant. If the requirement is drawn more narrowly, however, by stipulating (as Oregon and Washington do) that the patient must be within six months of death from their illness, then it is unjustifiable. Being terminal in this sense is neither necessary nor sufficient to qualify for PAD: not necessary because it is cruel to deny this option to a patient who is experiencing intolerable suffering but still has a life horizon beyond six months, and not sufficient because being terminal but not suffering provides no grounds for

hastening death. The eligibility criteria must therefore require only suffering, not an arbitrary length of remaining life.

4. How should patients make requests for PAD?

PAD is a treatment request, not a treatment refusal. A patient can refuse life-sustaining treatment simply by saying 'no' to it. It is standard for regulatory policies concerning PAD to require that requests be written rather than (or in addition to) verbal and that they be properly witnessed. The patient's written request then becomes part of the documentary record of the treatment. In the event that a patient is physically incapable of signing a written document, some other legally recognized means of registering the request must be provided. A requirement that the request be repeated at least once over a period of, say, a few days may also be appropriate in order to determine that this decision represents the patient's settled frame of mind. However, this requirement must be waivable in cases in which the patient's suffering would make it an act of cruelty to enforce a delay. A request must be revocable by the patient at any time.

Whatever form the patient's request takes, it must be both voluntary and informed. In order to be voluntary it must be free of undue influence, whether by family, friends, or health care providers. Influence will be 'undue' when it rises to the level of fraud, deceit, duress, or coercion. A patient's decision should be deemed to be voluntary unless there is some reason to think that it is not, in which case the patient should be offered counselling or access to a trusted adviser. In order for the request to be informed the patient must be provided with adequate information concerning their diagnosis and prognosis, the treatment options (both therapeutic and palliative) that are available, the probable outcome of each of these options, and the risks attached to each option. In short, patients must be given all the information that a reasonable person in their circumstances would require in order to make a considered decision to hasten death (whether by PAD or any other end-of-life measure). In order to ensure that the patient is adequately informed about other palliative treatment options, it would be sound practice to require a consultation with a palliative care team.

In the case of a noncompetent patient the request for assisted death must be made by a substitute decision-maker. The standard for such decision-making must be either substituted judgement (if the patient's wishes are known) or best interest (if they are not). An advance directive requesting PAD, executed by the patient while competent, should be considered conclusive for the purpose of the substituted judgement standard, unless there is reliable evidence that the patient subsequently changed their mind. Whichever standard is appropriate in a particular case, the substitute decision-maker must be provided with all of the information whose disclosure to the patient would be obligatory, were the patient decisionally capable. An informed request by a substitute decision-maker should be considered conclusive unless there is some reason to suspect an ulterior motive, such as personal gain. In that case, the request should be referred to a neutral body, such as an ethics committee, in order to ensure that it conforms to either of the foregoing standards.

5. Who should provide PAD?

The Court has struck down the laws prohibiting assisted suicide and euthanasia only in so far as they apply to physicians. PAD is a form of medical treatment and should be offered only by qualified medical practitioners. In this respect, therefore, a regulatory policy should follow the model provided by the Benelux countries and by Oregon and Washington, not that of Switzerland where assisted death is offered by private not for profit organizations. It would also be sound practice to require the attending physician to be present for an assisted suicide to deal with any possible complications (this is not currently the case in Oregon and Washington).

PAD is a controversial matter. Some physicians will have no religious or ethical objection to providing this service for their patients, while for others it will violate the dictates of their conscience. A policy must include a 'conscience clause' which enables providers to decline to offer the service on grounds of personal conviction. However, it must also require that they not abandon patients who request PAD; they must then be obliged to provide patients with an effective and timely referral to a provider willing to help them. On the other hand, publicly funded

health care institutions should be required to permit PAD on their premises if a physician is willing to provide it. Otherwise, patients in many communities with religiously affiliated hospitals will be denied timely access to the service.

6. What kind of review and oversight would be appropriate for PAD?

Every case of PAD must be fully documented at every stage and reported to a provincial review body. While the cause of death may be recorded as the patient's underlying illness, the manner of death must be reported as 'physician-assisted suicide' or 'physician-administered euthanasia'. The body that receives these reports should review them and flag any anomalies; suspicious cases should be reported to the provincial regulatory body or the appropriate officials in the criminal justice system for possible investigation. The provincial ministry of health should publish regular, preferably annual, statistical reports on the operation of the policy within its jurisdiction, providing such information as is necessary for effective oversight. In addition, provincial data should be aggregated at the national level by an oversight body which can publish annual reports for the country as a whole. This oversight body should also undertake regular studies of end-of-life practices in Canada. As in the Netherlands, this may be done by selecting a sample of death certificates over a chosen period based on the likelihood of some form of medical involvement in hastening patient death (whether by PAD, withdrawal of life-sustaining treatment, terminal sedation, or whatever). Questionnaires can then be sent to the attending physicians requesting more information on the cases in question. Among many other valuable types of data that can be acquired by this means, it will also provide information on whether some cases of PAD are not being reported as such.