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COMMISSION ITINÉRANTE

MOURIR DANS LA DIGNITÉ

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COMMISSION ITINÉRANTE

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Commission itinérante : Mourir dans la dignité
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Monsieur le Président
Mesdames et messieurs les Commissaires,

Je vous remercie pour cette occasion d'ajouter à mes propos du printemps dernier.

Je vous félicite pour la constance et le professionnalisme exemplaire dont vous avez fait preuve tout au long de ces audiences.

Sous les pluies d'automne et sauf erreur, mon temps alloué a rétréci de 25 à 15 minutes. Je devrai être bref. Je maintiens le contenu du texte originel précédemment soumis pour aujourd'hui, que je précéderai par un ajout, rendu nécessaire par un événement récent.
Dans un premier temps je prévoyais commenter la Loi canadienne telle que perçue par un citoyen moyen qui s'informe. Dans un second temps, je voulais offrir quelques critiques des principaux arguments opposés à l'IVV (ou euthanasie sur demande). Les contraintes de temps me limiteront à ce dernier item, tout en demeurant prêt à répondre à toute question sur l'ensemble de mon document.

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PROLOGUE

Considérant son ascendant historique qui lui confère autorité, le rapport soumis récemment par le Comité exécutif du programme de soins palliatifs de l'U. McGill, tient à juste titre un rôle de premier rang.
La responsabilité première des *détenteurs d'un savoir particulier*, est de vous informer le plus adéquatement possible. S'il doit en découler une influence, elle devrait provenir de la nature et de la qualité des informations transmises.

Pour avoir œuvré au sein de cette équipe pendant 18 ans, je me sens interpellé par le rapport que ce Comité vous a récemment transmis par la bouche du Dr Bernard Lapointe.
Articles en mains (que je vous transmets), je tiens à montrer que certaines données de ce rapport semblent manquer de rigueur scientifique et ce faisant, favorisent la position clairement énoncée des auteurs, d'être en opposition à l'IVV. Se pourrait-il qu'on aurait confondu *informer* et *influencer* ?

Je tiens en premier à dire que je souscris à l'agenda palliatif présenté de façon exhaustive. Répondre le mieux possible aux besoins des personnes en fin-de-vie, dans le but d'alléger leur fardeau et celui de

leurs proches, par la compétence clinique et une compassion polyvalente prodiguée dans la multidisciplinarité.
Une réserve cependant : IVV (euthanasie volontaire), dicte de laisser un temps de parole au patient. Or, le document soumis donne rarement la parole au mourant, surtout celui pour qui demander l'euthanasie consiste à demander un geste criminel. Il a donc toujours tort dans le contexte de la Loi actuelle. D'où, semble-t-il, l'inquiétude du Dre Marcia Angell qui voit les Soins palliatifs adopter peu à peu une attitude qui s'apparente à la suffisance et à l'inflexibilité –hubris and rigidity- écrit-elle (**1**).

Une première donnée à rectifier cite à *l'indicatif présent* une donnée périmée qui devrait l'être à *l'imparfait.* En p.XXX du rapport du Comité de McGill, on lit : «50% des cas néerlandais d'aide médicale au suicide et (au cas) d'euthanasie ne **sont** pas rapportés». Sans autre commentaire que deux références, de 1992 et de 2004, qui réfèrent à des faits antérieurs à 1990 et à 2001, années des révisions officielles néerlandaises (van der Maas et coll.).
Or, un rapport publié dans le NEJM de 2007, très souvent cité, résume les données de 1990, 1995, 2001 et 2005. Les % de cas rapportés pour ces années sont respectivement de 18%, 40%, 54.1% et 80% en 2005 (**28**). D'un coup d'œil, on voit là une quasi ligne droite dont la pente raide pointe au-delà de 95% en 2010, c'est-à-dire un maximum atteignable dans ce genre de compilations. Nous sommes très loin de 50%.

Dans un deuxième cas, une excellente étude de Battin et coll. (**20**), citée par le Comité McGill, étudie 11 sous-groupes de personnes dites «vulnérables». Un seul de ces 11 groupes, en Orégon et aux Pays-Bas, a recours à l'euthanasie ou au suicide-assisté en surnombre. Il s'agit de patients sidéens. Or, il ne s'agit pas pour eux d'euthanasie ou suicide-assisté sans demande expresse mais bien d'IVV. À noter, **aucun** des 10 autres sous-groupes de personnes vulnérables n'apparaît en surnombre dans les statistiques, *fait complètement ignoré dans le rapport de McGill*. Il ne s'agit donc pas de dérive envers les sidéens, comme on invite à croire, mais d'attributs particuliers à ce groupe, pour qui les services offerts aux autres s'avèrent insuffisants pour eux. Or, ce sont ces 10 sous-groupes qui inspirent tant d'inquiétude de dérive chez les opposants à l'euthanasie et qui ne sont pourtant pas ciblés, comme en ferait foi un surnombre d'euthanasies parmi eux. Ce cas d'espèce exigeait mention.

Dans un troisième exemple, le rapport du Comité McGill insiste pour interpréter les données d'une recherche dans un sens diamétralement opposé à celui des auteurs de l'article en question, eux-mêmes présents au chevet des malades impliqués (**27**). Le texte de McGill dit : «En extrapolant les résultats de l'étude de Chambaere au contexte du Québec…correspondrait à 1020 personnes euthanasiées sans demande explicite ». Or, le texte de l'article décrit ces cas comme étant davantage des « intensification de l'analgésie», en accord avec le principe du « double effet » et souvent sans abrégement de la vie. Il

s'agit de sédation palliative que le Collège des médecins et la FMSQ voudraient voir reconnus comme des soins appropriés.

On peut le voir, tout comme les médecins québécois, ceux de Belgique et des Pays-Bas demeurent perplexes quant aux frontières entre sédation et euthanasie et même quant à l'intentionnalité de l'euthanasie ou de l'option du «double-effet». Car la réalité veut que lorsqu'une sédation terminale est amorcée, aucun médecin ne souhaite qu'elle se prolonge indûment, ce qui revient à désirer qu'elle soit courte, donc à espérer la mort.
Espérer une mort qu'on ne veut pas causer, tout en posant des gestes qui peuvent la précipiter : la proximité de ces frontières éthiques les rend indéchiffrables. D'où le réalisme humaniste de la notion de «soins appropriés» mise de l'avant par le Collège des médecins.

Un dernier exemple. Le «document McGill» mentionne l'apport du chercheur canadien Chochinov au soulagement de l'indignité (Dignity Therapy), sans mention de l'incontournable étude à laquelle il a contribué avec Wilson et coll.(**2**). Donnant expressément la parole à près de 400 cancéreux en phase terminale répartis dans 8 services reconnus de soins palliatifs du pays, près de 6% ont répondu vouloir l'IVV immédiatement fut-elle légale au Canada.

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Je consacrerai le temps qui me reste à des commentaires sur les principaux motifs avancés pour contrer l'euthanasie (Voir p.5). Je débuterai par les risques d'abus, « l'argument dominant des opposants » selon l'expression de l'Hon. Baudouin. Je demeure prêt à répondre à toute question sur l'ensemble du texte que je vous ai soumis

OBJECTIONS À L'EUTHANASIE

1 Les personnes vulnérables et les abus

Cet argument, lors de l'arrêt Sopinka de 1993, fut mis en doute parce que sans fondement objectif. Plus de quinze années plus tard, il n'existe toujours pas de données probantes justifiant ces appréhensions. Au contraire, Margaret Battin, philosophe américaine reconnue, et des auteurs notoires de Hollande et de l'Orégon, ont analysé les données nationales de ce pays, de 1990,1995, 2001 et 2005 et celles de l'Orégon de 1996 à 2006. Ils n'ont rien trouvé pour soutenir l'hypothèse que des personnes appartenant à dix groupes « vulnérables » aient été ciblées par la pratique de l'euthanasie. Ces sous-groupes étudiés furent : niveau d'instruction faible, indigence, grand âge, d'âge mineur, handicap physique ou intellectuel, maladie mentale incluant la dépression, maladie

chronique, l'ethnie, la race, le SIDA. Seuls les sidéens étaient surreprésentés, mais depuis le début des années '80, ces tristes victimes ont toujours présenté un « cas d'espèce » dont l'analyse dépasse les bornes de cette présentation et n'infirme pas cette étude (20) tel que mentionné au début de ma présentation.

Les données de Belgique sont du même ordre dans ce domaine.

Quant aux prétendus abus d'euthanasies « sans demande explicite », ils reflètent une lecture partiale des colonnes de chiffres publiés par la Hollande, la Belgique et l'Orégon. On utilise fréquemment des données périmées, sans tenir compte des améliorations marquées et des données socioculturelles, reconnues comme peu transposables d'une culture à l'autre, dans leur nudité numérique.

La récente étude belge de Chambaere et coll.(2010) en est un exemple (27).
Elle présente des données qui suggèrent des euthanasies-sans-demande-expresse, que les auteurs de l'étude interprètent en fait comme des sédations palliatives. L'analyse minutieuse des circonstances de ces fins-de-vie pénibles et compliquées et *très différentes de celles rencontrées dans les cas d'euthanasie*, montre que les soignants sont essentiellement à la recherche de soins appropriés à chaque circonstance, 70 % de ces patients étant comateux et 21% inaptes.
Se référant à ces fins-de-vie potentiellement abrégées sans demande expresse, le texte de Chambaere dit : «Cela suggère que l'utilisation de drogues potentiellement (opiacés) létales dans ces cas, ressemble davantage à une intensification de l'analgésie qui accepte la règle du *double effet*, et dans de nombreux cas, sans devancer la mort ». Que souvent dans ces cas, les infirmières aient administré ces drogues, confirme qu'il s'agissait de sédation palliative *in extremis.*
Se référant à cette pratique, l'article ajoute : « Sa fréquence n'a pas augmenté en Belgique…Au contraire, elle a diminué de 3.2% en 1998 à 1.8% en 2007, niant ainsi la «pente glissante».
Cela ne semble-t-il pas plus prêt de « soins appropriés » que de dérive euthanasique ?

Je vous rappelle l'opinion de l'Hon. Baudouin : «les cas de bavures sont rares ou inexistants ». Cependant, écrit-il, «certains dérapages restent possibles et il faudra être vigilant». Nous en convenons tous : la vigilance sera toujours de mise.

2 Les demandes d'euthanasie sont si peu nombreuses… Pourquoi une nouvelle loi ?

Une loi ou une réglementation est nécessaire, parce que d'une part, des demandes justifiées existent ; d'autre part, on craint soient les abus ou bien qu'on laisse souffrir des mourants que les meilleurs soins ne savent soulager, par crainte de condamnation. Seule une loi balisée peut répondre à toutes ces

appréhensions, tout en respectant le droit à l'autodétermination du malade. Je ne puis concevoir que quiconque préfère la clandestinité à la légitimité décriminalisée.

Indirectement, de grands experts ont déjà répondu à cette question.
Le Dr.E.Cassell, le père de la notion de *souffrance* écrit que si « la plupart » des demandes s'effacent sous de bons soins, il faut reconnaître que celles qui persistent représentent les plus grandes souffrances, dont seuls les patients sont les juges de leur sévérité et que si tous les efforts ne soulagent pas, il faudrait exaucer leur demande (6).

Le Dre Marcia Angell, ex-rédactrice-en-chef du New England Journal of Medicine, reconnaît que de bons soins diminuent le nombre des demandes mais rappelle que pour être crédibles, ces données se doivent d'être recueillies dans un contexte où l'euthanasie est accessible (1).

Une excellente étude pan-canadienne a étudié cette question et mérite qu'on s'y arrête. Dirigée par deux chercheurs renommés, Wilson et Chochinov, on questionna 379 cancéreux en phase terminale répartis sur 8 Services **reconnus** de soins palliatifs du pays (dont un du Québec). On s'informa de leur opinion face à l'euthanasie, si elle était permise au Canada.

* 60% se dirent en faveur de l'euthanasie
* 40 % ne la désiraient pas actuellement mais y penseraient sérieusement si leur état se détériorait significativement.
* 5.8 % (22 patients) l'auraient demandé immédiatement. Ils étaient les plus malades même si leur survie n'en fut pas affectée. Plus déprimés, d'une religiosité moindre, aucun ne fut considéré inapte. Un seul a changé d'idée, son état s'étant amélioré. Les autres furent questionnés à nouveau une fois par semaine, certains pendant 4 semaines. Tous persistèrent dans leur demande.

Les auteurs concluent que si le désir d'euthanasie est parfois transitoire, il perdure quand il est fermement ancré (2).
Cette étude démontre que le nombre de demandes ne peut être relié directement à la qualité des soins. Il dépend tout autant de l'existence d'un choix. Cinq à 6% n'est pas insignifiant. De plus, elle confirme l'opinion du Dre Angell, que lorsque le choix n'existe pas, la rareté des demandes est peu crédible.

De même l'opinion que le théologien Paul Tillich exprime dans « Le courage d'être » s'en trouve supportée : « Elles sont plus nombreuses qu'on penses les personnes pour qui la notion de suicide ne s'adresse pas à ceux que la vie a vaincus mais à ceux qui ont triomphé de la vie et qui sont tout à la fois capables de vivre et de mourir et de choisir librement entre les deux » (16).

3 Les demandes d'euthanasie ne sont que des appels à l'aide et à la compassion

La moindre expérience auprès des mourants confirme en effet cette idée mais, il faut le souligner, seulement dans « la plupart » des cas. Or, l'euthanasie concerne précisément les personnes en marge de « la plupart », cette minorité dont parle le philosophe et théologien Tillich, laquelle peut et veut pouvoir choisir librement le moment de mourir et dont le Dr.Cassell dit qu'elle mérite d'être exaucée(6).

Les données probantes n'existent pas ici, sauf celles de Wilson et Chochinov, qui infirment lourdement cette prétention. Seul un paternalisme viril peut donner la certitude que ces sentiments intimes nous sont accessibles et soulageables (17). Cassell écrit que : «Prétendre qu'on peut soulager toute souffrance dénote une ignorance de sa nature et de ses sources (6).

Le prof.Kluge (12) déclara :« Il me semble qu'on fait bon marché de l'autonomie et du respect la personne ainsi que de la notion des droits individuels ». Puis citant C.S.Lewis, il ajoute : « Parmi toutes les tyrannies, celle qui est sincèrement imposée au nom du bien de ses victimes est peut-être la plus oppressive ».

4 La pratique de la sédation terminale élimine le besoin de pratiquer l'euthanasie

L'étude de Wilson / Chochinov ne mentionne pas comment ces 21 patients sont décédés. Combien ont poursuivi leur destin, mal soulagés, jusqu'à une mort naturelle ; ni si certains ont bénéficié d'une sédation terminale.

Depuis quelques années, la sédation terminale est présentée comme la panacée à toute demande d'euthanasie. Elle consiste à administrer des sédatifs pour rendre le patient inconscient de sa souffrance, intolérable et inapaisable. En tant que réponse à une demande d'euthanasie, elle doit être discutée avec le malade. Aucune nourriture ni hydratation sera donnée et l'inconscience sera maintenue jusqu'au décès. La durée, imprévisible, peut durer de quelques jours à au-delà de deux, voire trois semaines (26). Ces longues sédations deviennent intolérables pour les proches et très stressantes pour les soignants. De plus, prétendre que seule la maladie est responsable du décès –pour satisfaire au principe du double effet- est une aberration clinique, surtout dans les cas où la maladie ne s'accompagne pas d'anorexie marquée (e.g. SLA ou maladie de Lou Gherig)

Puisque ces souffrances sont non soulagées, si la sédation s'avère de courte durée, on se demande pourquoi avoir attendu si longtemps avant de soulager le mourant. Inversement, des soupçons peuvent être soulevés quant à une euthanasie. Par contre une sédation très longue, de l'avis de tous, est insupportables pour les proches (ce qu'anticipent ceux qui refusent) et tout autant pour les soignant. Cette stratégie, que des experts de l'U. Harvard ont appelée « euthanasie lente » (18) n'est pas balisée et n'impose aucun rapport officiel aux autorités contrairement à ce qui serait imposé à la pratique de

l'euthanasie. Elle échappe donc à l'évaluation et aux compilations. Plusieurs auteurs y voient là une lacune certaine.
Mis au courant de ces détails, certains patients refusent une sédation terminale pour éviter ce fardeau à leurs proches. Ils continueront donc à souffrir. Certains l'acceptent comme conforme à leurs valeurs. D'autres s'y résignent, à défaut d'euthanasie, ne pouvant plus endurer leur souffrance.
Il s'agit alors de l'imposition à un mourant de l'agenda du gouvernement, cautionné par la médecine, plutôt que de rejoindre le malade sur SON terrain, tel qu'enseigné par Dre Cicely Saunders (19).

5 Du Commandement TU NE TUERAS POINT et du Serment d'Hippocrate

Le grand bibliste A.Chouraqui nous rappelle qu'une meilleure traduction du Commandement serait TU NE COMMETTRAS PAS D'ASSASSINAT ; que justement, l'assassinat commis par Caïn se dit dans la Bible *lo taharog*, alors que le Commandement utilise *lo tirtz'a*, une expression dit Chouraqui, au sens complexe qui exclut les homicides de guerre, d'autodéfense ou par décrets juridiques. La sagesse juive faisait place aux exceptions (21). Notre loi manque-t-elle de sagesse ?

Quant au serment d'Hippocrate, vieux de 2500 ans, toutes les Facultés de médecine, une à une réécrivent ce texte pour l'adapter à nos mœurs. L'autonomie de la personne n'avait pas en son temps l'importance qu'elle a de nos jours, ni l'obligation morale de la respecter. Non plus l'avortement, qui ne se trouve plus mentionné dans les nouveaux textes. Dans l'Athènes antique dont nous aimons nous réclamer, le Sénat octroyait des suicides assistés sur représentations acceptables. Cette maturité nous a échappé…

6 L'essor des Soins palliatifs sera inhibé

La prétention que l'essor des soins palliatifs serait inhibé par l'accès à l'euthanasie est clairement infirmée par les données des législations où l'euthanasie ou le suicide assisté sont permis. Que ce soit aux Pays-Bas, en Belgique ou en Orégon, les témoins et acteurs en ce domaine sont unanimes à reconnaître le contraire : les soins palliatifs ont connu un essor remarquable sous cette nouvelle législation (3,4,6,22) Nous souhaitons tous l'essor des soins de fin-de-vie, et cette crainte est non-justifiée.
L'argument selon lequel on ne devrait même pas discuter d'euthanasie tant que l'accès à des soins palliatifs n'est pas disponible à tous est irrecevable. Ce genre d'argumentation revient à dire qu'on ne devrait pas greffer de reins ou de cœurs parce qu'on ne peut les offrir à tous ceux qui sont en attente. Le Dr. Cassell lui-même dans le texte déjà cité émet ce point de vue. Tous ont le droit de réclamer mais c'est le législateur qui décide de l'octroi des budgets pour l'ensemble de la population. Certaines priorités ne peuvent justifier d'en dépouiller d'autres impunément.

7 La relation patient / médecin souffrirait de l'euthanasie

Les opposants à l'euthanasie entrevoient une détérioration de la relation patient / médecin comme conséquence de la pratique de l'euthanasie. Il s'agit encore d'une pure hypothèse non fondée. L'ouverture, la communication obligée, la transparence et la compassion qu'exige l'euthanasie devrait au contraire raffermir les liens entre le médecin, son équipe, le malade et ses proches. C'est d'ailleurs ce qui est observé. Dans l'étude de Wilson déjà mentionnée, les demandeurs d'euthanasie y voyaient un geste de compassion et le refus d'aider comme inhumain. De fait, une étude comparant 6 pays européens sur le thème de la confiance accordée au médecin a donné le premier rang aux médecins hollandais, 97% des personnes questionnées leur accordant leur pleine confiance (22).

8 Une lutte de pouvoir

Certains avancent que les médecins recherchent le *pouvoir de tuer* alors que d'autres prétendent que les demandeurs d'euthanasie ont une personnalité avide de tout contrôler et veulent gérer leur mort. Le « droit de tuer » est une méconnaissance de la langue. Dans les situations *in extremis* où une agonie atroce se déroule, il s'agit de reconnaître, comme le demande le Collège des médecins, qu'écourter cette souffrance soit un geste considéré approprié, pour lequel le « bon vieux médecin de jadis » eut été remercié nous dit Cassell.
Le philosophe Beauchamp montre que la moralité d'une action repose sur sa justification et sa bienfaisance (29). C'est le médecin qui évalue la justification (diagnostic, phase terminale, aptitude et liberté dans la décision) et le patient détient la préséance dans l'évaluation de la bienfaisance.
Il n'y a pas de lutte de pouvoir mais un processus décisionnel essentiellement partagé.

Les demandes d'euthanasie qui ne s'apaisent pas sous de bons soins doivent toutes mener à un dialogue ouvert et respectueux. Et, répétition obligée des mots de l'Hon. Baudouin : « Le premier devoir du médecin n'est pas de préserver la vie à tout prix mais de respecter la liberté de choix du patient » (8). Promouvoir l'autonomie des patients est à l'opposé d'une recherche de pouvoir.

D'une manière générale, on admire les personnes décidées qui ont bien su mener leur vie. Les paroles de Paul Tillich et d'Hubert Doucet citées plus haut leur sont dédiées et méritent réflexion.

9 Prévenir le suicide plutôt qu'instaurer l'euthanasie

Notre société fait tout ce qu'elle peut pour prévenir le suicide. Alors pourquoi vouloir autoriser l'euthanasie ? On ne peut comparer une personne en santé, démolie par une peine d'amour ou par le décès récent d'un proche et voulant se suicider, à une personne à quelques semaines de sa mort et qui est affligée depuis des mois de souffrance qu'on ne sait soulager. La première ne demande pas l'aide

qui la sauverait, la seconde n'obtient pas l'aide qu'elle demande pour mettre fin à sa souffrance que *seule la mort peut soulager* selon l'expression du grand Sénèque.

En Orégon, le tiers des patients ayant obtenu les drogues devant servir à leur suicide ne les utilisent pas. Aux Pays-Bas, 9 sur 10 patients ayant formellement demandé l'euthanasie poursuivent leur destin sans s'en prévaloir. Les témoins sont unanimes : l'assurance que donne le «choix» est source de sérénité et sert à prolonger la vie de plusieurs patients (30)

Quoiqu'en disent certaines autorités, c'est mésestimer les 4 Juges minoritaires de la Cour suprême que de dénoncer une « culture de la mort » alors qu'il s'agit d'humanisme et de compassion respectueux de la personne, à l'écoute de la souffrance inapaisable. « En acceptant l'euthanasie et le suicide assisté comme une réponse à la souffrance du patient, la médecine fait sans doute preuve d'humanité » a écrit Hubert Doucet (13.

10 Données économiques

Plusieurs tiennent un discours alarmiste, imaginant une vague déferlante d'euthanasies advenant une légalisation en ce sens, le gouvernement y cherchant des économies. Se peut-il que se dissimulent dans chaque médecin et dans chaque infirmière des criminels intempestifs en puissance, l'un pouvant à peine agir sans l'autre. Il s'agit d'une méconnaissance des mécanismes hospitaliers, où plus de 70% des décès ont lieu.
Toute drogue doit être prescrite. Tout médicament administré doit être consigné, comptabilisé, justifié au dossier, surtout quand les doses sont significativement augmentées –étape essentielle à une euthanasie- le tout formellement déclaré aux autorités. Toute exagération serait vite décelée, voire impossible. La multidisciplinarité, incontournable, est elle-même gage de sécurité.

Que certains budgets ne soient pas au rendez-vous, tous en conviennent. Cette question est d'un tout autre ordre et ne doit pas se régler sur le dos de mourants inapaisables…

De plus, Battin encore, à la lumière des données hollandaises et américaines, a démontré avec ses collaborateurs, que si économies il y a, elles seraient de l'ordre de moins de 0.1% du budget total consacré à la Santé, et ses calculs ne tiennent pas compte des dépenses additionnelles générées par le patient installé dans le lit qu'on viendrait de libérer ! (23).

Les statistiques montrent que la grande majorité des euthanasies impliquent des cancéreux de moins de 65 ans. Que le nombre d'euthanasie chez les grands aînés est très limité, que le nombre de

personnes témoins dans tous les cas est élevé, que cela en soi est un frein incontournable à des abus massifs, seuls aptes à générer des économies significatives.
Si l'on ajoute à cela les témoignages compilés à date, le geste euthanasique s'avère stressant et les médecins qui y consentent s'y résignent par compassion et non de manière intempestive. L'opinion de l'Hon. Baudouin citée plus haut est de nature à en rassurer plus d'un. Reconnaissant que toute loi puisse être contournée, les fauteurs seront toujours l'exception. Par quelle logique choisirait-on la clandestinité alors qu'une transparence balisée serait le choix le plus serein ?

En conclusion, il incombe au gouvernement du Québec de déclarer que l'aide médicale demandée par certains malades, pour abréger leur fin-de-vie de souffrance intolérable et inapaisable, est appropriée à leurs besoins, dans le respect de leur droit fondamental de s'autodéterminer, sous réserve seulement des droits égaux et concurrents d'autrui.

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DE QUELQUES INTERVENTIONS ANTÉRIEURES

La Commission ayant déjà entendu de nombreux intervenants, je tiens à présenter quelques commentaires qui découlent d'interventions antérieures.

Deux arguments opposés à un élargissement de la loi partagent la rhétorique commune de favoriser le sort des uns au dépend des autres.

Le premier, exprimé de plusieurs manières, demande quel système de santé voulons-nous ? Un qui réponde aux besoins individuels ou un axé davantage sur les besoins de la majorité.
Cette vision ne reconnaît pas que dans ses grandes lignes, un système de santé s'articule à trois niveaux. En premier, dans la relation strictement individuelle du patient et de son médecin, celui-ci est déontologiquement responsable qu'au patient. C'est un autre niveau qui se préoccupe de l'ensemble de la population via ses spécialistes en santé communautaire et dont les décisions sont d'un tout autre ordre. Enfin, le niveau décisionnel pour l'ensemble est entre les mains des instances gouvernementales. Surtout en fin-de-vie, on ne peut soigner un malade en fonction des autres.
Il ne faut donc pas opposer ces niveaux mais les harmoniser le mieux possible.

Le deuxième suppose *l'a priori* que les soins palliatifs soient le terme essentiel qui gère l'équation qui va de la fin-de-vie à la mort. Or il faut militer en faveur de l'accès à d'excellents soins de fin-de-vie, mais d'incontournables travaux d'ici et d'outre-mer infirment cet *a priori* La grande utilité des soins palliatifs ne fait aucun doute mais la relation entre soins palliatifs et le nombre de demandes d'euthanasie ne dépend pas que de l'accès à ces soins. La criminalité de l'aide à mourir, tel que l'avait

soupçonné le Dre Marcia Angell (1) apparaît comme un frein important aux demandes, en même temps qu'une invitation à la clandestinité

* L'étude de Wilson (Canada) a démontré que plus de 5% d'une cohorte de cancéreux en phase terminale auraient demandé l'euthanasie, fut-elle un choix au pays (2). J'en reparlerai.
* Celle de van den Block (Belgique) a montré un nombre égal de demandes, de groupes de patients ayant accès ou pas à des soins palliatifs (3).
* En Orégon, 85% des demandeurs de suicide-assisté sont suivis en soins palliatifs. (4).
* Barkwell (Canada) il y a plus de 20 ans, a montré que le sens donné par le patient à sa maladie (punition ou défi à relever) avait beaucoup plus d'impact ($p< 0.0001$) pour diminuer douleur et dépression, qu'un suivi en soins palliatifs (5).

Il faut donc souhaiter un meilleur accès aux soins en général et en particulier en fin-de-vie et surtout à domicile, sans pour autant limiter ou remettre à plus tard, le droit à la liberté de la personne inscrite dans notre Charte des droits et Libertés.

Précisément à ce sujet, le Dr. Éric Cassell, le père de la notion de *souffrance,* tout en souhaitant l'essor des soins palliatifs, demande : «What about now…» « Que faire maintenant…» pour ces fins-de-vie atroces et inapaisables ? Il conclut en écrivant : « …leur demande (d'une IVV) devrait être exaucée» (6).

Une dernière remarque concerne les affirmations selon lesquelles, quelle que soit l'atrocité de certaines fins-de-vie, on ne doit jamais écourter intentionnellement une vie(7). Cette affirmation relève d'une croyance religieuse et mérite le respect en tant que telle, mais ne peut être imposée à autrui. L'Hon. JL. Baudouin écrit : « L'opinion qu'on se fait (de l'euthanasie volontaire médicalement assistée) dépend avant tout de ses propres convictions morales et religieuses» (8). Tous conviennent qu'en morale, toute règle doit pouvoir être violée lors de circonstances exceptionnelles. Théologiens et éthiciens énoncent clairement :« Ce n'est pas la vie qui est sacrée, c'est la personne»(9,10). Le Dr.Roy , décrivant une malade demandant l'euthanasie pour éviter une mort atroce, écrit :« le médecin aurait été entièrement justifié éthiquement de choisir avec la malade le moment de sa mort»(11).

Refuser toute exception s'apparente donc à une idéologie paternaliste où les soignants, en cautionnant la Loi, imposent leur agenda à des mourants, supposément pour leur bien. La plus oppressive des tyrannies nous dit CS Lewis, cité par l'éthicien EH.W. Kluge devant la Commission Sénatoriale Spéciale de 1994 (12).

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Me joignant à d'autres personnes, d'ici et d'ailleurs, j'inclus l' IVV ou l'euthanasie sur demande parmi les devoirs du médecin. Car comme l'a déclaré l'Hon. J.L.Baudouin dans son «Rapport de synthèse» d'un congrès de juriste en juin 2009 :
« Le premier devoir du médecin n'est donc plus de sauver la vie à tout prix mais plutôt de respecter la liberté de choix de son patient » (8).
Pour l'instant, cette liberté tronquée par la Loi, constitue le cœur même de la question à débattre.

PRÉAMBULE à la…

L'expérience confirme que des cas existent – peu nombreux, mais probablement plus nombreux qu'on pense-- où une souffrance insupportable demeure réfractaire aux meilleurs soins, alors qu'une sédation terminale contrecarre les valeurs profondes d'un patient, lequel demande lucidement que par humanisme, on devance sa mort.
La sédation terminale est en soi l'admission explicite que des fins-de-vie sont invivables.
Ces situations nous mènent à l'incongruité suivante, que les recteurs des universités bruxelloises ont bien décrite et qui vaut également pour le Canada.

> « Il est paradoxal qu'ayant pour règle formelle de respecter les choix des patients pendant le cours de leur maladie, les médecins se voient interdire par la Loi de les respecter face à leur mort ».

Le bio-éthicien québécois Hubert Doucet a exprimé semblable idée comme ceci : « La personne mourante est maintenant privée de sa mort alors qu'elle a été responsable de toute sa vie » (13).

****

Je m'en tiendrai aujourd'hui à deux propos principaux.
Le premier sera de jeter un coup d'œil, en tant que simple citoyen, sur les faiblesses décelées par des experts dans le Jugement Sue Rodriguez ,(dit Arrêt Sopinka) qui a maintenu en 1993, le *statu quo* juridique par la mince majorité de 5 contre 4.
Le second sera de répondre brièvement aux principales objections avancées contre l'IVV.

LA LOI

Dans la cause Sue Rodriguez, les Juges majoritaires ont reconnu que son droit d'exercer son autonomie pleine et entière sur sa vie était entravé par la Loi. mais que cela était justifié par deux arguments principaux. 1) par les risques encourus par les personnes dites vulnérables et 2) qu'un large consensus canadien existait quant au caractère sacré de la vie.

Or en 1993, ces risques, purement hypothétiques, n'étaient supportés par aucune données probantes (et ne le sont toujours pas). Ainsi en juin 2009, l'Hon. J.L. Baudouin déclarait : « Le système mis en place pour éviter les erreurs fonctionne bien et que s'ils existent, les cas de bavures sont rares ou inexistants »(1). Je reconnais que d'autres opinions existent mais les données les infirment.

Quant au caractère sacré de la vie, la Cour suprême ne pouvait en 1993, ignorer que déjà en 1979, jusqu'à 1990, tous les sondages canadiens donnaient de 70 à plus de 80% de support à l'euthanasie volontaire. Cette faveur ne s'est pas démentie à ce jour (14).. De plus, la loi sur l'avortement accordait préséance à la personne sur la vie.

Voilà entre autre, ce qui amena le premier éthicien à être reconnu comme témoin-expert dans les Cours canadiennes –le Prof. E.H.W. Kluge, à déclarer devant la Commission sénatoriale de 1994 : « J'affirme d'entrée de jeu…que la Cour suprême, avec tout le respect que je lui dois, s'est trompée quand elle a déclaré, par une faible majorité, que l'Article 1 de la Charte justifiait l'aliéna 241-b., qui criminalise l'aide au suicide (12).

Enfin, il faut noter que la loi actuelle impose à tout mourant voulant exercer sa liberté d'écourter sa vie, soit un geste cruel ou le geste souvent illicite de se procurer des drogues létales ou d'obtenir une aide criminelle passible de 10 à 14 ans de prison. Ces tristes scénarios ont amené le Prof. Kluge à inclure ce qui suit à son témoignage :« En d'autres termes, on a laissé entendre (à madame Rodriguez) qu'il était opportun pour elle de supporter la souffrance ».

À noter également, l'opinion du CCNE de France (Conseil consultatif national de l'éthique) offerte à la demande du gouvernement français, et valable pour le Canada :« La Loi, qui considère l'euthanasie comme un meurtre ou un assassinat, est extrêmement vertueuse et sévère»…« elle est rarement appliquée…Or l'hypocrisie d'une loi proclamée mais non appliquée pose de réels problèmes pour une démocratie» (15). La loi étant ici de moins en moins appliquée, il est désolant de constater que le législateur préfère la clandestinité à une réglementation bien balisée.

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Marcel Boisvert MD
Novembre 2010

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COMMISSION ITINÉRANTE

Critique MMS – 2

J'ajouterai quelques commentaires semblables au sujet de l'imposant Mémoire déposé par la Maison Michel Sarrazin, lequel soulève le même questionnement que celui de McGill. On y trouve le même silence sur d'importantes données et des interprétations contraires à celles faites par les auteurs d'articles, dont on ne peut nier la position privilégiée pour en faire l'analyse. Se pourrait-il qu'une confusion s'installe entre renseigner et influencer ?

Voici quelques exemples :

* mentionner que les Soins palliatifs éliminent la majorité des demandes d'euthanasie, alors que des études démontrent que cet effet provient principalement de la criminalisation de l'acte, tel que l'avait anticipé le Dr M.Angell (1). Cet effet n'est pas observé en Belgique par van den Block (3), ni en Orégon par Ganzini (4) ni quand l'hypothèse d'une légalité de l'euthanasie est proposée, comme le fit l'étude canadienne de Wilson (2).

* d'une manière similaire à celle du Comité McGill, à partir de chiffres publiés en 2007 (diminution des euthanasies et augmentations des sédations) on insinue «que la sédation serait utilisée de façon déguisée pour hâter la mort», une hypothèse contraire à l'explication des auteurs (van der Heide, réf. 28). L'article rappelle qu'entre 2001 et 2005, il fut déconseillé aux médecins d'utiliser les opiacés pour pratiquer l'euthanasie, amenant des médecins à associer certains décès à la sédation terminale plutôt qu'à l'euthanasie, alors que rien ne suggérait un changement de comportement des médecins, d'autant plus que les données faisaient état d'une amélioration de la pratique en général, fait reconfirmé par des études ultérieures (27, 28). Ces données n'évoquent pas une « pente glissante ».

Qu'on ait « clairement démontré qu'il n'y a pas d'exception en Soins palliatifs pouvant justifier des demandes d'euthanasie » est loin de l'être, d'autant plus que cela n'est pas conforme à certains écrits d'au moins deux des trois éthiciens suggérés. Je soumets que l'évaluation (Annexée) de l'Hon. J.L.Baudouin, à l'issue d'un congrès de juristes, est plus objective : « Les études belges et néerlandaises sur le sujet montrent que le système mis en place pour éviter les erreurs fonctionne bien et que, s'ils existent, les cas de bavures sont rares ou inexistants »(8).

RAPPORT DE SYNTHÈSE

CONGRÈS DE L'ASSOCIATION HENRI CAPITANT - 2009

JOURNÉES SUISSES
7-12 juin 2009

L'honorable Jean-Louis Baudouin
Avocat conseil
FASKEN MARTINEAU DuMOULIN
Professeur associé
Faculté de droit – Université de Montréal

peut-il, lorsque nécessaire pour la santé ou la sauvegarde des autres, devenir en quelque sorte partie du patrimoine commun de l'humanité et être ainsi revendiqué à titre de bien collectif ? Ce sont là des controverses que tous les pays auront à résoudre et dont la réponse devra probablement être puisée en partie du moins dans le nouveau droit international de la santé.

Il reste intéressant de constater donc qu'à l'extension du contrôle de l'individu sur son propre corps (qui est au fond une forme de narcissisme), s'oppose la revendication plus générale et encore mal définie d'un droit d'accès au corps de l'autre lorsque le bien de l'autre ou l'intérêt commun est en jeu.

Je ne pense pas que l'on puisse totalement exclure l'idée dans l'avenir, qu'au nom de la solidarité humaine, la gouvernance de la personne sur son corps se voit imposer des limites cette fois-ci dans l'intérêt commun et donc que l'individualisme cède, en partie du moins, sa place à une forme d'entraide forcée.

*
* *

Il en est, par contre, autrement de la maîtrise de l'homme sur sa mort.

Le combat du malade pour se réapproprier complètement sa mort est loin d'être terminé. À l'heure actuelle, du moins dans nos pays, on meurt, la plupart du temps, intubé, gavé, perfusé, anesthésié, dans l'anonymat d'une chambre d'hôpital, dans la solitude et loin de tout ce qui faisait la vie. Comme l'ont montré nos discussions sur le sujet, dans nos sociétés développées l'individu a été exproprié de sa mort par la science médicale.

La progression des mœurs à cet égard est intéressante à observer. L'ensemble des pays, sous une forme ou une autre, reconnaissent maintenant l'obligation pour le médecin de respecter les volontés de fin de vie, exprimées tantôt dans le cadre d'un mandat d'inaptitude (comme c'est le cas au Québec ou en Suisse), tantôt en donnant un effet juridique contraignant aux directives anticipées (comme en Espagne). L'acharnement thérapeutique est désormais presque universellement condamné comme contraire au droit à l'autodétermination. Le premier devoir du médecin n'est donc plus de sauver la vie à tout prix, mais plutôt de respecter la liberté de choix de son patient.

Par contre, nombreux sont les pays, à la différence des Pays-Bas, de la Belgique, du Luxembourg et de la Colombie, qui refusent de consacrer l'ultime conséquence logique de cette réappropriation et de reconnaître non plus un simple

droit de mourir dans la dignité mais un véritable droit à la mort par la décriminalisation de l'aide au suicide et la légalisation de l'euthanasie active, volontaire et médicalement contrôlée. Ce refus illustre bien le contraste entre deux visions philosophique et éthique divergentes sur l'exercice du pouvoir de l'homme sur sa destinée.

S'agissant en premier lieu du suicide assisté, la tentative de suicide raté n'est plus sanctionnée par le droit pénal, comme ce fut le cas pendant longtemps. Par contre, un nombre important de pays continuent à pénaliser l'aide ou l'assistance au suicide. On ne peut s'empêcher de souligner un certain paradoxe puisqu'il s'agit d'un cas où la loi punit la complicité d'un acte qui, lui-même, n'est plus criminalisé.

Ce paradoxe est plus apparent que réel pour deux raisons. La première est que moralement, toutes les sociétés réprouvent et fustigent le suicide comme constituant un acte socialement répréhensible et donc moralement condamnable. On peut donc considérer l'acceptation de l'aide du suicide, même pour le malade en phase terminale, comme une contradiction idéologique. La seconde est que l'aide au suicide ne se déroule pas toujours dans le cas du malade en phase terminale dont les souffrances physiques ou morales sont devenues insoutenables.

On se souviendra à cet égard du scandale provoqué en France, il y a quelques années, par la publication d'un livre intitulé «*Suicide, mode d'emploi*» et on ne peut qu'applaudir au combat mené actuellement contre les différents sites internet qui proposent sur le Web à tous et sans distinction divers moyens de mettre fin à ses jours.

La solution est peut-être, comme certains l'ont compris, de décriminaliser cette aide, mais uniquement dans l'hypothèse du malade en phase terminale et de continuer à la sanctionner dans les autres cas.

Le débat est évidemment encore plus vif et plus délicat dans le cas de l'euthanasie active, volontaire et médicalement assistée.

On peut penser personnellement ce que l'on veut sur cette question qui n'est certes pas nouvelle. L'opinion que l'on s'en fait et le sentiment individuel dépendent avant tout, en effet, de ses propres convictions morales et religieuses. Il n'en reste pas moins que l'euthanasie active, médicalement contrôlée, a désormais acquis ses lettres de créance par sa consécration officielle dans trois pays européens, par la Colombie et quelques États des U.S.A. Les études belges et néerlandaises sur le sujet montrent que le système de contrôle mis en place pour éviter les erreurs (argument dominant des opposants) fonctionne bien et que, s'ils

existent, les cas de bavures sont rares sinon inexistants. L'argument donc de la pente glissante ou du dérapage, invoqué pour l'écarter dans toutes les hypothèses a désormais moins de poids qu'on pourrait le croire. Certes, cependant certains dérapages restent possibles et il faudra être vigilant. L'explosion des coûts de la santé et la pression économique qui en résulte risquent de favoriser des programmes d'euthanasie pour certaines catégories de personnes plus vulnérables, dont le maintien en vie obère les finances de l'État.

Ceci obligerait donc à se prononcer sur la qualité de vie de l'autre. Mais qui est l'un pour en décider et juger la vie de l'autre ?

La consécration de l'euthanasie par la Belgique, la Hollande, le Luxembourg et la Colombie est un tournant important.

Jusqu'ici le droit de mourir s'analysait simplement comme un simple droit-liberté, soit la faculté de mourir en paix, dans le respect de ses propres choix et dans la dignité.

La reconnaissance de l'euthanasie active a institué un véritable droit-créance. Le médecin qui accepte de participer à cette procédure, lorsque toutes les conditions posées par la loi sont réunies, a donc désormais, sous réserve de

l'objection de conscience, l'obligation de donner la mort ou d'aider l'individu à le faire. Le rôle traditionnel du médecin strict sauveur de la vie est désormais remis en cause.

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En guise de conclusion, ce premier volet sur les nouveaux aspects du droit de la santé permet de mettre en évidence que la réflexion éthique sur le sujet reste hésitante, pluraliste, pour ne pas dire éclatée, et est encore loin d'être complétée.

D'un côté, comme on a pu le constater, le droit à l'autodétermination, et donc le contrôle que l'individu peut exercer sur son propre corps, est désormais bel et bien accepté. C'est la liberté retrouvée et la consécration de la gestion individualisée de la destinée humaine.

D'un autre côté, les avancées de la médecine et de la science ont démontré que le corps humain, cette fois-ci, le corps de l'autre, était aussi source de bien-être et donc que le principe de la solidarité humaine pouvait imposer des limites à l'individualisme. Le droit ne s'intéresse donc plus désormais seulement au corps que l'on est, mais aussi au corps que l'on a.

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SPECIAL ARTICLE

Previous Volume 356:1957-1965 May 10, 2007 Number 19 Next

End-of-Life Practices in the Netherlands under the Euthanasia Act

Agnes van der Heide, M.D., Ph.D., Bregje D. Onwuteaka-Philipsen, Ph.D., Mette L. Rurup, Ph.D., Hilde M. Buiting, M.Sc., Johannes J.M. van Delden, M.D., Ph.D., Johanna E. Hanssen-de Wolf, M.Sc., Anke G.J.M. Janssen, M.A., H. Roeline W. Pasman, Ph.D., Judith A.C. Rietjens, Ph.D., Cornelis J.M. Prins, M.Sc., Ingeborg M. Deerenberg, M.Sc., Joseph K.M. Gevers, Ph.D., Paul J. van der Maas, M.D., Ph.D., and Gerrit van der Wal, M.D., Ph.D.

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ABSTRACT

Background In 2002, an act regulating the ending of life by a physician at the request of a patient with unbearable suffering came into effect in the Netherlands. In 2005, we performed a follow-up study of euthanasia, physician-assisted suicide, and other end-of-life practices.

Methods We mailed questionnaires to physicians attending 6860 deaths that were identified from death certificates. The response rate was 77.8%.

Results In 2005, of all deaths in the Netherlands, 1.7% were the result of euthanasia and 0.1% were the result of physician-assisted suicide. These percentages were significantly lower than those in 2001, when 2.6% of all deaths resulted from euthanasia and 0.2% from assisted suicide. Of all deaths, 0.4% were the result of the ending of life without an explicit request by the patient. Continuous deep sedation was used in conjunction with possible hastening of death in 7.1% of all deaths in 2005, significantly increased from 5.6% in 2001. In 73.9% of all cases of euthanasia or assisted suicide in 2005, life was ended with the use of neuromuscular relaxants or barbiturates; opioids were used in 16.2% of cases. In 2005, 80.2% of all cases of euthanasia or assisted suicide were reported. Physicians were most likely to report their end-of-life practices if they considered them to be an act of euthanasia or assisted suicide, which was rarely true when opioids were used.

Conclusions The Dutch Euthanasia Act was followed by a modest decrease in the rates of euthanasia and physician-assisted suicide. The decrease may have resulted from the increased application of other end-of-life care interventions, such as palliative sedation.

The increasing importance of chronic diseases as a cause of death and the attention currently being paid to patient-centered care at the end of life have created interest in the role of medicine in the timing and mode of death and dying.[1] In many instances, death is not merely the result of the natural course of a lethal disease: medical decision making often contributes.[2,3,4,5] Such decision making concerns the use of medical treatment to prolong the life of seriously ill patients. Furthermore, the alleviation of severe symptoms sometimes involves the use of drugs that have as a potential side effect the shortening of life. Difficult situations can occur when patients feel that their suffering is unbearable, feel hopeless, and ask their physician to help them to terminate their life. In most countries, physicians are not allowed to grant such a request, although physician assistance in dying is now a topic of debate in many countries.[6,7,8]

In the Netherlands, euthanasia is defined as death resulting from medication that is administered by a physician with the explicit intention of hastening death at the explicit request of the patient.[9] In assisted suicide, the patient self-administers medication that was prescribed by a physician. In the early 1990s, the practices of euthanasia

and physician assistance in suicide were liable to legal prosecution in the Netherlands. The public prosecutor mostly dismissed physicians from prosecution if they were found to have adhered to a number of requirements. Research in 1990 indicated that the reporting rate for euthanasia and physician assistance in suicide was only 18.0%.[10] After the official establishment of a reporting procedure in 1993, the reporting rate increased to 40.7% in 1995.[11]

The reporting procedure was updated in 1998 to involve the initial review of the deaths by multidisciplinary review committees that advised the public prosecutor about whether or not the requirements for careful practice had been fulfilled. As a result, the reporting rate further increased to 54.1% in 2001.[12] The reporting procedure was widely endorsed by physicians, and the review committees only rarely found serious violations of the requirements for careful practice. Furthermore, the frequencies of euthanasia and assisted suicide seemed to have stabilized in 2001.[13] Nonreporting was most common in cases in which physicians had administered opioids rather than neuromuscular relaxants or barbiturates.[14]

1990 1995 2001 2005
% 18, 40.7, 54.1, 80.2

In April 2002, after three decades of debate and research, the Euthanasia Act was passed to regulate the ending of life by a physician at the request of a patient who was suffering unbearably without hope of relief. The act officially legalized euthanasia and physician-assisted suicide for the first time, but in effect it simply legalized an existing practice, since physicians had not been prosecuted for actions to end the lives of patients as long as the actions were consistent with the standards of care that had been established in the early 1990s. The most important change was that, under the act, the review committees forward to the legal prosecutor only cases in which the requirements for careful practice are not met.

Physician assistance in dying is also legally regulated in other countries. The Oregon Death with Dignity Act legalizing physician-assisted suicide was enacted into law in 1997, and in 2002 Belgium adopted a law on euthanasia that is largely similar to the Dutch law.[15,16,17,18,19] However, the Netherlands is the first country where large-scale research has provided insight into the practices of euthanasia and assisted suicide and their use in end-of-life decision making. Large nationwide studies of practices in 1990, 1995, and 2001 have provided data on the frequency and characteristics of euthanasia, physician-assisted suicide, and other medical acts that may hasten death.[10,13,20] These studies have proved the importance of end-of-life decision making in current medical practice, and they have had a major influence on national policymaking and the further development of end-of-life care. In 2005, we performed a follow-up study to assess the effects of the 2002 Dutch law and changes in end-of-life care. We also assessed the reporting rates for euthanasia and assisted suicide and physicians' reasons for nonreporting.

Methods

Study Design

We performed a death-certificate study that was largely similar to the large-scale studies of practices in 1990, 1995, and 2001.[10,13,20] A stratified sample of death cases was drawn from the central death registry of Statistics Netherlands, which receives death certificates for all deaths that occur in the Netherlands. All 43,959 deaths that occurred between August and November 2005 were assigned to one of five strata, which were denoted 1 through 5. When the cause of death was one in which it was clear that no physician's assistance in dying could have been provided (e.g., sudden death from a car accident), the death was assigned to stratum 1. These cases were retained in the sample, but no questionnaires were sent to the physicians, because no further information was needed to determine that no physician's assistance in dying had been provided. When the likelihood that a physician's assistance in dying had been provided was deemed to be high, the death was assigned to stratum 5. The final sample contained half the cases in stratum 5, 25% of the cases in stratum 4, 12.5% of those in stratum 3, 8.3% of those in stratum 2, and all cases in stratum 1.

For all sampled cases for which the cause of death did not preclude physician assistance in dying, attending physicians were mailed a four-page questionnaire (see the Supplementary Appendix, available with the full text of this article at www.nejm.org). The anonymity of both physicians and patients was guaranteed, because returned questionnaires were opened only after all information about the identities of the patient and physician had been removed.

Questionnaire

The questionnaire was mailed with a letter signed by the Chief Inspector for Health Care and the president of the Royal Dutch Medical Association. Of the 6860 questionnaires that were mailed to physicians, 5342 were returned (response rate, 77.8%). According to Dutch policy, the study did not require review by an ethics committee or written informed consent from the patients' families, because the data collection was anonymous with regard to the deceased patient and the attending physician.

The questionnaire focused on the characteristics of the end-of-life decision making that may have preceded the death of the patient involved. There were four key questions, addressing whether the respondent had withheld or withdrawn medical treatment while taking into account the possible hastening of death; had intensified measures to alleviate pain or other symptoms while taking into account the possible hastening of death or appreciating that possibility; had withheld or withdrawn medical treatment with the explicit intention of hastening death; or had administered, supplied, or prescribed drugs with the explicit intention of hastening death, resulting in the patient's death.

The wording of these questions was identical to that in the previous studies. If the last of the four key questions was answered affirmatively and if the act was performed in response to an explicit request by the patient, the act was classified as euthanasia if the physician had administered (or had assisted in administering) the drug and was classified as physician-assisted suicide if the patient had taken the drug himself or herself. For cases in which physicians responded affirmatively to more than one of the four key questions, the act that involved the most explicit intention with regard to the hastening of death was used to classify the act. For cases in which there was no single most explicit intention, the administration of drugs prevailed over the withholding or withdrawing of treatment.

The key questions were followed by questions about the decision-making process, the type of drugs that had been used, and the degree to which death had been hastened, as estimated by the physician. We also asked whether the patient had been deeply and continuously sedated before death. Our questionnaire also contained new questions about whether or not cases were reported as required by the Euthanasia Act, as well as about the reasons for nonreporting. Physicians were further asked to choose the term that they thought best described their act: refraining from treatment, alleviation of symptoms, palliative or terminal sedation, ending of life, assisted suicide, or euthanasia.

Statistical Analysis

The percentages reported were weighted to adjust for differences in the percentages of deaths sampled from each of the five strata and differences in response rates in relation to the age, sex, marital status, region of residence, and cause and place of death of the patients. After adjustment, the percentages were extrapolated to cover a 12-month period, to reflect the 136,402 deaths in the Netherlands in 2005. Weighting factors were calculated in three steps. First, the inverse of the percentage of deaths sampled from each stratum was taken. The resulting factor was multiplied by a second factor that was calculated by dividing the sampled number of deaths by the number of deaths for which we received a questionnaire from the physician for each combination of characteristics of patients. The weighting factor that resulted from steps 1 and 2 was multiplied by a factor that was calculated in the third step, by dividing the actual number of cases in the population of deceased

persons in 2005 for each combination of characteristics of patients by the number of cases from the first two weighting steps.

Confidence intervals were calculated for the estimates of the rates of euthanasia, assisted suicide, and other end-of-life practices. Rates across years were compared with the use of chi-square tests. Logistic-regression analysis was performed to assess the factors that helped to determine the physicians' labeling of their acts. All statistical procedures took into account the weighting procedure by standardizing the weighting factors to the actual total number of cases. P values of less than 0.05 were considered to indicate statistical significance.

Results

In 2005, 1.7% of all deaths in the Netherlands were the result of euthanasia, as compared with 2.6% in 2001, 2.4% in 1995, and 1.7% in 1990 (Table 1). Assisted suicide was less common than euthanasia in each year and, like the euthanasia rate, declined in frequency in 2005. Furthermore, 0.4% of all deaths were the result of the use of lethal drugs not at the explicit request of the patient; this percentage was not significantly different from those in previous years. Intensified alleviation of symptoms as the most important end-of-life decision increased in frequency from 20.1% in 2001 to 24.7% in 2005. However, the percentage of cases in which physicians intensified the alleviation of symptoms, rather than only cases in which that action was most important, were similar: 30.1% in 2001 and 30.2% in 2005. The withholding or withdrawing of potentially life-prolonging treatment as the most important decision decreased in frequency from 20.2% in 2001 to 15.6% in 2005. These percentages were 30.4% and 27.5%, respectively, when all cases involving the withholding or withdrawing of life-prolonging treatment were included, rather than only cases in which that action was most important. Of all deceased patients in 2005, 8.2% were continuously and deeply sedated before death. Such sedation was provided in conjunction with decisions that possibly hastened death, such as decisions to withhold hydration and nutrition, in 7.1% of deaths in 2005, as compared with 5.6% in 2001. In the remaining 1.1% of patients who were sedated, the sedation was not provided in conjunction with decisions that possibly hastened death. (No figure is available for 2001.)

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We had data from 2005 and 2001 about the rates of euthanasia, assisted suicide, ending of life without an explicit request by the patient, and continuous deep sedation in conjunction with possible hastening of death in various subgroups of patients (Table 2). The rates in 1995 and 1990 (data not shown) were similar to those in 2001. In both 2005 and 2001, the highest rates of euthanasia or assisted suicide were found for patients aged 64 years or younger, for men, and for patients with cancer. Furthermore, most acts of euthanasia or assisted suicide were carried out by general practitioners. The rate of euthanasia or assisted suicide was lower in 2005 than in 2001 for both sexes, all age groups, patients with all diagnoses, and all physician specialties. The rate of the ending of life without an explicit request by a patient was similar in each subgroup. Like euthanasia and assisted suicide, continuous deep sedation in conjunction with the possible hastening of death in 2005 was used most often in patients aged 64 years or younger, in men, and in patients with cancer; the rates of this practice in these subgroups were higher than those in 2001.

Before end-of-life decisions were made, physicians discussed euthanasia and assisted suicide with all patients whose death was caused by either act (Table 3). The physician also discussed the decision to perform euthanasia or assisted suicide with relatives of the patient in 75.5% of deaths in 2005 and with one or more colleagues in 87.7% of deaths. When life was ended without the explicit request of the patient, there had been discussion about the act or a previous wish of the patient for the act in 60.0% of patients, as compared with 26.5% in 2001. In 2005, the ending of life was not discussed with patients because they were unconscious (10.4%) or incompetent owing to young age (14.4%) or because of other factors (15.3%). Of all cases of the ending of life in 2005 without an explicit request by the patient, 80.9% had been discussed with relatives. In 65.3% of cases, the physician had discussed the decision with one or more colleagues.

In 73.9% of all cases of euthanasia or assisted suicide in 2005, life was ended with the use of neuromuscular relaxants or barbiturates; opioids were used in 16.2% of all cases. In the same year, the ending of life without an explicit request by the patient more frequently involved the use of opioids (58.5%). Physicians were asked to estimate the amount of time by which life was shortened owing to the use of lethal drugs. In 2005, life was estimated to have been shortened by at least 1 week in 53.9% of all cases of euthanasia or assisted suicide and in 11.6% of all cases of the ending of life without an explicit request by the patient. The type of drugs used and the extent to which life was shortened were similar in 2005 and 2001.

In absolute terms, the numbers of cases of euthanasia or assisted suicide in 2005 were 2297 and 113, respectively. The review committees evaluated 1933 of the 2410 cases in 2005, with a reporting rate of 80.2%. For 28 cases, the physicians were asked about the reasons for nonreporting; for 76.1% of these cases, physicians answered that they had not perceived their act as the ending of life. Other reasons given were that the physician

had doubts about whether the criteria for careful practice had been met (9.7%) or that the physician regarded the ending of life as a private agreement between physician and patient (6.6%). When asked to choose the most appropriate term for cases that were classified as euthanasia or assisted suicide in our study (an affirmative answer to the last of the four key questions) (260 cases), 76.2% of physicians chose "euthanasia," "assisted suicide," or the "ending of life." End-of-life practices in the remaining cases were labeled by physicians as "alleviation of symptoms" or "palliative or terminal sedation." Results of a logistic-regression analysis revealed that physicians were more likely to label the prescribing of drugs with the explicit intention of hastening death as "euthanasia" or "assisted suicide" when the drugs were neuromuscular relaxants or barbiturates than when the drugs were opioids or other types ($P<0.001$).

Discussion

The enactment of the Dutch euthanasia law was followed by a modest decrease in the rates of euthanasia, assisted suicide, and ending of life without an explicit request by the patient and an increase in the rate of continuous deep sedation near the end of life. These findings represent a significant reversal of the trends in end-of-life decision making that were found between 1990 and 2001.[13] The high response rate, the fact that both the study design and the key questions were kept constant over the years, the endorsement of the study by authoritative medical bodies, and the guarantee of anonymity of patients and physicians all strengthen the validity and reliability of our results.

We focus on three possible explanations for these trends. First, some epidemiologic factors should be considered. As a result of the aging of society, the percentages of deaths of people 80 years of age or older, which is the age group for which euthanasia and assisted suicide are least common, increased from 45.3% in 2001 to 48.4% in 2005. However, decreased rates of these practices were found in all age groups, and the age shift can explain only about 0.1% of the total decrease. The percentage of deaths from cancer, which is the most common diagnosis in patients receiving physician assistance in dying, remained stable between 2001 and 2005, as did the percentages of deaths attended by general practitioners, clinical specialists, and nursing home physicians.

Second, Dutch physicians have been found to consider high-quality end-of-life care as an alternative to euthanasia or assisted suicide, at least in some cases.[13] In our study, we found that euthanasia and assisted suicide were to some extent replaced by continuous deep sedation. Sedation was most common in the subgroups in which euthanasia or assisted suicide were also most common: patients under 80 years of age, men, patients with cancer, and patients attended by general practitioners. One study showed that the use of deep sedation near the end of life is often preceded by a discussion of the option of euthanasia.[21] The types of suffering that prompt requests for euthanasia overlap with those that prompt requests for sedation, although the emphasis is more on existential suffering and physical deterioration in euthanasia and more on physical suffering in sedation.[22] Physicians also sometimes administer sedatives when they have the explicit intention of hastening death, such that sedation and euthanasia are not mutually exclusive in all cases.

Third, the attitudes of physicians toward opioids and their understanding of the effects of the drugs may have contributed to a decrease in the frequency of euthanasia. During the last decade, there has been increasing evidence that the potentially life-shortening effects of opioids are often overestimated.[23,24,25,26] In the Netherlands, the results of the study of the 2001 practices[13] sparked a debate about whether or not opioids can be used for euthanasia, because of their doubtful lethal potential and the likelihood of side effects.[14,27] The review committees have disapproved the use of opioids for euthanasia. As a result, physicians may have become less inclined to attribute life-shortening effects to opioids. Thus, the decrease in the percentage of cases of euthanasia in which opioids were used in 2005 as compared with 2001 may be at least partly the result of variation in the attribution by physicians of their acts, not only from an actual change in practices. It is difficult to assess whether or not such variation in attribution is justified in all cases. The tendency among physicians to attribute less life-shortening effects to their acts may extend to end-of-life decision making in a broader sense,

relating to the decreased frequency in 2005 of decisions to withhold or withdraw potentially life-prolonging treatment. The shifting of attitudes toward the use of opioids may also have contributed to the trend of decreased rates of the ending of life without an explicit request by the patient. Apparently, the Dutch system of regulating euthanasia has not resulted in increased rates of this practice, which is sometimes referred to as nonvoluntary euthanasia.

The reporting rates for euthanasia and physician-assisted suicide increased from 18.0% in 1990, when these practices were illegal and the first procedure for review had yet to be developed, to 80.2% in 2005, a time when euthanasia and assisted suicide were no longer of questionable legality if performed according to established requirements for careful practice. Our study reports, for the first time, quantitative data about the causes of nonreporting. Few physicians indicated that they did not report their case because of doubts about whether they had met the criteria and feared legal prosecution. A large majority of nonreported cases appeared to have involved acts to end life as defined in our study (an affirmative answer to the last of the four key questions on the questionnaire) but were not labeled by the physician as euthanasia or physician-assisted suicide. These cases mostly involved drugs with uncertain lethal effects, such as opioids and sedatives. As a result, the review committees mainly evaluate cases in which death was hastened with neuromuscular relaxants or barbiturates. In such cases, physicians virtually always adhere to the requirements for careful practice. However, the transparency that is envisaged by the Dutch law apparently does not extend to all cases of euthanasia.

In conclusion, the enactment of the Dutch euthanasia law was followed by a moderate decrease in the rates of physician assistance in dying. This trend may have resulted from changes in epidemiologic patterns, an increased use of deep sedation and other means of alleviating symptoms near the end of life, and a decreased inclination among physicians to believe that opioids hasten death.

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Source Information

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Law, ethics and medicine

Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups

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Abstract

Background: Debates over legalisation of physician-assisted suicide (PAS) or euthanasia often warn of a "slippery slope", predicting abuse of people in vulnerable groups. To assess this concern, the authors examined data from Oregon and the Netherlands, the two principal jurisdictions in which physician-assisted dying is legal and data have been collected over a substantial period.

Methods: The data from Oregon (where PAS, now called death under the Oregon Death with Dignity Act, is legal) comprised all annual and cumulative Department of Human Services reports 1998–2006 and three independent studies; the data from the Netherlands (where both PAS and euthanasia are now legal) comprised all four government-commissioned nationwide studies of end-of-life decision making (1990, 1995, 2001 and 2005) and specialised studies. Evidence of any disproportionate impact on 10 groups of potentially vulnerable patients was sought.

Results: Rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. The only group with a heightened risk was people with AIDS. While extralegal cases were not the focus of this study, none have been uncovered in Oregon; among extralegal cases in the Netherlands, there was no evidence of higher rates in vulnerable groups.

Conclusions: Where assisted dying is already legal, there is no current evidence for the claim that legalised PAS or euthanasia will have disproportionate impact on patients in vulnerable groups. Those who received physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.

Responses to this article

Are vulnerable groups no more likely to receive physician-assisted dying?

Eleanor Grogan, Andrew Thorns, Colin Campbell, Claire Stark-Toller, David Oliver, Tim Harlow, Rosaleen Beattie, Rob George

J Med Ethics published online November 8, 2007

[Full text]

Articles citing this article

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F. Norwood, G. Kimsma, M. P Battin

Fam Pract 2009;26:472-480

[Abstract] [Full text] [PDF]

Euthanasia and free speech in Ireland

L. Doyal

Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey

Kenneth Chambaere PhD, Johan Bilsen RN PhD, Joachim Cohen PhD, Bregje D. Onwuteaka-Philipsen PhD, Freddy Mortier PhD, Luc Deliens PhD

**** See related research article by Inghelbrecht and colleagues, page 905

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Background: Legalization of euthanasia and physicianassisted suicide has been heavily debated in many countries. To help inform this debate, we describe the practices of euthanasia and assisted suicide, and the use of life ending drugs without an explicit request from the patient, in Flanders, Belgium, where euthanasia is legal.

Methods: We mailed a questionnaire regarding the use of life-ending drugs with or without explicit patient request to physicians who certified a representative sample (n = 6927) of death certificates of patients who died in Flanders between June and November 2007.

Results: The response rate was 58.4%. Overall, 208 deaths involving the use of life-ending drugs were reported: 142 (weighted prevalence 2.0%) were with an explicit patient request (euthanasia or assisted suicide) and 66 (weighted prevalence 1.8%) were without an explicit request. Euthanasia and assisted suicide mostly involved patients less than 80 years of age, those with cancer and those dying at home. Use of life-ending drugs without an explicit request mostly involved patients 80 years of older, those with a disease other than cancer and those in hospital. Of the deaths without an explicit request, the decision was not discussed with the patient in 77.9% of cases. Compared with assisted deaths with the patient's explicit request, those without an explicit request were more likely to have a shorter length of treatment of the terminal illness, to have cure as a goal of treatment in the last week, to have a shorter estimated time by which life was shortened and to involve the administration of opioids.

Interpretation: Physician-assisted deaths with an explicit patient request (euthanasia and assisted suicide) and without an explicit request occurred in different patient groups and under different circumstances. Cases without an explicit request often involved patients whose diseases had unpredictable end-of-life trajectories. Although opioids were used in most of these cases, misconceptions seem to persist about their actual life-shortening effects.

Euthanasia and physician-assisted suicide are heavily debated issues in medical practice. In recent years, three European countries (Belgium and the Netherlands in 2002, and Luxemburg in 2009) and two US states (Oregon in 1997 and Washington State in 2009) decriminalized euthanasia and physician-assisted suicide under formal conditions.[1–5] Canada is among a number of countries where the debate over legalization has flared up, with a proposed bill reaching Parliament and a pro-euthanasia proposal by the Quebec College of Physicians.[6]

Understandably, the issue of euthanasia triggers much emotion and can be fraught with speculative arguments.

Opponents of euthanasia often argue that legalizing the procedure will lead to a rise in the use of life-ending drugs without a patient's explicit request, especially in vulnerable patient groups.[7–10] Thus far, however, no indications of this have been found in studies of physician-assisted deaths before and after legalization in Belgium and the Netherlands.[9,11,12] In Belgium, the percentage of deaths in which life-ending drugs were used remained stable, and the proportion without an explicit request from the patient decreased.[12]

Other studies have shown that euthanasia, physician-assisted suicide and the use of life- ending drugs without explicit patient request are not confined to countries where physician-assisted death is legal.[13–16]

In addition to knowing the overall occurrence of physician- assisted death, it is equally important for an adequately informed, empirically based debate to know its performance in vulnerable patient groups and the care put into the decision and performance. In light of legalization and its alleged effects on the use of life-ending drugs without patient request, it is also important to map similarities and differences between euthanasia and the use of life-ending drugs without explicit patient request. In this article, we report our investigation of demographic and clinical characteristics associated with physician-assisted deaths in Flanders, Belgium; the involvement of the patient, relatives and other caregivers in the decision-making process; reasons for the decisions; aspects of the treatment trajectory; and details of the performance in terms of drug use and the people administering the life-ending drugs.

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Methods

Study design

In 2007 we conducted a large-scale study of death certificates in Flanders, the Dutch-speaking part of Belgium that has about six million inhabitants and 55 000 deaths per year. We obtained a stratified sample of all death certificates from June to November 2007 of Belgian residents aged one year or older from the Flemish Agency for Care and Health. We assigned the certificates to one of four strata according to cause of death and the corresponding estimated likelihood of an end-of-life decision. Sampling fractions for strata increased proportionally with this likelihood. The resulting sample comprised 6927 death certificates, which represented 25% of deaths during the study period and about 12% of all deaths in Flanders in 2007. Details of the methodology for this review have been described elsewhere.[17]

A five-page questionnaire and covering letter explaining the study were sent to the attending physician in each case. A response was regarded as implicit consent to participate. If the physician did not respond after three reminders, a one-page questionnaire was sent enquiring about the reasons for nonresponse.

Total anonymity for participating physicians and deceased patients was guaranteed through a rigorous mailing procedure involving a lawyer as intermediary be tween physicians and researchers. Information from the death certificates (patient sex, age, place of death and cause of death) was made available only after it had been coded, to preclude any identification of patient or physician. For the anonymity procedure, we received approval from the ethical review boards of the organizing universities, and recommendations from the Belgian Medical Disciplinary Board and the Belgian Federal Privacy Commission.

Questionnaire

We modelled the questionnaire after ones used and extensively validated in previous studies in Belgium and other European countries.11–13 For the present study, the questionnaire was validated through testing by a panel of physicians.

Physicians were asked about end-of-life decisions, defined as "medical decisions at the end of patients' lives with a possible or certain life-shortening effect." We identified cases as physician-assisted deaths if the physician gave an affirmative answer to the following question: "Was the death the consequence of the use of drugs prescribed, supplied or administered by you or another physician with the explicit intention of hastening the end of life or of enabling the patient to end his or her own life?" Additional questions dealt with the lifeending drugs used and who administered the drugs. Other sections of the questionnaire asked about the involvement of the patient, family and other caregivers in the decisionmaking process, the reasons for the decision, how long the patient had received treatment for the illness leading to death, the main goal of treatment in the last week before death and the estimated time by which the patient's life was shortened. For the deaths with an explicit request from the patient, we classified them as euthanasia if someone other than the patient had administered the drugs and as physician-assisted suicide when the patient had administered the drugs.

Statistical analysis

We weighted the reported percentages to correct for the disproportionate stratification of deaths and to correct for differences between the response sample and all deaths in Flanders in 2007 relating to sex, age, province of death, place of death and cause of death (differences were found relating only to place of death). We conducted statistical analyses with SPSS 17.0 software, using the complex samples procedure to account for the stratified sample design and associated standard errors. We used the Fisher exact test to compare differences in distributions between physician-assisted death with explicit patient request (euthanasia or assisted suicide) and the use of life-ending drugs without explicit patient request; statistical significance was set at a p value of less than 0.05.

Results

We received questionnaires for 3623 of the 6927 deaths. For 725 of the remaining 3304 deaths, a response was not possible because the physician no longer had access to the patient's medical file because of a change of workplace, or thephysician could not retrieve the identity of the patient. We removed these cases from the sample. The final response rate, therefore, was 58.4% (3623 of 6202 valid cases).

We identified 208 physician-assisted deaths: 142 (weighted prevalence 2.0%) with an explicit request from the patient (137 euthanasia, 5 assisted suicide) and 66 (weighted prevalence 1.8%) without an explicit request (Table 1).

Euthanasia and assisted suicide predominantly involved patients less than 80 years old (79.6%), those with cancer (80.2%) and those dying at home (50.3%). Of the cases without an explicit request from the patient, most involved patients who were 80 years of age or older (52.7%), those without cancer (67.5%) and those who died in hospital (67.1%). The distribution of patient characteristics for life-ending acts without explicit request was similar to that for all other deaths in Flanders, except that it was performed more often in hospital and by clinical specialists.

The decision to end life was discussed with the patient in 22.1% of the cases without an explicit patient request (Table 2). In cases where the decision had not been discussed with the patient, the physician specified as reason(s) that the patient was comatose (70.1% of cases) or had dementia (21.1%); in 40.4% of cases, the physician indicated that the patient had previously expressed a wish for ending life (not

equivalent to an explicit request for euthanasia). Physicians specified that the decision had not been discussed with the patient because the decision was in the patient's best interest (17.0%) or because discussion would have been harmful (8.2%). Compared with euthanasia or assisted suicide, the use of life-ending drugs without an explicit patient request was discussed less often with other caregivers, but as often with the patient's family. Pain and the patient's wish for ending life were more often reasons for carrying out euthanasia or assisted suicide, whereas family burden and the consideration that life was not to be needlessly prolonged were more often reasons for using life-ending drugs without explicit patient request.

Assisted deaths with and without an explicit request from the patient differed significantly with regard to length of treatment of the terminal illness, the primary goal of treatment during the last week and the estimated time by which life was shortened (Table 3). In most cases in which euthanasia or physician-assisted suicide was performed, the patients had been treated for their terminal illness for more than 6 months (80.3%), the goal of treatment in the last week was patient comfort (94.3%), and life was shortened by 1 week or more (44.5%). In contrast, the cases without an explicit request were more likely to have a shorter length of treatment of the terminal illness (< 1 month in 46.1% of cases), to have cure as a goal of treatment in the last week (14.6% v. 1.2% of cases with an explicit request) and to have a shorter estimated time by which life was shortened (< 24 hours in 47.9% of cases) (Table 3).

Compared with drugs used in euthanasia and assisted suicide, opioids were used far more often in the ending of life without an explicit patient request, especially when used as the sole drug (Table 4). In these cases, the dosage was strongly increased in the last 24 hours in 45.8%, and the physician indicated it to be higher than needed to alleviate the patient's symptoms in 46.8% (data not shown). Nurses were more often involved in the administration of the drugs when there was no explicit request from the patient than in cases of euthanasia or assisted suicide.

Interpretation

We found that, five years after the euthanasia law was enacted in Belgium, euthanasia and assisted suicide occurred in 2.0% of all deaths in Flanders during the study period. They predominantly involved patients less than 80 years or older and occurred in hospital. In the majority of cases, the patient was not involved in the decision, primarily because of coma or dementia; however, relatives and other caregivers were often consulted. Considerations involving the relatives and needless prolongation of life were reasons indicated by physicians for reaching the decision. Compared with euthanasia and assisted suicide, cases of assisted death without an explicit request from the patient had a shorter length of treatment of the terminal illness, were more likely to have cure as a goal of treatment in the last week, had a shorter estimated time by which life was shortened and more often involved the administration of opioids alone.

Our finding that euthanasia and assisted suicide were typically performed in younger patients, patients with cancer and patients dying at home is consistent with findings from other studies.[11,18–21]

Our finding that the use of life-ending drugs without explicit patient request occurred predominantly in hospital and among patients 80 years or older who were mostly in a coma or had dementia fits the description of "vulnerable" patient groups at risk of life-ending without request.[7–10]

Attention should therefore be paid to protecting these patient groups from such practices. However, when compared with all deaths in Flanders, elderly patients and patients dying of diseases of the nervous system (including dementia) were not proportionally at greater risk of this practice than other patient groups. In the Netherlands in 2005, use of life-ending drugs without explicit request was most often performed by clinical specialists (i.e., in hospital), but occurred relatively infrequently in older patients.[11]

The differences we observed in demographic and clinical characteristics between the cases of euthanasia or assisted suicide and those of life-ending drug use without an explicit patient request likely reflect differences in the illness trajectories of the patients concerned. Four out of five cases of euthanasia or assisted suicide involved patients with terminal cancer, which generally has a predictable illness trajectory.

For these patients, much time can pass between diagnosis and death, which creates the opportunity for anticipatory decisionmaking. In contrast, in the group without an explicit patient request, most of the patients had diseases other than cancer, which have less predictable end-of-life trajectories.[22,23] In addition, with cure being the main goal of treatment in the last week for some of these patients, and with the length of treatment of the terminal illness often being less than one month, we believe that the use of life-ending drugs without explicit patient request often involved chronically ill patients whose general condition suddenly and drastically deteriorated to a point that left them permanently unable to communicate. In these situations, as is apparent from our findings, physicians need to decide on a course of action together with the patient's family, which may result in a conflict of interest. This underscores the importance of advance care planning with family and caregivers, and of communication regarding the patient's wishes should he or she become comatose or incompetent. Such measures will undoubtedly limit the number of cases of life-ending without explicit patient request.

Physicians in our study who indicated an intention to hasten the patient's death without an explicit request from the patient most often used opioids, alone or with benzodiazepines. The use of opioids for ending life are discouraged because the patient may regain consciousness and because the procedure can take longer than expected.24–26 Furthermore, the life-shortening effect of opioids is subject to speculation.

Recent studies have shown that the actual effect on the end of life is prone to overestimation.[27–29] The estimated time by which life was shortened in many of the cases in our study was already very limited, especially compared with the estimated time in the cases of euthanasia and assisted suicide. We also found that, although physicians specified an intention to hasten death, opioids were often given in doses that were not higher than needed to relieve the patient's pain. This suggests that the practice of using life-ending drugs without an explicit patient request in reality resembles more intensified pain alleviation with a "double effect," and death was in many cases not hastened. The problem may also exist in other countries; for example, in the study in the Netherlands, opioids were also frequently administered to end life without an explicit patient request.[11,20,27]

This points to the need for education of caregivers about misconceptions of opioid use. We found that the use of life-ending drugs without a patient's explicit request occurred more often in Flanders, Belgium, than in other countries, including the Netherlands, where euthanasia is also legal.[11,13,16] Flemish physicians have been shown to be more open to this practice than physicians elsewhere,[30] which suggests a larger degree of paternalistic attitudes. This being said, its occurrence has not risen since the legalization of euthanasia in Belgium. On the contrary, the rate dropped from 3.2% in 1998 to 1.8% in 2007.[12]

In the Netherlands, the rate dropped slightly after legalization, from 0.7% to 0.4%.11 Although legalization of euthanasia seems to have had an impact, more efforts are needed to further reduce the occurrence of life-ending drug use without an explicit request from the patient.

Limitations

Our study is limited because we could not exclude some degree of nonresponse bias. However, by obtaining an acceptable response rate from a large population sample and weighting for differences with all deaths, we believe the results to be representative of all deaths. Another limitation is that the study provides information only from the physicians' perspective. Also, our study does not permit in-

depth case analysis, which impedes interpretation of the contents of discussion and of reported motivations in the
decision- making process.

Conclusion

Our study showed that physician-assisted death with an explicit request from the patient (euthanasia and assisted suicide) and use of life-ending drugs without an explicit request were distinct types of end-of-life decisions that occurred in different patient groups and under different circumstances. Unlike euthanasia and assisted suicide, the use of life-ending drugs without an explicit patient requestoften involved patients with diseases other than cancer, which have an unpredictable end-of-life trajectory.
This finding underscores the need for advance care planning. Finally, misconceptions seem to persist about the life-shortening effects of opioid use. Future research should closely monitor both types of physician- assisted deaths in various countries with and without legal regulations for euthanasia.

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Desire for Euthanasia or Physician-Assisted Suicide in Palliative Cancer Care

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Objective: To investigate the attitudes of terminally ill individuals toward the legalization of euthanasia or physician-assisted suicide (PAS) and to identify those who would personally desire such a death. ***Design:*** In the Canadian National Palliative Care Survey, semistructured interviews were administered to 379 patients who were receiving palliative care for cancer. Patients who expressed a desire for physician-hastened death were followed prospectively. ***Main Outcome Measures:*** Attitudes toward the legalization of euthanasia or PAS were determined, as was the personal interest in receiving a hastened death. Demographic and clinical characteristics were also recorded, including a 22-item structured interview of symptoms and concerns. ***Results:*** There were 238 participants (62.8%) who believed that euthanasia and/or PAS should be legalized, and 151 (39.8%) who would consider making a future request for a physician-hastened death. However, only 22 (5.8%) reported that, if legally permissible, they would initiate such a request right away, in their current situations. This desire for hastened death was associated with lower religiosity ($p = .010$), reduced functional status ($p = .024$), a diagnosis of major depression ($p < .001$), and greater distress on 12 of 22 individual symptoms and concerns ($p < .025$). In follow-up interviews with 17 participants, 2 (11.8%) showed instability in their expressed desire. ***Conclusion:*** Among patients receiving palliative care for cancer, the desire to receive euthanasia or PAS is associated with religious beliefs; functional status; and physical, social, and psychological symptoms and concerns. Although this desire is sometimes transitory, once firmly established, it can be enduring.

Keywords: euthanasia, physician-assisted suicide, cancer, palliative care

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The debate around the issue of legalizing euthanasia and/or physician-assisted suicide (PAS) for terminally ill patients has encouraged research into the frequency and correlates of requests for hastened death. To date, there are studies (a) of physicians who have engaged in these practices in jurisdictions where they are either legal (Onwuteaka-Philipsen et al., 2003; Sullivan, Hedberg, & Fleming, 2000; van der Maas, van Delden, Pijnenborg, & Looman, 1991) or illegal (Emanuel, Fairclough, Clarridge, et al., 2000; Meier, Emmons, Litke, Wallenstein, & Morrison, 2003), (b) of family members of deceased individuals (Ganzini, Silveira, & Johnston, 2002; Morita, Sakaguchi, Tsuneto, & Shima, 2004; Tolle, Tilden, Drach, Fromme, Perrin, & Hedberg, 2004), and (c) of the clinical records of patients who have requested euthanasia (Virik & Glare, 2002). Increasingly there are also studies of the attitudes of patients who actually have life-threatening illnesses. Of the studies that have interviewed patients directly, some have addressed broader constructs such as the desire for death rather than the more specific interest in receiving euthanasia or PAS (Albert et al., 2005; Breitbart et al., 2000; Chochinov et al., 1995; Kelly et al., 2002). Others have focused on patients who are contemplating suicide at some point in the future but not necessarily imminently (Emanuel, Fairclough, & Emanuel, 2000; Lavery, Boyle, Dickens, Maclean, & Singer, 2001; Pearlman et al., 2005). Few studies have attempted to interview terminally ill individuals who expressed an interest in initiating a physician-hastened death right at the time of the interview, and those identified only small numbers of such patients (Achille & Ogloff, 2003–2004; Akechi et al., 2004; Ganzini, Johnston, McFarland, Tolle, & Lee, 1998; Johansen, Hølen, Kaasa, Loge, & Matersvedt, 2005; Wilson et al., 2000).

In Canada, both voluntary euthanasia and PAS remain violations of the criminal code. These practices have been the subject of legislative review, however, and a special committee of the Canadian Senate recommended a program of research to clarify how often these acts might be requested in the event of legalization and to determine the factors that would motivate them (Special Senate Committee on Euthanasia and Assisted Suicide, 1995). In the Canadian National Palliative Care Survey, we interviewed patients who were receiving palliative care for cancer, the diagnosis of over 70% of patients who receive physician-hastened deaths in the Netherlands and Oregon (Onwuteaka-Philipsen et al., 2003; Sullivan et al., 2000). We inquired about their general attitudes toward the legalization of euthanasia and PAS; their personal interest in receiving a physician-hastened death; the physical, social, and psychological considerations that were associated with this interest; and its stability over time. These areas have been recognized as research priorities (Gordon et al., 2000; Sears & Stanton, 2001).

Method

Sites

The Canadian National Palliative Care Survey interviews were conducted between May 2001 and March 2003, in eight Canadian communities. The participating sites were broadly representative of the regions across southern Canada, both French- and English-speaking. Depending on the organization of palliative care services within a community, participants were recruited through inpatient palliative care units or hospices, consultation services to general hospitals, or home care.

Participants

Participants were recruited from consecutive admissions or referrals to each service. Eligibility was determined by the palliative care clinician most involved with the patient. The inclusion criteria were that (a) the patient's medical diagnosis was cancer and he or she had been informed that it was incurable, (b) the clinician considered the patient to be cognitively lucid and able to provide a valid interview, (c) the clinician estimated the survival duration to be under 6 months, (d) the patient was medically stable enough to attempt an interview, and (e) the patient was able to converse in either English or French. Eligible patients were first informed about the study by a member of the clinical staff, at a point when it was considered clinically and ethically responsible to introduce the topic of research into hastened death. If a patient was willing to participate, an interview was scheduled as soon as possible.

Procedure

The semistructured interviews were administered by professional staff with backgrounds in palliative care nursing, social work, psychology, or education. The interviews were tape-recorded to allow for the verbatim transcription of participants' narrative responses to open-ended questions. The content included a review of demographic and social characteristics, religious practices, attitudes toward euthanasia and PAS, the diagnostic assessment of depression and anxiety disorders, and an inquiry into a range of common physical, social, and existential symptoms and concerns.

The social variables included the size of the participant's social network, defined as the number of children, close relatives, and friends identified by the respondent. Religiosity was assessed with three items addressing religious self-perception, attendance at organized services, and frequency of private prayer. The sum of these items, which could range from 0 to 15, was used as the religiosity index (Chatters, Levin, & Taylor, 1992).

General attitudes toward euthanasia and PAS were assessed using a format described by Wilson et al. (2000). First, the topic was introduced with a definition of the terms *euthanasia* and *physician-assisted suicide,* and any questions the participant had about these practices were answered by the interviewer. Euthanasia was defined as an action in which a medical doctor gives an overdose of medication, usually by lethal injection, to purposely end a patient's life. PAS was defined as the provision of drugs and/or advice so that a patient could take his or her own life. Both actions were framed within the context of patients who were informed, mentally competent, ill with a life-threatening disease, and asking voluntarily for their physicians' help in hastening their deaths. The participant was then asked if he or she believed that each one of these practices was acceptable and if they should be legalized. The participant was also asked to indicate, in his or her own words, the reasons underlying those beliefs.

We also examined the occurrence of 22 individual symptoms and concerns, using a format of single-item screening (Wilson et al., 2004). The specific items were drawn from previous research into the correlates of euthanasia or PAS requests as well from a conceptual model of the quality of life of terminally ill patients (Stewart, Teno, Patrick, & Lynn, 1999). For each symptom or concern, the interviewer asked a standardized lead question, followed by a semistructured inquiry into the frequency, intensity,

and level of distress associated with the particular problem. The interviewer then rated the overall severity of the problem on a 7-point ordinal scale. This screening approach has been used in several previous studies of end-of-life concerns (Chochinov et al., 1995, 2002; Wilson et al., 2000), and the resulting ratings show good concordance with visual analog scale assessments (Wilson et al., 2004). Because many items were positively skewed, however, for the purpose of analysis we dichotomized the distributions to focus on severity ratings of 3 (*moderate*) or higher. This level corresponds to an issue that is acknowledged by the patient as "generally a significant problem" (Wilson et al., 2004, p. 352; see also Chochinov et al., 2002).

Interview items addressing anxiety, depression, hopelessness, and loss of interest or pleasure in activities were used as the core screening questions for discrete anxiety and depressive disorders. The remaining symptoms defining these diagnoses, as outlined in the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; American Psychiatric Association, 1994), were assessed with a symptom checklist from the interview guide of the Primary Care Evaluation of Mental Disorders (Spitzer et al., 1994).

At the conclusion of this diagnostic module, the interview returned to the issues of euthanasia and PAS, but this time from the perspective of the participant's unique experience. One question addressed whether, if these practices were legal, the participant might have asked for a physician-hastened death at any point to date in the illness trajectory. Other questions asked whether there were any future circumstances in which the participant could envision making such a request, and most important, whether the participant would in fact initiate such a request currently, at the time of the interview. The specific question about the participant's current interest asked "Based on the way you are feeling today, would you ask for euthanasia or assisted suicide *now* if they were legal and available to you?" If any of these questions were answered affirmatively, they were followed up with open-ended discussion of the reasons underlying the responses.

After the interview, the interviewer reviewed the participant's medical records in order to code the medications that had been prescribed. The interviewer also rated the participant on the Palliative Performance Scale (Anderson, Downing, & Hill, 1996), a measure of functional performance status with scores that range from 0 (*death*) to 100 (*normal activity with no evidence of disease*). Finally, for participants who indicated a current interest in receiving a physician-hastened death, we conducted up to four weekly follow-up interviews to monitor the stability of this interest over time.

Data Analyses

The data were examined in two sets of analyses. First, we identified subgroups of participants who either did or did not endorse the legalization of euthanasia or PAS, and we conducted comparisons between the subgroups on demographic characteristics. Next, we identified those participants who indicated that if a physician-hastened death were available to them, they would make a request for it in their current circumstances. These patients were then compared on demographic and clinical variables with those who would not currently initiate such requests. We used chi-square or Fisher's exact tests (for all p values reported) to compare groups on categorical variables and t tests for continuous measures.

The written transcripts of the participants' narrative responses to open-ended questions were subjected to an inductive content analysis, aided by the QSR NVivo 2 software program. First, each transcript was reviewed independently by two raters, who initially parsed the narratives into a series of conceptually unique statements, phrases, sentences, or paragraphs that answered particular questions. At this stage of analysis, the raters agreed on the identification of 61.9% of specific comments; a third rater resolved the discrepancies. Following this, three team members independently categorized those comments that had similar meanings, which they then discussed until consensus was reached as to appropriate code labels. Next, the coded statements were reviewed by members of a multidisciplinary team that comprised representatives from psychology, psychiatry, palliative medicine, nursing, and social work. Finally, these team members met as a group to develop the conceptual domains that best described the coded data. In total, 1,307 individual statements were classified, but only those themes that were mentioned by at least 5.0% of relevant respondents are reported.

Results

Participant Characteristics

Figure 1 shows the recruitment process, which involved screening of 7,564 consecutive patients with cancer who received palliative care consults or admissions to palliative care units. As shown in Table 1, the 379 participants who completed the interview included 210 women (55.4%) and 169 men (44.6%), most of whom identified themselves as Caucasian (n = 358; 94.5%). For the group as a whole, the median time until death was 63.0 days from the date of the interview.

Attitudes Toward the Legalization of Euthanasia and PAS

When asked to comment on the social policy issue of legalization, the majority of participants indicated that they were in favor of changing the law to permit euthanasia (n = 224; 59.1%) or PAS (n = 214; 56.5%). A total of 238 participants (62.8%) believed that at least one of the two practices should be legalized, whereas 99 participants (26.1%) were firmly against both and 42 (11.1%) were uncertain. Compared with those who were against legalization, those who were in favor were significantly younger (M = 65.8 years, SD = 13.7 years vs. M = 69.4 years, SD = 11.8 years), $t(335) = -2.38$, $p = .018$, and reported lower religiosity (M = 8.7, SD = 3.3 vs. M = 11.6, SD = 2.7), $t(333) = -8.65$, $p < .001$. The latter finding was also related to opinions expressed by members of different religious faiths, $\chi^2(3) = 23.76$, $p < .001$. Participants who acknowledged no religious affiliation were most likely to be in favor of legalization (55 of 62; 88.7%), followed by members of Protestant faiths (95 of 147; 64.6%), by those who indicated other religious affiliations (19 of 34, 55.9%), and finally by Roman Catholics (69 of 136, 50.7%).

Reasons For and Against Legalization

The participants who were in favor of changing the laws prohibiting euthanasia and PAS provided reasons for their opinion that we categorized into six domains (autonomy, suffering, per-

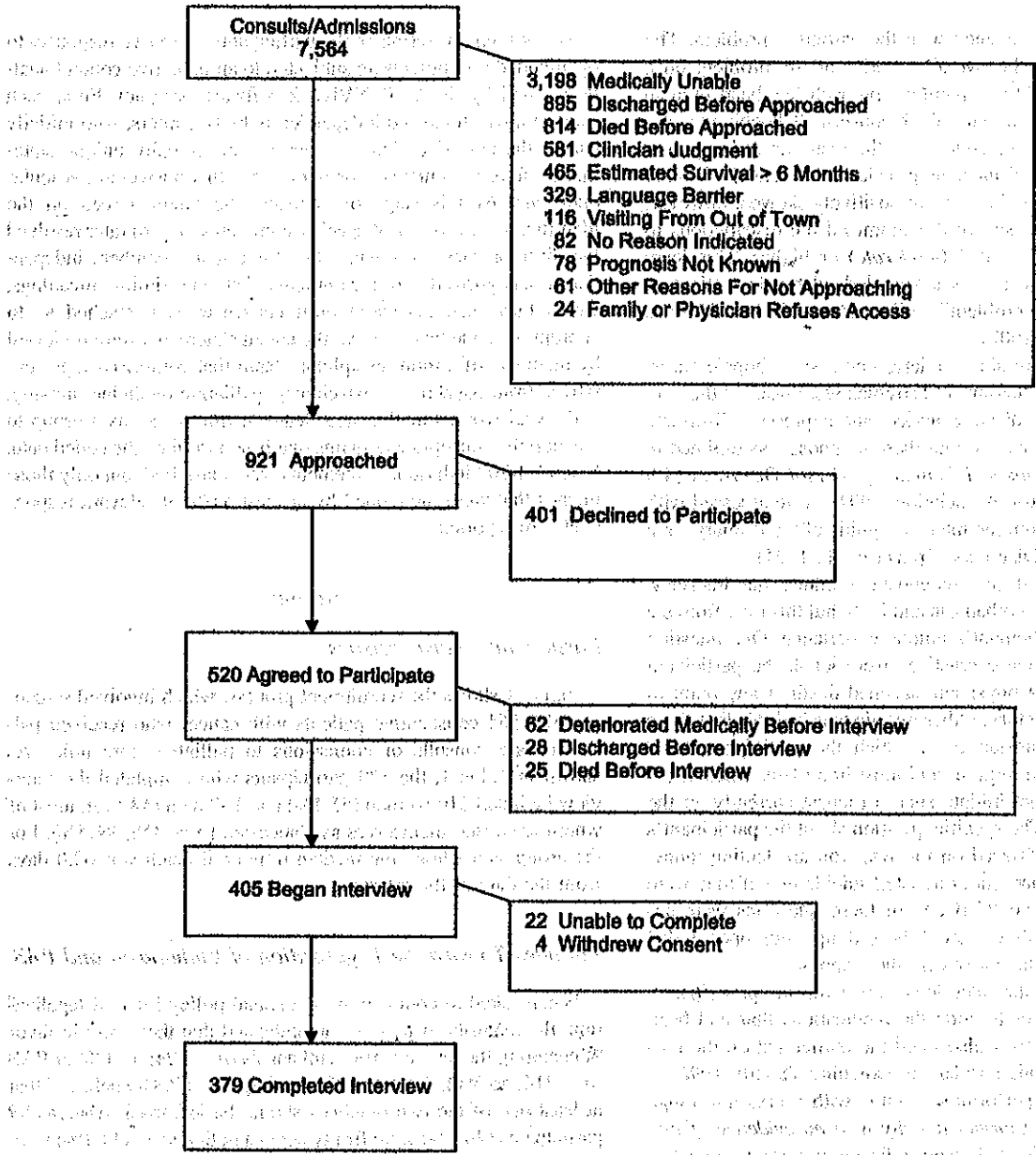

Figure 1. Recruitment into the Canadian National Palliative Care Survey.

ceived futility, compassion, experience, and concern for others). As shown in Table 2, these respondents believed that terminally ill individuals have the right to make autonomous choices regarding the circumstances and timing of their deaths. They also emphasized the significance of physical and mental suffering as a justification for physician-hastened death, particularly in a context of perceived futility for continued existence in the face of a lingering terminal illness. They viewed physician-hastened death as an act of compassion in such a situation. Less commonly, the respondents made reference to specific experiences that had helped to shape their opinions, through either their knowledge of the deaths of others or their familiarity with well-publicized cases of euthanasia or PAS that had appeared in the media. Finally, some participants believed that hastening one's death could be an altruistic act serving to reduce the stress and burden on strained family members or health care resources.

The participants who were opposed to legalization provided reasons for their view that we categorized into five domains (religious concerns, moral opposition, negative possibilities, physician's role, and unnecessary action). These respondents expressed a moral opposition toward any practice that involves the taking of human life, which many held to be against their religious beliefs. They also foresaw negative possibilities associated with the implementation and control of euthanasia or PAS. Some considered these practices to be unnecessary when good palliative care is available, and others cautioned that participating in ending of the

Table 1
Demographic and Clinical Characteristics of Participants With or Without a Current Interest in Physician-Hastened Death

Characteristic	All participants (n = 379)[a]				No current interest in hastened death (n = 357)[a]				Current interest in hastened death (n = 22)[b]				
	M	*SD*	*n*	%	*M*	*SD*	*n*	%	*M*	*SD*	*n*	%	*p*
Age (years)	67.2	12.9			67.2	12.9			66.6	12.9			.808
Gender													.381
Men			169	44.6			157	44.0			12	54.5	
Women			210	55.4			200	56.0			10	45.5	
Religion													.030
Protestant			147	38.8			137	38.4			10	45.5	
Roman Catholic			136	35.9			134	37.5			2	9.1	
Other			34	9.0			31	8.7			3	13.6	
None			62	16.4			55	15.4			7	31.8	
Religiosity index[c]	9.6	3.4			9.7	3.4			7.8	3.6			.010
Married/living with			195	51.5			182	51.0			13	59.1	.474
Social network size[c]	13.6	8.9			13.9	8.9			10.8	8.6			.131
Education													.820
Less than high school			135	35.6			126	35.3			9	40.9	
High school graduate			83	21.9			78	21.8			5	22.7	
More than high school			161	42.5			153	42.9			8	36.4	
Language													.607
English			320	84.4			300	84.0			20	90.9	
French			49	12.9			47	13.2			2	9.1	
Other			10	2.6			10	2.8			0	0	
Setting													.293
Palliative care unit			197	52.0			182	51.0			15	68.2	
Hospital inpatient			77	20.3			74	20.7			3	13.6	
Outpatient, home care			105	27.7			101	28.3			4	18.2	
Palliative Performance Scale[d]	54.6	13.7			54.9	13.6			48.2	14.0			.024
Medications[d]													
Opioids			292	77.2			273	76.7			19	86.4	.432
Antidepressants			71	18.8			65	18.3			6	27.3	.272
Benzodiazepines			173	45.8			158	44.4			15	68.2	.045
Neuroleptics			68	18.0			60	16.9			8	36.4	.039
Mental Disorders													
Depression (any disorder)			78	20.6			69	19.3			9	40.9	.026
Anxiety (any disorder)			52	13.7			46	12.9			6	27.3	.100

[a] For survival duration, *Mdn* = 63 days, *IQR* = 113, p = .388. [b] For survival duration, *Mdn* = 55.5 days, *IQR* = 117.5, p = .388. [c] Two participants were missing values. [d] One participant was missing values.

lives of their patients is an inappropriate, and probably stressful, action for physicians.

Past Interest in Physician-Hastened Death

There were 36 participants (9.5%) who believed that had euthanasia or PAS been legally available, they would already have asked for a physician-hastened death at some prior point in the course of their illness. It is important to note, however, that these individuals did not want to end their lives at the time of the interview, so they represent patients who, in effect, had changed their minds about suicide. We included qualitative questions that addressed the reasons why these participants would have made euthanasia or PAS requests, but because of an error in this aspect of protocol application these questions were asked of only 23 participants. In general, these individuals recounted episodes of suffering that incorporated both physical and psychological dimensions. Most commonly, they reported experiences of uncontrolled pain (n = 10; 43.5%). They also mentioned other specific physical symptoms (n = 8; 34.8%), generalized episodes of suffering (n = 3; 13.1%), and psychological considerations including mental stress (n = 6; 26.1%), low quality of life (n = 2; 8.7%), and the shock of receiving a terminal prognosis (n = 2; 8.7%). Each of these difficulties was either short-lived or treatable, however, and the wish to die subsided as the issues were resolved.

Future Interest in Physician-Hastened Death

When asked if there were any circumstances in which they could imagine making their own request for a physician-hastened death, 151 participants (39.8%) indicated that it could be possible in the future but not in their current situations. Their concerns revolved around three major domains. The first was a domain of suffering, characterized by worries about physical and psychological symptoms that might arise. The most frequently cited concern in this dimension was a fear of intolerable pain (n = 80; 53.0%). The other domains included a dimension of perceived futility of continued existence if one has far advanced illness, extreme functional loss or dependence, and no possibility of improvement. Finally, these participants also believed that they could be motivated to request a hastened death if they felt it would relieve the stress or burden on family members. However, these participants would not have initiated such a request at the time of the interview.

Table 2
Reasons For and Against the Legalization of Euthanasia or Physician-Assisted Suicide

Reason given	*n*	%
Reasons for legalization (n = 238)		
Autonomy		
Right to choose	93	39.1
Control	22	9.2
Suffering		
Suffering	77	32.4
Pain	62	26.1
Low quality of life, no pleasure	26	10.9
Negative outlook, stress	18	7.6
"Can't take it"	16	6.7
Perceived Futility		
Terminal illness	62	26.1
Lingering	29	12.2
Nothing to be done	24	10.1
Mental incompetence, vegetative	22	9.2
Functional loss, dependence	13	5.5
Compassion		
Merciful, peaceful, escape	30	12.6
Availability to animals	18	7.6
Dignified	12	5.0
Experience		
Experience of others	23	9.7
Famous cases	18	7.6
Concern for others		
Family stress	19	8.0
Burden to others, health system	16	6.7
Reasons against legalization (n = 99)		
Religious concerns		
God decides	41	41.8
Religious doctrine	12	12.2
Faith	10	10.2
Religious duty to live	9	9.2
Moral opposition		
Wrong to take life	32	32.7
Criminal act	15	15.3
Unnatural death	9	9.2
Sanctity of life	9	9.2
Negative possibilities		
Abuse	14	14.3
Unstable/irrational decisions	10	10.2
Fallible laws	6	6.1
Physician's role		
Inappropriate role	12	12.2
Too much responsibility	5	5.1
Unnecessary action		
Good care is available	8	8.2
Hope for life, cure	6	6.1

Note. Participants could give more than one reason for or against legalization.

Current Interest in Physician-Hastened Death

A total of 22 participants (5.8%) reported that if they could have access to euthanasia or PAS, they would definitely initiate a request to end their lives right away, in their current circumstances. Compared with those participants who would not have made an immediate request (n = 346; 91.3%) or who were uncertain (n = 11; 2.9%) these individuals reported lower religiosity, $t(375) = -2.59$, $p = .010$, and were less likely to have a Roman Catholic affiliation ($p = .006$), but they were comparable with respect to other demographic characteristics.

Clinically, those who desired a physician-hastened death were characterized by lower scores on the Palliative Performance Scale, $t(376) = -2.26$, $p = .024$, but comparisons of the median survival durations indicated that they were not closer to death ($p = .388$). They were more likely to have prescriptions for benzodiazepine medications ($p = .045$) and neuroleptics ($p = .039$), but they were not more likely to be taking opioids ($p = .432$) or antidepressants ($p = .272$). The groups did not differ with respect to place of care, $\chi^2(2, N = 379) = 2.46$, $p = .293$.

The prevalence rates of the 22 symptoms and concerns are shown in Table 3. Participants who desired a physician-hastened death had an average of 7.7 (SD = 3.9) issues that were rated at a moderate level or higher compared with 3.7 (SD = 3.2) among the other participants, $t(377) = 5.66$, $p < .001$. Individually, the prevalence rates among this group were higher for 12 of the 22 problems ($p < .025$). No single symptom or concern was expressed universally, however, and some (e.g., hopelessness, loss of control over daily events, serious communication issues with family members), although occurring at a higher prevalence than among the comparison group, had relatively low absolute rates.

The issues that emerged most prominently among these individuals were the physical symptoms of weakness, general malaise, and drowsiness and the social concern of self-perceived burden to others. Globally, they reported high levels of suffering and expressed a strong desire for death. Each of these concerns was rated as a significant issue for over 50% of the individuals who desired a physician-hastened death and at a significantly higher rate than among other participants.

Other issues are noteworthy because they did not differ reliably between participants with and without a desire for a physician-hastened death. These included serious financial worries, the frank admission of a spiritual crisis, a prominent concern with loss of dignity, an inability to achieve a state of acceptance, and a general dissatisfaction with life. Among the study group as a whole, these concerns were reported as significant ongoing problems by less than 10% of respondents. On the other hand, pain of at least moderate severity was reported by a larger number—about one third overall—but the rates were comparable between the two groups.

In the mental health assessments, participants with a desire for physician-hastened death had a higher prevalence of depressive disorders (n = 9; 40.9%) than did those without such a desire (n = 69; 19.3%; $p = .026$). This was particularly evident for the specific diagnosis of major depression (n = 9 vs. n = 40; 40.9% vs. 11.2%; $p = .001$). Six of the 9 depressed individuals were treated with antidepressant medication at the time of the interview.

Reasons for a Current Interest in Physician-Hastened Death

The qualitative reasons underlying the desire for physician-hastened death were categorized into seven themes. Those who wished to end their lives emphasized the apparent futility of continuing to exist in a functionally limited and deteriorating state of health, knowing that there is a fatal outcome in the near term. The specific comments within this theme made reference to terminal illness (n = 11; 50.0%), loss of function (n = 7; 31.8%), a sense of unwanted lingering (n = 5; 22.7%), treatments that were not helpful (n = 4; 18.2%), the pointlessness of continuing to live

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Table 3
Symptoms and Concerns Reported by Participants With or Without a Current Interest in Physician-Hastened Death

Symptom or Concern	No current interest in hastened death (n = 357)		Current interest in hastened death (n = 22)				
	n	%	n	%	p	Odds ratio	95% confidence intervals
Social concerns							
Isolation	37	10.4	7	31.8	.008	4.0	1.6–10.5
Communication problem	5	1.4	3	13.6	.008	11.1	2.5–50.0
Burden to others	85	23.8	13	59.1	.001	4.6	1.9–11.2
Financial problem[a]	31	8.7	3	13.6	.434	1.7	0.5–5.9
Existential issues							
Spiritual crisis[b]	11	3.1	0	0.0	1.000		
Difficulty accepting	30	8.4	3	13.6	.425	1.7	0.5–6.2
Dissatisfaction with life	16	4.5	3	13.6	.090	3.4	0.9–12.6
Loss of resilience[b]	27	7.6	7	31.8	.002	5.7	2.1–15.1
Loss of dignity	24	6.7	2	9.1	.656	1.4	0.3–6.3
Loss of control	21	5.9	5	22.7	.012	4.7	1.6–14.0
Physical symptoms							
General malaise	145	40.6	15	68.2	.014	3.1	1.3–7.9
Pain	119	33.3	9	40.9	.490	1.4	0.6–3.3
Drowsiness	109	30.5	13	59.1	.009	3.3	1.4–7.9
Weakness	204	57.1	19	86.4	.007	4.8	1.4–16.3
Nausea	59	16.5	6	27.3	.238	1.9	0.7–5.0
Breathlessness	91	25.5	7	31.8	.616	1.4	0.5–3.5
Psychological symptoms							
Anxiety	51	14.3	7	31.8	.059	2.8	1.1–7.2
Depression	46	12.9	7	31.8	.022	3.2	1.2–8.2
Loss of interest/pleasure[a]	49	13.8	4	18.2	.529	1.4	0.5–4.3
Hopelessness[b]	36	10.1	6	27.3	.025	3.3	1.2–9.0
Global considerations							
Suffering	85	23.8	12	54.5	.004	3.8	1.6–9.2
Desire for death[b]	28	7.9	18	81.8	<.001	52.6	16.6–166.0

Note. The severity of symptoms and concerns were rated using a semistructured interview. n refers to the number of participants in each group who were given ratings of "moderate" to "extreme" severity. Ratings of moderate severity represent the threshold at which each symptom or concern was generally regarded as a significant problem.
[a] One participant was missing values. [b] Two participants were missing values.

(n = 4; 18.2%), mere existence (n = 4; 18.2%), or the fact that they had reached a very old age (n = 2; 9.1%). Second, these participants expressed a theme of suffering. This included statements about pain (n = 4; 18.2%) and other physical symptoms (n = 4; 18.2%) as well as a psychological perspective encompassing a negative outlook (n = 4; 18.2%) or a loss of pleasure in life (n = 2; 9.1%). Some spoke of a difficult cancer experience that had been going on for a very long time (n = 2; 9.1%). In a third theme, over half of the respondents (n = 12; 54.5%) remarked that their health status and care needs made them feel like a burden to others or a drain on health care resources. Fourth, many expressed the sense that they were ready for, and had a desire for, death to come (n = 8; 36.4%). Indeed, some spoke of having had a good life (n = 2; 9.1%) with no fear of death (n = 2; 9.1%). Fifth, these individuals believed that access to physician assistance would be compassionate, providing them with an easier death (n = 4; 18.2%), and allowing them to avoid the suffering they experienced currently or were anticipating in the future (n = 5; 22.7%). In this light, they considered it to be inhumane to withhold assistance (n = 2; 9.1%). The sixth and seventh themes were the belief in retaining the autonomy to choose how and when they will die (n = 3; 13.6%) and the influence of having witnessed the death of others (n = 2; 9.1%). Although mentioned by only a few respondents, these were also factors that contributed to the desire for physician-hastened death.

Euthanasia Versus PAS

If both euthanasia and PAS had been available to these individuals, 3 were uncertain as to which method they would choose, and 3 would have selected either. Of those 16 participants who indicated a clear preference, the majority would have chosen euthanasia (n = 12; 75.0%) over PAS (n = 4; 25.0%), $\chi^2(1) = 4.00$, $p = .046$.

Stability of the Desire for a Physician-Hastened Death

At least one follow-up interview was conducted with 17 of the 22 participants (77.3%) who expressed a desire for physician-hastened death, for a total of 36 repeat interviews. The other 5 participants worsened medically and could not take part in follow-up interviews. There was an average of 23.7 days (SD =

13,4 days) between the first and last meetings. There was 1 individual who changed her position, believing that she would no longer request a hastened death. One other respondent also changed his mind but reverted to his original view later. The other 15 participants remained consistent in the belief that they would prefer a physician-hastened death.

Discussion

As in previous research (Emanuel, Fairclough, & Emanuel, 2000; Wilson et al., 2000), this study found that a majority (62%) of a cohort of terminally ill patients endorse the legalization of euthanasia or PAS. Indeed, this figure is comparable with the rates of support that are found in surveys of the Canadian general public (Singer, Choudry, Armstrong, Meslin, & Lowy, 1995). The present findings are compelling insofar as the participants involved were approaching their own deaths from advanced cancer. However, their general attitudes toward the social policy question of legalization may not be very different from those of the public at large.

About 40% of respondents reported that they could envision future circumstances in which they might personally request a hastened death. Even patients who are currently comfortable may have a fear of symptoms that might arise later in the progression of their illness, and for them, simply knowing that euthanasia or PAS was available could be a source of relief or control. In reality, however, most would never choose to exercise that option.

On the other hand, we found that had euthanasia or PAS been legally available, 5.8% of the participants believed that they would have taken direct action to end their lives. This is a much higher figure than in Oregon, where fewer than 0.1% of dying patients choose PAS (Sullivan et al., 2000), but it approaches the 7.4% incidence of hastened deaths in the Netherlands among patients with advanced cancer (Onwuteaka-Philipsen et al., 2003). Moreover, our findings are also similar to the Dutch experience in that if both euthanasia and PAS were legal, euthanasia would be chosen more frequently.

Although there was no single issue that characterized all of the 22 individuals who indicated a desire to receive a hastened death, as a group they did differ from the other participants in a number of ways. For one, they had lower religiosity and were less likely to be of the Roman Catholic faith. Therefore, they had no fundamental moral objections to euthanasia or PAS that were grounded in religious tenets. Clinically, they had more complex presentations, with a lower performance status and a greater number of symptoms and concerns that were rated as significant problems. They did not have a shorter life expectancy, however, so these findings were not simply attributable to their being further advanced in the course of illness at the time they were interviewed. The distress among this group seems to have been recognized by the clinical teams involved in their care, because they were also more likely to have prescriptions for benzodiazepine and neuroleptic medications.

The relative importance of physical versus psychological symptoms in requests for hastened death is one that has been the focus of some investigation (Chochinov et al., 1995; Rosenfeld, 2002), and the present findings indicate that both are relevant. The problem of pain is particularly noteworthy in this regard because public support for euthanasia or PAS is strongest for scenarios involving uncontrollable pain (Emanuel, Fairclough, Daniels, & Clarridge, 1996). Pain was reported as a problem of at least moderate severity by 9 (40.9%) of the participants who desired a hastened death. Therefore, pain was a contributing factor for some individuals, even though its overall prevalence was not elevated in this group in comparison to other participants. More generally, however, the physical symptoms that were more frequent were not acutely desperate crises with pain or dyspnea but rather the more protracted features of advanced disease, such as general malaise, weakness, and drowsiness—some of which may have been caused by medications used to treat other symptoms.

From a psychological perspective, prominent concerns with isolation and communication difficulties, existential issues regarding the loss of resilience and control, and symptoms of depression and hopelessness were more common among participants with a desire for hastened death, although in each case they were reported by only a minority. The only psychological concern that occurred in over 50% of these participants was the sense of self-perceived burden to others, a factor for which the significance is becoming increasingly apparent in recent studies (Akechi et al., 2004; Ganzini et al., 2002; Morita et al., 2004; Schneiderman, Kronick, Kaplan, Anderson, & Langer, 1994; Sullivan et al., 2000; Virik & Glare, 2002; Wilson, Curran, & McPherson, 2005). It is interesting to note that loss of dignity, which has been cited as a major concern of patients receiving euthanasia in the Netherlands (van der Maas et al., 1991), did not stand out as a factor that clearly underlies the desire for hastened death.

About 40% of the participants with a desire for euthanasia or PAS met diagnostic criteria for major depression, confirming the findings of other investigators of a link between depressive symptoms and the desire to die (Breitbart et al., 2000; Chochinov et al., 1995; Emanuel, Fairclough, & Emanuel, 2000; van der Lee et al., 2005; Wilson et al., 2000). There is evidence that depression can be treated in palliative care, so the significance of this finding lies in reaffirming the importance of screening for potentially treatable mental health problems. On the other hand, our findings also indicate that a desire for a hastened death can certainly occur in terminally ill people who are not depressed. Moreover, some investigators have pointed out that even when they are present, the influence of depressive symptoms in motivating these requests is unclear (Bharucha et al., 2003).

The role of depression in requests for hastened death is a particular case of a more general concern that arises in the legalization debate: that people might receive physician assistance in ending their lives because of problems that could be helped with better palliative care (Emanuel, Fairclough, & Emanuel, 2000; Blank, Robison, Prigerson, & Schwartz, 2001). This raises the question of the extent to which requests for hastened death remain stable over time. In other studies, some instability has been found in the expressed desire to die (Chochinov et al., 1995), and Johansen et al. (2005) have noted how attitudes toward euthanasia can be fluctuating and ambivalent. Our findings offer two perspectives on this issue. The first comes from the experience of patients who believed they might have asked for a physician-hastened death at an earlier point in their illness but who did not want it at the time of the interview. For these individuals, pain and symptoms, including mental stress, were reported as the most important reasons for the desire to die. However, their acute problems did turn out to be controllable, and their desire for death was transitory. It appears therefore, that potentially treatable symptoms can drive people to suicide. On the other hand, the participants who

reported a desire for euthanasia or PAS at the time of the interview all had access to palliative care services, and in most cases, their desire remained stable over time. For them, palliative measures had not yet diminished the consistent desire for a physician-hastened death. Apparently, then, this desire is sometimes transitory, but once firmly established, it can be enduring.

Although this research provides further clarification of the factors that motivate terminally ill patients to desire physician assistance in ending their lives, there are limitations to the study that should be recognized. Most important, the fact that we interviewed only a small minority of all patients seen by the palliative care services raises concerns about generalizing the findings too broadly. We did document the reasons for nonreferral, which has been done infrequently in large-scale studies in palliative care, and we found several possible sources of bias. For example, clinicians sometimes elected not to approach particular patients because of worries about compromising their care; among those who were approached, the refusal rate was high. It is not clear how these factors may have skewed the results. For example, among those patients who were very ill and near to death, the desire for euthanasia or PAS might have been higher than we observed. However, if the refusal to participate was motivated by an antipathy toward the topic of physician-hastened death, then negative attitudes toward these practices may have been underestimated. The ethical, clinical, and practical aspects of recruiting terminally ill patients into research studies, especially those addressing controversial topics, are significant issues in their own right (Addington-Hall, 2002; Casarett & Karlawish, 2000). Our findings are limited by the fact that we interviewed only mentally competent patients who were approaching death but still well enough, and willing, to take part in a detailed interview. However, these criteria would also apply to patients who made requests for euthanasia or PAS in areas where these practices are legal but require an appropriate assessment to ensure the patient's competence, rationality, and certainty. In this sense, the patients in this study are similar to those who would be considering the role of euthanasia or PAS in their end-of-life care if they were permitted access.

Nevertheless, it is important to note that euthanasia and PAS are illegal in Canada, so the participants were answering the survey questions in a hypothetical way; whether they would maintain the same attitudes and desires if these practices were legally available is unknown. The answer to this question must await further research conducted in jurisdictions where physician-hastened death is legal.

The participants in this study represented the two major language groups of Canadian society, but they were not diverse in other aspects of ethnicity. It is important to note that previous research has shown that members of some minority groups have lower rates of approval for euthanasia and PAS, so the present findings are unlikely to generalize to them (Braun, Tanji, & Heck, 2001; Lichtenstein, Alcser, Corning, Bachman, & Doukas, 1997). It is also noteworthy that all participants had access to publicly funded palliative care services. Although financial distress has not been found to be a major motivation for PAS requests in Oregon (Sullivan et al., 2000), differences in health insurance practices do exist between Canada and the United States, and these differences must be acknowledged in the interpretation of these findings.

Finally, the survey results are relevant for informing the ongoing debate around the possible legalization of euthanasia or PAS, but we caution that empirical research is limited when addressing issues that have an inherently moral dimension (Pellegrino, 1995). Whether these actions are ever ethically justifiable is a question that cannot be answered by patient surveys, but the moral and philosophical aspects of decision making remain central in any serious discussion of physician-hastened death.

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