

Notes on Ontario Medical Board End-of-life policy

February 3, 2015

General observations

- Though this policy purports to relate to people who are dying of a terminal illness, experience shows that such policies often have deleterious effects on people with severe physical and cognitive disabilities who may not be at the “end-of-life” but who need “life sustaining medical care.” Any “end-of-life” care policy which fails to recognize or address such effects perpetuates the discrimination against and disenfranchisement of elders, people of colour and people with disabilities in the medical system.
- This is not a policy document; it is a public-relations piece. It is not directed at physicians, or hospital administrators, as a policy statement would be. It also excludes many factors that enter into policy decisions, such as facilities management, resource allocation, staffing, etc.
- This “policy” does not recognize that physicians are placed in a double-bind vis-à-vis the people under their care. On the one hand, they are expected to provide and advocate for the best care possible. On the other hand, there is an unspoken demand that they keep an eye on the hospital’s bottom line when making care decisions. The Ontario Medical Board should do more to deal with this conflict and its negative effect on care and outcomes.

Principles that should be reflected in the policies

- Where there is doubt as to a person’s wishes, a bias for preserving life should guide all actions. Death is irrevocable, life is not.
- “End of life” should not mean “Ending of life.”
- **The word “Person” must be used rather than “patient”.** Over time, the Doctor/Patient relationship has evolved into a power differential far beyond what is needed to respect the clinician’s study and experience, and which devalues the person’s knowledge of her/his body and its needs. Continued use of the word “patient” re-enforces the clinician’s dominant position in the relationship and disempowers the individual, discouraging his/her active participation and taking responsibility for the outcome of medical treatment.
- Discriminatory beliefs, judgments and actions based on disability, race, gender, age, sexual orientation, income/class status and other

characteristics of the person are unacceptable. This applies especially to judgments as to the quality of life of elders and persons with disabilities. Clinicians must be alert to the effects of such discrimination on the quality of care and support received by persons under their care.

- In order to prevent requests to terminate treatment, each person must have a full range of *life* choices available so that the option of death becomes irrelevant and unnecessary.
- Any request for euthanasia, assisted suicide, to refuse or withdraw medical treatment, for continuous palliative sedation, or for any other sort of medical aid in dying must trigger the full range of suicide prevention measures. Anything less would be discriminatory.
- Each person shall have access to devices and services to allow for meaningful and independent communication, without having to rely on family or other interested parties. This includes access to print materials.
- Each person shall have timely access to medical equipment and services that are adapted to their needs so as to provide equal benefit of diagnostic and treatment services.
- Personal and comfort care should be provided at all times, even where a person has refused medical treatment.
- Engaging the state to help a person kill him/herself should be at least as onerous as determining if a person is able to manage his/her financial affairs.

Comments on specific policies

Principles

- “Self-regulation” is insufficient to prevent conflict of interest and lack of accountability. Practitioners should be answerable to a neutral public supervisory body including physicians, legal professionals, policy experts and consumers, as well as to courts.

Terminology

Important terms are not included/defined:

- End-of-life
- Futile care
- Standard of care
- Clinical Benefit

- Capacity
 - “understand”
 - “appreciate”
- Palliative sedation
- Comfort care
- Personal care
- Artificial nutrition and hydration
- Meaningful recovery (used in the section on quality care)
- “Do not resuscitate” order, including what treatment is or isn’t given, conditions under which a person will or will not be resuscitated (e.g. in surgery?)

Some terms need clarification:

- Life saving medical treatment
- Life sustaining medical treatment – does this include suctioning, kidney dialysis, administering antibiotics, turning & bed sore prevention, spoon-feeding, catheterization?
- “substitute decision maker” this definition is buried in a footnote but should be included in the terminology section, since the concept is essential to the policy statement.

Quality care

As this is (supposed to be) a policy statement, the bulleted list of “what is important to patients and their families” should be replaced with a list of standards of quality care. This new list should reiterate the legal standard of care expected of all physicians. Reframing the “list of what is important to patients in end of life care” in terms of standards of care might look like:

- Provide (or coordinate and ensure the provision of) state-of-the-art medical care to ensure the maximum level of functioning and quality of life.
- Provide (or coordinate and ensure the provision of) state-of-the-art pain and symptom management to relieve physical and psychological pain and symptoms.
- Advocate on the person’s behalf to obtain necessary authorization for medical treatment.

- Provide clear, honest, information to the person receiving treatment and his/her family. Communicate on a timely and consistent basis in language and by whatever means to ensure understanding and participation (including using language or sign interpreters, technology or facilitators). Inform the person of her diagnosis, prognosis, available treatments (their potential efficacy and drawbacks), and the consequences of any decision.
- Be honest, forthright and compassionate in all dealings with the individual, his/her family and other providers.
- Work with social service and rehabilitation professionals to ensure that each person obtains services to support the maximum level of independence and integration.
- Along with mental health providers, social service and chaplaincy staff, promote positive family participation in decision-making, achieving a sense of control and meaning, satisfying spiritual needs, completing important tasks, and preparing for the end of life by resolving conflicts, saying goodbye, and preparing for death.
- Ensure that all medical services, equipment and facilities are accessible and available to persons with disabilities in a timely fashion.
- Ensure that the person is free from abuse, exploitation and mistreatment.
- Care for the whole person, treating her/him with respect at all times. Affirm her/his inherent dignity by empowering the person to control his/her circumstance.
- Work cooperatively with allied professionals in the person's interest.

Communication

- Interpreters, technology and facilitators should be used when necessary to ensure effective communication. People who are unable to speak should be given every opportunity and assistance to communicate their wishes and actively participate in making care decisions.
- Information, especially medical information, should be made comprehensible to laypersons.
- Ample opportunity should be provided for persons to ask questions.
- People should have easy access to their medical charts/records, and help to read and understand chart notations.

- Physicians should deal directly with the individual as much as possible.
- Physicians should either record or make a transcript of any meetings, conversations, etc., regarding the person's condition for the person and/or the family to review later.

Advance Care Planning

- This section should be renamed "death planning" because of its bias in that direction.
- Of the two articles cited in footnote 7, one concerns the high cost of treatment at the end of life.
- Lines 144, 150. This section emphasizes that physicians should remind and encourage people to engage in advance care planning. One upshot of "initiat[ing] these discussions over multiple occasions" is that people with disabilities are often badgered to sign "do not resuscitate" orders, where non-disabled people are not so harassed. This is based on the common assumption by doctors that the quality of life with a disability is lower than that without a disability.
- The booklet and form referred to in footnote 8 assume that preparing for death is the goal of advance care planning, and that death is the outcome of "serious illness or injury." They do not discuss the options of rehabilitation and living with a disability. This reflects the negative valuation of disability and those who have it.
- Life sustaining treatment options (such as tube feeding and use of respirators) should be presented not as "limiting," "onerous," "undignified" or "burdensome," but as practical solutions that enable people to live independently with severe disability.

Consent to treatment

- The policy does not address the fact that refusing medical treatment is a suicidal gesture.¹

¹ § 7 of the HCCA describes the "common law duty of a caregiver to restrain or confine a person when immediate action is necessary to prevent serious bodily harm to the person..." The conflict between this duty and the right of the person to refuse treatment regardless of the consequences should be resolved through a more rigorous process for determining that the person not only has the ability to understand information and

- As with any person who is suicidal, a request to withdraw life-sustaining or life-saving treatment should raise doubt as to the person's capacity. Such doubts can be addressed through provision of palliative care, making available options for home-based care, and application of mental health screening and treatment, as well as suicide prevention measures.
- This section does not sufficiently address the different issues related to refusing treatment before it is administered, as opposed to withdrawing treatment that is already underway. (Lines 163-167, 231)
- Application of the "reasonable person" standard in HCCA § 11(2)(a) can have bizarre results in the context of advance care planning. How is it reasonable to expect that a person will retain the details of a three-minute delivery of a diagnosis by a doctor when they're ill and under the influence of medications?
- Physicians should use state-of-the art methods to detect and interpret consciousness and volition, as well as rehabilitation methods and adaptive equipment to facilitate communication before deferring to a substitute decision maker.
- Physicians should work with allied health professionals to verify that substitute decision makers are acting in the person's best interest and are not motivated by pecuniary interests.

Intervention and Care Management

- 203: Remove the word "However."
- 205: Physicians MUST seek the support or involvement in palliative care specialists. Most doctors are not trained in pain and symptom management, and are not aware of state-of-the-art techniques. Nor are they cognizant of the interplay between physical, psychological, social/logistical and spiritual needs of people with serious or terminal illness or conditions.
- In the paragraph beginning at line 208:
 - Physicians who undertake to provide palliative care must abide by the philosophy and standards for palliative care; what are those standards. They should be listed.

appreciate the consequences, but that judgment is not impaired by psychological or other factors. The person must also have a viable set of options among which to choose.

- This paragraph should mention the goal of improving the person's quality of life, with or without life-sustaining treatment.
- 221-222: "Physicians are not obliged to propose or provide life-saving or life-sustaining treatment that are not within the standard of care." This needs explanation/clarification, i.e. what is the "standard of care"? See also Line 226-227.
- How does the Medical board propose to eliminate bias and prejudice as factors in physicians' decision as to the benefit of providing life-sustaining treatment?
- 232-233 "The outcomes that would need to be achieved to warrant the continuation of treatment." This appears to impose a "performance standard" on persons with cognitive / communication disabilities. What rehabilitation services or adaptive technology will be provided to enable the person to achieve maximum functioning given their state of health?
- The paragraph beginning at line 236, dealing with "do not resuscitate" orders, should perhaps be included in the section on consent.
- Line 252: "Aggressive pain management" should not be considered only in the context of "end-of-life" care, nor should opioids be restricted to persons who are near death.
- The policy should clarify that "palliative sedation" is not intended to be "continuous." It is a tool to manage intractable pain, not to render a person permanently unconscious and thus remove all decision-making ability.

Dying at home

- This section reflects (once again) the unidirectional nature of this policy. There are many people with serious, life-threatening illnesses and conditions who, with the help of life-sustaining medical devices (respirators, tube-feeding), live as fully-integrated members of their communities.
- 264: Physicians should not only "assess" whether dying at home is manageable, they should coordinate with a team of allied health professionals (palliative care professionals, hospice providers, social workers, etc.) to ensure that necessary services and supports are in place.

Wishes and requests to hasten death

- 310-314: Pressure to hasten death may also come from family members. The suggested remediation in lines 315-322 should include the possibility of family intervention to prevent abuse/exploitation.
- Lines 324-334: Regardless of the state of the law, physicians should keep in mind that killing is not medical treatment. It is neither the duty nor the responsibility of medical staff to end the life of persons under their care, even if the person requests it. The medical profession is charged to value, preserve and improve the quality of life until the moment of natural death. This includes implementing the public policy of suicide prevention, not providing suicide assistance. A person who wishes to end his or her life may refuse medical treatment if s/he is too ill to take her own life, or otherwise commit suicide unaided.

Managing Conflict

- 337-340: It should be noted that the stakes in such conflict are also much higher.
- This policy should put physicians on notice of their legal responsibilities to watch for and report abuse of elders and other vulnerable persons.
- How does the Ontario Medical Board plan to deal with the problem of blackballing family members who point out problems in the treatment of their loved ones?

Documentation

- 372: As stated earlier, provision should be made (using transcription software that is now readily available) for recordings or transcripts of conversations about health status and care decisions.
- The policy should include basic procedures for informing all medical staff of the type of care to be undertaken (DNRs and orders for life-saving and life-sustaining treatment), how to record and verify requests to change type of care, and to ensure compliance with the person's request.
- People should have easy access to their medical charts/records, and help to read and understand chart notations.

Organ and tissue donation

- Persons and their families should not be asked about organ and tissue donation until after decisions about life-sustaining and life-saving treatments have been made.