



California’s End of Life Option Act: CPA Guidance for Psychologists

July 14, 2017

California Psychological Association End of Life Option Act Work Group *

Table of Contents

- I. Introduction 2
- II. Legal framework..... 2
 - A. Patient requirements 2
 - B. Health care professionals’ requirements 2
 - 1. Attending physicians..... 2
 - 2. Consulting physicians..... 3
 - 3. Mental health specialists 3
 - C. Protections and immunities 3
- III. Key issues 3
 - A. Values, beliefs, and culture 3
 - B. Ethics 4
- IV. Psychologists’ roles 6
 - A. Treating provider 6
 - B. Consultant 7
 - C. Mental health specialist 7
- V. Mental health specialist assessment..... 8
 - A. Preliminary considerations..... 8
 - B. Purpose of the assessment..... 8
 - C. Conducting the assessment..... 9
 - D. Coming to Conclusions..... 12
 - E. Report..... 13
- VI. Conclusion..... 13
- VII References 14
- VIII. Additional Resources 16

* The California Psychological Association (CPA) End of Life Option Act Work Group included: Cheryl A. Bowers, PhD, Andrew Harlem, PhD, David Jull-Patterson, PhD, Craig Lareau, JD, PhD, ABPP, Morton H. Shaevitz, PhD, ABPP, and Elizabeth Winkelman, JD, PhD. The work group wishes to thank Jo Linder-Crow, PhD and the members of the CPA Board of Directors for their valuable input regarding the development of this document.

I. Introduction

The California End of Life Option Act was passed in 2015 and went into effect on June 9, 2016. The Act allows terminally ill patients to obtain aid-in-dying drugs from a physician, if detailed requirements are met and specified procedures are followed. Psychologists are identified, along with psychiatrists, as “mental health specialists” who are authorized to provide assessments under this law. In addition to providing assessments, psychologists may be asked to address issues related to end of life options by patients, patients’ family members, or colleagues.

This document was developed by the California Psychological Association (CPA) End of Life Option Act Work Group to offer information and guidance to psychologists who provide or who are considering providing services related to the Act. The document outlines the requirements of the Act; explores several key issues (values, beliefs, culture, ethics); describes psychologists’ roles; and addresses how to conduct a mental health specialist assessment. Although primarily intended for psychologists, some aspects of this document may be useful to other types of health care professionals as well.

The guidance contained in this document is designed to be educational and to encourage a thoughtful, thorough approach towards end-of-life options. The guidance does not address individual considerations and is not intended to take precedence over psychologists’ judgment in any particular case. It is not intended to set a standard of care or to function as a set of mandatory guidelines.

II. Legal framework

The End of Life Option Act (ELOA) provides the legal framework for physician aid in dying in California. This law includes detailed requirements for patients to “qualify” to obtain lethal drugs. It also includes detailed procedures that must be followed by health care professionals who provide authorized services. In addition, protections for patients and their families as well as for involved health care professionals are spelled out. The main provisions of the Act are summarized below. The full text is available online at http://leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201520162AB15.

A. Patient requirements

The primary requirement for patients who seek physician aid in dying is that they must have a medically confirmed diagnosis of a terminal illness with a prognosis of less than six months to live. “Medically confirmed” means that the diagnosis and prognosis of the primary (attending) physician has been confirmed by a consulting physician who has examined the patient and the patient’s relevant medical records. In addition, patients must be adult residents of California with the capacity to make medical decisions and the ability to self-administer lethal drugs.

Patients must make three requests for aid-in-dying medications, including two oral requests made at least 15 days apart and one written request. The written request must be signed by the patient and two witnesses, using the required form specified in Health & Safety Code §443.11(a). Only one of the two witnesses may be a relative of the patient or entitled to a portion of the patient’s estate and only one witness may own or be employed at the facility where the patient is being treated. The requests must be made solely and directly by the patient and received directly by the attending physician. Patients are also required to complete a “Final Attestation” form within 48 hours prior to ingesting the aid-in-dying drugs.

B. Health care professionals’ requirements

1. “Attending physicians” are defined by the ELOA as physicians who have primary responsibility for the health care of an individual and for treatment of the individual’s terminal disease. The requirements for attending physicians who provide services under the Act are complex. The main requirements will be described below. More detailed guidance is available from the California Medical Association (2016).

A checklist and compliance form for attending physicians is available from the Board of Medicine (https://www.cdph.ca.gov/Documents/EOL_AtendingPhysicianChecklistComplianceForm.pdf).

Attending physicians must make an initial determination regarding whether the patient has a diagnosis of a terminal illness, a prognosis of less than six months to live and the capacity to make medical decisions. If there are indications of a mental disorder, the attending physician is required to refer the patient for a mental health specialist assessment.

Attending physicians must obtain thorough informed consent from the patient, including fully informing the patient about diagnosis, prognosis, alternative or additional treatment opportunities (e.g., hospice care, palliative care, pain control), potential risks and probable result of taking the drugs, and the possibility of obtaining but not ingesting the drugs. Attending physicians must also counsel the patient about the importance of issues such as participating in hospice or palliative care, safe maintenance of the drugs, notifying next-of-kin, and having another person present when ingesting the drugs.

2. “Consulting physicians” are defined by the ELOA as physicians who are independent from the attending physician and qualified by specialty or experience to make a diagnosis and prognosis regarding an individual’s terminal disease. Consulting physician requirements under the ELOA include: examining the patient and his/her medical records; confirming the diagnosis and prognosis; determining that the patient has the capacity to make medical decisions; confirming the patient has made a voluntary, informed decision; and completing the required consulting physician compliance form. If there are indications of a mental disorder, a referral for a mental health specialist assessment must be made by either the attending or consulting physician.

3. “Mental health specialists” are defined by the ELOA as psychiatrists or licensed psychologists. Mental health specialist requirements under the ELOA include: examining the patient and his/her relevant medical records; determining that the patient has the capacity to make medical decisions, act voluntarily, and make an informed decision; determining that the patient is not suffering from impaired judgment due to a mental disorder; and documenting the assessment by providing a report of the outcomes and determinations made.

C. Protections and immunities

The ELOA includes numerous protections for both patients and providers. For example, the detailed requirements for obtaining informed consent and for requesting lethal drugs serve to protect potentially vulnerable patients from coercion and ensure they are aware of alternative treatment options. In addition, the Act protects patients and their families by defining death resulting from ingesting a properly prescribed aid-in-dying drug as “not suicide” and by specifying that health and insurance coverage will not be affected differently than if death had resulted from the underlying disease.

The ELOA also includes protections and immunities for health care professionals and entities who provide services relating to aid in dying as well as for those who do not. The law specifically makes participation voluntary and allows persons or entities to decline to participate for reasons of conscience, morality, or ethics. Health care entities may prohibit their employees and independent contractors from providing such services while on their premises or within the scope of employment or contract. Health care providers are immune from “civil, criminal, administrative, disciplinary, employment, credentialing, professional discipline, contractual liability, or medical staff action, sanction, or penalty” for participating or for refusing to participate in activities authorized by the Act (Health & Safety Code §443.14).

III. Key issues

A. Values, beliefs, and culture

California first considered the question of legalized physician aid in dying with Proposition 161, which was on the state ballot in 1992. Subsequent efforts to pass assisted death legislation occurred in 1999, 2005, and 2006. In 2015, the legislature passed the ELOA and it was signed into law by Governor Brown. In each of these attempts to legalize physician aid in dying, the citizens of the state expressed a variety of views about the subject.

California psychologists reflect the views of the greater citizenry, so it is important for psychologists to be aware of their personal beliefs and values as they encounter patients who are considering the ELOA.

Fenn & Ganzini (1999) documented that psychologists “who strongly supported assisted suicide were less confident in psychologists’ ability to assess the quality of life of patients than were those who endorsed a more moderate view, but more confident that one could assess whether judgment was impaired with regard to the request for assisted suicide” (p. 240). Research has also demonstrated the following:

An evaluator who does not believe hastened death is acceptable may be more likely to perceive a person as incapable of making such a decision and may be less likely to work with the person to discuss this as a possibility than someone who does not have such negative views... On the other hand, an evaluator who supports a person’s right to hasten death may conduct a less thorough assessment and be more likely to approve of such a request than someone who does not have such a positive perspective. (Werth, Lewis, & Richmond, 2009, p. 88)

Religion can be the source of many practitioners’ moral beliefs, and a variety of stances toward aid in dying have been expressed by major religious groups in the U.S. (Pew Research Center, 2013). Individual psychologists may be more or less influenced by religious teachings and beliefs, and it’s important that they are aware of those influences on their professional behavior.

In addition, individual practitioners may hold beliefs that differ from the position taken by their employers or other institutions with which they are affiliated. From Catholic hospitals that do not participate in any activities authorized by the Act to health care systems that require a mental health expert assessment for *all* patients requesting medication to hasten death, institutions may approach implementation of the ELOA in a variety of ways. As noted above, the ELOA specifically permits practitioners and entities to decline to participate in providing services authorized by the Act.

Cognitive and cultural biases may be particularly salient when working with patients at the end of life. In particular, social biases may play a role in psychologists’ decisions about clinical interventions or evaluative decisions when working with individuals from specific groups, such as ethnic minorities, prisoners, elders, persons with disabilities, and other disenfranchised groups. Ongoing efforts are needed to counter the effect of biases. Tervalon & Murray-Garcia (1998) note that cultural humility includes a lifelong commitment to self-evaluation and self-critique. This is most effectively done as part of a group committed to such types of professional competence development. Ensuring that an interprofessional team or competence constellation (Johnson et al., 2013) is diverse in its membership helps counter the danger of remaining ignorant of or avoiding conflict about the presence of a bias that is affecting the provision of health care.

Because the values of different psychologists vary, developing awareness of how their own values, practices and beliefs may influence the care given becomes an important ongoing focus of professional development. “Examining their own cultural heritage, experiences, religious beliefs and spiritual practices, as well as differentiating between one’s personal cultural values and those of others, and raising awareness of cultural difference to avoid discrimination and prejudice” (Jünger & Payne, 2011, p. 249) enhances psychologists’ work with patients at the end of life.

B. Ethics

Applying ethical guidance has concerned health care providers throughout the considerations of legalizing aid in dying. The APA Ethical Principles of Psychologists and Code of Conduct (EPPCC, APA, 2010) Principle A (Beneficence and Nonmaleficence) urges psychologists to “strive to benefit those with whom they work and take care to do no harm.” Similarly, EPPCC Standard 3.04 (Avoiding Harm) requires psychologists to “take reasonable steps to avoid harming their clients/patients.” In addition, Principle E (Respect for People’s Rights and Dignity) urges psychologists to “respect the dignity and worth of all people, and their rights of individuals to...self-determination.” Each provider should consider ethically whether more harm is done to a patient who obtains physician aid in dying, or to a patient whose death is not hastened and faces possible unwanted pain, suffering, and other negative outcomes before dying. While psychologists are specifically identified, along with psychiatrists, as the only “mental health specialists” who can conduct assessments under the Act, there is no mention in the law of the clinical or consultative roles that psychologists may fulfill. The EPPCC provides some ethical guidance for psychologists who are considering these different professional roles.

To prevent a potential conflict of interest (EPPCC, Standard 3.06), psychologists should generally avoid providing clinical services and capacity evaluations for the same patient. Serving both a clinical and an evaluative role in the context of the ELOA could be viewed as a potentially harmful multiple relationship (EPPCC Standard 3.05). Because a multiple relationship may not always be avoidable, such as in rural or underserved settings, psychologists should document their thoughtful attention to objectivity, competence, and effectiveness if a multiple relationship arises.

When working in these various roles, psychologists should be mindful of the ethical standards related to requests from physicians or organizations for evaluations (EPPCC Standard 3.07), participating in interprofessional teams (EPPCC Standard 3.09), providing consultations to colleagues (EPPCC Standard 4.06), and providing services to patients and families who may also be receiving services from other mental health providers (EPPCC Standard 10.04).

Providers have the legal right to decline to participate in ELOA activities. However, this does not give psychologists the ethical right to abandon a patient considering this option (EPPCC Standard 10.10). Clinicians declining to participate in the ELOA process may opt to refer patients to other providers. Others may maintain treatment responsibilities for clinical concerns while referring to colleagues for consultations about the ELOA.

Competency (EPPCC Standard 2.01) in providing clinical, consultative, or evaluative services for patients and families considering end-of-life options requires relevant training, skills and experience. Without first obtaining specialized education and training in areas such as working with terminally ill patients and their families, the cultural aspects of death and dying, geropsychology, and capacity/competence evaluations, psychologists may run the risk of practicing outside the boundaries of their competence. “Psychologists planning to provide services...involving populations, areas, techniques or technologies new to them undertake relevant education, training, supervised experience, consultation, or study” (EPPCC Standard 2.10(c)).

To participate in end-of-life decision-making under the ELOA, a patient’s consent must be provided knowingly and voluntarily. Specific informed consent requirements for attending physicians are described in section II.B above. For psychologists, the process and foundations for informed consent are contained within the EPPCC. Standard 3.10 notes that psychologists providing assessment, therapy, or consulting services “obtain the informed consent of the individual or individuals using language that is reasonably understandable to that person or persons.” Standard 9.03 outlines the purpose of informed consent in assessments as follows: “Informed consent includes an explanation of the nature and purpose of the assessment, fees, involvement of third parties, and limits of confidentiality and sufficient opportunity for the client/patient to ask questions and receive answers.” Standard 10.01 addresses the responsibility of the therapist to inform the client of the nature of the psychological treatment and the potential risks involved.

The ethical standards emphasize the importance of communicating with patients in a manner that is in accord with their level of health literacy. The intention of informed consent is to communicate to the patient the purpose of the therapy, counseling, consultation and/or assessment, and to explain the risks involved so that the patient can make a voluntary and informed decision about participation. Informed consent should be obtained during the initial interview, both verbally and in writing, and can be revisited at subsequent meetings if there are concerns that retention of information might be difficult.

When obtaining informed consent for a mental health specialist assessment under the ELOA, in addition to addressing the issues mentioned above, the psychologist should disclose who has requested the evaluation; the professional who will receive the completed report; the limits of confidentiality regarding information from the evaluation; and what process to expect in the evaluation.

During the stressful process of an end-of-life decision, there are reasonable concerns that may arise regarding reimbursement for various types of services. In addition to discussing their own fee policies as part of obtaining informed consent (EPPCC 6.04, 9.03, 10.01), psychologists should strive to be aware of sources of coverage and potential associated costs such as hospice, in-home health care services, pain management and prescription drugs (including end-of-life drugs), and be prepared to discuss how these costs may be affecting patients’ decision making. The ELOA does not mandate insurance coverage for end-of-life drugs or related services, so reimbursement policies vary considerably.

For example, Medicare provides a prescription drug benefit and hospice benefits, but does not cover the cost of end-of-life drugs; whereas Medi-Cal and some insurers do currently cover the cost of end-of-life drugs.

IV. Psychologists' roles

A. Treating provider

Psychologists who treat terminally ill patients play a key role in providing competent and compassionate care aimed at the patients' specific psychosocial needs. Psychosocial care, as defined by the National Council for Hospice and Specialist Palliative Care Services, is "care concerned with the psychological and emotional well-being of the patient and their family/carers, including issues of self-esteem, insight into an adaptation to the illness and its consequences, communication, social functioning and relationships" (Onyeka, 2010). It is a form of care that encourages patients to express their feelings about the illness while at the same time providing ways by which the psychological and emotional well-being of such patients and their caregivers are improved (Schulman-Green, 2003).

Although the attending physician is the only professional who can prescribe aid-in-dying medications, in some instances terminally ill patients may initially choose to discuss end-of-life options with their treating psychologist. The patient may be accustomed to addressing complex psychosocial issues with their treating psychologist and the therapeutic relationship may provide a helpful framework for such discussions. Why, one might ask, since the treating psychologist is not the person who can initially recommend that this option be available? It is precisely because treating psychologists cannot initiate the end-of-life option that they might be consulted before the patient makes the request of the treating physician.

While we might initially think of aid in dying as something that only older or seriously depressed or otherwise psychologically/psychiatrically impaired patient would be considering, that might not be the case. For example, a young adult with a terminal illness and in extreme pain who is cognitively and emotionally intact might also be considering this option. In a highly informative article, Winograd (2012) discusses the ethical issues that may arise when providing treatment to a terminally ill patient.

In many cases, the role of the treating psychologist may be that of the truly empathetic listener, particularly if the patient has not yet decided whether to request lethal medication. However, in order to do this in an ethical, supportive, and non-judgmental way, treating psychologists need to assess whether they can do so responsibly. If the psychologist's own religious or moral beliefs make it difficult to provide the type of supportive counsel necessary to allow patients to make this critical decision, then the psychologist may need to seek consultation to address the potential impact of his or her beliefs or may need to make a referral to another mental health provider for adjunctive or alternative services.

In some cases, the wishes of the patient may diverge from those of the patient's family. For example, an emotionally and cognitively intact octogenarian who has been in extreme pain for a number of years and is planning to request aid in dying, may have a spouse strongly opposed to this plan. The patient may ask for the treating psychologist's help in gaining his wife's support or at least acceptance of his plan. Some potential options include: bringing the spouse in and hearing her concerns; meeting with them together in order to come up with a solution that is acceptable to both; or suggesting that the patient's wife seek consultation with another psychologist to help her address her concerns. There are no easy or simple answers in this scenario.

Psychosocial care of a terminally ill patient typically includes involving the patient's interpersonal and family relationships as well as the best of medical and social care, in order to optimize the quality of life for such patients (Onyeka, 2010). Compassion and empathy are the cornerstones of quality care for terminally ill patients. Interventions in palliative care aim at ensuring the patient lives a life as comfortable as possible until death (Breitbart & Poppito, 2014).

Finally, treating psychologists employed by public or private agencies that have chosen to participate in activities authorized by the ELOA cannot be mandated to be a part of the process even with their own patients. Similarly, if a psychologist has a private patient who is struggling with this decision, the psychologist may provide this type of counsel even though the organizations that employ them on a nonexclusive basis may not be supportive.

B. Consultant

While the ELOA specifically defines the role of psychologists under the law as providers of mental health specialist assessments, psychologists can also supply consultation to patients who are considering their options at the end of life, as well as to their family members and health care providers (Johnson, Cramer, Conroy, & Gardner, 2014; Kasl-Godley, King, & Quill, 2014). Consultation may serve as an adjunct to a patient's regular psychotherapy or as a stand-alone intervention. It is ethically and clinically critical to differentiate the role of consultant from that of therapist, highlighting the responsibilities and limitations of the consultant role.

The consideration of hastening death is one that patients tend to make over time. Psychologists can provide individual consultation to discuss end-of-life options (e.g., Goldblum & Martin, 1999) with patients who are responding to the diagnosis of a life-threatening disease. Psychoeducational meetings (Stein et al., 2013) can give patients the information that helps them define what types of care they want to receive at the end of life. Psychologists can also provide support, education, and guidance as a consultant to a patient's family members. Family meetings (Powazki & Walsh, 2014) may be facilitated by psychologists to help family members understand a patient's end-of-life options and to facilitate communication and collaboration between the patient, family, and care providers. Identifying a family's cultural values is a particularly useful endeavor in which a psychologist can participate; attitudes toward illness, perceptions of the health care system, the role of the family in caregiving, and beliefs about death may all be relevant. Teaching coping skills to family members (Feldman & Llamas, 2011) may also be helpful in alleviating some of the distress surrounding the patient's illness.

Psychologists will find that their effectiveness working in health care systems and providing consultations to other health care providers about end-of-life care can be increased by study and training in interprofessional care teams (Interprofessional Education Collaborative, 2011). These teams are viewed as the standard of care throughout U.S. for palliative care (National Consensus Project, 2013), and psychologists can make a variety of contributions to these teams. In addition to the roles mentioned above, psychologists are able to give professional support at the team level, and educate health care providers in subjects such as identifying and ameliorating professional burnout, improving communication skills used in delivering bad news, and utilizing a family's cultural values to increase the efficacy of care given to the patient.

C. Mental health specialist

As noted above in section II.B, in accordance with the Act, psychologists (as well as psychiatrists) may undertake the role of "mental health specialist." This role arises when an attending or consulting physician determines that a patient requesting an aid-in-dying drug has indications of a mental disorder. In such instances, the physician is required to refer the patient to a psychologist or a psychiatrist for an assessment. The purposes of that assessment are to determine that the patient: (1) has the mental capacity to make medical decisions, act voluntarily, and make an informed decision; and (2) is not suffering from impaired judgment due to a mental disorder. No aid-in-dying drug can be prescribed until these determinations are made. In order to make them, the mental health specialist is expected to meet with the patient one or more times, review his/her medical records, and produce a written report. More detailed information and recommendations for conducting a thorough assessment are provided in the following section.

V. Mental health specialist assessment

A. Preliminary considerations

As stated above, if there are questions or concerns about a patient's capacity to make medical decisions regarding end-of-life options, it is the role and responsibility of the attending physician and/or the consulting physician to refer the patient for a mental health specialist assessment. This referral usually will be predicated upon indications of a possible psychological or cognitive disorder that may preclude the patient's capacity to make an informed medical decision regarding the choice to seek aid-in-dying drugs. As mentioned earlier, the ELOA defines a "mental health specialist" (MHS) as a psychiatrist or licensed psychologist. Although the guidance provided in this document is aimed at psychologists, it may include some information that is useful to psychiatrists who provide assessments under the Act as well.

Prior to accepting a referral to assess a patient's decision-making capacity under the ELOA, the psychologist should determine whether he or she is the appropriate professional to perform the assessment. There are several considerations that may factor into this decision. First, as discussed in section III.A, psychologists should examine their own values, moral beliefs, and professional concerns about death, end-of-life decisions, and the appropriateness of terminally ill patients' requests for aid-in-dying drugs that will hasten their death. If there is any reasonable likelihood that one's beliefs about these issues could compromise an objective assessment, the psychologist should make a referral to another professional.

Second, as noted in section III.B, the psychologist should have the relevant skill, experience, and training to competently perform the assessment. Experience, training, and skill in areas such as end-of-life issues, geropsychology, working with medically ill and fragile patients, family systems, and providing capacity evaluations may be useful. Experience with forensic evaluations of competence in civil and criminal contexts may also be helpful preparation for the MHS role. Psychologists who are considering providing MHS assessments are encouraged to seek out relevant education and training as needed, and to be familiar with the palliative care and therapeutic options available to this population.

Third, as noted in section III.B, to avoid a potential conflict of interest, in most cases the psychologist performing the assessment should not have another relationship with the patient, such as a provider of therapeutic services. In the absence of significant mitigating or extenuating circumstances, the psychologist should decline to perform the assessment when a dual relationship exists. This is to protect the objectivity of the evaluator from the biasing effects of prior and/or incompatible relationships. An example of a significant mitigating or extenuating circumstance could include professionals providing services in rural or underserved areas where there are no other reasonable professional options. When such a multiple role exists, the psychologist should disclose the nature of the relationship with the patient, as well as the potential biasing effects of multiple relationships generally, to the patient and the referring physician, and document this disclosure and the informed consent received in the records.

B. Purpose of the assessment

As mentioned above, the purpose of the MHS assessment is to determine whether the terminally ill patient has the capacity to make medical decisions and is not suffering from impaired judgment due to a mental disorder. Generally, there is a presumption that an individual has the capacity to make medical decisions, unless there is evidence to the contrary. However, when there are indications of a mental disorder, the ELOA requires the attending or consulting physician to make a referral for a MHS assessment. Section §443.8 of the law states the role of the MHS in the assessment process:

- (a) Examine the qualified individual and his or her relevant medical records.
- (b) Determine that the individual has the mental capacity to make medical decisions, act voluntarily, and make an informed decision.
- (c) Determine that the individual is not suffering from impaired judgment due to a mental disorder.
- (d) Fulfill the record documentation requirements of this part.

The ELOA defines “capacity to make medical decisions” as follows: the ability to understand the nature and consequences of a health care decision; the ability to understand its significant benefits, risks, and alternatives; and the ability to make and communicate an informed decision (Health & Safety Code §443.1(e)).

It is noteworthy that this law makes a distinction between mental capacity and impaired judgment. The MHS assessment process will necessarily consider both the patient’s capacity for making decisions, as well as any mental health factors that could impair judgment. This language acknowledges that the decision regarding end-of-life issues may involve concerns beyond the mental ability of the terminally ill patient to make the decision, to include other psychosocial considerations that may impair or compromise judgment. In other words, the requirement of intact judgment goes beyond the requirement of decision-making capacity.

C. Conducting the assessment

Relevant Criteria

As noted above, there are two tasks of the MHS evaluator once the referral for an assessment has been made. First the evaluator must determine that the individual has the mental capacity to make medical decisions, act voluntarily, and make an informed decision. Second, the evaluator must determine that the individual is not suffering from impaired judgment due to a mental disorder. The capacity to make medical decisions generally involves four separate functional abilities, which are consistent with the Act’s definition of “capacity:”

1. Understand relevant information needed to make the decision;
2. Appreciate the situation and the consequences of different options;
3. Reason rationally about the different options; and
4. Communicate an enduring choice.

Understand relevant information: The patient must be able to describe what has been disclosed about the illness and his or her medical condition, the recommended treatment(s), and the benefits and risks of the treatment options.

Appreciate the situation and consequences: The patient must be able to acknowledge that the information disclosed applies to him or her, and to recognize the risks, benefits, and likely consequences of the various available options on his or her duration and quality of life.

Reason rationally about the different options: The patient must be able to use logic and rational thought processes to weigh the various options that are available and to come to a decision that is most consistent with his or her values, goals, and preferences.

Communicate an enduring choice: Once a decision is reached, the patient must be able to effectively communicate that choice unambiguously and consistently. Of course, patients have the right to change their minds, but this should be based upon new or different information that affects the rational decision-making process.

There are multiple complicating factors that can interfere with the patient’s capacity in these relevant abilities. It is through the evaluator’s clinical skill and experience that these factors will become known, and the relevance of these factors to the four core functional abilities can be assessed. Please note, however, that the presence of complicating factors does not necessarily mean that a patient lacks capacity to make end-of-life decisions; such factors are relevant only insofar as they impact the patient’s functional abilities.

Complicating factors may include:

1. Mental disorders (e.g., depression, anxiety, dementia, delirium, other cognitive impairment, etc.)
2. Medication/medically-induced symptoms
3. Personality functioning
4. Existential issues
5. Coercion by others

6. Perceptions of being a burden to others
7. Relevant family dynamics
8. Community and cultural factors
9. Idiosyncratic factors

In order to determine whether the patient's judgment is impaired due to a mental disorder, the MHS will thoroughly assess for the presence of various mental disorders that could impact the relevant functional abilities. Depression is of particular concern, and is addressed below. "Not surprisingly, a desire for death among the terminally ill is both common and often transient" (Cohen et al. 2000, p.199). Block (2000) noted, "psychological distress is a major cause of suffering among terminally ill patients and is highly correlated with poor quality of life" (p. 210). Emanuel, Fairclough, and Emanuel (2000) found that as many as 59% of patients requesting physician assisted death meet the diagnostic criteria for depression. It is therefore important that the MHS also evaluate for the psychosocial implications of "a request for a hastened death if they are saying they want to die but are possibly asking for help in dealing with depression, anxiety about the future, grief, lack of control, dependence, physical suffering or spiritual despair" (Block & Billings, 1995).

For patients with a terminal illness who may have multiple medical complications, it is not uncommon for various medications to cause side effects that can impair decision-making capacity. In other circumstances, the patient may have personality challenges that will interfere with the rational processes necessary to think through the various options available.

To fully assess for rational reasoning regarding the available options, the evaluator should inquire into various existential issues of the patient (such as views of life and death), the level of physical suffering that is tolerable, concerns of waiting "too long" and being unable to use the law, how the patient would prefer to die and what is reasonable in this regard, and whether the process would violate personal moral beliefs.

With the physical limitations that are common in terminal illnesses, both real and perceived coercion by others, as well as feelings of being a burden on others should be fully explored. The ELOA requires that the choice made by the patient is voluntary. If the patient is being coerced by others into a decision to hasten his or her death, then that decision would not be voluntary. Similarly, if the patient believes that he or she is being a burden on others, the reasonableness of this belief should be investigated with the patient and relevant others; such a belief would not necessarily bar an end-of-life decision, but would need to be rational and not the result of coercion.

Relevant family dynamics should also be explored, especially as they relate to caregiver issues, family finances, unresolved family conflicts, and family understanding of the disease progression, and life expectancy. Other psychosocial factors include cultural, ethnic, spiritual, and religious factors that could impact the decisional abilities of the patient.

Identifying and understanding the impact of social and cultural biases that may result in patients being perceived and/or being encouraged to perceive themselves as more expendable and less deserving of continued life (Goldblum & Martin, 1999) is a particularly important concern for the MHS. This identification includes the cultural values of the health care system in which the patient is receiving care.

Depression

The issue of capacity to make end-of-life decisions under the ELOA can become complicated by the presence of symptoms of clinical depression. For the evaluator, the presence of symptoms of depression is relevant because they can impact the patient's ability to make an informed choice, but will not necessarily do so. The question to be examined is whether symptoms of clinical depression are impairing judgment to the extent that it may be altering the reasoning and decision about whether to end one's life. For example, a decision that is inconsistent with long-held beliefs and preferences may be indicative of impaired judgment.

The diagnosis of depression in a terminally ill patient is much more difficult than in a patient without such an illness.

There are two major reasons for this. First, sadness and grief are normal and reasonable reactions to such a condition, and may not be pathological.

The patient may be coping with many difficult issues, ranging from significant pain to unresolved family conflicts. That these concerns may manifest in symptoms consistent with depression are expected. Second, due to the often physically-debilitating nature of a terminal illness, many of the physical manifestations of depression (e.g., fatigue, decreased psychomotor functioning, decreased appetite, cognitive changes) may be related to the disease or treatment-related medications as opposed to the presence of depression. For this reason, clinical signs of depression such as anhedonia, guilt, feelings of inadequacy, and feelings of helplessness and hopelessness can offer a clearer indication of the presence of depression than the neurovegetative symptoms that can be a reflection of the effects of disease or medication. Block (2000) cautioned that “when these symptoms are out of proportion to the patient’s actual situation, they are useful indicators of major depression” (p. 211).

To determine whether these symptoms reflect depression or the reality of the patient’s situation, the careful evaluator should probe these issues with nuance and subtlety, aware of the inherent physical limitations of the disease process and the inevitability of an impending death. It is when the patient has no interest or pleasure in life (which is out of proportion to present circumstances) that depression may be impairing the patient’s ability to make an informed choice. In such circumstances, psychotherapy or medications may be recommended to decrease the severity of depressive symptoms.

Sources of Data

To provide a thorough MHS assessment, multiple sources of information should be used. Werth, Benjamin & Farrenkopf (2000, p. 361) concluded, “An assessment that is based on multiple sources of data is much more likely to establish a valid and reliable finding about a person’s capacity and decision to request assisted death.” The ELOA requires that the MHS evaluator examine the patient and his or her relevant medical records (Health & Safety 443.7(a)). Additional sources of data may include: discussions with the patient’s health care team; collateral interviews with family, friends, and others; other relevant documents, including advance directives and other end-of-life information; and psychological testing. The prudent evaluator may also find it helpful to make liberal use of research and consultation with others with relevant expertise.

The first source of data the evaluator should use is the referral and related records of the patient’s medical condition. This information will form the foundation of the nature of the terminal illness, along with the information that has been provided to the patient about disease progression, life expectancy, and available options. The evaluator also should discuss the referral issues and the patient’s medical condition with the members of the patient’s health care team (e.g., physician, specialists, social worker, nurses, psychotherapist, hospice workers).

After gathering this background information, the MHS should formulate an assessment plan and approach that will elicit candid and relevant information from the patient. The goal is for the patient seeking physician aid in dying to understand, appreciate, and rationally reason through his or her diagnosis, disease progression, and treatment options. The evaluator should be sensitive to the ability of the patient to tolerate lengthy interviews and testing sessions, and one of the primary concerns of the evaluator should be to minimize the intrusion of the evaluation process on the patient, while gathering adequate information to offer a valid opinion.

In some instances, an interview will be the best and most effective method of assessing capacity, and will also be the most sensitive when dealing with an individual in physical pain and physical decline, with very limited physical and mental stamina. As an example, differences between clinical depression and normal grief might best be assessed through the interview process. Useful information from family, friends, and concerned others can augment the information from the clinical interview and may point to areas of inconsistency between information provided by the patient in the evaluation and that provided to others in different contexts. In other cases, the presence of cognitive deficits, waxing and waning delirium, or memory deficits that affect but do not preclude decision-making capacity may not be as easily determined through interview alone; this might warrant administration of some form of empirically validated tools of assessment.

Psychometric measures should be optimized to address and clarify possible mental health impediments to decision-making capacity including depression, anxiety, dementia, conditions that cause deterioration to the brain (stroke, metastatic disease), delirium (which can accompany medications intended to manage pain), psychosis, and personality disorders. Some of these conditions can cause impairment of mental focus and information storage, judgment and reasoning, and affective instability (Farrenkopf and Bryan, 1999). *However, it is crucial to emphasize that the presence of a mental health disorder does not necessarily imply a deficit in decision-making capacity for the purpose of deciding end-of-life options, including physician assisted death.* Moye et al. (2004) concluded that, “individuals with mild dementia can participate in decision-making, as defined by legal standards for competency” perhaps with strategies to compensate for problems with verbal recall, complex simultaneously processing, and intentional planning.

At present, there are no standardized test instruments proven to be valid and reliable in the assessment of capacity to make an end-of-life decision regarding physician aid in dying. There also are no tests with terminally ill patients as the normative group. While there are a number of test instruments that have been proven reliable and valid in the assessment of competence/capacity to make informed decisions in other arenas (e.g., standing trial, making financial decisions, making treatment decisions), there is a difference of opinion in the literature to date regarding which available standardized tests, if any, are best suited to be a part of a capacity assessment regarding end-of-life decisions (see EPPCC Standard 9.02 regarding the ethical use of assessment instruments when reliability and validity have not been established for use with a particular population). Some consider that the best approach is to view all formal testing as data for generating hypotheses only (WSPA, 2009, p. 3). Others have noted several objective assessment instruments that may be useful (Werth, Benjamin & Farrenkopf, 2000, pp. 366-367).

D. Coming to Conclusions

Some cases will be much easier than others. For example, patients who are cognitively intact with no evidence of symptoms of a mental disorder, who have loving and supportive families, and who are logical, rational, and reasonable will not present many challenges for the evaluator. Others can be exceptionally complicated, with evidence of mental illness, dysfunctional families with ulterior motives, variations in the intensity of debilitating physical symptoms, etc. The guidance provided in this document is designed to help the evaluator formulate the relevant questions that must be answered under the ELOA, to address the issues that may complicate the patient’s relevant functional abilities, and to develop a plan to collect the relevant data and information needed to complete an assessment.

Ultimately, the choice made by the patient is not the issue of importance to the evaluator. Rather, it is *how* the patient came to that choice (i.e., the deliberative process). If the patient’s choice reflects careful deliberation demonstrative of understanding, appreciation, and reasoning rationally through the various options, then the ultimate choice should be respected, even if different from what the evaluator or most others would do in a similar circumstance. If, however, there is evidence of compromised abilities in understanding, appreciation, and rational reasoning, the patient would lack the capacity to make a decision under the ELOA. The objective evaluator strives to be vigilant to issues of confirmatory bias in analyzing potentially conflicting data gathered in the evaluation process. Ultimately, the data about the relevant functional abilities should drive the conclusion.

There may be times when the evaluator cannot come to a firm conclusion, even after consultation with experienced and knowledgeable colleagues. This may occur when the patient is exhibiting transient symptoms that temporarily compromise functioning, or when the patient has affective symptoms that may respond well to psychotherapy or medications. In such circumstances, it is advisable to document why there is uncertainty and what interventions (e.g., time or therapy) may be useful in alleviating the sources of uncertainty. A second opinion may also be recommended.

In most circumstances, a thorough evaluation utilizing the various sources of data available that is sensitive to the presence and effect of complicating factors will allow the evaluator to come to a conclusion about the capacity of the patient to make end-of-life decisions under the ELOA.

E. Report

Upon completion of the evaluation, the MHS will prepare a report. Per Health & Safety Code §443.8(e), if a MHS assessment is performed, a “report of the outcomes and determinations made” must be included in the patient’s medical record. The report should offer a conclusion about whether the patient has the capacity to make an end-of-life decision to receive an aid-in-dying drug, and if not, what treatment or interventions would likely restore the patient’s capacity to do so. If the patient does not have the capacity to make medical decisions, and there is no likelihood that the patient’s capacity will be restored, the evaluator should offer that opinion. The MHS report should also offer a conclusion regarding the presence or absence of impaired judgment due to a mental disorder.

In the report, the evaluator should document the following, as appropriate:

- The referral source and the referral question
- The sources of data considered and relied upon
- The current medical status of the patient with respect to the terminal illness
- The patient’s relevant medical history
- The patient’s relevant mental health history
- Current mental status
- Behavioral observations
- Psychological functioning regarding relevant mental health symptoms
 - Document tests used, if any, and limitations to the results in this context
- Existential issues (e.g., views of life and death, how the patient would prefer to die)
- Psychosocial concerns (e.g., issues of coercion, family dynamics/conflicts/financial complications, sociocultural views of the patient’s worth, and feelings of being a burden)
- Analysis of the four core functional abilities:
 - Understanding
 - Appreciation
 - Rational reasoning
 - Making an enduring choice
- Conclusion about capacity
- Conclusion about voluntariness
- Conclusion about whether a mental disorder has impaired the patient’s judgment
- Recommendations

VI. Conclusion

This document addresses important topics to be considered by psychologists involved in end-of-life care activities under the ELOA, whether in the role of treating provider, consultant, or mental health specialist. These topics include: the requirements of the Act; the components of a mental health specialist assessment; and key issues such as values, beliefs, culture, and ethics. In summary, it is important for psychologists to know the law, know their values, and know the types of knowledge, skills and experience needed to most effectively provide services related to end-of-life options. It is hoped that this guidance will promote an informed, thoughtful and thorough approach to this evolving and complex area of practice.

VII References

- American Psychological Association (2010). *Ethical principles of psychologists and code of conduct*. Retrieved from <http://www.apa.org/ethics/code/>
- Block, S.D. & Billings, J. A. (1995). Patient requests for euthanasia and assisted suicide in terminal illness: The role of the psychiatrist. *Psychosomatics*, 36(5), 445-447. [https://doi.org/10.1016/S0033-3182\(95\)71625-5](https://doi.org/10.1016/S0033-3182(95)71625-5)
- Block, S. D. (2000). Assessing and managing depression in the terminally ill patient. *Annals of internal medicine*, 132(3), 209-218. <https://doi.org/10.7326/0003-4819-132-3-200002010-00007>
- Breitbart, W. S., & Poppito, S. R. (2014). *Individual meaning-centered psychotherapy for patients with advanced cancer: A treatment manual*. Retrieved from <http://proxy.wi.edu/login?url=http://search.proquest.com/docview/1653147450?accountid=25365>
- California Medical Association (2016). *The California End of Life Option Act*. Retrieved from <http://www.cmanet.org/resource-library/detail/?item=the-california-end-of-life-option-act>.
- Cohen, L. M., Steinberg, M. D., Hails, K. C., Dobscha, S. K. & Fischel, S. V. (2000). Psychiatric evaluation of death-hastening requests. *Psychosomatics*, 41(3), 195-203. <https://doi.org/10.1176/appi.psy.41.3.195>
- Emanuel, E. J., Fairclough, D. L. & Emanuel, L. L. (2000). Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*, 284(19), 2460-2468. <https://doi.org/10.1001/jama.284.19.2460>
- End of Life Option Act, Assemb. B 15, 2015 2nd Ext. Sess. Ch. 1 (Cal. Stat. 2015). Retrieved from https://leginfo.ca.gov/faces/billTextClient.xhtml?bill_id=201520162AB15
- Farrenkopf, T., & Bryan, J. (1999). Psychological consultation under Oregon's 1994 Death with Dignity Act: Ethics and procedures. *Professional Psychology: Research and Practice*, 30(3), 245-249. <https://doi.org/10.1037/0735-7028.30.3.245>
- Feldman, D. B., & Llamas, J. (2011). Working with family caregivers of persons with terminal illness. In S. H. Qualls & J. E. Kasl-Godley (Eds.), *End-of-life issues, grief, and bereavement: What clinicians need to know* (pp. 64-84). Hoboken, NJ: John Wiley & Sons. ISBN-13: 978-0470406939
- Fenn, D. S., & Ganzini, L. (1999). Attitudes of Oregon psychologists toward physician-assisted suicide and the Oregon Death With Dignity Act. *Professional Psychology: Research and Practice*, 30(3), 235-244. <https://doi.org/10.1037//0735-7028.30.3.235>
- Goldblum, P. B., & Martin, D. J. (1999). Principles for the discussion of life and death options with terminally ill clients with HIV. *Professional Psychology: Research and Practice*, 30(2), 187-197. <https://doi.org/10.1037/0735-7028.30.2.187>
- Interprofessional Education Collaborative Expert Panel (2011). *Core competencies for interprofessional collaborative practice: Report of an expert panel*. Washington, D.C.: Interprofessional Education Collaborative. Retrieved from <http://www.aacn.nche.edu/education-resources/ipecreport.pdf>
- Johnson, S. M., Cramer, R. J., Conroy, M. A., & Gardner, B. O. (2014). The role and challenges for psychologists in physician assisted suicide. *Death Studies*, 38(9), 582-588. <https://doi.org/10.1080/07481187.2013.820228>
- Johnson, W. B., Barnett, J. E., Elman, N. S., Forrest, L., & Kaslow, N. J. (2013). The competence constellation model: A communitarian approach to support professional competence. *Professional Psychology: Research and Practice*, 44(5), 343-354. <https://doi.org/10.1037/a0033131>
- Jull-Patterson, D. (2016). Psychology's ethics and the End of Life Option Act. *California Psychologist*, 49(4), 35. Retrieved from http://c.ymcdn.com/sites/www.cpapsych.org/resource/resmgr/cp/2016/Fall_Free_Article.pdf
- Jünger, S., & Payne, S. (2011). Guidance on postgraduate education for psychologists involved in palliative care. *European Journal of Palliative Care*, 18(5), pp. 238-252.

- Kasl-Godley, J. E., King, D. A., & Quill, T. E. (2014). Opportunities for psychologists in palliative care: Working with patients and families across the disease continuum. *American Psychologist*, *69*(4), 364-376. <https://doi.org/10.1037/a0036735>
- Koh, M. Y. H., Chong, P. H., Neo, P. S. H., Ong, Y. J., Yong, W. C., Ong, W. Y., . . . Hum, A. Y. M. (2015). Burnout, psychological morbidity and use of coping mechanisms among palliative care practitioners: A multi-centre cross-sectional study. *Palliative Medicine*, *29*(7), 63-642. <https://doi.org/10.1177/0269216315575850>
- Moye, J., Karel, M. J., Azar, A. R., & Gurrera, R. J. (2004). Capacity to consent to treatment: Empirical comparison of three instruments in older adults with and without dementia. *The Gerontologist*, *44*(2), 166-175.
- National Consensus Project for Quality Palliative Care (2013). *Clinical practice guidelines for quality palliative care* (3rd ed.). Pittsburgh, PA: Author. Retrieved from http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf
- Onyeka, T. C. (2010). Psychosocial issues in palliative care: A review of five cases. *Indian Journal of Palliative Care*, *16*(3), 123-128. <https://doi.org/10.4103/0973-1075.73642>
- Pew Research Center (2013, November 21). *Religious groups' views on end-of-life issues*. Retrieved from <http://www.pewforum.org/2013/11/21/religious-groups-views-on-end-of-life-issues/>
- Powazki, R. D., & Walsh, D. (2014). The family conference in palliative medicine: A practical approach. *American Journal of Hospice & Palliative Care*, *31*(6), 678-684. <https://doi.org/10.1177/1049909113499444>
- Schulman-Green, D. J. (2003). Psychosocial issues in palliative care: Physicians' self-perceived role and collaboration with hospital staff. *American Journal of Hospice and Palliative Care*, *20*(1), 34-40. <https://doi.org/10.1177/104990910302000110>
- Stein, R. A., Sharpe, L., Bell, M. L., Boyle, F. M., Dunn, S. M., & Clarke, S. J. (2013). Randomized controlled trial of a structured intervention to facilitate end-of-life decision making in patients with advanced cancer. *Journal of Clinical Oncology* *31*(27), 3403-3410. <https://doi.org/10.1200/JCO.2011.40.8872>
- Tervalon, M., & Murray-García, J. (1998). Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved*, *9*(2), 117-124. <https://doi.org/10.1353/hpu.2010.02331>
- Washington State Psychological Association (2009). *The Washington Death with Dignity Act: WSPA guidelines for mental health professionals*. Retrieved from http://c.ymcdn.com/sites/www.wapsych.org/resource/resmgr/Docs/DWD_Guidelines_6-3-09.pdf.
- Werth, J. L., Jr., Benjamin, G. A., & Farrenkopf, T. (2000). Requests for physician-assisted death: Guidelines for assessing mental capacity and impaired judgment. *Psychology, Public Policy, and Law*, *6*(2), 348-372. <https://doi.org/10.1037/1076-8971.6.2.348>
- Werth, J. L., Jr., Lewis, M. M., & Richmond, J. M. (2009). Psychologists' involvement with terminally ill individuals who are making end-of-life decisions. *Journal of Forensic Psychology Practice*, *9*(1), 82-91. <https://doi.org/10.1080/15228930802427130>
- Winograd, R. (2012). The balance between providing support, prolonging suffering, and promoting death: Ethical issues surrounding psychological treatment of a terminally ill client. *Ethics & Behavior*, *22*(1), 44-59. <http://dx.doi.org/10.1080/10508422.2012.638825>

VIII. Additional Resources

Compassion & Choices www.EndOfLifeOption.org

Coalition for Compassionate Care <http://coalitionccc.org/>

Jull-Patterson, D. (2017). Psychologists in Palliative Care Syllabus. Retrieved from <http://tinyurl.com/SyllabusPalliativeCare>