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Physician-Assisted Death Psychiatric Assessment: A Standardized Protocol to Conform to the California End of Life Option Act

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### Authors

Bourgeois, James A  
Mariano, Maria Theresa  
Wilkins, James M  
et al.

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## Original Research Report

# Physician-Assisted Death Psychiatric Assessment: A Standardized Protocol to Conform to the California End of Life Option Act



James A. Bourgeois, O.D., M.D., Maria Theresa Mariano, M.D.,  
James M. Wilkins, M.D., D.Phil., Rebecca Weintraub Brendel, M.D., J.D.,  
Lawrence Kaplan, D.O., Linda Ganzini, M.D., M.P.H.

**Background:** *The California End of Life Option Act (EOLOA), which legalized physician-assisted death (PAD), became effective in 2016. The EOLOA does not require a mental health consultation in all cases nor does it state the standards for the mental health assessment.*

*University of California, San Francisco Medical Center (UCSFMC) policy makers decided to require a mental health assessment of all patients seeking PAD under the EOLOA. Objectives:* *The Department of Psychiatry was tasked with developing a standard protocol for the mental health assessment of patients seeking PAD. Methods:* *Members of the consultation-liaison (C-L) service developed a document to guide members in completing the mental health evaluations for patients requesting PAD.*

**Results:** *A committee at UCSFMC developed a clinical*

*protocol informed by the law with an additional local expectation of an evaluation by a psychiatrist or clinical psychologist. The C-L psychiatry group at UCSF developed a standard protocol for the psychiatric assessment for use by clinicians performing these assessments. Attention to the cognitive, mood, and decisional capacity status pertinent to choosing PAD is required under the clinical guidance document. Case vignettes of 6 patients evaluated for PAD are presented. Conclusions:* *The local adoption of the California EOLOA by UCSFMC requires a mental health assessment of all patients requesting EOL services at UCSF. The clinical guideline for these assessments was locally developed, informed by the literature on EOL in other jurisdictions where it has already been available.*

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**Key words:** decisional capacity assessment, physician-assisted death, end of life, neurocognitive disorders.

### INTRODUCTION

Since physician-assisted death (PAD) in the United States became legal in Oregon in 1994, 6 other US jurisdictions have followed suit.<sup>1</sup> The general parameters of PAD laws in the US allow a terminally ill patient to request, and if eligible, receive, a prescription for a lethal dose of medication for self-administration in the future with the purpose of causing death. In the last 2 years alone, California, Colorado, and Washington DC have enacted PAD statutes.<sup>2–9</sup>

Table 1 is a summary of jurisdictions in the US where PAD is legalized with common local qualification and procedural requirements summarized.<sup>1–9</sup>

Received December 26, 2017; revised February 1, 2018; accepted February 20, 2018. From the Baylor Scott and White Health Central Texas Division (J.A.B.), Psychiatry; Texas A&M Health Science Center School of Medicine, Psychiatry, Temple, TX; University of British Columbia (M.T.M.), Psychiatry, Vancouver, Canada; Division of Geriatric Psychiatry (J.W.), McLean Hospital, Belmont, MA, USA; Department of Psychiatry (J.W.), Harvard Medical School, Boston, MA, USA; Center for Law, Brain, and Behavior (R.W.B.), Department of Psychiatry, Massachusetts General Hospital, Boston, MA, USA; The center for Bioethics and the Department of Psychiatry (R.W.B.), Harvard Medical School, Boston, MA, USA; University of California San Francisco (L.K.), Psychiatry, San Francisco, CA; HSR&D Center of Innovation (L.G.), VA Portland Health Care System, Portland, OR, USA; Department of Psychiatry (L.G.), Oregon Health & Science University, Portland, OR, USA. Send correspondence and reprint requests to James Bourgeois, O.D., M.D., Psychiatry, Baylor Scott and White Health Central Texas Division Temple, TX; e-mail: james.bourgeois@bswhealth.org, jwilkins1@partners.org, linda.ganzini@va.gov

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# Physician-Assisted Death Psychiatric Assessment

The California End of Life Option Act (EOLOA), which legalized PAD, was enacted in 2016. Institutions have the option to decline to participate. The University of California San Francisco Medical Center (UCSFMC) decided to participate, and the consultation-liaison (C-L) service at UCSFMC became actively involved in shaping the psychiatric policy around PAD. Elements of the EOLOA pertinent to psychiatric function and evaluation are shown in Table 2.<sup>2</sup>

## ROLE OF PSYCHIATRISTS IN PAD ASSESSMENTS: CONSIDERATIONS

In Oregon, where PAD has been available for many years, lethal prescriptions are most typically sought by patients with terminal illness with concerns of loss of independence; a desire to control manner, time, and

place of death; and fear of increasing pain and decreased quality of life (QOL), as opposed to seeking death as a manifestation of a comorbid psychiatric illness.<sup>10</sup> Nonetheless, psychiatric evaluation to clarify these issues is often recommended. Overall, psychiatrists have expressed a range of opinions on the elements of the psychiatric evaluation for PAD and thresholds for permitting this act, and differ on the wisdom and value of a mandatory mental health evaluation.<sup>11,12</sup>

In studies from Oregon soon after the PAD law was passed, psychiatrists and psychologists indicated that they anticipated having difficulty with these evaluations. These laws not only require the determination of whether the patient had a mental disorder but whether the mental disorder influenced the decision to pursue PAD. An early survey of Oregon psychiatrists and psychologists showed support for PAD; 56% of psychiatrists and 78% of psychologists favored enactment of the Oregon Death with Dignity Act, yet only 6% of psychiatrists and 7% of psychologists felt very confident that in a single psychiatric evaluation they could determine eligibility under the law.<sup>13</sup> In this study and a subsequent national study of forensic psychiatrists, the psychiatrists' views on the ethical permissibility of PAD influenced their personal opinions of the standards and thresholds for PAD, and how they would evaluate a PAD-requesting patient. Among Oregon psychiatrists who opposed PAD but were willing to complete a mental health evaluation of a requesting patient, half indicated that even if the patient was *without a mental disorder and competent*, they would still try to prevent the patient from using a lethal prescription. Forensic psychiatrists who personally opposed PAD were more likely to endorse that *all* patients with major depression be denied PAD, that there should be more than one independent psychiatric examiner in assessments, and that the PAD evaluation should include judicial review.<sup>14</sup>

Because most patients requesting PAD do not have a depressive disorder, and because those with one would be identified with a screening instruments, Ganzini<sup>15</sup> expressed opposition to mandatory mental health evaluation as “burdensome, unnecessary, (and) unworkable.” In this context, the PAD psychiatric consultation can become a *de facto* ethics consultation on the issue of PAD. Additional concerns on the role of mandatory psychiatric consultation in PAD cases were raised by Sullivan et al.,<sup>16</sup> including the fact that

**TABLE 1. US Jurisdictions Where Physician-Assisted Death is Legal<sup>1-9</sup>**

Oregon Death with Dignity Act (1997)  
Washington Death with Dignity Act (2009)  
Montana Supreme Court ruling (2009)  
Vermont Patient Choice and Control at End of Life Act (2013)  
California AB-15 End of Life Option Act (2016)  
Colorado End of Life Option Act (2016)  
Washington DC Death with Dignity Act (2017)

### Common requirements<sup>a</sup>

#### I. Patient eligibility

- Mentally capable adult resident of the state who is terminally ill<sup>b</sup> and can self-administer the medication
- Provide 2 oral requests separated by 15 days
- Provide a written request with at least 2 witnesses
- Can rescind request at anytime

#### II. Physician assessments

- Attending physician
- Consulting physician
- Mental health assessment by a psychiatrist or psychologist<sup>c</sup> if either attending or consulting physician is concerned of impaired judgment due to a mental disorder
- Participation is voluntary

#### III. Designated state reporting agency

<sup>a</sup> Except Montana where there is no law to date that provides detailed requirements. The court ruling specifies that a “competent, terminally ill patient has a right to die with dignity..., which includes protection of the patient’s physician from prosecution...”

<sup>b</sup> Within reasonable medical judgement, the patient is expected to die within 6 months.

<sup>c</sup> Vermont law also allows a clinical social worker to do this assessment.

**TABLE 2. California AB-15 End-of-Life Option Act (2016) (Items abstracted)<sup>2</sup>**

- 443.1 (d) "Capacity to make medical decisions" means that, in the opinion of an individual's attending physician, consulting physician, psychiatrist, or psychologist, pursuant to Section 4609 of the Probate Code, the individual has 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 to health care providers, including communication through a person familiar with the individual's manner of communicating, if that person is available.
- 443.1.(k) "Mental health specialist assessment" means one or more consultations between an individual and a mental health specialist for the purpose of determining that the individual has the capacity to make medical decisions and is not suffering from impaired judgment due to a mental disorder.
- 443.1. (l) "Mental health specialist" means a psychiatrist or a licensed psychologist.
- 443.5. (a) Before prescribing an aid-in-dying drug, the attending physician shall do all of the following:
- (1) Make the initial determination of all of the following:
    - (i) Whether the requesting adult has the capacity to make medical decisions.
    - (ii) If there are indications of a mental disorder, the physician shall refer the individual for a mental health specialist assessment.
    - (iii) If a mental health specialist assessment referral is made, no aid-in-dying drugs shall be prescribed until the mental health specialist determines that the individual has the capacity to make medical decisions and is not suffering from impaired judgment due to a mental disorder.
- 443.8. Upon referral from the attending or consulting physician pursuant to this part, the mental health specialist shall:
- (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.
- 443.9. All of the following shall be documented in the individual's medical record:
- (c) The attending physician's diagnosis and prognosis, and the determination that a qualified individual has the capacity to make medical decisions, is acting voluntarily, and has made an informed decision, or that the attending physician has determined that the individual is not a qualified individual.
  - (d) The consulting physician's diagnosis and prognosis, and verification that the qualified individual has the capacity to make medical decisions, is acting voluntarily, and has made an informed decision, or that the consulting physician has determined that the individual is not a qualified individual.
  - (e) A report of the outcome and determinations made during a mental health specialist's assessment, if performed.

there is no clearly defined clinical method to distinguish "rational" from "irrational" suicide. In addition, there is also a lack of scientific precision in methods for decisional capacity determinations more generally. This leaves open the possibility that the psychiatrists' own views on the ethics of PAD impact the ultimate decision to allow PAD.<sup>14</sup>

#### PSYCHIATRIC STATUS OF PAD REQUESTORS

Although there continues to be a debate in the profession around the circumstances warranting content of the evaluation of individuals requesting PAD in jurisdictions where it is legal, a growing body of data provides a critical backdrop. Ganzini<sup>17</sup> has extensively reported on the Oregon PAD experience over the past 2 decades. Since the law passed, there have been 1127 cases of PAD. Most patients had cancer (78%), while patients with ALS accounted for 8% of the cohort. Hospice enrollment was common (90%), and most patients died at home (95%). Patients who died by using the PAD option were 10 times more likely to

have had a bachelor's degree than all other Oregon deaths, and current pain was not commonly a reason for choosing PAD.<sup>18</sup> Common reasons cited for PAD included a desire to maintain independence/control, to minimize dependence, and a wish to die at home. Although all PAD laws in the US require that patients have an evaluation of decisional capacity for PAD before provision of the lethal prescription, this evaluation does not necessarily need to be completed by a mental health provider. These laws included the requirement for mental health evaluation if there is concern that the patient has a mental health disorder influencing the decision for PAD. For example in the Oregon law, the presence of any *psychiatric illness impacting judgment* requires an evaluation by a psychiatrist/psychologist, where the psychiatrist or psychologist determines that the patient is capable and not suffering from a psychiatric or psychological disorder or depression (sic) causing impaired judgment.<sup>1</sup> In practice, the rate of psychiatric consultation has been low (5%) for PAD completers in Oregon though it is unknown how often mental health

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evaluation excludes patients<sup>19</sup> screening for psychiatric symptoms using standardized instruments, such as the Patient Health Questionnaire-9 (PHQ-9) or the Geriatric Depression Scale (GDS), has been recommended to determine which patients should be referred for mental health consultation.<sup>20</sup>

Ganzini et al. also studied the prevalence of anxiety and depression in 58 Oregonians who had initiated evaluation for or inquired about physician aid-in-dying. Using the Hospital Anxiety and Depression scale and a structured clinical interview, they found that 13 individuals (22%) met their predetermined criteria for an anxiety disorder and 15 (26%) for a depressive disorder. Eighteen of the individuals eventually received a prescription for the lethal drug, 9 of whom died following ingestion. Three patients identified as depressed died by lethal ingestion, though only one of the three believed that their mood state influenced their desire for PAD.<sup>21</sup>

### DEFINING A PAD MENTAL HEALTH ASSESSMENT

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Mental health guidance documents from Oregon and Washington provide some specific advice for the evaluation of patients by psychiatrists or clinical psychologists in the context of PAD requests.<sup>22,23</sup> Items highlighted in these guideline documents include specific assessment for illness (e.g., depressive disorder, dementia, delirium, traumatic brain injury, psychotic disorder, substance use disorder, and posttraumatic stress disorder), a formalized assessment of decisional capacity specific for the PAD procedure, and other factors which may affect decisional capacity (e.g., knowledge deficits, coercion). The authors recommended assessing patients' understanding of their terminal medical illness and benefits of other clinical interventions, such as palliative and comfort care. Review of advance directives and other end-of-life legal documents should be considered to inform the extent to which the decision to access a lethal prescription is consistent with the patient's prior values. This determination, however, does not mean that a change in wishes renders the patient *de facto* incapacitated, but rather that a discussion about what has changed would ensue.

Orentlicher et al., based on the work of a multi-disciplinary committee, proposed clinical criteria for the assessment for PAD, including (1) discussion

of the patient's reasons for requesting PAD, (2) the assessment of decisional capacity for PAD, and (3) assessment of patient understanding of palliative interventions in lieu of or concurrent with PAD.<sup>24</sup> Efforts to maximize patient performance, individual evaluation, attention to the effects of fatigue on patient performance, focal (rather than exhaustive) evaluation, and supplementary use of standard clinically practical validated psychometric instruments (e.g., PHQ-9, GDS, Saint Louis University Mental Status Examination [SLUMS], Montreal Cognitive Assessment [MoCA]) may be considered.<sup>24</sup>

In states where PAD is legalized, medical centers have attempted to develop programs that facilitate access to PAD in requesting patients, but assure that all the legal requirements are met. The programs endeavor to determine which patients should be evaluated by a mental health professionals. Loggers et al. reviewed the Seattle Cancer Care Alliance's implementation of a Death with Dignity policy for patients who initiate requests for PAD over the period March 2009-December 2011.<sup>25</sup> The policy follows the Death with Dignity law, with additional requirements. For example, the patient must sign an agreement not to take the lethal prescription in a public place. Each patient is assigned an advocate (a clinical social worker from the Seattle Cancer Care Alliance) who assists the patient, his or her family, pharmacists, and physicians through the process. These advocates complete standardized assessments of anxiety and depression based on standardized clinical interviews, e.g., PHQ-9 and Generalized Anxiety Disorder-7 (GAD-7) and review any mental health history in the medical record, to help determine which patients require further mental health assessment. The authors report that no patients with either current or previous depressive disorder or decision incapacity persisted in requesting PAD.<sup>25</sup>

### UCSFMC PROTOCOL DEVELOPMENT AND EARLY EXPERIENCE

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For the development of the psychiatric assessment specific to the UCSFMC EOLOA Protocol, the director of the C-L service was approached by the Risk Management Office, and tasked with development of a local document to guide psychiatric assessments. The California law does not require a psychiatric evaluation in every EOLOA case, but



the policy development committee (Risk Management/Legal was the major organizer) decided to require an evaluation in every case, to be completed by a psychiatrist or psychologist. This requirement was in substantial part because of psychiatry's expertise in assessment of decisional capacity in general, and the thrust of this policy development was that, irrespective of other considerations in the clinical evaluation (e.g., mood state, treatable psychiatric illness, social matters impacting patient motivation), the EOLOA assessment is in substantial part a decisional capacity determination. Using the UCSFMC electronic medical record, consultants have access to reports from all current medical and psychotherapy clinicians at UCSFMC as part of the evaluation process.

The faculty psychiatrists on the C-L service developed the protocol in an iterative fashion, using the current C-L psychiatry literature as guidance, with Risk Management (Legal) review of the final version. The Appelbaum and Grisso decisional capacity criteria were used as a framework for assessment of decision-making capacity.<sup>26</sup> These criteria have 4 elements of decisional capacity and include assessment of the patient's understanding of relevant information, appreciation of the current situation and its consequences, ability to manipulate information rationally and communicate a (consistent) choice.<sup>26</sup> Inasmuch as the PAD assessment is necessarily a decisional capacity assessment, describing the patient's capacity on these 4 dimensions specific to the PAD procedure encourages fidelity with the usual procedures to assess decisional capacity for all other clinical interventions.

Applied specifically to the PAD procedures, the assessment of decision-making capacity includes having the patient demonstrate (1) understanding of the terminal illness/prognosis, (2) understanding that the EOLOA ingestion is intended to lead to death, (3) understanding that the dose must be self-administered, (4) understanding that ingestion may not result in death and rather the patient could aspirate and/or live on in a more compromised state, and (5) rational decision-making and communication of a consistent choice regarding the lethal ingestion itself, as a medical procedure. Further, to keep roles and boundaries separate, the group made the decision that the evaluating clinician would not become the treating clinician. If the clinician completing the evaluation wished the patient to engage in treatment for an active psychiatric illness affecting the decisional

capacity process, the clinician has the option of recommending treatment and then re-evaluating the patient later.

Areas of lack of consensus or controversy within the psychiatry group were debated with consensus established. For example, the committee decided that patients with significant past suicidality or suicide attempts would, in general, be excluded. This conservative stance that past, well-remitted depressive disorder with suicide attempt would, in fact, be disqualifying was considered by some on the committee as excessive. This caution was balanced against concern by some stakeholders that some patients who are recurrently suicidal would use the EOLOA methodology to act upon preexisting suicidal ideation in a surreptitious way.

Other than the consensus on clinical protocol development, the group did not have a method or clinical resources to have patients evaluated more than once, to assess interrater reliability. In addition, the perceived marginal benefit of a second evaluation was balanced against the burden on a terminally ill patient, who would already have had to complete 3 PAD consultations. On the other hand, finding the patient with a reversible delirium or other psychiatric illness impacting decisional capacity could be a situation in which the patient might be reevaluated after treatment. Although all clinical psychologists and psychiatrists on the C-L service were offered the opportunity to participate both in protocol development and in the eventual assessment of patients, 3 psychologists and 2 C-L psychiatrists declined participation on personal grounds, 1 citing religious reasons. This left 3 psychiatrists available to complete these assessments. The protocol took effect in June of 2016. Procedurally, patients are only referred for psychiatric evaluation after initial PAD request and 2 independent evaluations by other physicians to validate terminal illness and less than 6-month survival prognosis. Six early cases, evaluated under this protocol, are summarized here. The Psychiatric Clinical Protocol for EOLOA assessment is shown in [Table 3](#).

### Case Vignettes

Six cases evaluated at UCSF illustrate aspects of the PAD assessment that psychiatrists encountered in the early period of implementation. Five cases (#1–5) were judged to have intact decisional capacity to

**TABLE 3. UCSF PAD Psychiatric Assessment Protocol**

1	Medical and medication history
2	Psychiatric history, including substance use
3	Family history
4	Decisional capacity determination regarding PAD and other alternative therapies (e.g., pain management, palliative care) according to the Appelbaum and Grisso formulation (addressing each item) of understanding, appreciation, rationality, communication of a consistent choice
5	Assessment of psychiatric status over the past 30 days including mood, psychotic, anxiety, cognitive, other (as relevant) symptoms and current MSE. Any previous history of dementia, psychotic illness, and/or suicide/other self-harm attempts will <i>a priori</i> disqualify patient (this is a conservative standard and not without some internal difference of opinion)
6	Formal rating scales (e.g., Hamilton Depression Rating Scale, PHQ-9, GAD-7, and MoCA)
7	Narrative regarding seeking of PAD, including patient’s research into PAD, communication of desire for PAD to others, opposition/support of others, coercion pro/con, model of another close person who has completed PAD
8	Diagnostic formulation
9	Specific commentary on cognitive status, presence of delirium-provoking meds (even if not delirious at the time of assessment), elements of decisional capacity rubric (Understanding/Appreciation/Rationality/Communication of Choice)
10	Patient must understand that assessment is not treatment, but consultant can recommend treatment. Consultant cannot then become the treating clinician.
11	Report of consult in EMR

proceed with the PAD protocol and were without disqualifying mental health conditions. A subsequent case, #6, found to be without decisional capacity, was seen after the authors began initial drafts of this paper.

Case 1: Mr. A, an 81-year-old man with metastatic urothelial cancer, had completed a course of chemotherapy, with neck pain resulting from a pathologic fracture of the first cervical vertebra. He was no longer a candidate for curative treatment. He initiated a request for PAD with his primary care physician and a second physician confirmed his terminal diagnosis. Mr. A reported good understanding of his medical condition and limited survival. He denied any history of psychiatric illness. He reported having a thorough understanding of what the aid-in-dying protocol entailed, including the possibility that he might survive the intended lethal ingestion in a more compromised condition. His request for aid-in-dying had been a consistent choice expressed to his primary care physician. He stated, “I’ve lived a full life, I feel like I’ve

done everything I wanted to.” He had communicated this request for aid-in-dying with family and caregivers and denied coercion for or against his choice. He was concerned for further functional decline and increased pain, which was already “intolerable.” On interview, he was well-groomed with appropriate eye contact and a cervical collar in place. On the MoCA, he scored 18/30 points (mild impairment), with deficits in language repetition, fluency, and short-term recall.<sup>27</sup> On the Hamilton Depression Rating Scale (HDRS), he scored 15 points with 10 points attributed to systemic illness (e.g., insomnia, difficulty eating, weight loss). Using the Appelbaum and Grisso criteria, he understood the relevant information, appreciated the current situation and its consequences, manipulated information rationally, and communicated a consistent choice regarding PAD. His cognitive deficits did not impact his decision-making capacity for PAD and he was assessed not to have mental health barriers to PAD. Recommendations included mirtazapine for sleep and appetite and continued monitoring by his primary medical team as he was considered at high risk of later loss of capacity with disease progression.

Case 2: Ms. B, a 67-year-old woman diagnosed with multiple system atrophy (MSA) and recurrent major depressive disorder (MDD), had dysarthria, small and large motor deficits, and an inability to walk unaided. She was concerned that she would have increasingly debilitating motor impairment and become ever more dependent on others; this concern, plus increasingly poor quality of life, motivated her to seek PAD. Per the EOLOA protocol, 2 physicians were of the opinion that her life expectancy was less than 6 months. She reported a history of recurrent depressive disorder, treated with combined psychotherapy and various psychotropic medications, currently mirtazapine, venlafaxine, and rivastigmine. She was a former alcoholic with sobriety for 20 years and was a former user of marijuana. She denied psychiatric hospitalization or suicide attempts. She understood the protocol of PAD, including that she must self-administer the final dose of medications. She understood risks, benefits, and adverse effects of the ingestion, including the possibilities of aspiration, sedation without death, and allergic reaction. She had discussed her request for PAD with her spouse and adult daughters, who were supportive and respected her decision. She was engaging in closure activities (e.g., taking care of administrative and logistical

arrangements) in advance of her expected death. On mental status examination, she was wheelchair bound, with appropriate eye contact with multiple spontaneous choreiform movements and poor coordination. She described her mood as “sad” and her affect was dysphoric but reactive and nontearful. Her MoCA was 27/30, her HDRS was 15 (3 points for suicidal ideation related to the PAD request, 3 points for symptoms of MSA; hence 9 points were attributable solely to the mood state), her PHQ-9 was 8, and her GAD-7 was 8 (PHQ-9 and GAD-7 scores were subsyndromal for MDD and generalized anxiety disorder, respectively). Regarding PAD, she had an intact understanding of relevant information, appreciation of the current situation and its consequences, was manipulating information rationally, and communicating a consistent choice. Her cognitive, mood, and decisional capacity status for the PAD protocol were intact, given her current stable treatment for depressive disorder. Her HDRS was subsyndromal for MDD; her current mood state was not affecting judgment and decisional capacity regarding PAD.

Case 3: Mr. C, a 55-year old man diagnosed with primary refractory acute myelocytic leukemia (AML) complicated by a prolonged pancytopenia, bacteremia, persistent neutropenic fever, and fungal pneumonia, with regression to myelodysplastic syndrome and a 6-month prognosis confirmed by his 2 hematologist/oncologists, requested PAD. He described his diagnosis as “an unusual type of AML,” was able to recount in detail his treatment history and treatment options, the range of benefits, and adverse effects and the likelihood of death within 6 months. He understood the risks associated with ingestion of PAD medications, including risk of aspiration and/or lingering in a persistent vegetative state. His primary concerns were to avoid further loss of function, specifically related to fatigue and inability to care for himself, with greater reliance upon caregivers. His daughter and son-in-law were supportive of his wishes and had researched the CA EOLOA extensively. He endorsed ongoing fatigue, with difficulty falling asleep for which he took lorazepam 1 mg at bedtime. He denied all other psychiatric symptoms or thoughts for hastened death outside of PAD. His MoCA score was 28/30 indicating no significant cognitive impairment. Scores on the PHQ-9 and GAD-7 were both 1 (subsyndromal for MDD and generalized anxiety disorder, respectively). About PAD, he had an intact

understanding of relevant information, appreciation of the current situation and its consequences, was able to manipulate information rationally, and had the ability to communicate a clear and consistent choice. He was assessed to have no psychiatric disorder, and was clearly able to articulate the key elements required to fulfill criteria for decision-making capacity under PAD protocol.

Case # 4: Ms. D, a 47-year-old woman with peritoneal carcinomatosis secondary to metastatic disease with ovarian primary, with worsening abdominal pain and constipation, was offered chemotherapy followed by surgery vs comfort care and hospice. She elected hospice care and was interested in pursuing PAD. She had witnessed her stepfather dying of cancer, and she had the support of close friends and family for her decision to pursue PAD; “When these things start to happen, tubes, I want my body deciding on its own, I don’t want anyone deciding it for me, in the state I could be in, with someone changing my diapers and puke.” She discussed that when her suffering were to become intolerable (“when I reach that point I want to have my friends around”), she would consider having an event where she would ultimately take the medication to end her life. In terms of risks associated with ingesting the medication, she stated: “I might not die right away; one person went on for five days.” Her sleep was variable, generally awakened by pain every 2–3 hours, energy was “crappy,” concentration poor (“get stuck in the middle of sentence a lot”). Appetite was “not good.” She had a psychiatric history of depressive disorder, anxiety disorder, PTSD, and substance use disorder in long-sustained remission. MoCA was 26/30 (unimpaired range), PHQ-9 was 9, and GAD-7 was 5 (subsyndromal for MDD and generalized anxiety disorder, respectively). About PAD, she had an intact understanding of relevant information, appreciation of the current situation and its consequences, was able to manipulate information rationally, and had the ability to communicate a clear and consistent choice.

Case #5: Mr. E, a 65-year-old man with a medical history significant for hypothyroidism had a left frontal glioblastoma multiforme (GBM) diagnosed 5 years ago. A few months after his diagnosis, his wife was also diagnosed with a GBM and died 6 months following her diagnosis. During the 5 years, he met with palliative care intermittently to reiterate his goals of care that emphasized maintaining as much



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functional independence as possible. At the time of recurrence, he developed a profound nonfluent expressive aphasia that worsened under stress. With few treatment options other than symptom management, coupled with his worsening expressive aphasia, Mr. E inquired into the PAD option. Prior to his GBM diagnosis, he was an excellent communicator and was quite articulate, from which he derived a strong sense of purpose and meaning in his life. He discussed his wishes with his daughter, who was supportive of his wishes. He was well known to both his treating primary and consulting physicians to whom he had expressed his wishes over time in relation to his goals of care and quality of life.

Mr. E pursued the required oral and written requests from his attending and consulting physicians, 15 days apart, as required by local state law. Both physicians were in general agreement with a six-month terminal prognosis and believed that Mr. E possessed the majority of the key elements for decisional capacity, and he was referred for a mental health evaluation given the significant expressive aphasia. Mr. E was given the option to write his responses, given his aphasia. The psychiatric evaluation was conducted to allow adequate time for him to express himself with modification of communications by various techniques, such as hand and body gestures, cues, and various prompts. In meeting the benchmarks of decisional capacity, he was able to recount from the time of diagnosis various treatment regimens and disease progression without any current treatment options other than palliative care and hospice. He elaborated that the inability to express himself far outweighed his history of headaches relative to his request, which alone would not have motivated him for such a request. His PHQ-9 and GAD-7 scores were 5 and 3 (subsyndromal for MDD and generalized anxiety disorder, respectively). Although his expressive aphasia precluded him from fully participating in the MoCA, he successfully completed the salient aspects of the Frontal Assessment Battery, including the “Luria, Go/No-go,” among other attentional tasks with his cognitive/neurological deficits correlating well with his left frontal lesion on MRI.

Case 6: Mr. F, a 52-year-old man diagnosed with a left parietal glioblastoma with worsening right-sided weakness, right hemianopia, had a nonfluent expressive aphasia, with a history of depressive disorder, generalized anxiety disorder, neurocognitive disorder,

and alcohol use disorder in remission, on multiple psychotropic medications, including lamotrigine, temazepam, buspirone, trazodone, lorazepam, memantine, quetiapine, and sertraline.

Although his oncologist believed that he had decisional capacity for the purposes of EOLOA, he had a very limited ability to participate in the interview due to a severe expressive aphasia. He became very tearful at times while searching for words, with limited ability to even respond to polar (e.g., “yes/no”) questions with head gestures. Written communication was also very limited. Using gestures, he was able to convey having had 2 previous surgeries, with aphasia especially worse after his second surgery. He indicated that his family was very supportive and aware of his request for medication to end his life. He also gestured to feeling like a burden on his family, while denying this was a primary reason for requesting PAD.

On mental status examination, Mr. F appeared fatigued with good eye contact and right hemiplegia. He appeared sad, dysphoric, and tearful. He was unable to participate in a PHQ-9, GAD-7, MOCA, or informal cognitive testing. The assessment was notable for significant nonfluent expressive aphasia, and unclear receptive aphasia, with apparent cognitive deficits per informal objective testing in MSE. He additionally appeared to have impairments in attention, naming, and orientation, with potential contributions from subclinical hypoactive delirium secondary to toxic-metabolic etiologies, superimposed on a progressive left parietal glioblastoma. He was only minimally able to participate in the evaluation and unable to articulate a general rudimentary understanding of EOLOA, and the 4 key elements required for medical decision-making capacity. Based upon this assessment, we were unable to reliably and confidently assert that he had decisional capacity with regard to EOLOA, and he was disqualified from receiving a lethal prescription. A subsequent meeting of the UCSF Ethics Committee affirmed the finding of decreased decisional capacity.

### DISCUSSION

The California law explicitly allows institutions to opt out and not offer PAD. UCSFMC decided to participate but chose to require a mental health evaluation in every case of proposed PAD. The relevant part of the EOLOA pertinent to requesting a mental health

evaluation is “If there are indications of a mental disorder, the physician shall refer the individual for a mental health specialist assessment.”<sup>2</sup> Institutions participating in PAD assessments can add additional procedural requirements beyond what is in the law (as was done here), though this could be controversial if the additional requirements were seen as unduly burdensome or obstructive. This concern must be balanced against the institutional interests in clinical accuracy and precision, as well as assurances of thorough assessments of candidate patients. As noted previously, Seattle Cancer Care Alliance has additional requirements for PAD patients not found in law, and some large health care systems in Oregon required mental health consultation in every case for the first several years after legalization of PAD.

Elements covered in the PAD psychiatric assessment include decisional capacity regarding PAD, cognitive status, mood status, psychiatric history, MSE, and formal rating scales. The decision to require a full psychiatric consultation (rather than a narrow focus only on the state of decisional capacity) permits the identification of potentially treatable psychiatric symptoms that may relieve some elements of patient suffering, detection of family agreement that may support the authenticity of the request vs family conflict that may require further intervention and counseling, identification of need for other supportive services to maximally improve quality of remaining life, and diagnostic formulation to support any finding of decisional incapacity for PAD. Within the consultation, the decisional capacity elements are critical, as an assessment of decisional capacity is called for in the law. Regarding decisional capacity *per se*, the degree of depressive disorder (if present) is “dimensional” (i.e., depression affecting cognitive status/decisional capacity is “disqualifying” while mild/moderate/non-suicidal depression not impacting decisional capacity is “not”).

Elements #4 (Decisional capacity for PAD determination) and #7 (Narrative regarding pursuit of PAD) were included to garner a full assessment of the patient’s perspective regarding PAD to ascertain understanding and the broader context for the PAD request. In element #7, consideration of issues of social support and coercion were modeled on organ donor psychiatric evaluations, where the social context is an important part of the broader understanding of the case. The consultant then takes all of these areas into

account in the final consideration of the case—both determining eligibility for the PAD law as well as any recommendations that would improve the patient’s quality of remaining life. There is significant room for interpretation and mental health consultant discretion within the framework.

As reflected in the case vignettes, the impact of psychiatric illness and psychiatric status regarding PAD requests in our cases was dimensional, not categorical. Mild to moderate depressive disorder typically does not affect cognitive status so profoundly as to render a patient incapable of decisional capacity, even for PAD. Similarly, mild cognitive impairment (validated by quantification with a standardized cognitive assessment instrument) may be compatible with intact decisional capacity for PAD. This is especially the case if the other salient elements of the consultant’s assessment (e.g., understanding, appreciation, rationality, communication of a consistent choice, and quantitation of mood state) are supportive of a finding of intact decisional capacity. In the UCSFMC protocol development, we arranged for a complete psychiatric assessment in each case, including the possibility of symptomatic relief of psychiatric and/or physical symptoms (e.g., sleep) with conventional psychiatric interventions to improve QOL, even if patients were found to have intact decisional capacity for PAD (and thus be free to complete PAD thereafter). Such recommendations were included in the EMR note and shared with the referring physicians.

Regarding the potentially perceived “burdensomeness” of the PAD psychiatric evaluation, we endeavored to schedule these assessments promptly when requested, and offered to complete these assessments by telemedicine for patients with significant mobility and/or transportation challenges, which would have made face-to-face assessments more problematic. We did not assess whether patients objected to the institutionally-required PAD psychiatric assessment, but highlighted that our findings were shared with other treating physicians in a collaborative way confirming to the protocol. Research on patient response to the requirement of a psychiatric consultation would be worthy of later consideration (e.g., perceived “burdensomeness” of the consultation).

Regarding the requirement for a psychiatric consultation for all cases of PAD under EOLOA, Drs. Bourgeois and Kaplan (both UCSF-affiliated at the

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time of the protocol development) agree that the requirement for the consultation as stipulated is reasonable and may well generalize to other, similar institutions. Three benefits to this approach are (1) the psychiatry consultant assesses decisional capacity according to a literature- and evidence-based approach to decisional capacity methodology, (2) the consultant assesses for psychiatric (e.g., neurocognitive, depressive) disorders which could impact decisional capacity, and (3) the consultant can offer advice for modification of medication management to other physicians for patients suffering psychiatric illnesses common in terminal illness (e.g., depressive disorders, delirium).

The experience over time of requiring mental health evaluations of all patients requesting PAD represents a natural experiment that will inform discussion of the benefits and burdens/costs of this requirement. For example, a finding that lack of decisional capacity and coercion are unusual, and that these referred patients rarely have mental health conditions that impact their decision-making, might lead to the conclusion that the burdens and costs of a mandatory evaluation are not supported. On the contrary, finding that mandatory psychiatric evaluation results in discovery of disqualifying mental health conditions, such as in case #6, would further support arguments for requiring this evaluation in all cases.

These guidelines will likely be re-examined over time depending on collective ongoing clinical

experience. For example, the protocol standard at present does not support PAD requests for those with a history of suicidal behavior or psychotic illness. A future, modified iteration of the protocol could perhaps allow for the PAD option for those with a distant history of suicidal behavior or fully compensated psychotic illness. Consultants performing these assessments need to examine the “suicide vs PAD” paradigm and be willing to “de-medicalize” some “death-seeking” behavior.

This article was developed by authors from various institutions who collaborated on an Academy of Psychosomatic Medicine symposium to encourage a discussion on this controversial but timely topic. The authors have a variety of viewpoints on this topic but agree that it is worthwhile to discuss the various clinical, ethical, and legal considerations of developing institutional protocols for PAD assessment and the involvement of psychiatrists and other consultants in these assessments.

In summary, integrated, complete consultation, not “just a decisional capacity evaluation” offers an opportunity for the clinician to evaluate the patient for psychiatric illness that may be impacting decisional and other areas of psychiatric and social function that may be treatment responsive. In addition, this thorough evaluation allows for identification and management of neurocognitive disorders (delirium or dementia or both) that may impact decisional capacity.

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