

THE WASHINGTON DEATH WITH DIGNITY ACT: WSPA GUIDELINES FOR MENTAL HEALTH PROFESSIONALS

*Prepared by the
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A. Introduction

Since 1996, the Washington State Psychological Association (WSPA) has been a leader among national and state psychological associations as well as other mental health organizations in the debate on the death with dignity (DWD) movement. WSPA signed an amicus curiae brief submitted by a coalition of mental health professionals to the U.S. Supreme Court in 1996 (Amicus Curiae Brief for WSPA, *Washington v Glucksberg and Vacco v Quill*, 1997; Werth & Gordon, 2002), and subsequently signed similar briefs submitted to several courts in the intervening years (Miller & Werth, 2006; Tucker, 2008). These briefs present empirical data demonstrating that psychologists have appropriate and effective diagnostic tools to assess the competence of a terminally ill patient.

WSPA presents the guidelines below for those psychologists and psychiatrists who may serve terminally ill adults wishing to use the Washington Death With Dignity Act, RCW 70.245 (see <http://apps.leg.wa.gov/RCW/default.aspx?cite=70.245>). WSPA has developed these guidelines to ensure that patients requesting DWD are adequately assessed through the process specified in RCW 70.245. These recommendations serve to complement Chapter 9 of the Oregon Death With Dignity Act Guidebook for Health Care Professionals (Oregon Department of Health Services, 2009; <http://www.oregon.gov/DHS/ph/pas/publications.html>, hereafter referred to as the “Oregon Guidebook”). Chapters 2, 3, 5, 6, 7, and 11 of the Oregon Guidebook will also be useful to mental health professionals as they contain comprehensive information about: duties, responsibilities, protections, and liabilities for health care providers; safeguards for patients; and demographic information and normative data on typical motivations for requests for DWD. In addition, the 2008 Annual Report of the Department of Health (<http://oregon.gov/DHS/ph/pas/index.shtml>) summarizes 11 years of operation of the Oregon Death With Dignity Act and is updated annually. Together these materials provide a wealth of relevant contextual information. All participating psychologists and psychiatrists are encouraged to review the new Washington law so that their work is in compliance with RCW 70.245 (<http://apps.leg.wa.gov/RCW/default.aspx?cite=70.245>).

B. Preliminary Considerations for Participating Psychologists and Psychiatrists

Before accepting a referral for assessing a patient requesting use of Washington’s Death with Dignity law, psychologists and psychiatrists are urged to assess their own personal and professional beliefs, values, and mores about dying, end-of-life choices, and end-of-

life decision-making. They will serve the best interests of their patients by understanding the degree to which their attitudes, beliefs, and assumptions might bias or limit their ability to work with dying patients requesting life-ending medications. Psychologists and psychiatrists are encouraged to determine whether, given their own attitudes and values, they can be objective, nonjudgmental providers of assessment and recommendations (Katz & Johnson, 2006). If the psychologist or psychiatrist determines that his or her personal viewpoints might limit the capacity to provide accurate, objective, patient-centered assessment, a referral to another professional is advisable.

Special competencies and knowledge are required on the part of psychologists and psychiatrists who choose to conduct these evaluations. Obtaining appropriate training and consultation and staying current vis-à-vis professional developments in the field are necessary. Additionally, consultation or supervision, discussion, and case reviews can provide opportunities to determine if the psychologist's or psychiatrist's process and interpretation of findings are appropriate and comprehensive. Psychologists and psychiatrists are encouraged to see themselves as part of a larger, multidisciplinary team and to engage with and use the expertise of the other professionals involved with the presenting patient.

In order to avoid a potential conflict of interest, the psychologist or psychiatrist is urged to provide either assessment or therapeutic services to the patient and not to serve in the dual roles of determining competency while treating the patient. The psychologist or psychiatrist also shall avoid any other type of multiple relationships when conducting the work of this process. Unless there are mitigating circumstances, the psychologist or psychiatrist shall decline to perform an assessment when a dual relationship exists. Providing service in a rural or underserved area with limited professional options is an example of a possible mitigating circumstance. In this type of instance, the psychologist or psychiatrist shall disclose the nature of the multiple relationships to the patient and the attending physician, and document the disclosure in the patient record.

C. Overview of Duties and Responsibilities

In Washington, the attending and consulting physicians must verify that the patient is competent to make an informed decision in order for the patient to receive a prescription for life-ending medication. The definitions of competence and informed decision are given in RCW 70.245.010, subsections (3) and (7) respectively:¹

¹ According to *Grannum v. Berard*, 70 Wash.2d 304, 422 P.2d 812 (1967), “[the law] will presume that every man is sane and fully competent until satisfactory proof to the contrary is presented. Washington State holds that the standard of proof required to overcome this presumption, in civil cases, is that of clear, cogent and convincing evidence” (p. 814). Under RCW 70.245.060, the physicians or psychologist/psychiatrist, determine whether the patient is competent to make an informed decision.

(3)“Competent” means that, in the opinion of a court or in the opinion of the patient’s attending physician or consulting physician, psychiatrist, or psychologist, a patient has the ability to make and communicate an informed decision to health care providers, including communication through persons familiar with the patient’s manner of communicating if those persons are available.

(7)“Informed decision” means a decision... that is based on an appreciation of the relevant facts and after being fully informed by the attending physician of: (a) His or her medical diagnosis; (b) His or her prognosis; (c) The potential risks associated with taking the medication to be prescribed; (d) The probable result of taking the medication to be prescribed; and (e) The feasible alternatives including, but not limited to, comfort care, hospice care, and pain control.

In addition, RCW 70.245.060 mandates a “counseling referral” to a licensed psychologist or psychiatrist under certain circumstances:

If, in the opinion of the attending physician or the consulting physician, a patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment, either physician shall refer the patient for counseling. Medication...shall not be prescribed until the person performing the counseling determines that the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment.

The challenge for each participating psychologist or psychiatrist will be to develop clinical protocols that are: consistent with his or her own style for working with patients facing end-of-life decisions; sensitive to the needs of the patient, including physical and mental limitations as well as health-care needs; valid and reliable approaches to providing services to patients facing end-of-life decisions; and congruent with the requirements of RCW 70.245. The discussion and recommendations that follow address (1) how to evaluate whether the mental health requirements of the law have been met, and (2) the advisability of using standardized instruments in this process, as recommended in the Oregon Guidebook (see Chapter 9).

The suggestions presented here are neither prescriptive nor exhaustive. Because the patient is near the end of life, the psychologist or psychiatrist must be sensitive to the fact that the patient may suffer from weakness and fatigue associated with the terminal illness, and may be receiving treatment or medications that can compromise the amount of time s/he is able to participate comfortably in the assessment interview. Further, the psychologist or psychiatrist must be able to differentiate between a diagnosable mental or cognitive disorder, such as clinical depression or dementia, and the effects of illness or treatment. (See, for example, APA Guidelines for the Evaluation of Dementia and Age-Related Cognitive Decline, at <http://www.apa.org/practice/dementia.html>.)

Any evaluation can be stressful, even for individuals with no illness at all. The assessment should therefore be conducted with respect for the energy level of the patient, and if standardized tests are used they should be limited to the minimum necessary to make a sound assessment. A balance needs to be struck between not unduly burdening the patient and failing to gather the necessary data to effectively determine competency.

At the conclusion of the evaluation, the psychologist or psychiatrist must be able to document the findings that support his or her conclusions.

D. Beginning the Evaluation Process

The following information should be disclosed to the patient orally and in writing at the outset of the evaluation process:

- a. The entity or individual that has requested the evaluation;
- b. The entity or individual responsible for the bill;
- c. The fee structure;
- d. The name of the attending physician who will receive the results or the report;
- e. The limits on confidentiality;
- f. The general procedures to be followed.

Finally, the patient's consent for services should be obtained.

E. Sources of Information

An assessment that is based on multiple sources of data will lead to a valid and reliable finding about a patient's competency and to recommendations regarding how to regain competency if the patient is found to lack competence. The data sources may include:

1. The patient's medical record and the reason for the referral;
2. Members of the patient's health care team including physicians, social workers, nurses, chaplains, hospice workers, psychotherapist, etc.;
3. Face-to-face interviews with the patient;
4. Collateral contact interviews with any of the following: family, friends, caregivers, witnesses to the request for medication to hasten death, those who will be involved in the death, or persons who are aware of any religious, ethnic, and cultural issues involved in the case;
5. Written declarations from collateral sources who may be unable to travel to an interview;

6. Written documentation submitted by the patient that shows the history and intentions of how the patient wants to be treated at the end of life; this may include advance directives, or the Physician Order for Life Sustaining Treatment-POLST (<http://www.wsma.org/patients/polst.html> [http](http://www.candcofwa.org/polst.html) or <http://www.candcofwa.org/polst.html>);
7. Psychological testing of the patient.

F. Assessment Procedures: Competence

There is no consensus about the best way to assess for competence to provide an informed decision. In particular, impaired judgment may prevent an informed decision due to depression, or other affective or cognitive conditions. A clinical interview conducted by a psychologist or psychiatrist receiving a referral from the attending physician may be sufficient for determining competence.

Given the requirement of competence for valid informed consent, the assessment of the patient's capacity to make decisions is an intrinsic aspect of every physician-patient interaction.... Any physician who is aware of the relevant criteria [see RCW 70.245.010, subsections (3), (7) above] should be able to assess a patient's competence... (Appelbaum, 2007, p. 1837)

After reviewing the medical records and the referral notes from the attending and consulting physicians, the psychologist or psychiatrist plans a comprehensive evaluation process that explores the patient's competence to make an informed decision. This process includes assessment of the five factors described above related to competency (see Section C, definition of "informed decision").

During the clinical interview, the psychologist or psychiatrist also may find it helpful to gather information about biopsychosocial factors that could shed light on how impaired judgment may impact competence: (1) reasons for the request; (2) expectations, fears, and values; and (3) personal assessment of quality of life. The conversation in which the patient communicates his or her understanding of these issues will permit a determination regarding both how the patient makes sense of the reality that life is coming to an end and whether his/her long-held values and goals are consistent with the DWD request. Such consistency may further corroborate a finding that the patient is competent to make an informed decision about receiving life-ending medications and that judgment is not impaired.

Several empirically validated models of therapeutic communication are available to assist in planning a comprehensive, respectful, clinical assessment interview: see Appelbaum (2007) (Table 1, p. 1836); Back et al. (2009a) at <http://depts.washington.edu/oncotalk>, especially module 5; Back et al. (2009b); Farber (2009a) at <http://www.fammed.washington.edu/palliativecare>, especially module 2 didactics; Farber (2009b); Quill & Arnold (2008a, b). These sample approaches are not intended to be

fixed or prescriptive. Rather they are intended for referencing so that providers can develop an approach that, while grounded in science and clinical practice, is consistent with their own styles of working with patients near the end of life.

During the interview, observations regarding the patient's appearance, attitude, motor activity, affect, mood, speech, thought process, attention/concentration, thought content, and cognitive functioning may be useful to note. Findings about some or all of the following areas may be relevant as to whether a patient is competent to provide an informed decision under the law:

1. Mental health/psychological and cognitive disorders that could affect judgment, such as psychotic symptoms, clinical depression, dementia, substance abuse, PTSD;
2. Psychosocial: family dynamics and support systems (including care giving issues), financial concerns, spiritual issues, work situation, cultural, ethnic, and religious factors;
3. Existential: sense of personal meaning and fulfillment in life, life values, what suffering means to the patient besides physical pain, the patient's definition of a "good death" and, conversely, what would make life unbearable or not worth living;
4. Medical: the diagnosis and prognosis in the medical record; organic/cognitive deficits, traumatic head injury history, dementia, delirium, side effects of medication, availability of adequate health care;
5. The patient's advance directives, living will, durable power of attorney for health care, POLST;
6. Palliative and alternative treatments/measures: the extent to which options such as withdrawing and withholding treatment, stopping eating and drinking, palliative sedation, etc. were identified, offered and/or tried, possible additional viable alternatives, and reasons why such alternatives were declined or not.

The American Psychological Association Report on Assisted Suicide and End-of-Life Decisions (2000) (see <http://www.apa.org/pi/aseolf.html>) includes a comprehensive discussion of issues to consider when exploring end-of-life decisions, including those that may hasten death (see especially p. 20 and Appendix F, pp. 79-86). See also Werth and Blevins (2006, especially Chapters 5-7).

The use of standardized test instruments should be kept to a minimum and may not be additive to the structured clinical interview. The WSPA End-of-Life Committee's Death With Dignity Guidelines Task Force*, which prepared these guidelines, has concerns regarding the validity and reliability of psychological tests for depression when used with this specific population of terminally ill patients requesting life-ending medications. Thus, it is recommended that standardized instruments be used only for hypothesis generation, and to look to all measures (interviews, collateral data, tests, etc.) for multiple

measure corroboration for arriving at any findings. The decision to use standardized instruments must be made on a case-by-case basis in consideration of the unique nature of the issues presented by the particular patient and his or her situation.

G. Assessment Procedures: Depression

A common question that is raised when a terminally ill patient requests life-ending medications is whether the patient is asking because s/he is depressed. For psychologists and psychiatrists, this involves two issues of particular concern:

First, the issue is whether a finding of depression precludes the ability to make an informed decision: "clinical depression, in and of itself, may not interfere with a person's ability to reason so much that it would lead to the individual being declared incapable of making health care decisions..." (Werth, 2001, p. 408). The question is whether clinical depression is impairing judgment to the extent that the person is unable to consider feasible alternatives to DWD or is making a decision that, while informed, is inconsistent with long-held values.

Second, diagnosing depression in terminally ill patients is challenging. DSM IV criteria alone are inadequate for this patient population (Block & Billings, 1994; Van Loon, 1999), as the somatic symptoms associated with depression in medically well populations, such as weakness, fatigue, change in appetite, sleep disturbance, changes in psychomotor functioning, and cognitive disturbances are frequently present as a result of medications, paraneoplastic syndromes, the disease itself, or being terminally ill. Block (2000) stated that "evidence of hopelessness, helplessness, worthlessness, and guilt..." are better indications of depression in people who are terminally ill than vegetative symptoms, while noting that these feelings, too, may be realistic in the context of the patient's physical condition. "However when these symptoms are out of proportion to the patient's actual situation, they are useful indicators of major depression" (p. 209).

Additionally, grief can mimic depression in dying patients. Grief and sadness are normal, expected reactions to facing terminal illness and death and thus must be differentiated from true clinical depression (Block, 2001, 2006; Cohen & Block, 2004).

The Oregon Guidebook recommends "... that all patients who request a lethal prescription under the...Act be screened for depression with a validated instrument such as the Patient Health Questionnaire (PHQ-9). If the screening indicates possible depression, the person should be referred to a psychiatrist or psychologist" ("Qualifications of the Patient Under the Act," pp. 43-44). With regard to the Patient Health Questionnaire (PHQ-9), see the PHQ toolkit in the MacArthur Initiative on Depression and Primary Care (http://www.depression-primarycare.org/clinicians/toolkits/materials/forms/phq9/treatment_response). PHQ-9 scores will vary depending on the patient's physical health status. Providers are strongly urged not to rely solely on the PHQ-9 or any other depression inventory to diagnose depression in this population because norms for scoring these inventories have

not been established for this specific population of terminally ill patients actively requesting life-ending medication.

An example of the subtleties involved in using standardized testing to determine depression in dying patients is, for instance, any question regarding anhedonia (i.e. little interest or pleasure in doing things, feeling down). The MacArthur Toolkit (http://www.depression-primarycare.org/clinicians/toolkits/materials/forms/phq9/treatment_response) recommends that physicians may screen for depression by using the following 2 items from the PHQ-9, which, if they are both endorsed by a patient requesting DWD, should then lead to a referral for a mental health evaluation:

- During the past month, have you often been bothered by:
1. Little interest or pleasure in doing things
 2. Feeling down, depressed, or hopeless (p. 14)

However, terminally ill patients whose physical and mental capacities may be compromised by end-stage processes may endorse these items based on the reality of their situation. Answers to these questions may be quite variable and may not reflect clinical depression *or* an impaired decision-making process. When using the PHQ-9 as a screening tool, E.R. Goy (personal communication, March 19, 2009) suggests rephrasing the questions as follows:

“What about feeling interest or pleasure in things? You may not be able to do all the things that used to give you pleasure, but do you still enjoy hearing, reading, or watching TV about those activities? Does anything give you a sense of excitement, enthusiasm, or interest? Are there other pleasures that you experience now, even though you are not as active?”

In addition, Goy (ibid.) suggests that the examiner explain to the patient the reason for the question. She notes:

Sometimes I will even explain that we are trying to get at this core feature of depression, when people just totally lose their ability to react to ANYTHING with interest or pleasure. Once they understand why I am asking the question, they...usually can say quite reliably, “Oh, yes, I still get excited when my grandkids are coming to visit,” or “that's it exactly; I just don't enjoy anything at all any more.”

Chochinov, Wilson, & Lander (1997) found that the question, “Have you been depressed most of the time for the past two weeks?” was sensitive and accurate in detecting both a major depressive episode and minor depression. This question could be further elaborated as Goy suggests above.

If standardized instruments are chosen there should be a clear rationale, given the extra burden on the dying individual, and the psychologist or psychiatrist should be thoroughly

familiar with scoring, norms, and limitations of these tests. “The clinical interview is the gold standard for the diagnosis of depression” (Block, 2000, p. 210; also see Farber, 2009a; Quill & Arnold, 2008a, 2008b).

H. Final Report and Recommendations

The psychologist or psychiatrist will maintain a written record of the evaluation. At a minimum, the written record shall include the following:

The referral notes from the attending or consulting physician and signed consent from the patient that indicates that the patient received an oral and written description of the procedures of the evaluation;

The written fee agreement;

Appropriate signed authorizations for release of information from anyone other than the attending or consulting physician who will be interviewed as a collateral during the process;

Documentation of dates of service, nature of service and fees charged;

Notes taken during all interviews of the collaterals, with any narrative material from the collateral interviews that will be included in the report reviewed, if at all feasible, by the collaterals for accuracy;

The documents amassed during the course of the evaluation;

All correspondence associated with the case;

A copy of the evaluation report, which delineates the information and sources used for the evaluation.

The psychologist or psychiatrist may make recommendations regarding whether the patient is competent, and if lacking competence, what treatment, if any, would likely restore the patient to competency. Recommendations and conclusions reached in this process are based on information from more than one source and are supported by the data collected. Any limitations of tests used, and of any data acquired through testing, should be stated within the report.

I. Summary

Assessment of competence to make informed decisions and of psychiatric distress in dying individuals requires specialized skills, compassion, and considered reflection on the part of psychologists or psychiatrists who choose to participate in providing services

to patients requesting life-ending medications. Sensitive, methodical exploration of the complex nature of the patient's concerns is essential in formulating an accurate determination and appropriate recommendations for patients who wish to die with dignity, using Washington's new law.

*The WSPA End-of-Life Committee's Death With Dignity Guidelines Task Force includes G. Andrew Benjamin, Jr., J.D., Ph.D., ABPP, Judith R. Gordon, Ph.D., and Renee S. Katz, Ph.D., FT, who prepared the final report; and Janet Abrams, Psy.D., Karen M. Sanders, Ph.D., and Alison Ward, Ph.D., who reviewed numerous drafts and provided recommendations.

NOTE: This document was finalized on June 3, 2009. These recommendations may be revised periodically based on new scientific data and clinical experience regarding implementation of the Washington Death With Dignity law.

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