

Original Article

Mental Health Outcomes of Family Members of Oregonians Who Request Physician Aid in Dying

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Abstract

Oregon legalized physician aid in dying over 10 years ago but little is known about the effects of this choice on family members' mental health. We surveyed 95 family members of decedent Oregonians who had explicitly requested aid in dying, including 59 whose loved one received a lethal prescription and 36 whose loved one died by lethal ingestion. For comparison purposes, family members of Oregonians who died of cancer or amyotrophic lateral sclerosis also were surveyed. A mean of 14 months after death, 11% of family members whose loved one requested aid in dying had major depressive disorder, 2% had prolonged grief, and 38% had received mental health care. Among those whose family member requested aid in dying, whether or not the patient accessed a lethal prescription had no influence on subsequent depression, grief, or mental health services use; however, family members of Oregonians who received a lethal prescription were more likely to believe that their loved one's choices were honored and less likely to have regrets about how the loved one died. Comparing family members of those who requested aid in dying to those who did not revealed no differences in primary mental health outcomes of depression, grief, or mental health services use. Family members of Oregonians who requested aid in dying felt more prepared and accepting of the death than comparison family members. In summary, pursuit of aid in dying does not have negative effects on surviving family members and may be associated with greater preparation and acceptance of death. *J Pain Symptom Manage* 2009;38:807–815. © 2009 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

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Key Words*Euthanasia, family, outcomes***Introduction**

The State of Oregon now has over a decade of experience with legalized physician aid in dying. The Death with Dignity Act allows a physician to prescribe a lethal dose of a medication, usually a short-acting barbiturate, for the purposes of self-administration to a competent, terminally ill requesting patient.¹ Studies have examined many aspects of the Death with Dignity Act, including health care professionals' views on, and experiences around, this law and patients' interest in aid in dying and reasons for making the request.²⁻⁷ Individuals request assisted death in Oregon primarily to maintain a sense of control and dignity, to avoid dependence on others, and to die at home. They are worried about future physical discomfort, and loss of autonomy and function.^{3-5,8} However, only one in six requests to a physician for a lethal prescription is honored. Reasons patients do not progress through the aid-in-dying process are that they are unable to find a willing physician, they do not meet the legal requirements, or they change their mind or die before completing the requirements.³

Family members of patients who request assisted suicide most often support the choice.⁹ Hospice nurses reported that family opposition was the most important predictor of requesting patients failing to receive a lethal prescription.¹⁰ Compassion and Choices of Oregon is an advocacy organization that offers counseling and assistance for about three-quarters of individuals in Oregon who die by lethal prescription.¹¹ Of 315 Compassion and Choices clients who have hastened death, 289 had one or more family members present (the other 26 had a friend or Compassion and Choices volunteer present; G. Eighmey, personal communication, March 28, 2009). Although the law requires that the patient "self-administer" the lethal medication, a family member's assistance may range from organizing the necessary physician appointments, obtaining the medications from the pharmacy, preparing the medication, and, potentially, helping the patient take it. Little attention,

however, has been paid to the impact of physician-assisted death on family members.

Grief after death of any loved one can be persistent, painful, and functionally debilitating.^{12,13} For many years, clinicians have identified a group of individuals with persistent psychiatric disability after the loss of a loved one. Initially referred to as complicated grief, and more recently as prolonged grief disorder, symptoms include distressing and disruptive levels of yearning for the deceased, an inability to accept the death, feeling detached from others, a sense of purposelessness of life, and bitterness over the loss.¹³ Bereavement also has been identified as a risk factor for major depressive disorder among community-dwelling elders.¹⁴ Some experts have suggested that family members of persons who choose assisted suicide may be at risk for more severe grief reactions.¹⁵ How physician aid in dying, which may be morally and psychologically troubling, may complicate grief has not been explored. Suicidologists point out that the most difficult aspect of suicide is its effect on survivors, with qualitative studies indicating substantial shame, guilt, stigma, and sense of rejection.¹⁶

The primary objectives of this study were to describe how patients' end-of-life choices affected family caregivers of Oregonians who requested aid in dying and to measure severity of grief symptoms, use of mental health services, and depression in these family caregivers. A secondary objective was to compare these outcomes to those of family caregivers of decedent Oregonians who had not pursued hastened death.

Methods

The study was approved by the institutional review boards at the Portland Veterans Affairs Medical Center and the participating medical centers and hospices, and all participants gave written informed consent to participate.

Recruitment

We recruited family caregivers of Oregonians, now deceased, who had explicitly

requested aid in dying from a physician or who had a case file opened at Compassion and Choices. Compassion and Choices is an advocacy organization that offers information and support for clients who qualify for the Death with Dignity Act. In 2005, Compassion and Choices reported that they had given information to or assisted 180 of the 246 (73%) persons who accessed aid in dying under Oregon's law.¹¹ Additional cases were recruited from two large medical centers, three large hospices in northwest Oregon, and the Amyotrophic Lateral Sclerosis (ALS) Association of Oregon. Four of these organizations kept a centralized registry of patients who pursued aid in dying to assure compliance with the law. Potential participants were excluded if the organization was not confident that the family member was aware of the request.

Comparison participants (controls) were family caregivers of Oregonians who had died of cancer or ALS but who had never requested physician aid in dying. Comparison family members were recruited from the same institutions (not Compassion and Choices) as aid-in-dying family members. Each organization sent letters to family members who, if they wished to learn more about the study, contacted the research team either by phone or by mail. Study participants were not contacted until at least four months and as long as three years after the death. Most interviews were completed in a convenient and comfortable location, most often the family members' homes.

Measures

Case family members verified that the patient had requested aid in dying from a physician or had sought out information about aid in dying from Compassion and Choices. Comparison family members confirmed that the patient never requested aid in dying from a physician or contacted Compassion and Choices.

In addition to demographic information, we measured all participants' views on aid in dying, their support of aid in dying for the patient, and whether they themselves might ever request aid in dying. Importance of religion in the family members' life was measured on a 100 mm scale, with endpoints labeled "religion not important to me" (0) and "religion

is very important to me" (100).¹⁷ Social support was measured by the 16-item Interpersonal Support Evaluation List, with scores ranging from 16 (low support) to 64 (high support).^{18,19}

Prolonged grief was measured with the Inventory of Complicated Grief-Revised (ICG-R) short form, developed by Prigerson and Jacobs.²⁰ The ICG-R has repeatedly demonstrated excellent reliability and validity. The measure includes four items measuring severity of separation distress (e.g., preoccupation, longing, loneliness), with scores ranging from 1 = almost never/less than once per month to 5 = always/several times per day, and 11 items measuring traumatic distress (e.g., avoidance, numbness, disbelief, emptiness, bitterness), with scores ranging from 1 = none to 5 = overwhelming. The duration of symptoms was marked as lasting more or less than two months, and the family member rated the degree to which these symptoms cause social and occupational impairment, with 1 = no functional impairment and 5 = completely functionally impairing. The items were summed to form a continuous measure of severity of prolonged grief. A diagnosis of prolonged grief disorder, modified from criteria proposed by Prigerson et al.,¹³ was made if at least one or more separation distress items were rated as at least 4, five or more traumatic distress items rated as at least 4, the duration of symptoms was two months or more, at least six months had elapsed since death, and the functional impairment was rated at least four.²⁰

Mental health service use was measured by asking study participants if they ever discussed mental health concerns with any professional or accessed mental health treatment or hospice bereavement services after their loved one's death. Depression severity in the week before the interview was measured with the 21-item Beck Depression Inventory (BDI), in which each depression item was rated in severity from 0 to 3 and depression summed scores ranged from 0 (no symptoms of depression) to 63 (very high depression symptom severity).^{21,22} Major depressive disorder, as defined by the American Psychiatric Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM), 4th ed., text revision,²³ was determined by use of the Structured Clinical Interview for Disorders-Revised Version,

administered by a psychologist (E. R. G.).^{24,25} Individual items were developed to measure preparation for, regrets about, and acceptance of death; and surprise about, peacefulness with, and sense of inclusion or rejection around their loved ones choices at the end of life, all on a scale ranging from 1 = not at all and 4 = a great deal. These items were developed from concerns brought up in interviews with hospice nurses, social workers, and physicians around the law.^{5,26} The quality of the last week of life was rated on a 10-point scale where 0 = terrible experience and 10 = almost perfect.²⁵

Summary data are presented as frequencies and proportions for categorical data, and means with standard deviations (SD) for continuous data. Means are compared with Student's *t*-test. All *P*-values are two sided and the alpha level was set at 0.05.

Results

Aid-in-Dying Family Members

We enrolled 95 family members of 84 patients who requested aid in dying, including 59 family members of 52 patients who received a lethal prescription and 36 family members of 32 patients who died after lethal ingestion. Nine aid-in-dying primary informants referred one other family member for participation, and one referred two other family members.

The study was about family members' individual experiences; therefore, these secondary informants were retained in the analysis. Because they constitute a small proportion of participants, secondary informants were treated as independent observers. Compassion and Choices referred 81% of primary informants whose loved one requested aid in dying. They identified 180 eligible primary informants, of whom 68 (38%) participated. The patients who requested physician-assisted death had died a mean of almost 14 months before the interview with the family member.

Most aid-in-dying family members were well educated older widows who had known the decedent, on average, for four decades (Table 1). Most decedents were terminally ill with cancer and 87% were enrolled in hospice before death (Table 2). Aid-in-dying family members overwhelmingly supported legalization of physician-assisted death, wanted this option for their loved one, and would consider this option for themselves (Table 3).

Two aid-in-dying family members met study criteria for prolonged grief disorder and one in 10 had major depressive disorder (Table 4). Perceived social support was high. Over one-third had accessed some form of mental health treatment since the death and 15% had availed themselves of hospice bereavement services.

We compared the 59 family members who cared for a patient who received a lethal prescription with the 36 family members in which

Table 1
Characteristics of Family Members^a

Family Member	Loved One Requested Aid in Dying (<i>n</i> = 95)	Comparison Family Member (<i>n</i> = 63)	<i>P</i> -value
Relationship to patient, <i>n</i> (%)			
Spouse/partner	52 (55)	37 (59)	NS
Child	28 (29)	17 (27)	
Other	15 (16)	9 (14)	
Sex, <i>n</i> (%)			NS
Male	29 (31)	13 (21)	
Female	66 (69)	50 (79)	
Family member ethnicity, <i>n</i> (%)			NS
Caucasian	95 (100)	61 (97)	
Asian	0 (0)	1 (2)	
African American	0 (0)	1 (2)	NS
Age (years)	60.9 (13.1)	60.1 (14.2)	
Educational achievement (years)	16.2 (3.1)	14.5 (3.2)	<0.001
Religiousness (mm) ^b	30.3 (37.1)	58.4 (38.2)	
How long known patient (years)	41.0 (15.2)	38.6 (16.8)	NS
Months of bereavement	13.8 (8.6)	14.7 (6.9)	NS

NS = not statistically significant.

^aValues are expressed as mean (SD) unless otherwise specified.

^b100 mm scale where 0 = "religion not important to me" and 100 = religion very important to me."

Table 2
Characteristics of Decedents

Decedent	Aid-in-Dying Requester (<i>n</i> = 84), <i>n</i> (%)	Comparison Decedent (<i>n</i> = 63), <i>n</i> (%)	<i>P</i> -value
Sex			NS
Male	48 (57)	36 (57)	
Female	36 (43)	27 (43)	
Hospice enrolled	73 (87)	60 (95)	NS
Referring agency			<0.001
Compassion and Choices	68 (81)	0 (0)	
Hospice	13 (15)	48 (76)	
ALS society	2 (2)	8 (13)	
Medical center	1 (1)	7 (11)	
Terminal diagnosis			NS
Cancer	68 (81)	50 (79)	
ALS	4 (5)	6 (10)	
Other	12 (14)	7 (11)	

NS = not statistically significant.

the patient requested but did not receive a lethal prescription. There were no differences between the two groups in measures of prolonged grief or depression symptoms, diagnosis of either disorder, or any measure of mental health service use (data not shown). Family members of Oregonians who requested but did not receive a lethal prescription were more likely to endorse that they had regrets about how the loved one died (patient received lethal prescription, mean [SD] = 1.6 [1.0]; patient did not receive lethal prescription, 2.5 [1.2]; $P < 0.001$) and less likely to endorse that the patient's preferences for care at the end of life were honored (received prescription 3.9 [0.4]; no prescription, 3.2 [1.2]; $P < 0.001$). Family members whose loved one received a lethal prescription were less likely to endorse that caring for their loved one was a burden (received prescription 1.3 [0.6]; no prescription, 1.7 [0.9]; $P = 0.03$). Family members whose loved one accessed a lethal

prescription rated the quality of the last seven days of life (4.2 [2.8]) as higher than those whose loved one requested but did not receive a lethal prescription (2.9 [2.2]; $P = 0.03$).

Among the 36 family members of the 32 patients who died by lethal ingestion, the following views were endorsed "somewhat" or "a great deal:" Over 90% felt at peace with and included in the decedents' end-of-life choices, accepted the death, and were satisfied with the opportunities to say goodbye (Table 5); 11% had regrets on how the loved one died; and one in four either wanted more opportunities to care for the loved one or found it difficult to talk about the death.

Comparison Family Members

We compared demographic data and outcomes of aid-in-dying family members to 63 family members of decedent Oregonians who never requested hastened death. Three-quarters of comparison family members were

Table 3
Family Member Views on Aid in Dying

Family Member Viewpoint	Family Member of Aid-in-Dying Requester (<i>n</i> = 95), <i>n</i> (%)	Comparison Family Member (<i>n</i> = 63), <i>n</i> (%)	<i>P</i> -value
Family member views on aid in dying			<0.001
Support	95 (100)	39 (62)	
Neutral	0 (0)	11 (17)	
Oppose	0 (0)	13 (21)	
Family member views on aid in dying for a loved one			<0.001
Support	93 (98)	49 (78)	
Neutral	1 (1)	9 (14)	
Oppose	1 (1)	11 (17)	
Whether family member would ever consider aid in dying for self			<0.001
Yes	93 (98)	41 (65)	
No	0 (0)	21 (33)	
Missing	2 (2)	1 (2)	

Table 4
Mental Health Outcome for Family Members

Mental Health Outcome	Aid-in-Dying Family Members (<i>n</i> = 95)	Comparison Family Members (<i>n</i> = 63)	<i>P</i> -value
Current major depressive disorder, ^a <i>n</i> (%)	10 (11)	9 (14)	NS
Prolonged grief disorder, <i>n</i> (%)	2 (2)	0 (0)	NS
Current Beck depression score, ^b mean (SD)	7.1 (5.9)	8.5 (7.8)	NS
Prolonged grief, ^c mean (SD)	22.5 (7.4)	24.6 (8.8)	NS
Social support, ^d mean (SD)	56.6 (6.1)	56.7 (6.3)	NS
Mental health care use, <i>n</i> (%)			
Discussed emotional problems with a professional since loss	42 (44)	33 (52)	NS
Mental health treatment since loss	36 (38)	26 (41)	NS
Hospice bereavement services	14 (15)	11 (17)	NS

^aStructured Clinical Interview for DSM diagnosis.¹⁸

^bBDI: scores range from 0 (no depression) to 63 (severe depression).¹⁶

^cInventory of Complicated Grief: scores range from 15 (no grief) to 65 (severe prolonged grief).¹⁵

^dISEL: scores range from 16 (low support) to 64 (high support).^{13,14}

referred by hospices. The comparison family members, similar to the aid-in-dying family members, were mostly Caucasian widows, whose loved ones had died of cancer or ALS a mean of 15 months before the interview (Table 1). Family members of the patients requesting aid in dying had higher educational attainment and were less religious than comparison family members. In contrast to aid-in-dying family members, 62% of comparison family members supported legalized aid in dying ($P < 0.001$), 78% would have supported it for their loved one ($P < 0.001$), and 65% might consider aid in dying for themselves ($P < 0.001$; Table 3).

There were no differences between aid-in-dying and comparison family members in prolonged grief diagnosis or symptom severity (Table 4). Aid-in-dying families did not request or access more mental health services after the death compared with control families, nor did they perceive diminished social support compared with comparison families. There were no differences between the two groups in diagnosis of major depressive disorder or severity of depressive symptoms as measured by the BDI. Depression is most severe in the first year after a loss, but there was no difference in BDI score between the two groups in the first year after death (aid-in-dying family members, $n = 53$, mean [SD] BDI = 7.8 [6.5]; comparison family members, $n = 29$, mean BDI [SD] = 8.9 [8.0]; $P = 0.50$).

Aid-in-dying families felt more prepared for and accepting of their loved one's death and were less likely to indicate that they wanted more opportunities to care for the decedent

(Table 5). Aid-in-dying family members, which included many in whom a lethal prescription was not obtained, were less likely to endorse, as a group, that their loved one's care preferences at the end of life were honored, compared with control family members. There were no differences between aid-in-dying and comparison family members in other measures reflecting views on the loved one's choices including regrets about the death; feeling included in, rejected by, surprised by, or at peace with end-of-life choices; or finding it difficult to discuss the death. The two groups did not differ in their endorsement of the importance of caring for the ill individual or the degree to which they felt burdened by care.

Discussion

We surveyed 95 family members of decedent Oregonians who requested aid in dying. We found that an average of 14 months after death, family members had a low prevalence of depression and grief, and few negative perceptions about the death in relation to their loved one's request for assisted suicide. In addition, among those whose loved one requested aid in dying, whether they did or did not receive a lethal prescription was not associated with any of these mental health outcomes. Those whose loved one accessed this option were more likely to believe their loved one's choices were honored and less likely to have regrets about how the loved one died compared with family members in which the loved one requested aid in dying but did not receive a lethal prescription.

Table 5
Family Member Views on Loved One's Choices at the End of Life

Family Member Views ^a	Loved One Requested Aid in Dying (<i>n</i> = 95), mean (SD)	Comparison Family Members (<i>n</i> = 63), mean (SD)	<i>P</i> -value ^b	Endorsed "Somewhat" or a "Great Deal" by Family Member Whose Loved One Died by Lethal Ingestion (<i>n</i> = 36), <i>n</i> (%)
I have regrets about how he died	1.9 (1.2)	2.2 (1.3)	0.13	4 (11)
I felt prepared for his death	3.2 (1.0)	2.8 (1.2)	0.02	30 (83)
I wanted more opportunities to care for him	1.7 (1.0)	2.1 (1.3)	0.03	9 (25)
I was surprised at the choices he made about his medical care at the end of life	1.4 (0.8)	1.3 (0.7)	0.40	5 (14)
I was at peace with the choices he made at the end of life	3.8 (0.6)	3.7 (0.6)	0.37	34 (94)
Caring for him at the end of life was a burden	1.5 (0.8)	1.4 (0.8)	0.58	3 (8)
He included me in decisions that he made at the end of his life	3.6 (0.8)	3.5 (0.9)	0.44	34 (94)
I am satisfied that I had the opportunity to say goodbye to him	3.7 (0.7)	3.7 (0.7)	0.72	35 (97)
I have accepted his death	3.8 (0.5)	3.6 (0.7)	0.05	36 (100)
It is difficult to talk about his death to others	1.7 (0.9)	1.8 (0.9)	0.58	9 (25)
Because of the choices he made I felt rejected	1.1 (0.5)	1.1 (0.4)	0.76	2 (6)
His preferences for care at the end of life were honored	3.6 (0.9)	3.9 (0.4)	0.04	35 (97)
It was important for me to care for him at end of life	3.8 (0.7)	3.9 (0.4)	0.22	32 (89)

^aFour-point scale with 1 = not at all and 4 = a great deal. Gender-specific options used.

^bComparison of loved one's request for aid in dying with controls by *t*-test.

Compared with other family members of decedent Oregonians who did or did not request aid in dying, there appeared to be little impact on mental health outcomes, including prolonged grief symptoms and diagnosis, depressive symptoms or diagnosis, or mental health care use. However, as compared with control families, families in which aid in dying was requested felt, on average, more prepared for the death, felt more accepting of the loved one's death, and were less likely to endorse that they wanted more opportunities to care for the loved one.

Terminally ill patients who wish to hasten death must often depend on family members to play a role in facilitating this choice. In a previous study of hospice nurses' experiences around legalized aid in dying in Oregon, family opposition to aid in dying was an insuperable barrier for patients who wanted physician-assisted death, even if the patients were otherwise competent and eligible under the law.¹⁰ Starks et al.²⁷ point out that family members have a pivotal role in planning and implementing hastened death; yet, they must live with moral, psychological, and social consequences

of whatever level of participation they choose. Failing to participate may result in a memory of the deceased that is full of conflict and a failure to help with suffering. Participation may result in a sense of violation such as believing they had murdered their loved one. Both action and inaction may have the risk of complicating grief and leaving the loved one with regrets. Our data suggest that in many families, as a group, whether or not the patient did access this option did not alter the risk for prolonged grief nor the views of the quality of the loved one's death. However, among family members whose loved one requested aid in dying, there was more regret and sense of dishonoring the patient than among those whose loved one did not ultimately access a prescription under the law.

Grief, the emotional distress associated with the loss of a loved one, is a normal response to bereavement; however, unresolved and persistently severe levels of grief can be chronically distressing and disabling, and represent a failure to move toward grief resolution.¹³ Prolonged grief symptoms include separation distress (e.g., longing, preoccupation, loneliness) and traumatic distress (e.g., avoidance,

numbness, disbelief, emptiness, bitterness). Chronic mourning has been recognized for decades. There is no recognized diagnosis in the current psychiatric nosology; however, prolonged grief disorder, previously called traumatic grief or complicated grief, has been proposed for inclusion in the APA DSM-V. This symptom complex can be distinguished from major depressive disorder and normal grief. Prolonged grief is associated with increased risk for suicidal ideation and attempts, hospitalization, adverse health events, and decreased quality of life. Maciejewski et al.²⁸ reported that in a sample of 317 widows and widowers, 58 (18%) had prolonged grief disorder. Bascom and Tolle¹⁵ proposed that physician-assisted death was more likely to complicate grief. Our data suggest, however, that in the context of legal suicide, prolonged grief among survivors is not common. We hypothesize that when patients bring up the option of physician-assisted death, family members' denial is diminished and they are pushed to accelerate grieving and resolve grief.²⁹ Barry et al.³⁰ also found that greater preparation for death was associated with lower rates of complicated grief among bereaved individuals. Swarte et al.³¹ reported that bereaved family and friends of patients who died of euthanasia in The Netherlands, in fact, had fewer traumatic grief symptoms compared with family of those who died of natural causes.

Our findings are similar to those reported in studies of grief after suicide. In a systematic review of 41 studies comparing suicide survivors with other bereaved persons, there was no evidence of worse general mental health, depression, post-traumatic stress disorder, anxiety, or suicidal behavior among suicide survivors.¹⁶ Barry et al.³¹ reported that four months after the death of a loved one, 9% of survivors met criteria for major depressive disorder. Suicide survivors do, however, report feelings of rejection, shame, stigma, blaming, and need for concealment of the cause of death, compared with other survivor groups. In contrast to suicide survivors, we found that aid-in-dying survivors do not appear to have worse outcomes compared with survivors of other deaths and, in some respects, have more favorable outcomes. Among the 36 family members whose loved one chose physician-assisted death, only two felt rejected by the

choice, 94% felt included in the patient's decisions, and only 11% had "somewhat" or "a great deal" of regrets about the death. One in four had difficulty talking about the death, but this difficulty was not more common than in the comparison group.

A strength of our study is that it was conducted in one of two jurisdictions in the United States that has legalized physician aid in dying (the state of Washington recently legalized this option). Reliable and well-validated instruments were used to measure mental health outcomes. Aid-in-dying and comparison family members were similar in factors associated with mental health outcomes, such as time since death. Limitations were the low participation proportion among aid-in-dying family members and the use of a convenience sample among comparison family members. This may limit generalizability as it is unknown if factors associated with nonresponse may be associated with mental health outcomes. Similar to the population of Oregon, particularly those who choose aid in dying, aid-in-dying families were overwhelmingly Caucasian. Persons in Oregon who choose aid in dying are almost seven times more likely to be college educated than other decedents, and not surprisingly, this difference in educational level is mirrored in their family members.¹

In summary, pursuit of physician aid in dying does not appear to have a negative effect on surviving family members and, in fact, may help some family members prepare for death. Although a few family members of Oregonians who died by lethal ingestion felt regret more often, some family members of individuals who requested but did not receive a lethal prescription felt that their loved one's final wishes were dishonored.

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