

## Original Article

## Factors Associated With Terminally Ill People Who Want to Die



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**Abstract**

**Context.** The decision to request and proceed with euthanasia or physician-assisted dying is complex, and predictors of such decisions are heterogeneous with regard to physical health, psychological, and social factors. Local research is therefore needed.

**Objectives.** To examine the interplay of demographic, clinical, and psychosocial factors routinely collected by a standardized clinical instrument, the interRAI Resident Assessment Instrument for Palliative Care (interRAI-PC), in people with a prognosis of less than 12 months who wanted to die.

**Methods.** All New Zealanders who had an interRAI-PC in 2018 were included. The outcome variable was the single item *Wants to die now*. Independent variables included biopsychosocial factors and health index scales generated by interRAI-PC. A binary logistic regression was used to determine the predictive factors of *Wants to die now* (yes vs. no).

**Results.** There were 771 individuals included (mean age 76.0 years; SD 11.6; female 50.1%); 9.3% of whom reported yes to *Wants to die now*, 59.8% no, and for 30.9%, the assessor was *unable to determine*. The factors with the largest odds ratios (ORs) were awareness of terminal prognosis (OR 4.8; 95% CI 2.2–10.3), high level of depression (OR 4.6; 95% CI 1.7–12.6), not finding meaning in day-to-day life (OR 3.8; 95% CI 1.8–8.1), and pain (less than severe: OR 3.7; 95% CI 1.3–10.4 and severe to excruciating: OR 3.5; 95% CI 1.1–10.7).

**Conclusion.** Addressing the significant factors we identified should form part of a multidisciplinary assessment when terminally ill patients express a wish to die, to ensure their physical, psychological, and existential needs are adequately met. *J Pain Symptom Manage* 2020;60:539–548. © 2020 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

**Key Words**

*Euthanasia, physician-assisted dying, terminal illness, palliative care, wish to die, death wishes, interRAI*

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**Key Message**

This study examined associations between biopsychosocial factors of people with a prognosis of less than 12 months who wanted to die. The results indicate that those who wanted to die were more likely to be aware of their terminal prognosis, experiencing pain and depression, and not finding meaning in life.

**Introduction**

Euthanasia and physician-assisted dying (PAD) is a legally available option for terminally ill people who

want to end their life in several parts of the world. These places include The Netherlands, Belgium, Switzerland, Luxembourg, Canada, Colombia, Germany, the U.S. jurisdictions of California, Colorado, Oregon, Vermont, Hawaii, Washington, Montana, Maine, New Jersey, and District of Columbia, and the Australian state of Victoria. The proportion of euthanasia and PAD among all deaths ranges from 0.1% to 0.2% in the U.S. states (Oregon and Washington) and Luxembourg to 1.8%–2.9% in The Netherlands.<sup>1</sup> The number of reported euthanasia/PAD cases is increasing in some countries.<sup>2,3</sup> For example, in

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Belgium, the rate of euthanasia among all deaths increased from 0.2% in 2003 to 1.7% in 2013.<sup>2</sup> Cancer/malignancy is the most common reason for people to request euthanasia and PAD.<sup>4–6</sup>

The decision to request and proceed with euthanasia/PAD is complex, and there are many interacting factors why this might arise.<sup>7</sup> A review of the literature in European countries and U.S. states where euthanasia/PAD is legal suggested that the typical person who died with assistance was a well-educated male patient with cancer aged between 60 and 85 years.<sup>1</sup> However, other studies such as one conducted in Switzerland have found that euthanasia/PAD was associated with other factors, such as female gender, living alone, being divorced, higher education, and higher socioeconomic position.<sup>8</sup> Furthermore, a Canadian study found a number of biopsychosocial factors that were associated with people who were receiving palliative care and expressing a wish to die.<sup>9</sup> They included being widowed/not married, a shorter estimated prognosis, depressive symptoms, functional impairment, an excessive amount of sleep, feeling completion regarding financial/legal matters, and struggling with the meaning of life.<sup>9</sup>

A recent systematic review of predictors associated with death by euthanasia/PAD, attitudes toward it, and wishes and requests for it concluded that the findings were heterogeneous with regard to physical health, psychological, and social factors.<sup>10</sup> Therefore, local research is much needed to better understand these complex factors in different countries where macrofactors such as historical and socio-cultural-spiritual issues, public education level, health care system, and political system are likely to play a role in the general public's acceptance of euthanasia/PAD.

The New Zealand Parliament recently passed the End of Life Choice Bill, and the general public will make the final decision on this legislation in a referendum in late 2020. However, New Zealand has very limited empirical research aimed at understanding euthanasia and PAD in terminally ill people. A previous New Zealand study found that older adults (65+) with terminal cancer who died by suicide had a low rate of depression, and the suicide motives of most cases were seen as understandable and resembled rational suicide.<sup>11</sup>

The main objective of this study was to examine the interplay of demographic, clinical, and psychosocial factors collected using a standardized palliative care instrument, the interRAI Resident Assessment Instrument for Palliative Care (interRAI-PC), among people who wanted to die. The interRAI-PC was released in 2003 after testing in Canada, Czech Republic, Iceland, The Netherlands, Sweden, Spain, and the U.S.<sup>12</sup> It focuses on the needs of palliative care patients, with particular emphasis on symptom management,

strengths, preferences, psychosocial and spiritual issues, and stress among the informal caregivers.<sup>12,13</sup> It is aimed at improving the quality of care and support for patients with a palliative care diagnosis, using the guidance of a set of palliative-specific clinical assessment protocols. Clinical assessment protocols are used to identify specific clinical conditions or situations to inform care plans. The interRAI-PC was introduced to New Zealand in 2017 and can be used with community-dwelling people who have a prognosis of less than 12 months, instead of the usual interRAI home care assessment (Appendix Fig. 1).<sup>13</sup> Since 2012, the interRAI home care assessment has been routinely used for all older adults assessed for publicly funded home support and entry to long-term aged residential care in New Zealand.

## Methods

### Setting

This was a cross-sectional study, and the study sample consisted of all people who had received an interRAI-PC assessment anywhere in New Zealand between January 1 and December 31, 2018. The interRAI assessors used face-to-face assessments with their patients and were trained to use multiple sources of information when completing the assessment (e.g., referral note, interview with the person, observation, discussion with family, carers, or health professionals) to ensure the most accurate assessment.

New Zealand Technical Advisory Services provided access to deidentified interRAI data from people who gave consent to have their records used for research purposes at the time of their interRAI assessment.

### Participant Records

Fig. 1 shows the flowchart of the participant records selection process. Where there was more than one assessment for an individual in the study period, only the most recent assessment was included in the analysis, resulting in a final sample of 771 unique individuals.

### Measures

*Outcome Variable: Wants to Die Now.* This interRAI item explores the person's wish of wanting to die now. The person could be making this statement to family members, friends, or staff members. It has three responses: yes, no, and unable to determine. This interRAI item is part of the section on responsibilities and advanced directives. The assessment for this section is a conversation with the person and family in general. The assessor discusses advanced directives and end-of-life wishes, but some people are not willing or able to talk about these decisions at the time of assessment,

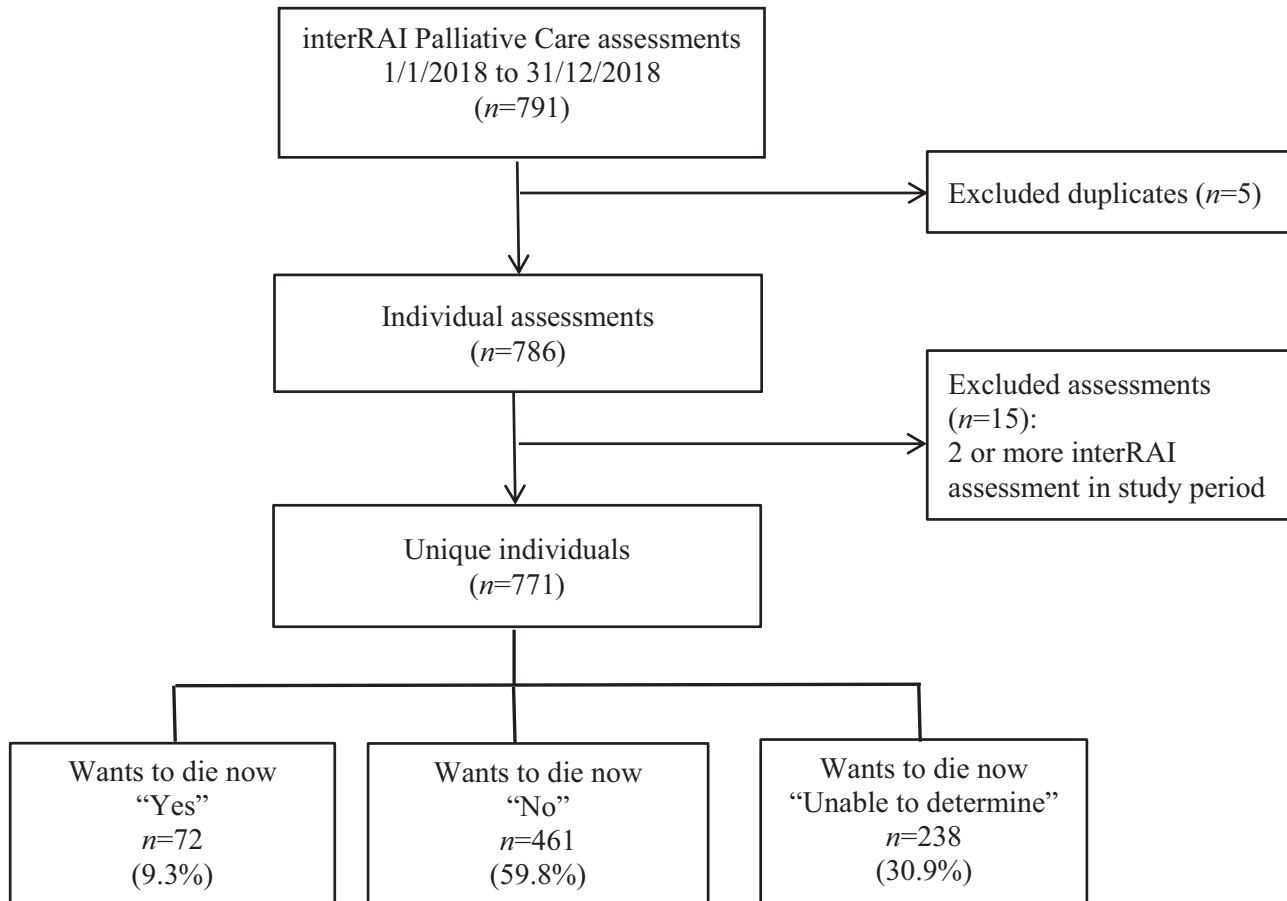


Fig. 1. Flowchart of study subjects selection.

for example, if they are not ready or too unwell. In these cases, the assessor will not probe the issue but can code this item as unable to determine. For the purpose of this study, it is important to emphasize that this interRAI item *wants to die now* does not equate to a desire to seek euthanasia/PAD.

**Independent Variables.** In addition to demographic, clinical, and psychosocial variables, a number of health index scales are generated by the interRAI assessment. The following variables and scales were chosen based on existing literature on suicide/euthanasia/PAD in those with terminal illness, and minor adjustments of the response codes were performed to allow meaningful clinical interpretation of the variables.

**Demographic Factors.** Age, gender, ethnicity, marital status, and whether the person lived alone are the demographic factors.

**Terminal Illness-Related Factors.** Cancer vs. noncancer diagnosis, estimated survival, patient's awareness of

terminal prognosis, and having an advance care plan in place are the terminal illness-related factors.

**Physical Symptoms.** Hiccups, dry mouth, nausea, fecal impaction, bloating, dyspnea, and fatigue are the physical symptoms.

**Life Completion.** Sense of completion of formal responsibilities (e.g., financial, legal), sense of making progress regarding completion of personal goals, accepting of situation, and strengths that can be fostered are included in life completion.

**Self-Reported Spirituality.** Finds guidance in religion or spirituality, struggling with meaning of life, finds meaning in day-to-day life, and at peace with life.

**Social Support and Carer stress.** Strong and supportive family relationship; family or close friends report feeling overwhelmed by person's support needs; informal helper(s) unable to continue in caring activities; primary informal helper expresses feelings of

distress, anger, or depression; contact with family/significant other/friend; and pastoral services.

**Health Index Scales.** There are five health index scales that can be automatically generated once the assessment has been completed. Higher scores on all scales indicate worse performance.

1. *Activities of daily living (ADL) Self-performance Hierarchy Scale.* This is used to measure an individual's degree of dependence in ADLs. It measures four performance areas: personal hygiene, locomotion, toilet use, and eating. The range of activities included in the scale extend from activities that tend to decay first (such as personal hygiene) to those that are kept the longest (such as eating independently). These items are assessed as a range into a hierarchical ranking scale providing scores from 0 to 6 (0 = no to minimal dependence; 1–2 = mild to moderate dependence, and 3+ = severe dependence).<sup>14</sup>
2. *Changes in Health, End-Stage Disease, Signs and Symptoms Scale.* This is calculated by adding sign and symptom variables up to a maximum of two, then adding three other variables (i.e., change in decision-making, change in ADL status and end-stage disease), resulting in a scale that ranges from 0 to 5: 0–1 = little or no health instability; 2–3 = moderate instability; and 4–5 = high level of instability).<sup>15</sup> The Changes in Health, End-Stage Disease, Signs and Symptoms scale has been shown to be a strong predictor of mortality in people receiving health care in both community and institutional settings.
3. *Cognitive Performance Scale.* The Cognitive Performance Scale score is determined by an algorithm using items about daily decision-making ability, short-term memory, procedural memory, ability to make oneself understood, and ability to feed oneself. These items are combined into a hierarchical ranking scale providing scores from 0 to 6 (0 = no impairment; 1–2 = minimal to mild impairment; and 3 = moderate to severe impairment).<sup>16</sup>
4. *Pain Scale.* This scale uses two items (pain frequency and pain intensity) to create a score from 0 to 4 (0 = none; 1–2 = less than severe; and 3–4 = severe to excruciating pain).<sup>17</sup>
5. *Depression Rating Scale.* The scale consists of seven mood items with possible scores ranging from 0 to 14 (0–2 = no to minimal risk; 3–5 = moderate risk; and 6+ = high risk of depression).<sup>18</sup> A recommended cutoff score of

3+ has been shown to have predictive validity for clinical depression.<sup>19</sup>

### Statistical Analysis

Data were analyzed using IBM Statistical Package for the Social Sciences for Windows, version 25 (IBM Corp., Armonk, NY). To address our main study objective of examining the interplay of factors among terminally ill people who wanted to die, we compared individuals who answered yes to the variable *Wants to die now* with those who answered no. Descriptive statistics for demographic, clinical, and psychosocial variables and clinical outcome scales were obtained for these two groups of individuals. Bivariate analysis with Chi-squared tests was used to investigate the significance of the relationships between the independent variables and the presence of *Wants to die now*. Fisher's exact tests were used for discrete variables when the cells contained less than five expected cases. An independent t-test was used to compare age, a continuous variable, between the two groups. Next, binary logistic regression was used to determine the predictive variables of the variable *Wants to die now*. All the variables that proved to be significantly ( $P < 0.01$ ) related to *Wants to die now* in the bivariate analysis were entered as independent variables in the logistic regression. Because of the large number of variables, we set a more stringent level of significance at 1% (instead of the usual 5%) to reduce the risk of Type I error. Odds ratios (ORs) and 95% CIs were calculated as measures of association.

### Results

Within the total sample ( $n = 771$ ), the mean age was 76.0 years (SD 11.6; range 20–100). About half (50.1%) of the sample were female, and most (87.0%) were European (Māori 8.7%, Asian 1.7%, Pacific people 1.7%, and other 0.9%). There were 9.3% of the sample who reported yes to *Wants to die now* variable, 59.8% reported no and, for 30.9%, assessors were unable to determine. **Table 1** shows the bivariate analysis of the relationships between the independent variables and the two groups of individuals who reported yes vs. no to the *Wants to die now* variable. **Table 2** shows the results of the logistic regression analysis. The model was significant ( $\chi^2 = 96.7$ ;  $P < 0.000$ ; degrees of freedom = 15) and explained 31.0% of the variance in the presence or the absence of *Wants to die now* ( $R^2$  Nagelkerke). The following factors were statistically significantly associated with the variable of *Wants to die now*: higher age, awareness of terminal prognosis, not finding meaning in day-to-day life, pain, and high level of depression. The factors with the largest ORs in the model were awareness of terminal prognosis

Table 1  
 Bivariate Analysis of the Relationships Between *Wants to Die Now* and Demographic, Clinical, Life-Completion, Self-Reported Spirituality, Social Support, and Carer Stress Variables and interRAI-Generated Scales

Variables	Wants to Die Now		P
	No N = 461; n (%)	Yes N = 72; n (%)	
Age; mean (SD)	75.4 (11.5)	80.2 (8.4)	0.001
Gender			
Female	225 (48.8)	36 (50.0)	0.851
Male	236 (51.2)	36 (50.0)	
Marital status <sup>a</sup>			
Married or in a relationship	231 (50.1)	30 (41.7)	0.183
Not married or in a relationship	230 (49.9)	42 (58.3)	
Ethnicity			
European	407 (88.3)	66 (91.7)	0.399
Non-European	54 (11.7)	6 (8.3)	
Living arrangement before admission			
Lived alone	188 (40.8)	32 (44.4)	0.557
Lived with others	273 (59.2)	40 (55.6)	
Diagnosis <sup>a</sup>			
Cancer	351 (77.0)	53 (73.6)	0.532
Noncancer	105 (23.0)	19 (26.4)	
Estimated survival			
Less than six weeks	58 (12.6)	23 (31.9)	<0.001
Between six weeks and six months	221 (47.9)	34 (47.4)	
Six months or longer	182 (39.5)	15 (20.8)	
Awareness of terminal prognosis			
Yes	246 (53.4)	60 (83.3)	<0.001
No	215 (46.6)	12 (16.7)	
Finds guidance in religion or spirituality			
Yes	158 (34.3)	23 (31.9)	0.416
No	215 (46.6)	39 (54.2)	
Person could not/would not respond	88 (19.1)	10 (13.9)	
Finds meaning in day-to-day life			
Yes	307 (66.6)	29 (40.3)	<0.001
No	53 (11.5)	27 (33.8)	
Person could not/would not respond	101 (21.9)	16 (22.2)	
Struggling with meaning of life			
Yes	29 (6.3)	7 (9.7)	0.408
No	333 (72.2)	53 (73.6)	
Person could not/would not respond	99 (21.5)	12 (16.7)	
At peace with life			
Yes	296 (64.2)	47 (65.3)	0.918
No	66 (14.3)	11 (15.3)	
Person could not/would not respond	99 (21.5)	14 (19.4)	
Accepting of situation			
Yes	371 (80.5)	64 (88.9)	0.087
No	90 (19.5)	8 (11.1)	
Completion of responsibilities			
Yes	344 (74.6)	63 (87.5)	0.017
No	117 (25.4)	9 (12.5)	
Progress toward personal goals			
Yes	326 (70.7)	51 (70.8)	0.984
No	135 (29.3)	21 (29.2)	
Strengths that can be fostered			
Yes	378 (82.0)	47 (65.3)	0.001
No	83 (18.0)	25 (34.7)	
Pastoral services			
Not ordered/did not occur/not implemented	409 (88.7)	59 (81.9)	0.102
Implemented in last three days	52 (11.3)	13 (18.1)	
Strengths—strong and supportive relationship with family			
Yes	412 (89.4)	67 (93.1)	0.335
No	49 (10.6)	5 (6.9)	
Unsettled relationship—family or close friends report feeling overwhelmed by person's support needs			
Yes	185 (40.1)	38 (52.8)	0.043
No	276 (59.9)	34 (47.2)	
Informal helper(s) is unable to continue in caring activities <sup>a</sup>			
Yes	98 (21.6)	26 (37.1)	0.005
No	355 (78.4)	44 (62.9)	

(Continued)

Table 1  
Continued

Variables	Wants to Die Now		P
	No N = 461; n (%)	Yes N = 72; n (%)	
Primary informal helper expresses feelings of distress, anger, or depression <sup>a</sup>			
Yes	130 (28.7)	25 (35.7)	0.232
No	323 (71.3)	45 (64.3)	
In last 24 hours, how long has any family member, significant other, or friend been with the person			
Zero to four hours	219 (47.5)	31 (43.1)	0.482
More than four hours	242 (52.5)	41 (56.9)	
Having an advance care plan in place			
Completed	71 (15.4)	17 (23.6)	0.081
Not completed	390 (84.6)	55 (76.4)	
Hiccups			
Present	30 (6.5)	6 (8.3)	0.611 <sup>b</sup>
Not present	431 (93.5)	66 (91.7)	
Dry mouth			
Present	247 (53.6)	36 (50.0)	0.571
Not present	214 (46.4)	36 (50.0)	
Nausea			
Present	185 (40.1)	35 (48.6)	0.174
Not present	276 (59.9)	37 (51.4)	
Fecal impaction			
Present	19 (4.1)	5 (6.9)	0.352 <sup>b</sup>
Not present	442 (95.9)	67 (93.1)	
Bloating			
Present	119 (25.8)	18 (25.0)	0.883
Not present	342 (74.2)	54 (75.0)	
Dyspnea			
Absence of symptom	201 (43.6)	31 (43.1)	0.931
Present at rest or when performed activities	260 (56.4)	41 (56.9)	
Fatigue—inability to complete normal daily activities			
None to minimal	204 (44.3)	15 (20.8)	<0.001
Moderate to very severe	257 (55.7)	57 (79.2)	
Scale—ADL Self-performance Hierarchy			
0 (no to minimal dependence)	161 (34.9)	11 (15.3)	0.002
1–2 (mild to moderate dependence)	114 (24.7)	18 (25.0)	
3+ (severe dependence)	186 (40.3)	43 (59.7)	
Scale—CHESS			
0–1 (little or no health instability)	42 (9.1)	4 (5.6)	0.016
2–3 (moderate health instability)	285 (61.8)	35 (48.6)	
4–5 (high level of health instability)	134 (29.1)	33 (45.9)	
Scale—CPS			
0 (no cognitive impairment)	229 (49.7)	26 (36.1)	0.079
1–2 (minimal to mild impairment)	193 (41.9)	40 (55.6)	
3+ (moderate to severe impairment)	39 (8.5)	6 (8.3)	
Scale—Pain			
0 (none)	106 (23.0)	5 (6.9)	0.004
1–2 (less than severe)	247 (53.6)	42 (58.3)	
3–4 (severe to excruciating)	108 (23.4)	25 (34.7)	
Scale—DRS			
1–2 (no to minimal risk of depression)	375 (81.3)	44 (61.1)	<0.001
3–5 (moderate risk of depression)	64 (13.9)	16 (22.2)	
6+ (high risk of depression)	22 (4.8)	12 (16.7)	

InterRAI = interRAI Resident Assessment Instrument; ADL = activities of daily living; CHESS = Changes in Health, End-Stage Disease, Signs and Symptoms; CPS = Cognitive Performance Scale; DRS = Depression Rating Scale.

<sup>a</sup>Missing data in less than 2% of the sample.

<sup>b</sup>Fisher's exact test.

(OR 4.8; 95% CI 2.2–10.3), high level of depression (OR 4.6; 95% CI 1.7–12.6), not finding meaning in day-to-day life (OR 3.8; 95% CI 1.8–8.1), and pain (less than severe pain: OR 3.7; 95% CI 1.3–10.4; severe to excruciating pain: OR 3.5; 95% CI 1.1–10.7).

## Discussion

This study found that 9.3% of terminally ill people in our sample wanted to die. They were more likely than the rest of the sample to be older, aware of their



Table 2  
Binary Logistic Regression Including all the Significant Variables From the Bivariate Analysis

Variables	Adjusted OR (95% CI)	P
Age	1.06 (1.03–1.10)	<0.001
Estimated survival		
Six months or longer	Reference	0.112
Less than six weeks	1.33 (0.54–3.28)	
Between six weeks and six months	0.63 (0.29–1.38)	
Awareness of terminal prognosis		
Yes	4.75 (2.19–10.32)	<0.001
Finds meaning in day-to-day life		
No	3.82 (1.81–8.05)	0.002
Informal helper(s) is unable to continue in caring activities		
Yes	1.29 (0.65–2.53)	0.466
Fatigue— inability to complete normal daily activities		
Moderate to very severe	1.30 (0.63–2.66)	0.478
Strengths that can be fostered		
No	1.27 (0.62–2.57)	0.514
Scale—ADL Self-performance		
Hierarchy		
0 (no to minimal dependence)	Reference	0.530
1–2 (mild to moderate dependence)	1.49 (0.62–3.57)	
3+ (severe dependence)	1.62 (0.69–3.77)	
Scale—Pain		
0 (none)	Reference	0.047
1–2 (less than severe)	3.67 (1.30–10.37)	
3–4 (severe to excruciating)	3.46 (1.12–10.70)	
Scale—DRS		
1–1 (no to minimal risk of depression)	Reference	0.009
3–5 (moderate risk of depression)	1.86 (0.84–4.09)	
6+ (high risk of depression)	4.63 (1.70–12.64)	

OR = odds ratio; ADL = activities of daily living; DRS = Depression Rating Scale.

terminal prognosis, experiencing pain and significant signs/symptoms of depression, and not finding meaning in day-to-day life. Our findings of pain and depression are consistent with the international literature on their role in terminally ill people expressing a desire for death or requesting euthanasia/PAD.<sup>20–22</sup> For example, pain was associated with terminally ill patients being more likely to consider euthanasia or PAD in a hypothetical situation;<sup>21</sup> and the desire for death was correlated most significantly with depression among terminally ill patients.<sup>22</sup>

A number of indistinct phrases and concepts related to *Want to die* are used in the literature, including wish to die, desire to hasten death, desire to die, wish to hasten death, and desire for early death.<sup>23</sup> People with terminal illness may wish to hasten their death to reduce pain and suffering before their physical condition progressively worsens.<sup>11</sup> Sometimes, however, an expression of wanting to die equates to a genuine desire for death to be hastened but not always;<sup>9</sup> and interRAI-PC does not directly explore a desire to hasten death. A previous New Zealand study with healthy older people concluded that those who supported

medical practices to hasten death have serious concerns about their perceived future incapacities and dependency on others as well as fears around becoming a burden.<sup>24</sup> A German study suggested that desire to hasten death among palliative care patients was used as an extreme coping strategy to maintain control against anticipated agony;<sup>25</sup> although a study in Switzerland found that, among terminally ill cancer patients, the wish to die was about wanting *to spare others from the burden of oneself*.<sup>26</sup>

Depression is a relatively common psychiatric illness, particularly as a comorbid condition in people with a physical illness. Although sharing similar end symptoms, many subtypes of depression exist and they have different etiological and phenomenological factors. Existential depression is one such example, and we need to consider this diagnosis in terminally ill people who are not finding meaning in their life and want to die. There are many definitions of meaning in life in the literature. Steger et al.,<sup>27</sup> who developed the Meaning in Life Questionnaire, defined it as *the sense made of, and significance felt regarding, the nature of one's being and existence*. Indeed, the thought of death can result in a depressive existential crisis with the core symptom of hopelessness; and a person may consider suicide if they suddenly sense that their life has no intrinsic significance.<sup>28</sup> Berra<sup>29</sup> defined existential depression as *a condition in which the mood is oriented in a depressive sense, and stems from particular reflections and considerations on the nature of existence*. He also argued that existential depression is a nonpathological mental state and does not necessarily benefit from the usual pharmacological or psychotherapeutic interventions.<sup>28</sup>

Previous studies suggested that some people changed their mind about euthanasia/PAD when their depressive symptoms improved,<sup>21,30,31</sup> and such findings could potentially apply to other symptoms, such as pain, that are associated with the wish to die in terminally ill people. Galushko et al.<sup>32</sup> proposed a three-level framework for palliative care health professionals to guide their practice when a patient desires a hastened death. First-level interventions are at the patient level, which include a careful evaluation of the reasons for the wish to die and the control of physical symptoms. For example, our study found that pain was a significant factor associated with terminally ill people wanting to die, and better pain control could be relevant. Galushko et al.<sup>32</sup> also suggested exploring the person's sense of meaning in their lives by using psychoeducational techniques such as the generation of life perspectives, reorientation, and hope. However, some of the challenges associated with these interventions include the identification and treatment of psychological and psychiatric symptoms associated with the wish to die such as the rates of depression found in our study.<sup>33–35</sup>

Second-level interventions focus on the interactions with the patient, in terms of the use of appropriate communication techniques to generate empathy, closeness, and to express understanding. These techniques include active listening, providing information about future expectations, maintaining a dialogue focused on emotions and feelings, and, if necessary, referring the patient to health professionals specialized in psychosocial distress.<sup>32</sup> These strategies are designed to manage psychological adjustment, well-being, and distress.<sup>33</sup> Our study found that people who were aware of the terminal prognosis of their illness were more likely to want to die; therefore, it would be critical to explore with them the psychosocial impact of having a terminal illness. There are also empirically researched psychotherapies such as dignity therapy and meaning-centered psychotherapy that can be useful for alleviating suffering and helping terminally ill patients and their families to maintain a sense of dignity, meaning, and peace as they approach the end of life.<sup>36</sup> Spiritual care has also been shown to result in better quality of life in patients with advanced cancer.<sup>37</sup>

Third-level interventions are at the health professional level, and they include responses to suicide risk assessment and working interprofessionally, such as with ethics committees and mental health clinicians.<sup>32</sup> Other guidelines also have been developed to address psychological symptoms and conditions associated with terminally ill people wanting to die;<sup>38–40</sup> however, adequately funded specialist palliative care services are essential to ensure that the complex needs of terminally ill people are met.

We need to acknowledge a number of limitations of this study. First, the sample size is relatively small, compared with more than 30,000 deaths in New Zealand each year.<sup>41</sup> The interRAI-PC assessment is currently not routinely used for all terminally ill people but as an alternative to the usual interRAI home care assessment. For these reasons, we may not be able to generalize our findings to the New Zealand palliative care population. We also did not perform a separate analysis on the main ethnic minority groups (Māori, Asian, and Pacific people) in New Zealand because they were under-represented in our sample (2018 census: European 70.2%, Māori 16.5%, Asian 15.1%, and Pacific people 8.1%).<sup>42</sup> Previous New Zealand studies have found that support for euthanasia/assisted dying is lower among ethnic minority groups.<sup>43</sup> However, the interRAI-PC assessment provides a comprehensive evaluation of a large number of physical, psychological, social, and spiritual factors in people with terminal illness. Our study has provided, for the first time in New Zealand literature, some insight into the presentations of a sample of New Zealanders who had both a terminal condition and a wish to die. Although euthanasia/PAD can

sometimes be considered to be a rational choice or right to die by terminally ill people, our study provides the general New Zealand population with some understanding of the physical, psychological, and existential issues related to the wish to die among terminally ill people in New Zealand.

Second, because of the cross-sectional nature of this study, the temporality of the phenomena cannot be considered for analysis. The interRAI-PC just started to be used in New Zealand in 2017, and we will be able to conduct a longitudinal analysis once there are more data collected. Third, we must be cautious when interpreting the outcome *Wants to die now* used in this study because it does not equate with *Wanting euthanasia/PAD*. Because euthanasia/PAD is not legal in New Zealand, there may be an underestimation of people who would express wanting to die now as it is not a currently available option. Alternatively, there may be an overestimation of people who express wanting to die now but would not necessarily carry that through to requesting euthanasia/PAD, if it was available. However, our findings are also largely consistent with international literature related to these topics. For example, a previous report suggested that desire for hastened death in people under palliative care is relatively common and can reach up to 10% in terminally ill patients;<sup>32</sup> whereas 10.6% of terminally ill patients reported seriously considering euthanasia or PAD for themselves in a hypothetical situation.<sup>21</sup>

A fourth limitation is that in 30% of assessments, it was not possible to determine whether the person wanted to die now. The closed-ended nature of this question (yes or no answer only) did not allow interRAI assessors to expand on the reasons why they were unable to determine this response. It would be useful to have more information about this group of individuals. A previous survey of more than 15,000 New Zealanders in 2014–2015 found that 21.7% of the participants indicated they were neutral/unsure when asked whether they would support the legalization of euthanasia.<sup>44</sup> Future research would be useful to explore some of the difficulties and factors that can facilitate such decision-making related to end-of-life care. Fifth, we discussed earlier that some people changed their mind about euthanasia/PAD when their depression and/or pain improved, but we do not have information on whether individuals in this study were under active treatment for these conditions. Future studies could clarify the relationship among these factors (treated vs. untreated depression/pain and wishes to die now) in the New Zealand population. Finally, education, religion, and socioeconomic status are not routinely recorded in the interRAI-PC assessment, and these factors could play a role in people requesting euthanasia and PAD.<sup>10</sup>



In conclusion, this study has highlighted that terminally ill people who wanted to die were more likely to be aware of the terminal prognosis of their illness, experiencing pain and depression, and not finding meaning in life. Although the wish to die can sometimes be considered as a rational choice or right to die by a terminally ill person, clinicians working with people with a terminal illness should be aware of the significant factors identified in our study. Addressing these factors should form part of a multidisciplinary assessment when a terminally ill patient expresses such a wish, to ensure their physical, psychological, and existential needs are adequately met. The routine use of a standardized and comprehensive clinical instrument such as the interRAI-PC should be encouraged to maximize the quality of individual patient care by clinicians working in the community with terminally ill people. The wish to die is routinely screened with the interRAI-PC. This offers an opportunity for palliative and mental health clinicians to provide further assessment and management to reduce suicide risk.

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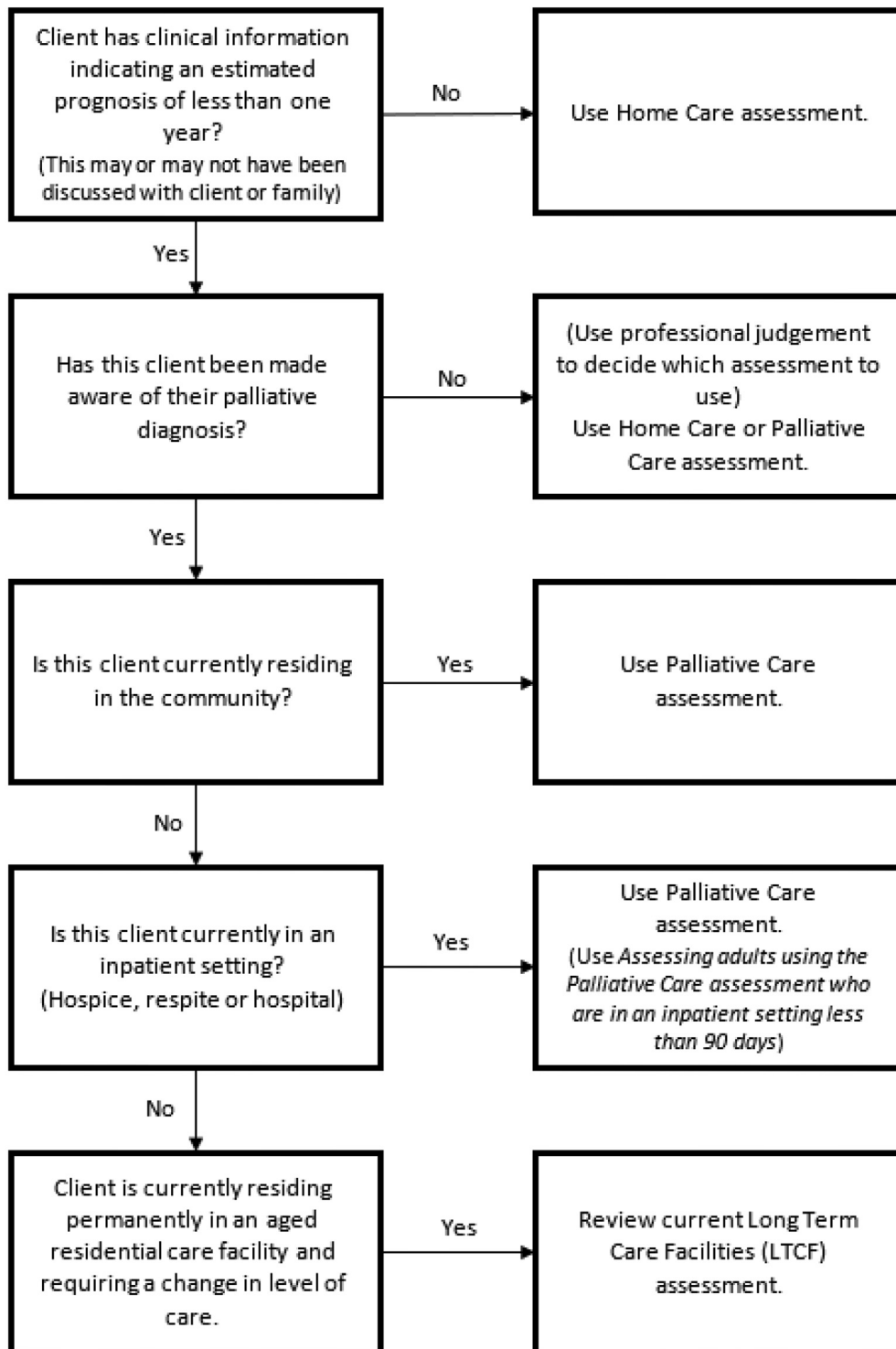
### References

1. Steck N, Egger M, Maessen M, Reisch T, Zwahlen M. Euthanasia and assisted suicide in selected European countries and US states: systematic literature review. *Med Care* 2013;51:938–944.
2. Dierickx S, Deliens L, Cohen J, Chambaere K. Euthanasia in Belgium: trends in reported cases between 2003 and 2013. *CMAJ* 2016;188:E407–E414.
3. Preston R. Death on demand? An analysis of physician-administered euthanasia in The Netherlands. *Br Med Bull* 2018;125:145–155.
4. Muller MT, van der Wal G, van Eijk JT, Ribbe MW. Active euthanasia and physician-assisted suicide in Dutch nursing homes: patients' characteristics. *Age Ageing* 1995;24:429–433.
5. Carter GL, Clover KA, Parkinson L, et al. Mental health and other clinical correlates of euthanasia attitudes in an Australian outpatient cancer population. *Psychooncology* 2007;16:295–303.
6. Ganzini L, Beer TM, Brouns M, Mori M, Hsieh Y. Interest in physician-assisted suicide among Oregon cancer patients. *J Clin Ethics* 2006;17:27–38.
7. McCue RE, Balasubramaniam M. Rational suicide in the elderly. Cham: Springer, 2017.
8. Steck N, Junker C, Maessen M, et al. Suicide assisted by right-to-die associations: a population based cohort study. *Int J Epidemiol* 2014;43:614–622.
9. Freeman S, Smith TF, Neufeld E, Fisher K, Ebihara S. The wish to die among palliative home care clients in Ontario, Canada: a cross-sectional study. *BMC Palliat Care* 2016;15:24.
10. Castelli Dransart DA, Lapierre S, Erlangsen A, et al. A systematic review of older adults' request for or attitude toward euthanasia or assisted-suicide. *Aging Ment Health* 2019:1–11.
11. Cheung G, Douwes G, Sundram F. Late-life suicide in terminal cancer: a rational act or underdiagnosed depression? *J Pain Symptom Manage* 2017;54:835–842.
12. interRAI. Palliative care (PC). 2020. Available from <https://www.interrai.org/palliative-care.html>. Accessed February 22, 2020.
13. interRAI New Zealand. Palliative care assessment. 2020. Available from <https://www.interrai.co.nz/help/palliative-care/>. Accessed February 22, 2020.
14. Morris JN, Berg K, Fries BE, Steel K, Howard EP. Scaling functional status within the interRAI suite of assessment instruments. *BMC Geriatr* 2013;13:128.
15. Hirdes JP, Frijters DH, Teare GF. The MDS-CHESS scale: a new measure to predict mortality in institutionalized older people. *J Am Geriatr Soc* 2003;51:96–100.
16. Morris JN, Fries BE, Mehr DR, et al. MDS cognitive performance scale. *J Gerontol* 1994;49:M174–M182.
17. Fries BE, Simon SE, Morris JN, Flodstrom C, Bookstein FL. Pain in U.S. nursing homes: validating a pain scale for the minimum data set. *Gerontologist* 2001;41:173–179.
18. Burrows AB, Morris JN, Simon SE, Hirdes JP, Phillips C. Development of a minimum data set-based depression rating scale for use in nursing homes. *Age Ageing* 2000;29:165–172.
19. Martin L, Poss JW, Hirdes JP, et al. Predictors of a new depression diagnosis among older adults admitted to complex continuing care: implications for the depression rating scale (DRS). *Age Ageing* 2008;37:51–56.
20. Braun KL. Do Hawaii residents support physician-assisted death? A comparison of five ethnic groups. *Hawaii Med J* 1998;57:529–534.
21. Emanuel EJ, Fairclough DL, Emanuel LL. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA* 2000;284:2460–2468.
22. Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry* 1995;152:1185–1191.
23. Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, Mahtani-Chugani V, Balaguer A. What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients. *PLoS One* 2012;7:e37117.

24. Malpas PJ, Wilson MK, Rae N, Johnson M. Why do older people oppose physician-assisted dying? A qualitative study. *Palliat Med* 2014;28:353–359.
25. Pestinger M, Stiel S, Elsner F, et al. The desire to hasten death: using grounded theory for a better understanding “When perception of time tends to be a slippery slope”. *Palliat Med* 2015;29:711–719.
26. Ohnsorge K, Gudat H, Rehmann-Sutter C. What a wish to die can mean: reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliat Care* 2014;13:38.
27. Steger MF, Frazier P, Oishi S, Kaler M. The meaning in life questionnaire. *J Couns Psychol* 2006;53:80–93.
28. Berra L. Existential depression: a nonpathological and philosophical-existential approach. *J Humanist Psychol* 2019.
29. Berra L. The depressive dimension. From pathological depression to existential depression. Milan: Libreria Universitaria, 2018.
30. Blank K, Robison J, Doherty E, et al. Life-Sustaining treatment and assisted death choices in depressed older patients. *J Am Geriatr Soc* 2001;49:153–161.
31. Hooper SC, Vaughan KJ, Tennant CC, Perz JM. Preferences for voluntary euthanasia during major depression and following improvement in an elderly population. *Australas J Ageing* 1997;16:3–7.
32. Galushko M, Frerich G, Ferrar KM, et al. Desire for hastened death: how do professionals in specialized palliative care react? *Psychooncology* 2016;25:536–543.
33. Hudson PL, Schofield P, Kelly B, et al. Responding to desire to die statements from patients with advanced disease: recommendations for health professionals. *Palliat Med* 2006; 20:703–710.
34. Bascom PB, Tolle SW. Responding to requests for physician-assisted suicide: “These are uncharted waters for both of us ...”. *JAMA* 2002;288:91–98.
35. Turner J, Zapart S, Pedersen K, et al. Clinical practice guidelines for the psychosocial care of adults with cancer. *Psychooncology* 2005;14:159–173.
36. Saracino RM, Rosenfeld B, Breitbart W, Chochinov HM. Psychotherapy at the end of life. *Am J Bioeth* 2019;19: 19–28.
37. Balboni TA, Paulk ME, Balboni MJ, et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. *J Clin Oncol* 2010;28:445–452.
38. Riches S. The Royal College of Nursing guidance on responding to a request to hasten death. *Int J Palliat Nurs* 2011;17:578–579.
39. Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *BMJ* 2007; 335:184–187.
40. Van Loon RA. Desire to die in terminally ill people: a framework for assessment and intervention. *Health Soc Work* 1999;24:260–268.
41. interRAI Services and Technical Advisory Services. Trajectories of care at the end of life in New Zealand. Available from <https://www.interrai.co.nz/news/presentations/trajectories/>. Accessed February 22, 2020.
42. Statistics New Zealand. 2018 census population and dwelling counts. Available from <https://www.stats.govt.nz/information-releases/2018-census-population-and-dwelling-counts>. Accessed March 19, 2020.
43. Young J, Egan R, Walker S, Graham-DeMello A, Jackson C. The euthanasia debate: synthesising the evidence on New Zealander’s attitudes. *Kōtuitui* 2019;14:1–21.
44. Lee CHJ, Duck IM, Sibley CG. Demographic and psychological correlates of New Zealanders’ support for euthanasia. *N Z Med J* 2017;130:9–17.

Appendix

### When to use the Palliative Care assessment



Appendix Fig. 1. When to Use the Palliative Care Assessment. Source: interRAI Resident Assessment Instrument New Zealand 2019 training material for the interRAI Resident Assessment Instrument—palliative care implementation project.