

Original Article

The Desire for Hastened Death in Patients with Metastatic Cancer

Gary Rodin, MD, Camilla Zimmermann, MD, MSc, Anne Rydall, MSc,
Jennifer Jones, PhD, Frances A. Shepherd, MD, Malcolm Moore, MD,
Martin Fruh, MD, Allan Donner, PhD, and Lucia Gagliese, PhD

Departments of Psychosocial Oncology and Palliative Care (G.R., C.Z., J.J.) and Medical Oncology (F.A.S., M.M., M.F.), Princess Margaret Hospital, University Health Network, Toronto; Behavioral Sciences and Health Research Division (G.R., C.Z., A.R., J.J., L.G.), Toronto General Research Institute, University Health Network, Toronto; Faculty of Medicine (G.R., C.Z., J.J., F.A.S., M.M., M.F., L.G.), University of Toronto, Toronto; Department of Epidemiology and Biostatistics (A.D.), University of Western Ontario, London, Ontario; and Department of Kinesiology and Health Science (L.G.), York University, Toronto, Ontario, Canada

Abstract

A substantial minority of patients in palliative care settings report a high desire for hastened death (DHD), in association with physical and emotional distress, low social support, and impaired spiritual well being. To clarify to what extent DHD emerges in association with suffering prior to the end of life, we determined its prevalence and correlates in ambulatory patients with metastatic cancer, the majority of whom had an expected survival of >6 months. We hypothesized that DHD in this sample would be directly linked to physical and psychological distress, and inversely related to perceived social support, self-esteem, and spiritual well being. Three hundred twenty-six outpatients completed the Schedule of Attitudes Toward Hastened Death (SAHD), Brief Pain Inventory, Memorial Symptom Assessment Scale, Beck Depression Inventory-II (BDI), Beck Hopelessness Scale (BHS), Medical Outcomes Study Social Support Survey, FACIT-Spiritual Well-Being Scale, Rosenberg Self-Esteem Scale, and Karnofsky Performance Status. Over 50% of participants reported pain, >20% reported elevated levels of depression ($BDI \geq 15$) and hopelessness ($BHS \geq 8$), but <2% had a high DHD ($SAHD \geq 10$). DHD was correlated positively with

This study was supported by grants from the Canadian Institutes of Health Research (CIHR #MOP-62861 [GR]) and York University (LG). The authors gratefully acknowledge this support. The sponsors of this study had no role in study design, data collection, data analysis, interpretation of findings, or writing of this report. None of the authors declare any conflicts of interest.

Preliminary data have been presented at the 14th and 15th Annual Provincial Conferences on Palliative and End-of-Life Care, Toronto, Ontario, Canada, 2004 and 2005; the Annual Conferences of the Canadian Association of Psychosocial Oncology (CAPO), Toronto, Ontario, Canada, 2004, and Victoria, British Columbia, Canada, 2005; the

American Pain Society/Canadian Pain Society Joint Scientific Meeting, Vancouver, British Columbia, Canada, 2004; the American Society for Clinical Oncology (ASCO) 40th Annual Meeting, New Orleans, Louisiana, USA, 2004; and the 7th World Congress of Psycho-Oncology, Copenhagen, Denmark, 2004.

Address reprint requests to: Gary Rodin, MD, Department of Psychosocial Oncology and Palliative Care, Princess Margaret Hospital, University Health Network, 16th Floor, Room 724, 610 University Avenue, Toronto, Ontario M5G 2M9, Canada. E-mail: gary.rodin@uhn.on.ca

Accepted for publication: September 25, 2006.

63 *hopelessness, depression, and physical distress, and negatively with physical functioning,* 116
 64 *spiritual well being, social support, and self-esteem; it was not associated with treatment* 117
 65 *status or proximity to death. Over 34% of the variance in predicting SAHD scores was* 118
 66 *accounted for by hopelessness, depression, and functional status. The relative absence* 119
 67 *of a strong DHD in this sample suggests that the will to live tends to be preserved in* 120
 68 *cancer patients prior to the end of life, in spite of significant emotional and physical* 121
 69 *suffering. J Pain Symptom Manage 2007;■■■■. © 2007 U.S. Cancer Pain Relief* 122
 70 *Committee. Published by Elsevier Inc. All rights reserved.* 123
 71 124

72 **Key Words** 125

73 *Desire for hastened death, metastatic cancer, depression, hopelessness, demoralization,* 126
 74 *burden of illness, will to live, proximity to death* 127
 75 128
 76 129
 77 130
 78 131
 79 132

80 **Introduction** 133

81 The desire for hastened death (DHD) has 134
 82 been associated with depression, hopelessness, 135
 83 physical suffering, low social support, poor 136
 84 spiritual well being, and low self-esteem in 137
 85 a number of studies of patients at the end of 138
 86 life.^{1–11} However, the longitudinal trajectory 139
 87 of this phenomenon is not known, nor is it 140
 88 clear to what extent the DHD in such patients 141
 89 is a manifestation not only of suffering and 142
 90 demoralization but also of proximity to death. 143
 91 Because most previous studies have evaluated 144
 92 the DHD in palliative care settings during the 145
 93 last days or weeks of life, it is unclear to what 146
 94 extent similar contributing factors operate ear- 147
 95 lier in the course of disease. The only available 148
 96 studies of the DHD reported in nonpalliative 149
 97 settings were conducted by Jones et al.,¹² with 150
 98 a mixed sample of 224 cancer inpatients across 151
 99 all stages of disease, and by Ransom et al.,¹³ with 152
 100 small sample of 60 outpatients with advanced 153
 101 cancer and their spouse caregivers. Jones 154
 102 et al.¹² suggested that the DHD was significantly 155
 103 related to hopelessness and more-advanced dis- 156
 104 ease, whereas Ransom et al.¹³ found that an in- 157
 105 creased DHD was independently predicted by 158
 106 better dyadic adjustment reported by the pa- 159
 107 tient, and the number of hours spent by care- 160
 108 givers performing caregiving activities. 161

109 The present study was undertaken to deter- 162
 110 mine to what extent the DHD is present in 163
 111 association with physical suffering and psycho- 164
 112 logical distress in a large sample of ambulatory 165
 113 cancer patients with metastatic disease, the ma- 166
 114 jority of whom had an expected prognosis of 167
 115 >6 months. Research has demonstrated that 168
 pain and suffering increase toward the end

of life,^{14–15} although patients with cancer 131
 may report considerable disease burden prior 132
 to this time.^{16–17} However, it is not clear to 133
 what extent significant physical and/or emo- 134
 tional suffering prior to the terminal phase 135
 of the disease is associated with the DHD. Sui- 136
 cide is the most obvious indicator of this phe- 137
 nomenon, but it is an uncommon event in 138
 such populations, accounting for only 0.03% 139
 of deaths in palliative care settings,^{17–18} and 140
 0.2% of all deaths in cancer patients.¹⁹ The 141
 DHD may be a more sensitive indicator of de- 142
 moralization and the loss of the will to live in 143
 this context, but its meaning and significance 144
 are complex and may be affected by such fac- 145
 tors as the fear of increasing dependency²⁰ 146
 and the readiness for death.²¹ 147

148 Comparison among studies examining the 149
 DHD has been difficult because of variability 150
 in sample characteristics, participation rates, 151
 settings, methodologies, measures, and cutoff 152
 scores used. Table 1 presents an overview of 153
 the quantitative studies that have evaluated 154
 the DHD among cancer patients thus far.^{1,2,6,10–13,22–26} 155
 Although the Schedule of 156
 Attitudes Toward Hastened Death (SAHD)²⁷ 157
 is the most common measure used, there is 158
 variability in the cutoff scores used and in 159
 the reported distribution of scores. When a cut- 160
 off of 10 or more on the SAHD was used, ele- 161
 vated DHD scores were found in 17% of 162
 cancer patients in an American palliative care 163
 unit¹ and in 5% of patients in a Greek pal- 164
 liative care unit, the latter based on the 165
 G-SAHD.^{23–26} In these patients, elevated 166
 scores were associated with physical and emo- 167
 tional distress^{1,25} and impaired spiritual well 168

Table 1
Quantitative Studies of the DHD in Cancer Patients^a

Authors	Year	Setting	Sample (n)	Measure	Cutoff Score	Elevated DHD (%)
Chochinov et al. ²²	1995	Palliative care facility	Terminally ill cancer patients (200)	DDRS (interviewer rated six-item scale)	≥4 moderate; ≥5 strong; ≥6 extreme	7.5% moderate; 0.5% strong; 0.5% extreme
Breitbart et al. ¹ Rosenfeld et al. ²	2000	Palliative care hospital	Terminally ill inpatient palliative care patients (92)	SAHD (patient-rated 20-item scale)	≥10 high	15–16 of 92 (16.3–17%) high
Kelly et al. ⁶	2003	Inpatient hospice unit, home palliative care service, and general hospital palliative care consulting service	Terminally ill mixed cancer patients (256)	Modified WTHD (adapted from DDRS) (rated by study personnel)	≥5 high	14% high
Jones et al. ¹²	2003	Cancer hospital	Mixed cancer inpatients; all stages of disease (224)	SAHD	≥10 high	2% high
Mystakidou et al. ^{23–26}	2004a,b; 2005a,b	Pain relief and palliative care unit	Terminally ill mixed cancer outpatients receiving palliative treatment (120)	G-SAHD	≥7 high; ≥11 strong	8.3% high; 5% strong
O'Mahony et al. ¹⁰	2005	Pain and palliative care service at a cancer center and patients newly admitted to hospital	Outpatient and hospitalized cancer patients (all with cancer pain) (131)	DDRS (rated by study personnel)	≥2 moderate; ≥4 strong	16 of 64 (25%) ≥ moderate at Time 2 (number with high scores not specified)
Mystakidou et al. ¹¹	2006	Pain relief and palliative care unit	Terminally ill mixed cancer patients (106)	G-SAHD	≥7 high; ≥11 strong	28% high or strong
Ransom et al. ¹³	2006	Cancer center	Stage IIIB or IV cancer patients (60) and their partners recruited at scheduled appointment with treating physician	SAHD	≥10 high	0% high at Time 1; 3.3% high at four-month follow-up

DHD = Desire for Hastened Death; SAHD = Schedule of Attitudes Toward Hastened Death; G-SAHD = Greek-SAHD; WTHD = Wish to Hasten Death Scale; DDRS = Desire for Death Rating Scale.
^aOnly quantitative studies in cancer populations in which distribution of DHD scores was reported are presented here.

169
170
171
172
173
174
175
176
177
178
179
180
181
182
183
184
185
186
187
188
189
190
191
192
193
194
195
196
197
198
199
200
201
202
203
204
205
206
207
208
209
210
211
212
213
214
215
216
217
218
219
220
221

222
223
224
225
226
227
228
229
230
231
232
233
234
235
236
237
238
239
240
241
242
243
244
245
246
247
248
249
250
251
252
253
254
255
256
257
258
259
260
261
262
263
264
265
266
267
268
269
270
271
272
273
274

being.⁷ In the two studies in nonpalliative settings,^{12–13} using a cutoff of 10 or more on the SAHD, elevated scores were found in 2% of a sample of cancer inpatients, and in 0%–3.3% of cancer outpatients, respectively.

We report here the first systematic study of the prevalence and correlates of the DHD in a large sample of ambulatory patients with metastatic gastrointestinal (GI) or lung cancer that includes an examination of the association between the DHD and proximity to death. Based on findings reported in the palliative care literature,^{1–11} we hypothesized that the DHD in this population, who were not considered to be imminently dying, would be similarly related to physical and psychological distress, and inversely related to perceived social support, self-esteem, and spiritual well being.

Methods

Subjects and Eligibility

Participants for this study were recruited from consecutive patients attending their outpatient medical and/or radiation oncology clinic appointments with a treating oncologist at Princess Margaret Hospital (PMH), University Health Network, a comprehensive acute-care cancer center located in Toronto, Canada. Patients were eligible if they had been diagnosed with Stage IIIA, IIIB, or IV lung cancer or Stage IV GI cancer,²⁸ were 18 years of age or older, and were able to speak and read English sufficiently to provide informed consent and complete self-report questionnaires. Patients were excluded if they had a diagnosis of carcinoid or neuroendocrine carcinoma, or if significant cognitive impairment was documented on the medical chart, identified by their physician, or demonstrated by a failure to meet the predetermined cutoff score on the Short Orientation-Memory-Concentration Test (SOMC)²⁹ at the time of recruitment. This study received approval from the University Health Network Research Ethics Board, and all patients provided written, informed consent.

Procedures

An oncology clinic nurse or volunteer presented potential participants with an introductory letter requesting permission for a research

team member to approach them regarding participation in the study. If permission was granted, a member of the research team who was not involved in the patients' clinical care described the study and obtained informed written consent. Patients were briefly interviewed to screen for cognitive impairment using the SOMC cutoff score of <20 (equivalent to >10 errors),²⁹ to obtain demographic information, and to rate Performance Status based on Karnofsky criteria.³⁰ Eligible patients were then given a package of self-report questionnaires to complete in the clinic or at home. Each measure was described and instructions for completing it were explained. Patients were explicitly given the option of not completing any questions or measures with which they felt uncomfortable. They were provided with a stamped, addressed envelope to return the questionnaire package. Reminder telephone calls were made if the package had not been returned within two weeks. Those who required or requested assistance completing the questionnaires were read the questions by a research team member. Referral to the PMH Psychosocial Oncology and Palliative Care Program was offered to patients who requested psychosocial assistance, or who reported significant emotional distress or suicidality.

Measures

Medical and demographic data extracted from the medical record of each patient and from the initial brief interview included the following: age, gender, marital status, education, socioeconomic status (approximated by mean family income based on Statistics Canada census data grouped by postal code), current living arrangements, country of birth, religious affiliation, date of diagnosis, cancer site, stage of disease, treatment status at the time of study participation (defined here as: 1) receiving active treatment [i.e., chemotherapy]; 2) asymptomatic and not receiving active chemotherapy treatment, but under watchful surveillance; and 3) active treatment had been discontinued due to advancing illness or toxicity), and date of death (at the time of data analysis), if applicable.

Cognitive functioning was assessed using the SOMC,²⁹ a six-item mental status exam validated for use in acute-care settings.

381 *Physical functioning* was rated by a member of
382 the research staff with patient input, using the
383 Karnofsky Performance Status (KPS) scale,³⁰
384 a widely used observer-rated measure of the extent
385 to which individuals can carry out normal
386 activities and self-care that has been used as
387 a predictor of survival.³¹ Ratings are made
388 along a continuum ranging from 100 (normal
389 activities, no complaints, no signs of disease)
390 downward in decrements of 10–0 (dead). A
391 rating of ≥ 70 has been reported to correspond
392 roughly to, or to be indicative of, a prognosis
393 of >six months to two years.^{31–32} KPS has
394 been widely used in oncology settings and
395 has demonstrated good reliability and predictive
396 and construct validity as a global measure
397 of functional status.^{33–34}

398 *Physical symptoms* were assessed using 1)
399 a shortened version of the Memorial Symptom
400 Assessment Scale (MSAS),³⁵ a multidimensional
401 self-report scale developed to assess the presence,
402 frequency (rated on a four-point scale, from 1
403 “rarely” to 4 “almost constantly”), severity (rated
404 on a four-point scale, from 1 “slight” to 4
405 “very severe”), and distress (rated on a five-point
406 scale, from 1 “not at all” to 5 “very much”) associated
407 with common symptoms of cancer (23 physical;
408 six psychological) in the past week. In addition,
409 a global symptom distress index score was calculated
410 as the mean symptom frequency ratings of four
411 items: feeling sad, worrying, feeling irritable,
412 and feeling nervous, and the mean symptom
413 distress ratings of five items: lack of energy,
414 pain, feeling drowsy, constipation, and dry
415 mouth. This measure has demonstrated good
416 reliability and validity;³⁵ and 2) the Brief Pain
417 Inventory (BPI),³⁶ a widely used numeric rating
418 scale of pain intensity (rated from 0 “no
419 pain” to 10 “pain as bad as you can imagine”) and
420 pain interference (rated from 0 “does not
421 interfere” to 10 “completely interferes”) in the
422 past 24 hours. Mild pain intensity is defined as
423 a pain score of 1–4, moderate pain as 5–6,
424 and severe pain as 7–10. Mean pain intensity
425 was calculated as the average of the pain intensity
426 ratings over the past 24 hours for “worst,”
427 “least,” “on the average,” and “pain right
428 now” items. Pain interference scores can be
429 derived for affective interference (i.e., interference
430 with enjoyment of life, relations with others,
431 and mood), and interference with daily
432 activities (i.e., interference with walking ability,
433

normal work, sleep, and general activity). This
434 measure has been used extensively internationally
435 to measure the severity and impact of
436 pain and the adequacy of pain management
437 in cancer patients.^{37–39}

438 *Psychological distress* (depression and hope-
439 lessness) were assessed using: 1) the Beck Depression
440 Inventory-II (BDI-II),⁴⁰ a 21-item self-report
441 measure of the intensity of symptoms of depression,
442 which is consistent with the criteria of the Diagnostic
443 and Statistical Manual of Mental Disorders, 4th Edition,
444 Text Revision (DSM-IV-TR)⁴¹ for major depressive
445 disorder. Items (rated 0–3) are summed to give a
446 total score ranging from 0 to 63, with higher scores
447 reflecting more severe depressive symptoms. This
448 measure has been widely used in cancer populations;^{42–46}
449 and 2) the Beck Hopelessness Scale (BHS),⁴⁷
450 a 20-item self-report true/false scale that was
451 developed to quantify hopelessness and negative
452 expectancies. After reverse scoring of positively
453 worded items, items are summed to give a total
454 score ranging from 0 to 20, with a higher score
455 reflecting increased hopelessness. The BHS has
456 high internal consistency and validity and has
457 previously been used in terminally ill cancer
458 populations.^{1,2}

459 *DHD* was assessed by the SAHD,²⁷ a 20-item
460 self-report true/false measure of the DHD that
461 has been validated in cancer patients in a palliative
462 care setting.² It includes items related to the
463 desire for a hastened death, the will to live and
464 the anticipated burden of physical and emotional
465 suffering. After reverse scoring of positively
466 worded items, items are summed to give a total
467 score ranging from 0 to 20, with a higher score
468 reflecting a higher DHD.

469 *Social support* was rated using the Medical
470 Outcomes Study Social Support Survey (MOS-SSS),⁴⁸
471 a 20-item self-report scale developed for use in
472 chronically ill populations that measures multiple
473 domains of social support including 1) emotional/
474 informational support; 2) tangible support; 3) affectionate
475 support; 4) positive social interactions; and 5) global
476 social support (calculated as the mean of the
477 preceding four domain subscales of support). Patients
478 are asked to rate how often each type of support
479 is available to them if they need it. Items are
480 rated on a five-point scale ranging from 1 “none
481 of the time” to 5
482
483
484
485
486

487 “all of the time.” Raw scores are transformed
488 to a 0–100 scale as described by Sherbourne
489 and Stewart,⁴⁸ with higher scores indicating
490 higher perceived availability of social support.
491 This measure has demonstrated high levels of
492 reliability, and convergent and discriminant
493 validity.⁴⁸

494 *Self-esteem* was assessed using the Rosenberg
495 Self-Esteem Scale (RSES),⁴⁹ a widely used
496 and well-validated self-report measure of self-
497 concept consisting of 10 items rated from 1
498 “strongly agree” to 4 “strongly disagree.” After
499 reverse scoring of negatively worded items,
500 items are summed to give a total score ranging
501 from 10 to 40, with higher scores reflecting
502 more positive self-esteem. This measure has
503 demonstrated reliability and concurrent, pre-
504 dictive, and construct validity.⁵⁰

505 *Spiritual well being* was assessed using the
506 Functional Assessment of Chronic Illness
507 Therapy-Spiritual Well-Being Scale (FACIT-Sp-
508 12),⁵¹ a 12-item self-report scale validated in
509 a large sample of medically ill patients⁵² to
510 measure important aspects of spirituality in-
511 cluding sense of meaning in one’s life, har-
512 mony, peacefulness, and a sense of comfort
513 and strength from one’s faith. Items are rated
514 on a five-point scale ranging from 0 “not at all”
515 to 4 “very much” and are averaged (after re-
516 verse scoring) to generate an overall spiritual
517 well being score, and two subscale scores: spir-
518 itual meaning and peace and spiritual faith.
519 Possible scores range from 0 to 4, with higher
520 scores reflecting higher spiritual well being.

521 Patients also completed measures of attach-
522 ment (relationship) security (i.e., the Experi-
523 ences in Close Relationships Scale⁵³) and
524 religiosity (i.e., the Intrinsic Religious Motiva-
525 tion Scale⁵⁴), as part of the larger question-
526 naire package, results of which will be
527 discussed elsewhere.⁵⁵

529 *Statistical Analysis*

530 Data were analyzed using the Statistical
531 Package for the Social Sciences (SPSS), version
532 12.0 for Windows 2000.⁵⁶ Descriptive statistics
533 were calculated for the demographic, physi-
534 cal/illness-related and psychosocial/psychol-
535 ological variables, and the relationship
536 between the DHD and these factors was evalu-
537 ated using multiple regression analysis. Statisti-
538 cal tests were two-tailed with alpha set at 0.05,
539 with the exception of between-group *t*-tests in

540 which a Bonferroni correction for multiple
541 comparisons was used to set a more conserva-
542 tive significance level ($P < 0.003$), and for the
543 sequential backward elimination regressions,
544 in which alpha was set at 0.10.

545 An examination of missing data did not re-
546 veal any systematic or nonrandom patterns,
547 and missing scale scores were minimal, rang-
548 ing across study measures from 1.5% (on the
549 primary outcome SAHD measure) to 7.7%
550 (on the social support measure). Scale total
551 scores were calculated only if 75% or more of
552 the items in the given scale had been an-
553 swered. In order to preserve sample size and
554 degrees of freedom, missing mean scale scores
555 were imputed from the available data using
556 multiple imputation by cancer site (GI or
557 lung), but only if $\geq 75\%$ of the individual’s en-
558 tire study assessment package had been com-
559 pleted. If an individual had completed $< 75\%$
560 of his or her assessment package, the data
561 were considered incomplete, and the individ-
562 ual was excluded from the study sample (three
563 individuals were excluded due to insufficient
564 data). Analyses run both with and without im-
565 putation of mean scores by cancer site resulted
566 in minimal, nonsignificant changes in the
567 means and standard deviations for these mea-
568 sures, and demonstrated no change to the
569 study conclusions.

570 Exploratory analyses led to the logarithmic
571 transformation of three variables (SAHD total
572 score, duration of illness, and mean family in-
573 come) to reduce skewness and improve the
574 normality of the distributions. These log-
575 transformed variables were used in the correla-
576 tion matrix and in the regression analyses
577 described below. All variables entered in the
578 regression analyses, with the exception of gen-
579 der, marital status (married or common law
580 relationship vs. rest of the sample), education
581 (high school education or higher vs. rest of
582 the sample), cancer site (GI vs. lung), treat-
583 ment status (active treatment discontinued vs.
584 rest of the sample), and, in the subset of pa-
585 tients who had died, survival (died within three
586 or six months of study participation [tested
587 separately] vs. rest of the sample) were contin-
588 uous variables. A series of sequential backward
589 elimination regressions was used (first in the
590 whole sample, and then in the subset of sub-
591 jects who had died at the time of data analysis)
592 to build in a stepwise manner, predictive

593 multivariate models to extend our understand- 646
 594 ing of the relationships between the DHD and: 647
 595 1) *demographic* (age, gender, marital status, ed- 648
 596 ucation, and socioeconomic status [based on 649
 597 mean family income]); 2) *physical and illness-* 650
 598 *related* (cancer site, duration of illness [log 651
 599 of], treatment status, functional status, num- 652
 600 ber of physical symptoms, physical symptom 653
 601 severity, global symptom distress, average 654
 602 pain intensity, pain interference [affective 655
 603 and activity-related interference], and, in the 656
 604 subset of patients who had died, proximity to 657
 605 death [in months], survival less than three 658
 606 months from date of participation, and sur- 659
 607 vival less than six months [tested separately]); 660
 608 and 3) *psychosocial and psychological* (spiritual 661
 609 well being, as measured by spiritual meaning 662
 610 and peace and spiritual faith, overall social 663
 611 support, self-esteem, depression, and hopeless- 664
 612 ness) factors. 665
 613 666

615 **Results**

617 *Sample Characteristics*

618 A total of 1,014 consecutive patients with 619
 619 Stage IV (metastatic) GI or Stage IIIA, IIIB, 620
 620 or IV (recurrent or metastatic) lung cancer 621
 621 who attended the ambulatory outpatient 622
 622 clinics at PMH between November 1, 2002 623
 623 and January 31, 2006 (recruitment in the 624
 624 lung tumor site began in January 2004) were 625
 625 considered for participation in this study. 626
 626 Two hundred eighty-three of these patients 627
 627 [Q1] were excluded because they were not able to 628
 628 speak or read English ($n = 262$) or were cog- 629
 629 nitively impaired ($n = 21$). Of the 731 eligible pa- 630
 630 tients (483 GI and 248 lung), 434 (59.4%) 631
 631 consented to participate in the study (283 GI 632
 632 [58.9%] and 151 lung [60.9%]). Of the 434 633
 633 consenting patients, 17 subsequently died, 634
 634 and 80 withdrew from the study prior to re- 635
 635 turning their questionnaires; eight patients 636
 636 had not returned their questionnaires at the 637
 637 time of the following analyses. Three hundred 638
 638 twenty-nine participants returned their ques- 639
 639 tionnaires, and 326 (216 GI and 110 lung) pro- 640
 640 vided sufficient data to be included in the 641
 641 analyses (participation rate, 44.6%; comple- 642
 642 tion rate, 75.1%).

643 Patients who refused study participation 644
 644 ($n = 297$) did not differ from the 326 partici- 645
 645 pants in terms of gender or primary cancer

646 site (GI vs. lung) (these were the only data 647
 647 available for comparison due to strict guide- 648
 648 lines at our institution regarding privacy and 649
 649 confidentiality of patient information). The 650
 650 majority of patients did not provide a reason 651
 651 for refusal as they had declined to allow re- 652
 652 search personnel to approach them about 653
 653 the study; of those that did provide a reason, 654
 654 most indicated they were not interested, or 655
 655 felt too ill or too tired to participate. A limited 656
 656 amount of demographic and medical informa- 657
 657 tion was documented at recruitment for the 658
 658 consenting patients who did not return their 659
 659 questionnaires ($n = 8$), returned largely in- 660
 660 complete questionnaires ($n = 3$), or who sub- 661
 661 sequently withdrew ($n = 80$) or died ($n = 17$) 662
 662 before returning their questionnaires. Com- 663
 663 parison of these 108 “noncompleters” with 664
 664 the 326 participants, using independent sam- 665
 665 ples t -tests (with a Bonferroni correction ad- 666
 666 justing type-2 error rate to 0.02) and Pearson 667
 667 Chi-squared tests, indicated that study partici- [Q2] 668
 668 pants were slightly older (61.8 [SD 10.6] vs. 669
 669 58.8 [SD 11.5] years; $t(432) = 2.47$, $P < 0.01$), 670
 670 had somewhat better functional status as rated 671
 671 on the KPS (81.3 [SD 9.1] vs. 77.2 [SD 12.0]; 672
 672 $t(431) = 3.71$, $P < 0.001$), and were more likely 673
 673 to be Canadian born (63% vs. 49%; $\chi^2 [1,$ 674
 674 427] = 6.18, $P < 0.01$), compared to the non- 675
 675 completers, respectively. Participants and non- 676
 676 completers did not differ in terms of gender, 677
 677 marital status (married/common law vs. not), 678
 678 education (\geq high school vs. less), living ar- 679
 679 rangements (alone vs. other), primary lan- 680
 680 guage (English vs. other), primary disease 681
 681 site (GI vs. lung), or duration of illness.

682 Two hundred seven of the participating pa- 683
 683 tients (63.5%) were less than 65 years of age 684
 684 (median 61.9 years), 111 (34%) were within 685
 685 six months of their cancer diagnosis, and 201 686
 686 (61.7%) were receiving active chemotherapy 687
 687 treatment at the time of study participation. 688
 688 At the time of data analysis, 251 (77%) subjects 689
 689 had died (172/216 GI patients [79.6%] and 690
 690 79/110 lung patients [71.8%]). Almost 70% 691
 691 of the 251 deaths were among GI patients; 692
 692 however, recruitment of lung patients began 693
 693 more than one year after recruitment of GI pa- 694
 694 tients had started. Forty-three of the 251 695
 695 (17.1%) deaths (or 13.2% of the total sample) 696
 696 were within three months of study participa- 697
 697 tion; 89 (35.5%) (or 27.3% of the total sample) 698
 698 were within six months of study participation.

There were no significant gender differences on any of the main study outcome variables, with the exception of male patients in our sample being significantly more likely to be married than female patients (82.3% vs. 50%, respectively [Fisher's Exact Test, $P < 0.0005$]). GI patients reported fewer physical symptoms compared to lung patients (6.3 [SD 4.8] vs. 8.0 [SD 4.8], respectively [$t = -3.11(324)$, $P < 0.002$]) and had slightly higher self-esteem scores (34.5 [SD 4.4] vs. 32.9 [SD 4.9], respectively [$t = 2.96(324)$, $P < 0.003$]). Additional sample characteristics and scale means are presented in Table 2. Intercorrelations among the main nondemographic study variables are presented in Table 3.

Physical Functioning, Pain and Symptomatic Distress

KPS ratings of functional status in the sample ranged from 50 (requires considerable assistance and frequent medical care) to 90 (able to carry out normal activity with minor signs or symptoms of disease), with 309 patients (94.8%) rated 70 (able to care for self, but unable to carry on normal activity or do active work) or above, which is associated with an estimated prognosis of more than six months to two years.³¹ Pain in the past 24 hours was reported by 166 (50.9%) patients, 28 of whom (28/166 [16.9%], or 8.6% of the total sample) rated their pain intensity as being moderate to severe (i.e., mean pain intensity rating ≥ 5 on the BPI). Patients reported an average of 6.9 (SD 4.9) physical symptoms on the MSAS, with a range of 0–25. The most commonly reported physical symptoms were lack of energy (72.4%), feeling drowsy (51.5%), and pain (50.9%). Almost 65% (210 patients) reported suffering from five or more current physical symptoms, 19.3% reported their symptoms as “frequent” or “almost constant,” 40.8% reported them to be “moderate” to “very severe” in intensity, and 72.1% indicated they were “a little bit” to “very much” distressed by their symptoms.

Psychosocial Factors and Psychological Distress

Social support in this sample was relatively high across all domains of support, with 257 patients (78.8%) reporting that their overall support was adequate or available “most” to

“all of the time” (transformed score ≥ 70). Self-esteem was also relatively high in this sample, with positive self-esteem responses (i.e., “agree” or “strongly agree” on items 1, 3, 4, 6, and 7 and “disagree” or “strongly disagree” on items 2, 5, 8, 9, and 10) endorsed on average by 81.9% of patients. Seventy-six patients (23.3%) scored ≥ 15 on the BDI-II, a cutoff with high sensitivity and specificity for the diagnosis of major depression in cancer populations.⁴³ Using a suggested cutoff of ≥ 8 on the BHS,⁴⁷ 75 patients (23%) reported moderate to severe levels of hopelessness.

DHD

One hundred twenty-one patients (37.1%) reported no DHD (score of 0 on the SAHD), 173 (53.1%) had a low DHD score (scores of 1–4), 27 (8.3%) had mildly elevated scores (scores of 5–9), and 5 (1.5%) had high scores (≥ 10), based on cutoffs reported in prior SAHD validation studies.^{1,2} Table 4 presents the characteristics of the five subjects with the highest DHD scores in the sample (SAHD ≥ 10). All of the individuals who reported a high DHD also reported high levels of hopelessness and depression. The DHD, as measured by the SAHD, was significantly correlated with higher levels of depression, hopelessness, physical symptom severity, global symptom distress, pain intensity, and pain interference (both affective and activity-related), and with lower levels of physical functioning, spiritual well being (both spiritual meaning and peace and spiritual faith), social support, and self-esteem (see Table 3). Age, gender, cancer site, duration of illness, treatment status (active treatment discontinued vs. rest of the sample), proximity to death (in months), and survival (i.e., died within three or six months of study participation vs. rest of the sample) were not significantly correlated with the DHD. The frequency of positive endorsement of items on the SAHD was examined to illustrate attitudes related to suffering, the DHD and the will to live. Over 35% of the sample reported that they expected to suffer a great deal from physical problems in the future because of their illness, but only 3.1% indicated that they hoped their disease would progress rapidly because they would prefer to die rather than continue living with their illness. The will to live was strong in this sample,

Table 2
Sample Characteristics (n = 326)

Variable Domain	Variable	Description
Demographic	Gender: (f/n [%])	
	Male	186/326 (57.1%)
	Female	140/326 (42.9%)
	Age (years) (mean [SD]; range)	61.8 (10.7) (24.0–88.3)
	Marital status: (f/n [%])	
	Married or common law	223/326 (68.4%)
	Separated or divorced	45/326 (13.8%)
	Widowed	20/326 (6.1%)
	Single	38/326 (11.7%)
	Education (highest level completed): (f/n [%]) ^a	
	Grade school	20/324 (6.2%)
	High school	96/324 (29.6%)
	Trade school	3/324 (0.9%)
	College or university	159/324 (49.1%)
	Graduate or professional training	46/324 (14.2%)
	Living alone (f/n [%])	64/326 (19.6%)
	Canadian born (f/n [%]) ^b	203/322 (63.0%)
Primary language is English (f/n [%]) ^c	272/323 (84.2%)	
Mean family income (based on postal code)	\$95,750 (\$65,268)	
Illness-related	Cancer site: (f/n [%])	
	Colon or appendix	109/326 (33.4%)
	Rectal or anal canal	31/326 (9.5%)
	Pancreas	28/326 (8.6%)
	Liver, gallbladder, or biliary ducts	33/326 (10.1%)
	Stomach (gastric) or esophageal	15/326 (4.6%)
	Lung	110/326 (33.7%)
	Illness duration (years) (mean [SD]; range)	1.7 (2.1) (0.08–14.7)
	Proximity to death (months) (mean [SD]; range)	10.3 (7.9) (0.2–50.0)
	Treatment status: (f/n [%]) ^d	
	Receiving active chemotherapy treatment	201/325 (61.8%)
	No treatment/under surveillance	98/325 (30.2%)
Active treatment discontinued	26/325 (8.0%)	
Physical symptoms ^e	Number of physical symptoms (mean [SD] [range])	6.9 (4.9) (0–25)
	Physical symptom frequency (mean [SD])	2.2 (0.8)
	Physical symptom severity (mean [SD])	1.7 (0.7)
	Physical symptom distress (mean [SD])	2.3 (0.9)
	Global Distress Index (GDI) (mean [SD] [range])	2.1 (1.0) (0–4.7)
	Pain intensity (average) (mean [SD] [range])	1.4 (1.9) (0–7.5)
	Pain interference (affective) (mean [SD] [range])	1.6 (2.5) (0–10)
	Pain interference (activity) (mean [SD] [range])	1.8 (2.6) (0–10)
	Karnofsky Performance Status (mean [SD] [range])	81.4 (9.2) (50–90)
Psychosocial and psychological ^f	Overall social support (mean [SD] [range])	82.2 (18.4) (6.6–100)
	Self-esteem (mean [SD] [range])	34.0 (4.6) (19–40)
	Spiritual meaning and peace (mean [SD] [range])	3.2 (0.7) (1–4)
	Spiritual faith (mean [SD] [range])	2.4 (1.2) (0–4)
	Depression (mean [SD] [range])	10.8 (7.3) (0–51)
	Hopelessness (mean [SD] [range])	5.3 (4.6) (0–20)
Desire for hastened death (mean [SD] [range])	1.7 (2.2) (0–12.9)	

^aEducation: missing data for two study participants.

^bCountry of birth: missing data for four study participants.

^cPrimary language: missing data for three study participants.

^dTreatment status: missing data for one study participant.

^eNumber of physical symptoms, physical symptom frequency, severity and distress, and global symptom distress (MSAS); pain intensity (average of pain intensity ratings over the past 24 hours) and pain interference (activity and affective) (BPI); Performance Status (KPS).

^fOverall Social Support (MOS-SSS); self-esteem (RSES); spiritual meaning and peace and spiritual faith (FACIT-Sp-12); depression (BDI-II); hopelessness (BHS); desire for hastened death (SAHD).

with 65.6% indicating they wanted to continue living no matter how much pain or suffering their disease causes, and 96.9% reporting that despite their illness, their life still had meaning and purpose.

Multivariate Analyses

A series of sequential backward elimination regressions was used to build in a stepwise manner, a reduced multivariate model predicting the DHD (SAHD total score, log of).

Table 3
Intercorrelations Among the Main NonDemographic Study Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Desire for hastened death	—												
2. Hopelessness	0.56 ^a	—											
3. Depression	0.45 ^a	0.54 ^a	—										
4. Social support	-0.24 ^a	-0.25 ^a	-0.32 ^a	—									
5. Spiritual meaning and peace	-0.35 ^a	-0.53 ^a	-0.57 ^a	0.41 ^a	—								
6. Spiritual faith	-0.17 ^a	-0.37 ^a	-0.19 ^a	0.21 ^a	0.41 ^a	—							
7. Self-esteem	-0.26 ^a	-0.40 ^a	-0.48 ^a	0.34 ^a	0.59 ^a	0.19 ^a	—						
8. Performance status	-0.29 ^a	-0.16 ^a	-0.30 ^a	0.01	0.19 ^a	0.01	0.18 ^a	—					
9. No. of physical symptoms	0.08	0.06	0.42 ^a	-0.12 ^b	-0.19 ^a	0.11	-0.22 ^a	-0.36 ^a	—				
10. Physical symptom severity	0.18 ^a	0.16 ^a	0.42 ^a	-0.07	-0.23 ^a	0.01	-0.13 ^b	-0.28 ^a	0.42 ^a	—			
11. Global symptom distress	0.20 ^a	0.21 ^a	0.48 ^a	-0.13 ^b	-0.28 ^a	-0.04	-0.17 ^a	-0.28 ^a	0.42 ^a	0.70 ^b	—		
12. Pain intensity	0.15 ^a	0.09	0.32 ^a	-0.11 ^b	-0.14 ^b	0.14 ^b	-0.15 ^a	-0.27 ^a	0.38 ^a	0.35 ^a	0.35 ^a	—	
13. Pain interference (activity)	0.18 ^a	0.08	0.40 ^a	-0.11 ^b	-0.21 ^a	0.14 ^a	-0.20 ^a	-0.37 ^a	0.38 ^a	0.31 ^a	0.31 ^a	0.80 ^a	—
14. Pain interference (affective)	0.19 ^a	0.11 ^b	0.44 ^a	-0.10	-0.22 ^a	0.10	-0.22 ^a	-0.36 ^a	0.38 ^a	0.32 ^a	0.35 ^a	0.76 ^a	0.92 ^a

N = 326; Pearson Correlations.

Desire for hastened death (SAHD; log of); Hopelessness (BHS); Depression (BDI-II); Social support (overall) (MOS-SSS); Spiritual meaning and peace and spiritual faith (FACIT-Sp-12); Self-esteem (RSES); Performance status (KPS); Number of physical symptoms, physical symptom severity and global symptom distress (MSAS); pain intensity (average of pain intensity ratings over the past 24 hours), and pain interference (activity and affective) (BPI).

^aSignificance (two-tailed): $P < 0.01$.

^b $P < 0.05$.

[Q5]

Table 4
 Characteristics of the Five Participants with High SAHD Scores

Subject	Gender	Age (years)	Marital Status	Cancer Site	Treatment Status	KPS Score	SAHD Score ^a	BDI-II Score ^b	BHS Score ^c	BPI Average Pain ^d	Time to Death (months) ^e
A	Female	74.2	Widowed	Lung	Under surveillance ^f	70	12.9	17.9	19.0	No Pain	1.3
B	Male	62.0	Married	Lung	Receiving chemotherapy	80	12.6	27.0	15.0	No Pain	n/a
C	Male	57.4	Married	GI	Receiving chemotherapy	80	11.0	15.0	14.0	Mild (1.8)	3.1
D	Female	55.4	Single	GI	Receiving chemotherapy	80	11.0	35.0	17.0	Moderate (5.8)	3.3
E	Female	58.5	Separated	GI	Receiving chemotherapy	80	10.5	18.9	14.0	No Pain	n/a

KPS = Karnofsky Performance Status; SAHD = Schedule of Attitudes Toward Hastened Death; BDI-II = Beck Depression Inventory-II; BHS = Beck Hopelessness Scale; BPI = Brief Pain Inventory.

^aSAHD cutoff ≥ 10 : represents a high desire for hastened death.

^bBDI-II cutoff ≥ 15 : represents clinically significant depressive symptoms.

^cBHS cutoff ≥ 8 : represents elevated hopelessness.

^dBPI average pain ≥ 5 : represents elevated pain (average of: *least*, *average*, and *worst* pain in the past 24 hours and *pain right now*, on a scale from 0 [no pain] to 10 [severe pain]).

^eTime to death n/a: patient was alive at the time of data analysis (range 17–27 months after study participation).

^fUnder surveillance: patient was asymptomatic and not receiving chemotherapy, but was under surveillance.

Demographic variables were entered in the first block (step 1), followed by physical and illness-related factors (step 2), and then psychosocial and psychological variables entered together in the next stepwise block (step 3). At each step, nonsignificant predictors were dropped and the models rerun in order to conserve degrees of freedom and maintain statistical power. In the first step in this series of analyses, results indicated that none of the demographic factors on their own were significant predictors of the DHD and were therefore dropped from the model at the next step. In the second step, physical and illness-related variables were entered into the model, and results demonstrated that 6.5% of the variance (adjusted R^2) in predicting the DHD was accounted for by higher global symptom distress ($P < 0.006$, $\beta = 0.154$) and lower physical functioning (as measured by the KPS) ($P < 0.002$, $\beta = -0.178$). In the third step, psychosocial and psychological predictors were entered in one block into a model that retained the significant predictor variables identified in the earlier steps (i.e., global symptom distress and physical functioning). Results demonstrated that once the strong psychological predictors of hopelessness and depression are included in the model, all of the other physical/illness-related and psychosocial factors, with the exception of physical functioning, no longer contribute significantly to the prediction of the DHD. Regression results for

this final reduced model fit through a series of sequential backward elimination regressions are reported in Table 5 and demonstrate that 34.4% of the variance (adjusted R^2) in predicting the DHD (SAHD score, log of) was accounted for by higher levels of hopelessness ($P < 0.0005$, $\beta = 0.442$), elevated symptoms of depression ($P < 0.001$, $\beta = 0.185$), and lower physical functioning ($P < 0.05$, $\beta = -0.094$). Regression coefficients in the final model indicate that hopelessness has the greatest relative influence on the DHD. Comparative analyses run using untransformed variables in the model resulted in similar findings (results not shown).

A second series of sequential backward elimination regressions was used in the subset of 251 patients who had died at the time of these analyses, to build in the same stepwise manner as described earlier, a second reduced multivariate model predicting the DHD (SAHD score, log of). Regression results for this final reduced model that included proximity to death (in months) and survival of less than three months or less than six months (tested separately) demonstrated similar findings to those reported above. Among those who had died, 35% of the variance (adjusted R^2) in predicting the DHD was accounted for by higher levels of hopelessness ($P < 0.0005$; $\beta = 0.428$) and elevated symptoms of depression ($P < 0.001$; $\beta = 0.215$). As described above for the whole sample, once hopelessness and

Table 5
Sequential Regression Predicting the Desire for Hastened Death^{a,b}

	β	SE	β	F	Signif of F
Demographic variables ^c					
• None significant	—	—	—	—	—
Physical and illness-related variables ^d					
• Functional status	-0.001	0.000	-0.094	4.02	$P < 0.046$
Psychosocial and psychological variables ^e					
• Depression	0.002	0.001	0.185	11.30	$P < 0.001$
• Hopelessness	0.007	0.001	0.442	69.04	$P < 0.0005$
Model $R^2 = 0.350$					
Model R^2 (adjusted) = 0.344					

^aDependent variable: desire for hastened death (SAHD total score, log of); $N = 326$.

^bFinal reduced model fit through a series of sequential backward elimination regressions (with alpha set at 0.10), with nonsignificant variables dropped from the model at each step and the models rerun.

^cDemographic variables: age, gender, marital status (married/common law vs. not), education (beyond high school vs. not), and mean family income (log of).

^dPhysical and illness-related variables: cancer site (GI vs. lung), duration of illness (log of); survival (<6 months vs. rest of the sample); treatment status (active treatment discontinued vs. rest of the sample), physical functioning (KPS); total number of physical symptoms, physical symptom severity, and global symptom distress index score (MSAS); pain intensity (average of BPI intensity ratings), affective pain interference, and activity-related pain interference (BPI).

^ePsychosocial and psychological variables: spiritual meaning and peace and spiritual faith (FACIT-Sp); overall social support (MOS-SSS); self-esteem (RSES); depression (BDI-II); and hopelessness (BHS).

depression are included in the model, they are the strongest predictors of the DHD. Physical functioning approached, but did not reach, significance in this model ($P < 0.06$). Of particular note, proximity to death, survival of less than three months and less than six months from date of study participation (tested separately), treatment status, and age were not significant predictors in this model.

Discussion

Findings from this study suggest that the DHD is uncommon in patients with Stage IV GI or Stage III or IV lung cancer prior to the terminal phase, despite considerable physical and psychological distress in a substantial minority of these patients. Although more than 20% of this sample reported significant symptoms of depression and hopelessness and more than 50% reported pain and other physical distress, fewer than 2% reported high scores on the self-report measure of the DHD. All five of the participants with a high DHD score reported elevated levels of hopelessness and elevated symptoms of depression (see Table 4). No participant reported a high DHD in the absence of other significant psychological distress. However, the DHD was not necessarily associated with discontinuation of active treatment or with pain, because four

of the five patients with high scores were receiving chemotherapy treatment at that time, and three of the five patients did not report current pain.

The low frequency of a strong DHD in this sample of ambulatory cancer patients with metastatic disease contrasts strikingly with rates as high as 17%, which was reported in a study of palliative care inpatients with a mean time to death of 28 days.¹ In the present study, the univariate analyses showed that the DHD was associated with less spiritual well being (particularly spiritual meaning and peace), social support, and self-esteem, and with greater physical and psychological distress and functional impairment. These correlates of the DHD are similar to those found in studies of patients at the end of life.^{1,2}

In the present study, the multivariate analyses conducted in the whole sample, and in the subsample of those who had died, tested the contributions of demographic, physical, and illness-related, and psychosocial and psychological factors to the prediction of the DHD. In both cases, results demonstrated main effects for hopelessness and depression; together these variables accounted for over 34% of the variance in predicting DHD scores in this sample. The association of the DHD with hopelessness and depression has been a relatively consistent finding in the research conducted thus far.^{1,12,22,25} In the present

1229 study, hopelessness had by far the greatest relative
1230 influence on the DHD, accounting for
1231 over 30% of the variance.

1232 The low frequency of the DHD in the present
1233 study is compatible with the view that there
1234 is a "natural instinct" among human beings to
1235 continue existence,⁵⁷ at least until proximity to
1236 death supervenes. The relative absence of
1237 a strong DHD in the present study is similar
1238 to the findings in patients with advanced
1239 AIDS admitted to a long-term care facility,⁵⁸
1240 and in a mixed sample of cancer patients
1241 across all stages of illness admitted to a comprehensive
1242 cancer center.¹² A somewhat higher
1243 frequency of 5% was found in a palliative
1244 care unit in which patients were admitted
1245 for pain and symptom relief, although the
1246 expected survival of that sample was not
1247 reported.²⁵ Higher rates in palliative care settings
1248 have been explained by their association
1249 with psychosocial and physical distress, but it is
1250 possible that other factors associated with
1251 more-advanced disease and/or with palliative
1252 care units also play a role.

1253 The increased DHD in palliative care settings
1254 may also be partly related to the degree
1255 of death preparation that has occurred by
1256 the time patients have been admitted. The latter
1257 may be reflected in the acceptance by patients
1258 of the usual admission criteria to palliative
1259 care units, which may include termination
1260 of life-prolonging therapies and acceptance
1261 of do-not-resuscitate orders.⁵⁹ Such
1262 institutionalized requirements may encourage
1263 the acknowledgment that life is coming to an
1264 end and could increase the perceived acceptability
1265 of the DHD.

1266 Multiple other explanations may be proposed
1267 for the relatively low prevalence of the DHD
1268 in this sample, compared to that found in
1269 studies of patients in palliative care units.
1270 The relative preservation of functional capacity,
1271 and the greater perceived distance to the
1272 time of death may both help to preserve the
1273 will to live in ambulatory patients with
1274 metastatic disease. Almost 95% of patients in
1275 this sample scored 70 or above on the KPS at
1276 recruitment, a level that has been associated
1277 with a prognosis of more than six months.³¹⁻³²
1278 In addition, 61.8% were still receiving chemotherapy
1279 suggesting that there may have remained
1280 some hope among these patients for some
1281 kind of improvement, ranging from

1282 palliation to possible cure, which may not
1283 have been the case for those no longer receiving
1284 any sort of treatment. Although closeness
1285 to death and survival time were not significant
1286 predictors of the DHD in this sample, this is
1287 likely because the entire sample was not close
1288 to death, with only 13.2% dying within three
1289 months of study enrollment. As disease and
1290 disability progress toward the end of life, cancer
1291 patients may be at greater risk to experience
1292 existential, psychological, social, and
1293 physical distress or the loss of dignity,⁶⁰⁻⁶¹ all
1294 of which may contribute to the DHD. It is noteworthy,
1295 however, that the preservation of the will to live
1296 in our sample did not appear to be based upon
1297 a lack of awareness of their condition. In fact,
1298 almost 40% of the sample indicated that they
1299 expected to suffer a great deal from physical
1300 problems in the future because of their illness.

1302 *Methodological Strengths and Limitations*

1303 This study is the first with a relatively large
1304 sample size to evaluate the DHD and its correlates
1305 in an unselected consecutive sample of
1306 ambulatory patients with metastatic cancer
1307 prior to the terminal phase of their disease. Almost
1308 95% of the sample had an estimated prognosis
1309 of more than six months, based on KPS ratings
1310 at recruitment, making this the largest sample
1311 of nonterminally ill patients to be evaluated
1312 with regard to this phenomenon. Further, this
1313 study included an evaluation of proximity to death
1314 and active treatment status in relation to the
1315 DHD, as well as factors such as self-esteem that
1316 may protect from hopelessness and the DHD in
1317 this context. However, several limitations must
1318 be considered in the interpretation of the data.
1319 The sample was drawn from outpatient oncology
1320 clinics in a comprehensive cancer center. These
1321 patients may differ in important ways, including
1322 in their will to live, from patients with
1323 metastatic disease in the community, which may
1324 include those who are too disabled or demoralized
1325 to attend an outpatient oncology clinic. In
1326 addition, although the consent rate of nearly
1327 60% and the completion rate of 75% were
1328 relatively high for a study of this kind in
1329 patients with metastatic disease, participants
1330 may have differed in some undetected way
1331 from those who declined or were unable to
1332 participate. Approximately one quarter of
1333 potentially

eligible patients were non-English speaking/reading, and therefore, unable to be considered for participation. Finally, the restricted range of SAHD scores limits the conclusions that can be drawn about high scorers on this measure. Research is needed to examine the will to live among especially vulnerable groups of cancer patients, including those unable to attend outpatient clinics and those with linguistic barriers, which may limit the ability to communicate verbally with healthcare providers. Longitudinal research of the risk factors and of the trajectory of this phenomenon would be a valuable addition to the literature and could identify opportunities for intervention.

Conclusion

High scores on a measure of the DHD were found to be extremely uncommon in ambulatory patients with metastatic cancer, although symptoms of depression and hopelessness were reported by more than 20% of these patients, and pain by over 50%. The DHD was associated with psychological and physical distress when it occurred in these ambulatory patients, but high scores were reported by less than 2% of the sample. The infrequent occurrence of the DHD in this sample, in spite of the frequency of symptomatic distress, suggests that this phenomenon may be a response not only to immediate suffering or distress but also to the proximity of the end of life. Proximity to death did not prove to be a significant correlate or predictor of the DHD in the subset of our sample who had died by the time of data analyses, although all of the participants were drawn from a sample of patients who were not regarded as near death. Further research is needed to clarify the relationship of the DHD to such constructs as death acceptance and death preparation and to evaluate how factors such as age, life stage, treatment setting, and therapeutic interventions may be related to this phenomenon. Further, identifying the DHD when it first occurs may lead to opportunities for therapeutic intervention.

Acknowledgments

The authors thank their research staff and colleagues who contributed to this project,

including Dr. Michal Braun, Andrew Walsh, Rinat Nissim, Leanne Ferreira, their many student and volunteer research assistants, the PMH GI and lung clinic staff and volunteers who facilitated recruitment for their study, and especially their study participants who so kindly gave their time and effort to help the authors better understand the experience of living with cancer.

References

- Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and the desire for hastened death in terminally ill patients with cancer. *JAMA* 2000;284:2907–2911.
- Rosenfeld B, Breitbart W, Galietta M, et al. The schedule of attitudes toward hastened death: measuring desire for death in terminally ill cancer patients. *Cancer* 2000;88:2868–2875.
- Akechi T, Okamura H, Kugaya A, et al. Suicidal ideation in cancer patients with major depression. *Japanese J Clin Oncol* 2000;30:221–224.
- Tiernan E, Casey P, O'Boyle C, et al. Relations between desire for early death, depressive symptoms and antidepressant prescribing in terminally ill patients with cancer. *J Royal Soc Med* 2002;95:386–390.
- Kelly B, Burnett P, Pelusi D, et al. Terminally ill cancer patients' wish to hasten death. *Palliat Med* 2002;16:339–345.
- Kelly B, Burnett P, Pelusi D, et al. Factors associated with the wish to hasten death: a study of patients with terminal illness. *Psychol Med* 2003;33:75–81.
- McClain CS, Rosenfeld B, Breitbart W. Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet* 2003;361(9369):1603–1607.
- Morita T, Sakaguchi Y, Hirai K, Tsuneto S, Shima Y. Desire for death and requests to hasten death of Japanese terminally ill cancer patients receiving specialized inpatient palliative care. *J Pain Symptom Manage* 2004;27:44–52.
- Arnold EM, Artin KA, Person JL, Griffith DL. Consideration of hastening death among hospice patients and their families. *J Pain Symptom Manage* 2004;27:523–532.
- O'Mahony S, Goulet J, Kornblith A, et al. Desire for hastened death, cancer pain and depression: report of a longitudinal observational study. *J Pain Symptom Manage* 2005;29:446–457.
- Mystakidou K, Parpa E, Katsouda E, Galanos A, Vlahos L. The role of physical and psychological symptoms in desire for death: a study of terminally

- 1441 ill cancer patients. *Psychooncology* 2006;15:
1442 355–360.
- 1443 12. Jones JM, Huggins MA, Rydall AC, Rodin G.
1444 Symptomatic distress, hopelessness, and the desire
1445 for hastened death in hospitalized cancer patients.
1446 *J Psychosom Res* 2003;55:411–418.
- 1447 13. Ransom S, Sacco WP, Weitzner MA,
1448 Azzarello LM, McMillan SC. Interpersonal factors
1449 predict increased desire for hastened death in late-
1450 stage cancer patients. *Ann Behav Med* 2006;31:
1451 63–69.
- 1452 14. Butler LD, Koopman C, Cordova MJ, et al. Psy-
1453 chological distress and pain significantly increase
1454 before death in metastatic breast cancer patients.
1455 *Psychosom Med* 2003;65(3):416–426.
- 1456 15. Jordhoy MS, Fayers P, Loge JH,
1457 Ahlner-Elmqvist M, Kaasa S. Quality of life in pallia-
1458 tive cancer care: results from a cluster randomized
1459 trial. *J Clin Oncol* 2001;19:3884–3894.
- 1460 16. McCarthy EP, Phillips RS, Zhong Z, Drews RE,
1461 Lynn J. Dying with cancer: patients' function, symp-
1462 toms, and care preferences as death approaches.
1463 *J Am Geriatric Soc* 2000;48(Suppl 5):S110–S121.
- 1464 17. Bolund C. Suicide and cancer: I. demographic
1465 and social characteristics of cancer patients who
1466 committed suicide in Sweden, 1973-1976. *J Psycho-
1467 soc Oncol* 1985;3(1):17–30.
- 1468 18. Ripamonti C, Filiberti A, Totis A, De Conno F,
1469 Tamburini M. Suicide among patients with cancer
1470 cared for at home by palliative-care teams. *Lancet*
1471 1999;354(9193):1877–1878.
- 1472 19. Crocetti E, Arniani S, Acciai S, Barchielli A,
1473 Buiatti E. High suicide mortality soon after diagno-
1474 sis among cancer patients in central Italy. *Br J Can-
1475 cer* 1998;77(7):1194–1196.
- 1476 20. Tan A, Zimmermann C, Rodin G. Interpersonal
1477 processes in palliative care: an attachment perspec-
1478 tive on the patient-clinician relationship. *Palliat
1479 Med* 2005;19(2):143–150.
- 1480 21. Moody LE, Beckie T, Long C, Edmonds A,
1481 Andrews S. Assessing readiness for death in hospice
1482 elders and older adults. *Hospice J* 2000;15:49–65.
- 1483 22. Chochinov HM, Wilson KG, Enns M, et al. De-
1484 sire for death in the terminally ill. *Am J Psychiatry*
1485 1995;152:1185–1191.
- 1486 23. Mystakidou K, Rosenfeld B, Parpa E, et al. The
1487 schedule of attitudes toward hastened death: valida-
1488 tion analysis in terminally ill cancer patients. *Palliat
1489 Supp Care* 2004;2:395–402.
- 1490 24. Mystakidou K, Parpa E, Katsouda E, Galanos A,
1491 Vlahos L. Influence of pain and quality of life on de-
1492 sire for hastened death in patients with advanced
1493 cancer. *Int J Palliat Nurs* 2004;10(10):476–483.
25. Mystakidou K, Rosenfeld B, Parpa E, et al. De-
sire for death near the end of life: the role of de-
pression, anxiety and pain. *Gen Hosp Psychiatry*
2005a;27:258–262.
26. Mystakidou K, Parpa E, Katsouda E, Galanos A,
Vlahos L. Pain and desire for hastened death in ter-
minally ill cancer patients. *Cancer Nurs* 2005b;
28(4):318–324.
27. Rosenfeld B, Breitbart W, Stein K, et al. Measur-
ing desire for death among patients with HIV/
AIDS: the Schedule of Attitudes Toward Hastened
Death. *Am J Psychiatry* 1999;156:94–100.
28. Greene FL. American Cancer Society. In: Amer-
ican College of Surgeons, & American Joint Com-
mittee on Cancer, ed. *AJCC cancer staging
manual/American Joint Committee on Cancer*,
6th ed. New York: Springer-Verlag, 2002.
29. Katzman R, Brown T, Fuld P, et al. Validation of
a short Orientation-Memory-Concentration Test of
cognitive impairment. *Am J Psychiatry* 1983;140:
734–739.
30. Karnofsky DA, Burchenal JH. The clinical evalua-
tion of chemotherapeutic agents in cancer. In:
Macleod CM, ed. *Evaluation of chemotherapeutic
agents*. New York: Columbia University Press, 1949:
191–205.
31. Evans C, McCarthy M. Prognostic uncertainty in
terminal care: can the Karnofsky index help? *Lancet*
1985;1(8439):1204–1206.
32. Kaasa S, Loge JH. Quality of life in palliative
care: principles and practice. *Palliat Med* 2003;17:
11–20.
33. Yates JW, Chalmer B, McKegney FP. Evaluation
of patients with advanced cancer using the Karnof-
sky Performance Status. *Cancer* 1980;45:
2220–2224.
34. Lassaunière JM, Vinant P. Prognostic factors,
survival, and advanced cancer. *J Palliat Care* 1992;
8:52–54.
35. Portenoy RK, Thaler HT, Kornblith AB, et al.
The Memorial Symptom Assessment Scale: an in-
strument for the evaluation of symptom prevalence,
characteristics and distress. *Eur J Cancer* 1994;30A:
1326–1336.
36. Cleeland CS. Measurement of pain by subjective
report. In: Chapman CR, Loeser JD, eds. *Advances
in pain research and therapy*, 12th ed. New York:
Raven Press, 1989:391–430.
37. Serlin RC, Mendoza TR, Nakamura Y,
Edwards KR, Cleeland CS. When is cancer pain
mild, moderate or severe? Grading pain severity by
its interference with function. *Pain* 1995;61:
277–284.
38. Cleeland CS, Nakamura Y, Mendoza TR, et al.
Dimensions of the impact of cancer pain in a four
country sample: new information from multidimen-
sional scaling. *Pain* 1996;67:267–273.
39. Twycross R, Harcourt J, Bergl S. A survey of pain
in patients with advanced cancer. *J Pain Symptom
Manage* 1996;12:273–282.

- 1547 40. Beck AT, Steer RA, Brown GK. Manual for the
1548 Beck Depression Inventory-II. San Antonio, TX:
1549 Psychological Corporation, 1996.
- 1550 41. American Psychiatric Association. Diagnostic
1551 and statistical manual of mental disorders. text revision
1552 (DSM-IV-TR), 4th ed. Washington, DC: American
1553 Psychiatric Association Press, 2000.
- 1554 42. Chochinov HM, Wilson KG, Enns M, Lander S.
1555 Depression, hopelessness and suicidal ideation.
1556 Psychosomatics 1998;39:366–370.
- 1557 43. Berard RMF, Boermeester F, Viljoen G. Depres-
1558 sive disorders in an out-patient oncology setting:
1559 prevalence, assessment, and management. Psycho-
1560 oncology 1998;7:112–120.
- 1561 44. Schneider RA. Concurrent validity of the Beck
1562 Depression Inventory and the Multidimensional Fatigue
1563 Inventory-20 in assessing fatigue among cancer
1564 patients. Psychol Reports 1998;82:883–886.
- 1565 45. Portenoy RK, Payne D, Jacobsen P. Break-
1566 through pain: characteristics and impact in patients
1567 with cancer pain. Pain 1999;81:129–134.
- 1568 46. Chawla S, Mohanti BK, Rakshak M, et al. Tem-
1569 poral assessment of quality of life of head and
1570 neck cancer patients receiving radical radiotherapy.
1571 Qual Life Res 1999;8:73–78.
- 1572 47. Beck AT, Weissman A, Lester D, Trexler L. The
1573 measurement of pessimism: the Hopelessness Scale.
1574 J Consult Clin Psychol 1974;42:861–865.
- 1575 48. Sherbourne CD, Stewart AL. The MOS Social
1576 Support Survey. Soc Sci Med 1991;32:705–714.
- 1577 49. Rosenberg M. Society and the adolescent self-
1578 image, Revised edition. Middletown, CT: Wesleyan
1579 University Press, 1989.
- 1580 50. Blascovitch J, Tomaka J. In: Robinson JP,
1581 Shaver PR, Wrightsman LS, eds. Measures of person-
1582 ality and social psychological attitudes, Measures of
1583 self-esteem, Vol. 1. New York, NY: Academic Press,
1584 1991:115–160.
- 1585 51. Cella DF, Tulsky DS, Gray G, et al. The func-
1586 tional assessment of cancer therapy scale:
1587 development and validation of the general measure.
1588 J Clin Oncol 1993;11:570–579.
- 1589 52. Brady MJ, Peterman AH, Fitchett G, Mo M,
1590 Cella D. A case for including spirituality in quality
1591 of life measurement in oncology. Psychooncology
1592 1999;8:417–428.
- 1593 53. Brennan KA, Clark CL, Shaver PR. Self-report
1594 measurement of adult attachment: an integrative
1595 overview. In: Simpson JA, Rholes WS, eds. Attach-
1596 ment theory and close relationships. New York,
1597 NY: The Guilford Press, 1998:46–76.
- 1598 54. Hoge DR. Validated intrinsic religious motiva-
1599 tion scale. J Sci Study Relig 1972;11:369–376.
- 1600 55. Rodin G, Zimmermann C, Walsh A, et al. The
1601 contribution of social support and attachment secu- [Q3]
1602 rity to depressive symptoms in patients with meta-
1603 static cancer. Submitted for publication.
- 1604 56. George D, Mallery P. SPSS for Windows. Step by
1605 step: a simple guide and reference. [11.0 update],
1606 4th ed. Boston: Allyn & Becon, 2003.
- 1607 57. Carmel S. The will to live: gender differences
1608 among elderly persons. Soc Sci Med 2001;52:
1609 949–958.
- 1610 58. Pessin H, Rosenfeld B, Burton L, Breitbart W.
1611 The role of cognitive impairment in desire for hast-
1612 ened death: a study of patients with advanced
1613 AIDS. Gen Hosp Psychiatry 2003;25:194–199.
- 1614 59. Zimmermann C., Seccareccia D., Clarke A.,
1615 Warr D., Rodin G. Bringing palliative care to a Cana- [Q4]
1616 dian cancer center: the palliative care program at
1617 Princess Margaret Hospital. Support Care Cancer
1618 2006 June 27 [epub ahead of print].
- 1619 60. Chochinov HM, Hack T, Hassard T, et al. Digi-
1620 nity in the terminally ill: a cross-sectional, cohort
1621 study. Lancet 2002;360(9350):2026–2030.
- 1622 61. Chochinov HM, Hack T, Hassard T, et al. Un-
1623 derstanding the will to live in patients nearing
1624 death. Psychosomatics 2005;46:7–10.
- 1625 1592
1593
1594
1595
1596
1597
1598
1599
1600
1601
1602
1603
1604
1605
1606
1607
1608
1609
1610
1611
1612
1613
1614
1615
1616
1617
1618
1619
1620
1621
1622
1623
1624
1625
1626
1627
1628
1629
1630
1631
1632
1633
1634
1635
1636