

# Predicting Patient Survival Before and After Hospice Enrollment

Nicholas A. Christakis

**SUMMARY.** Despite the apparent advantages of hospice care, several barriers exist in terms of patient referral. Physicians' prognoses play a large role in determining when hospice care should begin. Predicting patient survival is a subjective decision dependent on several factors that vary before and after hospice enrollment. Currently, the stay of patients in hospice is very short; this can be attributed to late referral by physicians. Additional research on physician behavior and prognostication could help optimize the use of hospice as a valuable health care resource, thereby improving end of life care for terminally ill patients. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-342-9678. E-mail address: [getinfo@haworth.com](mailto:getinfo@haworth.com)]

## INTRODUCTION

### *Hospice Care in the U.S.*

At some point in the care of a seriously ill patient, a physician may come to see the patient as "terminally" ill and may move from

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Nicholas A. Christakis, MD, PhD, MPH, is Assistant Professor of Medicine and Sociology, Departments of Medicine and Sociology, University of Chicago.

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a primarily curative to a primarily palliative management strategy. If so, the physician may speak to the patient about referral to a hospice. Hospice care emphasizes attention to a patient's physical, emotional, and spiritual pain and suffering. Its primary goal is the palliation and relief of pain and suffering rather than treatment of the patient's underlying disease. Hospice care may offer a number of advantages over traditional, hospital-based terminal care: it may be delivered directly in a patient's home, facilitates at-home death (Moinpour and Polissar, 1989; Mor and Hiris, 1983), may provide better pain relief (Greer et al., 1986), and may foster patient self-determination and satisfaction (Kane et al., 1985; Wallston et al., 1988; Dawson, 1991). Furthermore, hospice care is cost-effective (Mor and Kidder, 1985; Mor, Greer and Kastenbaum, 1988; Kidder, 1992; Hannan and O'Donnell, 1984; Brooks and Smyth-Staruch, 1984).

A substantial and increasing number of terminally ill Americans are cared for at hospices: in 1993, 256,900 patients in the U.S. received hospice services (Strahan, 1994) from approximately 2,000 hospice care providers, more than 80 percent as outpatients (NHO, 1993). While about 80 percent of hospice patients have some form of cancer, a growing fraction consists of patients with non-cancer diagnoses, such as congestive heart failure, chronic obstructive pulmonary disease, and Alzheimer's disease. Indeed, hospice is increasingly being advocated as an appropriate form of terminal care for such non-cancer conditions. Approximately 80 percent of patients receiving hospice care in the United States do so under the Medicare hospice benefit.<sup>1</sup>

### ***Barriers to Timely Hospice Referral***

Despite its advantages, there are a number of barriers to referral to hospice. First, patients and their families may resist referral, typically out of a fear of managing death at home, a fear of stopping curative therapy, or a fear of being abandoned by the medical establishment. Second, difficulties with communication may hamper referral, and physicians, who understandably have difficulty breaking bad news, often avoid discussing the fact that the illness has entered its terminal phase.<sup>2</sup> Third, there may be a lack of knowledge about hospice availability on the part of both physicians and patients, particularly in non-cancer diagnoses.<sup>3</sup> Fourth, financial and logistic

concerns may be a problem; for example, insurance benefits may be inadequate or a hospice may not provide services in the area where a patient lives. Fifth, physicians may worry that they will lose control of their patients if they refer them. And sixth, physicians may experience difficulties with prognostication and so fail to anticipate when optimally to make the referral.<sup>4</sup> These barriers to hospice referral have at least two consequences. First, an unnecessarily small fraction of terminally ill patients might be referred to hospice. And second, referral, when it occurs, might be delayed.

Here, I will address the problem that predicting patient survival poses for hospice referral. According to Medicare regulations, which govern the great majority of hospice admissions, a beneficiary is eligible for the hospice benefit only if the patient's doctor and the hospice medical director both certify that the patient is "terminally ill" which is defined as having "a medical prognosis that the individual's life expectancy is six months or less" (Social Security Act 1861). Physicians may have difficulty interpreting or applying this standard, however (Lynn, Teno and Harrell, 1995). Indeed, commentators have noted that physicians typically make poor judgments about intermediate term survival in terminally ill outpatients and that unduly "optimistic" prognoses (with consequent late referral to hospice) and unduly "pessimistic" prognoses (with early referral) have adverse implications (Pearlman, 1988; Brody and Lynn, 1984; Potter, 1980). Some editorialists, concerned especially with the problem of late referral, have remarked that "in the absence of objective criteria, the only patients referred to the hospice may be those who are so obviously close to death that the hospice's palliative care will be offered too late" (Brody and Lynn, 1984). Despite the importance of this problem, however, little is known about patient, physician, or hospice attributes which influence physician decisions about whether and when to refer patients to hospice, and little is known about the accuracy and mechanism of physician prognostication in terminally ill outpatients in general and in those referred to hospice in particular.

### *Consequences of Sub-Optimal Timing of Referral*

To reap the maximum benefit from hospice care, the decision to refer a patient should be properly timed. Unnecessarily long or

short stays—which might arise from unduly early or late referral, respectively—should be avoided. However, as we shall see, numerous studies have shown that many patients die quite soon after referral and, conversely, some live for quite a long time after referral. Such short or long stays may have adverse clinical implications for patients and adverse economic implications for payers.

“Early” death due to unduly late referral provides several reasons for concern. For patients, early death may reflect an inadequate use of what many patients and caregivers consider to be a desirable mode of terminal care. For such patients, a longer stay in hospice would make their experience of terminal illness more humane and more clinically appropriate. Early death often means that hospice professionals have inadequate time to become familiar with the patient, to evaluate properly the patient and the home situation, and to develop and implement a comprehensive care plan. In addition, late transfer of a patient to hospice results in a discontinuity at a critical point in the patient’s illness, and may be undesirable because death might have been managed just as well by the referring hospital or doctor, avoiding the need to establish new caregiver-patient relationships. For hospices, the extensive work typically necessary at the beginning of the care of a new patient is organizationally disruptive and possibly financially burdensome (HCFA, 1994; Carney, Burns and Brobst, 1989). Finally, early death may mean that the patient received costly and possibly unnecessarily aggressive care for too long prior to referral.

Of course, some early deaths at hospice may be both unavoidable and quite appropriate. For example, a patient might become terminally ill suddenly, be immediately referred to hospice, and then die rapidly (or “early”). In such a situation, the physician would not have had an opportunity to refer earlier. However, such cases probably account for a small minority of early deaths, given the pattern of chronic diagnoses seen in all studies of patients referred to hospices.

“Late” death due to unduly early referral also provides several reasons for concern. In some situations where death occurs very late after referral, the patient may actually have been more suited to, and have derived greater benefit from, long-term nursing care or rehabilitative care rather than hospice care. Premature referral to hos-

pice may thus have adverse clinical implications. In addition, such an extended stay in a constant state of anticipation of death may be demoralizing to the patient and may oblige hospice nurses to deliver a type of routine nursing care which is inconsistent with their specialized training. To the extent that a lengthy stay results in the needless use of hospice resources, it may result in cost inefficiencies (HCFA, 1994).

## ***PREDICTING SURVIVAL AFTER HOSPICE ENROLLMENT***

### ***Duration of Survival After Referral***

Multiple studies have shown that length of stay at hospice tends to be quite short. Studies of patients admitted to single hospices in the U.S. have revealed median survival times of 22 days (Schonwetter et al., 1990), 25 days (Forster and Lynn, 1989), 29 days (Christakis, 1994), and 62 days (Kane et al., 1984), while studies that have reported data from multiple hospices have found median survival times of 26 days (Hannan and O'Donnell, 1984) and 35 days (Greer et al., 1986). In general, therefore, duration of survival after referral tends to be short. Indeed, 15 percent of patients die within a week of admission to hospice, and 25 percent die within two weeks.<sup>5</sup>

### ***Factors Associated with Survival***

Researchers have identified a number of clinical and non-clinical patient factors associated with duration of survival after hospice referral, factors which may assist physicians and others in making survival predictions in hospice patients. Using data from their landmark 1982 National Hospice Study, Reuben and colleagues showed that, for cancer patients, a low Karnofsky performance status was the most important clinical factor associated with short hospice survival, though five other symptoms (dyspnea, anorexia, dysphagia, dry mouth, and weight loss) also were associated with short survival (Reuben, Mor and Hiris, 1988). Interestingly, age, gender, and diagnosis were not associated with survival in this study. Other

studies, confirming or extending these findings, have shown the importance in hospice patients of performance status (Evans and McCarthy, 1985; Forster and Lynn, 1994), weight loss (Bruera et al., 1992), dyspnea (Reuben and Mor, 1986), dry mouth (Schonwetter, Robinson and Ramirez, 1994), and disorientation (Reuben, Mor and Hiris, 1988; Bruera et al., 1992; Christakis, 1994). Though some investigators have found that non-clinical patient attributes, such as religion (Jarvis and Northcott, 1987; Phillips and Smith, 1990) and social support (Schoenbach et al., 1986), affect survival of patients in general, others have found that various psychosocial factors are *not* associated with survival in terminally ill hospice patients (Christakis, 1994; Reuben, Mor and Hiris, 1988).

In the 1982 National Hospice Study, cancer patients with Karnofsky performance status scores of 10-20 had a median survival of 17 days, those with scores of 30-40 had a median survival of 50 days, and those with scores  $\geq 50$  had a median survival of 86 days. Having a greater number of the five symptoms outlined above was associated with shorter survival. For example, a patient with a Karnofsky score of  $\geq 50$  without symptoms had a predicted median survival of 172 days. If such a patient had dyspnea, however, the predicted median survival declined to 137 days. Shortness of breath and dysphagia decreased the predicted median survival to 104 days. And a patient with a Karnofsky score of  $\geq 50$  with all five symptoms had a predicted median survival of 54 days (Reuben, Mor and Hiris, 1985).

A 1992 study published by Eduardo Bruera and his colleagues found that a three-symptom constellation of dysphagia, cognitive failure, and weight loss were strongly associated with survival after hospice referral. Indeed, an index composed of these three symptoms could predict survival better than two experienced clinicians (Bruera et al., 1992). A 1995 study of 1,081 cancer patients in an inpatient hospice found a median survival of 11 days and documented that the extent to which a patient was bedridden (which is closely analogous to the Karnofsky performance status) was a strong predictor of survival (Allard, Dionne and Potvin, 1995).

Importantly, many prior studies have either neglected the role of diagnosis in hospice survival (Bruera et al., 1992), grossly oversimplified the role of diagnosis (Allard, Dionne and Potvin, 1995), or

failed to show a relationship between diagnosis and duration of survival after referral (Reuben, Mor and Hiris, 1988). Other studies, however, have found that patients with certain diagnoses, such as prostate cancer and COPD, have relatively longer survivals after referral, and patients with other diagnoses, such as leukemia, have shorter survivals (Christakis, 1994). In general, patient with non-cancer diagnoses tend to live substantially longer after hospice referral than patients with cancer. This observation has recently motivated close scrutiny by the Health Care Financing Administration and the National Hospice Organization. The latter has promulgated guidelines for determining prognosis in selected non-cancer diagnoses; these guidelines stress the importance of evidence of progression of the patient's disease as well the existence of certain symptoms in making survival predictions and in admitting patients to hospice programs (Stuart et al., 1995).

Researchers have also investigated provider factors that might be associated with duration of survival after hospice enrollment, such as the for-profit status of the hospice or the specialty of the referring physician. For example, the length of stay at hospice does not appear to be influenced by whether the referring doctor is a sub-specialist. Some internists, particularly oncologists, who refer patients to hospices have suggested that they continued to treat a patient aggressively until they felt that the patient had less than one month to live. On the other hand, family practitioners and general internists have tended to endorse the hospice approach and described their practice style as one of earlier referral. At least one study that investigated this hypothesis about different lengths of hospice stay according to physician specialty, however, failed to find quantitative support for it (Christakis, 1994). Another study, conducted in England, found precisely the opposite pattern (Evans and McCarthy, 1984).

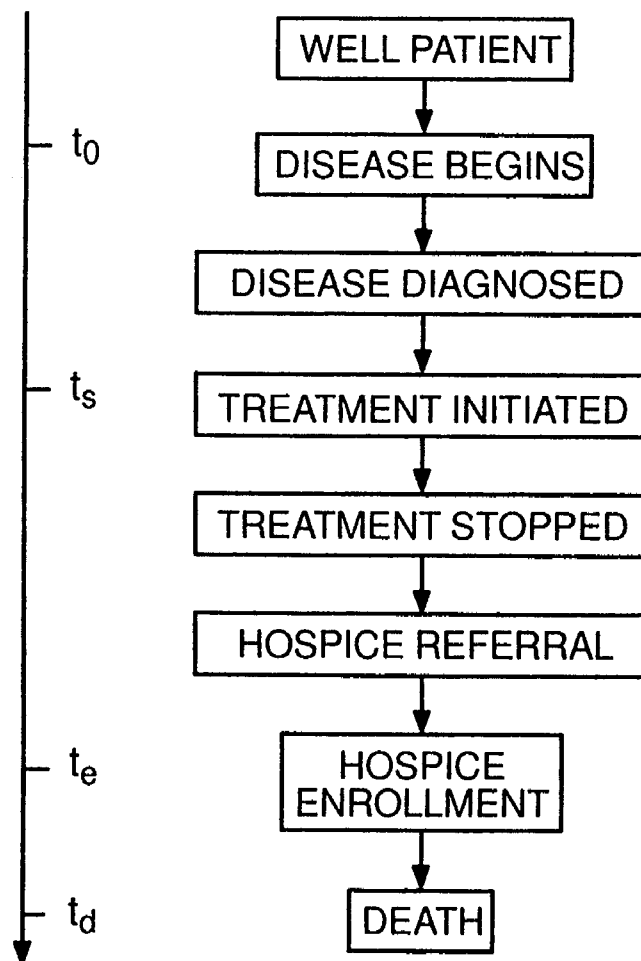
### *The Role of Timing of Referral in Observed Patient Survival*

Figure 1 illustrates the schematized trajectory a patient might follow from the onset of his or her disease through referral to hospice and until subsequent death. The observed duration of survival after hospice enrollment is the difference between a patient's time of death,  $t_d$ , and the time of enrollment,  $t_e$ . Ordinarily, one

thinks of factors associated with longer survival, such a high performance status, as being associated with a  $t_d$  that is delayed, i.e., that occurs later in time. Such a  $t_d$  in turn results in the difference between  $t_d$  and  $t_e$  (that is, the observed survival) being longer. However, since survival is measured at a point in time that is under the control of human decision-makers, there is another way that observed survival can be longer: patients might be referred earlier, that is, have an earlier  $t_e$ . This possibility is especially apparent when paradoxical associations are detected in the study of hospice survival.

For example, compared to non-depressed patients, those that are depressed should have shorter survivals (Cassileth et al., 1985; Zuckerman, Kasl and Ostfeld, 1984; Idlerand and Kasi, 1992; Frasure-Smith, Lesperance and Talajic, 1993). Yet depression has been associated with relatively longer survival in at least one study of

FIGURE 1. Trajectory of Illness and Referral in Hospice Patients





hospice patients (Christakis, 1994). It is more likely that depressed patients are referred earlier to hospice, i.e., have an earlier  $t_e$ , than that depression confers some kind of survival advantage, i.e., a later  $t_d$ . How might depression be associated with earlier referral? Depressed patients with terminal illness might be considered more unmanageable by their doctors and so be referred earlier. Alternatively, depressed patients might feel their symptoms to be more severe than similarly situated nondepressed patients; hence, both patient and physician might overestimate how physiologically “sick” the patient is and refer relatively early. Finally, depression typically occurs relatively early in the stages through which terminally ill patients pass as they cope with their disease (Kubler-Ross, 1969); thus, depression may simply be a marker for earlier disease stage or more recent diagnosis, and hence, perhaps, less severe pathology.

Finally, some studies have suggested that patients with certain diseases receive late referral to hospice and so have stays observed to be relatively short. One study suggested that prostate cancer and cardiovascular disease patients are referred to hospice sooner in the course of their diseases (Christakis, 1994). Another study suggested that patients with lymphoma and leukemia—deemed by physicians to be more “treatable” than other diseases—might receive later referral (Hyman and Bulkin, 1990).

Such findings suggest that an important—and possibly primary—determinant of length of survival may be the timing of the patient’s referral, as opposed, for example, to the aggressiveness of the therapy the patient receives after arrival at the hospice or the relative severity of the patient’s underlying pathology.<sup>6</sup> On average, patients referred to hospice early in their illness will have longer stays and those referred late will have shorter stays. Certainly, however, both factors that affect the  $t_d$  and the  $t_e$  will be associated with the measured duration of survival.<sup>7</sup>

## **PREDICTING SURVIVAL BEFORE HOSPICE ENROLLMENT**

### ***A Model of Physician Referral Behavior***

When a physician contemplates referring a seriously ill patient to hospice, the physician must decide when precisely to interrupt the

current trajectory of the patient's management and redirect the patient to a hospice care provider. There are three components to this decision: (1) the physician must decide how far in advance of death a patient should ideally be redirected to hospice (the preferred "lead time"), (2) the physician must make a prediction about when death is expected to occur, and (3) the physician must decide how to cope with the anticipated and unavoidable uncertainty in such a prediction. Each of these components may be expected to influence, albeit in different ways, the survival distribution of patients referred to hospice.

With respect to the first component decision, physicians must implicitly or explicitly decide upon their preferred "lead time." Given perfect information about the patient's illness trajectory, how long would they ideally wish for their patients to spend under hospice care before dying? In principle, physicians could differ among themselves with respect to their lead time preference, and some of this variation could be explainable by measurable characteristics, such as specialty (Evans and McCarthy, 1985; Hyman and Bulkin, 1990; Christakis and Iwashyna, submitted). Some, like oncologists, might choose to use hospice only for the last month of life; others, like general practitioners, might choose to use hospice for the last three months of life. Preferred lead time might also increase with the amount of experience physicians have referring patients to hospice. In principle, physicians might also be influenced in their preferred lead time by patients' social attributes, such as the degree of home support or religion. Moreover, one might imagine that attributes of the patient's disease might have some influence on the desired lead time. For example, some diseases might be associated with symptoms that the physician feels are particularly well handled by hospice care and that warrant earlier patient referral.

With respect to the second component decision, the physician must predict when a particular patient is going to die. Developing such a prognosis is not an easy task, and the physician must typically synthesize considerable physiological, psychosocial, and therapeutic information. Individual physicians may be systematically disposed to render unduly favorable or unfavorable prognoses in their patients regardless of the patient's diagnosis or the patient's true prognosis. As with the decision regarding preferred lead time,

it is at least in principle possible that different types of physicians (e.g., of different specialties or clinical experience) will have different behavior in this respect; some may offer more favorable prognoses than others (Wolraich, Siperstein, and Reed, 1991; Siegler, 1975).

With respect to the third component decision, the physician must decide how to cope with, and respond to, the uncertainty inherent in the survival prediction that has been made. When such decisions are conscious, the problem is best characterized as one of whether the physician wishes, given this uncertainty, to avoid an unduly early or unduly late referral. Here, the issue is not whether the physician systematically offers favorable or unfavorable prognoses, but rather whether, faced with high uncertainty, which error the physician would prefer to make (Scheff, 1972). In general physicians appear to prefer unduly late to unduly early referral and so refer patients to hospice only when the situation is manifestly hopeless. They cope with the uncertainty by temporizing until the moment of death is quite near and uncertainty has been considerably reduced.

Despite the foregoing focus on physicians' decisions, it is certainly the case that physicians are not the only decision makers in hospice referral. Others—including the patient, family, insurers, and hospice providers themselves—also influence whether and when patients are enrolled in hospice programs. Nevertheless, physicians are critical: they are legally an essential part of the process, initiate the bulk of referrals, and, at least theoretically, are capable of modifying their practice style so as to minimize early or late referral.

### *Evaluation of Physicians' Prognostic Abilities*

There have been very few studies evaluating physicians' ability to make predictions about patient outcomes in terminally ill patients in general and in hospice patients in particular. The landmark SUPPORT study found that for 4,028 hospitalized adults with one of nine illnesses, physicians performed as well in predicting six-month survival as a complex statistical model, with a measure of prognostic accuracy known as the "area under the ROC curve" assuming the reasonably high value of 0.78 (Knaus et al., 1995). In this study, physicians tended to be somewhat pessimistic in their predictions, meaning that patients tended to live slightly longer than predicted.

A few studies have evaluated the accuracy of physicians responsible for referring or treating hospice patients. A 1972 study of more than 60 physicians' predictions of patient survival upon hospice admission found that 83 percent of prognostic errors were in the optimistic direction, with observed survival being substantially shorter than predicted (Parkes, 1972). Forster and Lynn also found that five experienced predictors (including physicians, nurses, and social workers) tended to be unduly optimistic (Forster and Lynn, 1988) though another study of two physicians did not show such substantial optimistic bias (Bruera et al., 1992).

Elsewhere, I have called this pattern of prognostic behavior in physicians the "ritualization of optimism" (Christakis, 1995). This term denotes the favorable outlook held by physicians regarding a patient's outcome in spite of, and as a result of, the uncertainty inherent in the patient's predicament, and often in spite of evidence suggesting an unfavorable prognosis. This outlook is ritualized in that it reflects a systematic, widespread, symbolically important, patterned cognitive and behavioral means of prognostication among physicians.

### ***TOWARDS BETTER SURVIVAL PREDICTIONS IN HOSPICE PATIENTS***

In summary, patients currently being referred to hospice programs have very short survivals. And physicians generally offer unduly optimistic predictions of survival in patients referred to hospice. Additional work is needed to clarify the extent to which these two observations are linked. Nevertheless, it is clear that patients might benefit from longer hospice stays and that physicians referring patients to hospice should consider earlier referral, regardless of their own prediction of the patient's survival prospects.<sup>8</sup> Usually, there is ample opportunity to refer patients earlier, and very few patients currently being admitted to hospice programs have clinical histories that preclude earlier referral. Whatever advantages optimism may have in patient care, optimistic bias in survival predictions may be depriving patients of timely access to hospice care.

There are a number of areas of research that would support more accurate prognostication and, possibly, earlier referral. Most gener-

ally, an investigation of a broader set of physician and patient variables associated with length of survival after referral seems necessary. There is a paucity of research regarding patient attitudes both toward hospice care and toward the timing of its optimal initiation; for example, certain patients may be more likely than others to be willing to accept hospice care (e.g., patients with lengthier experience with their illnesses). Part of such a research effort might involve an investigation of the determinants of patient and family satisfaction with the terminal care that is currently provided outside hospices (Christakis, 1996). Prognostic staging systems for terminally ill outpatients with an intermediate survival expectation (one week to one year) in general and with certain diseases in particular are also needed. Such systems would be efficacious because they would decrease prognostic uncertainty in referring physicians. Furthermore, research in a number of areas regarding physician behavior could investigate: (1) the efficacy of providing feedback to physicians regarding the survival of their patients after hospice referral; (2) the means by which physicians make use of prognostic information; (3) the qualities of physicians (e.g., experience, specialty) that make them better prognosticators; and (4) small area variation in physician attitudes and behavior regarding hospice referral. Closer attention to accurate prognostication in different types of terminally ill patients and more timely referral to hospice might help to optimize the use of this health care resource from both patient and societal perspectives.

## NOTES

1. Regarding the Medicare benefit, see, for example, F.A. Davis (1988). Medicare Hospice Benefit: Early Program Experience. *Health Care Financing Review* 9, 99-111.

2. See, for example, R. Buchman (1992). *How to Break the Bad News*. Baltimore: Johns Hopkins Press.

3. For example, see D. Luchins; P. Hanrahan (1993). What is Appropriate Health Care for End-Stage Dementia? *JAGS* 41, 25-30.

4. See, for example, R.S. Schonwetter et al. (1990), 65-79. In the case of dementia, for example, 80% of hospices identified this difficulty in predicting survival time as the major problem in serving dementia patients; see P. Hanrahan; D.J. Luchins (1995). Access to Hospice programs in End-Stage Dementia: A National Survey of Hospice Programs. *JAGS* 43, 56-59.

5. See for example, N.A. Christakis (1994), 314-320.
6. Finding that race or gender is associated with survival, even after adjusting for other measurable patient attributes, would tend to support this contention, since there is little reason to believe that race or gender would influence mortality when one is considering the last few months of life.
7. A sophisticated randomized trial would probably be required to definitely sort out the relative importance of these two factors. Since patients would probably have to be willing not only to be randomized either to hospice or conventional care, but also to be randomized to receive hospice referral at different times in the course of their disease, such a study is essentially un-doable. However, other methods may eventually afford an answer to the question of the relative importance of  $t_e$  and  $t_d$  in duration of survival after referral.
8. Regarding physicians' predictions in general see N.A. Christakis; G.A. Sachs (1996). The Role of Prognosis in Clinical Decision Making. *Journal of General Internal Medicine* 11(7), 422-425.

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