Appendix A. The Scope of the "End of Life"

People die in their own way, with highly individual courses near death and with no one's last chapter being quite the same as another person's. Yet, the courses do tend to be rather similar for people with similar medical conditions and co-morbidities, similar symptoms and disabilities, and ordinary living circumstances. At least as an initial organizing principle, looking to those patterns and highlighting a small number of very common patterns yields a productive anchor for designing care systems, organizing information, and catalyzing reforms.

A recent idea in end-of-life care is that of "trajectories" of the course while living with fatal illnesses. A trajectory is essentially the time course of care needs and patient experiences from the onset of serious illness to the end of life, and it might well be more useful in designing reliable and effective care arrangements than strategies that rely upon diagnoses, procedures, or settings of care. A limited recent literature builds the case for a relatively small set of trajectories that could warrant separate planning for care needs. Lunney et al[1] proposed one trajectory for a short course of rapidly progressive disability in the last two months of life (often seen with solid cancers), one for a longer course of slow decline with intermittent life-threatening exacerbations and usually a sudden death (often seen with chronic lung or heart failure), and one for a very long course of slow decline with self-care disability arising from dementia or frailty.

Teno et al[2] confirmed Lunney's claim that the time course of disability in the last year was quite different for persons living with cancer as compared to those with stroke, chronic obstructive lung disease, diabetes and heart failure. Teno found that cancer patients were much less disabled until their last few months, when disability accelerated substantially and rapidly became more severe than the relatively mild increases for other conditions. Covinsky et al[3] evaluated the time course of disability in the conditions of frailty and dementia, showing that they are characterized by serious disability with slow worsening, with dementia being more severely disabling than frailty but with similar trajectoryie of decline over time.

At what point in these courses would it be appropriate to label the person as having come to the "end of life"? As with many definitions, a consideration of how it will be used is important. The definition that targets support to the caregiver and advance care planning with the patient would usually include much more time than a definition that identifies imminent dying. Lack of consistent definitions hinders building a coherent body of work regarding end-of-life care. Teno and Coppola[4] and George[5] have pointed out the serious problems that affect research when the "denominator problem" has not been addressed or resolved. As George noted in her systematic review,[5] most studies simply do not articulate the population to which the results could be generalized. In reports that did articulate the population of focus, we found three basic concepts of the scope. Some use "end of life" to mean the patient's last few days or hours, when it is quite clear that the person will not live long, when family should gather and last words be said, and when there is little thought of adding new medical treatments that might still delay death. This corresponds roughly to what hospice nurses often call "active dying." Others use the term to mean people who would be eligible and appropriate for hospice, in that they have a prognosis of less than six months' survival and have decided that

treatment should be focused upon palliative efforts. A third approach uses the term to denote a broader category that includes the part of life when the person is seriously afflicted with an eventually fatal condition, even if the prognosis remains ambiguous and some people live in this way for many years. Initial conversations with the NINR and AHRQ project officers and the Technical Expert Panel (see chapter 2) made clear that our Evidence-Based Report was to use the third, broad, definition of the category; but we were directed also to summarize the evidence as to how well the available literature supported each possible definition of the category. To this end, the EPC marked each article that we found in the searches described in Chapter 2 as to whether that article spoke to the question of prognosis. We supplemented this list of articles with those contributed by experts on the staff, in the TEP, in systematic reviews, and in expert reviews. The results of this review of the evidence underlying the definition of the category itself are presented below.

Search Results

We identified 348 articles from our title search including 299 in the title or abstract review phase and 48 contributed by expert reviewers. Of these, 90 were not about prognosis, or not quantitative (e.g., a review or ethics reflection). Forty citations described the natural history of a cohort, including mortality and effects of treatments. We identified 66 of these titles as not about chronic illness. Fifty-two citations described worse or better prognosis with one or a few factors in strata or simple association and merely quantified an obvious relationship. Sixteen regarded prognosis for a year or more. Twenty-one concerned only prognostication for patients already enrolled in a hospice or palliative care program. We identified a total of 63 articles to inform the question of when 'end-of-life' begins.

Defining the "end of life" as "active dying"

In case reports written by hospice and palliative care providers, the phrase "active dying" commonly designates a period of time in which the patient is declining markedly, is having irregularities in vital functions like breathing and circulation, and is reliably expected to die without any recovery within a few hours or at most a few days. In the articles identified in our broad search, no article addresses how often the designation is in error (in that the patient actually has a substantial period of stability before dying), how reliably different nurses and others designate patients as "actively dying," how many patients have this discernible phase before dying, or what the rate of various characteristics turns out to be among those identified as "actively dying." Clearly, if some aspect of clinical care or research is to turn on this definition, some empirical description and regularizing of the definition is in order.

Defining the end of life by patient "readiness"

While enrollment in hospice in the U.S. requires that the physician certify that the patient has "six months or less" to live, hospice enrollment also requires that the patient sign a statement giving up efforts at "curative" medical treatment and providing consent to treatment in a hospice program. Perhaps, at least for typical hospice patients, the prognosis requirement is mostly permissive and actual enrollment depends on the patient,

family, and clinicians being convinced that the patient is best served by extensive supportive care, usually because the patient is so sick and disabled. Of course, this status is loosely tied to prognosis, but it also is tied to how the people involved perceive the patient, including age, social situation, religious outlook, depression, weariness with life, and other factors. Perhaps the very definition of the category of "end of life" might be allowed to depend on preferences and perspectives of patient and family, at least among patients who are sick enough to die. A patient who is fiercely trying to regain stability with heart failure and who won't talk of dying might place herself in the category of "usual patients," while a person with similar physical impairments who is weary of fighting for breath, tired of it all, and ready to die might thereby be in the category of "end of life" patients.

One article provides an important window upon the question of patient "readiness" by assessing the correlation of cancer patients' self-assessment of prognosis with their preferences for life-sustaining treatment. Weeks et al[6] reported that cancer patients who estimated that they had at least a 10% chance of dying within six months had markedly more likelihood of preferring to avoid resuscitation than did those who thought that they had a better chance to live longer. This finding persisted whether or not their perceptions were accurate, and whether or not their views were in accord with their physicians. This raises the interesting possibility that patient "readiness" turns on certain thresholds or experiences that are not tightly tied to specific prognoses.

Another report on patient readiness to address end of life issues supports this point. Pfeifer et al[7] showed that sicker patients with chronic obstructive lung disease (COPD) were no more or less interested in end-of-life discussions than were somewhat less severely ill patients. Since the typical course of COPD includes periods of nearly stable life, intermittent exacerbations, and rather sudden dying, more or less severe illness might well have little effect upon the patient's perception of urgency, especially if patients are waiting for a warning that time is short. Most COPD patients will never know that time is short until death is close at hand in an exacerbation that is not going well.

At least with the search strategy that we used, no articles addressed the performance characteristics of a categorization that would turn in part upon patient and family preference for priorities of treatment or goals of care.

Defining the "end of life' by severity of illness

One practical way to define a category of people who are coming to the "end of life" would be to articulate explicit thresholds of severity of commonly fatal illnesses and to include the part of life lived with illness that severe or worse. This would allow the criteria to be disconnected from their performance as prognostic elements and to use instead those markers of severity that are commonly available, or readily obtained, and that mark the onset of substantial disability or suffering. The indices of severity could be linked to specific illnesses, or to trajectories, with the latter having the potential advantage of accounting for multiple co-morbidities.

Discerning the category by severity underlies a question used to help clinicians find the patients who are at the end of life: "Is this patient sick enough that is would not be a surprise if he or she were to die within six months?" It might not matter much whether one uses the reference category of 3, 6, or 12 months, since the question mostly

encourages the clinician to recognize that the patient already has an illness that might well take his or her life. The question was first reported in a quality improvement endeavor at the Franciscan Health System in Tacoma, Washington[8] and has since become more widely used.[9] However, no research has evaluated its performance characteristics formally.

Defining the "end of life" by prognosis

Prognosticating the patient's course is one of the oldest and most controversial parts of medical arts. Hippocratic teaching admonished physicians both to "declare the past, diagnose the present, foretell the future" and to "give necessary orders…revealing nothing of the patient's future or present condition."[10] In modern times, commentators admonish physicians both to inform the patient accurately as to what he or she faces and to avoid taking away hope. In most of the discussion, little attention goes to discerning what it is that the physician could possibly say about prognosis.

Giving a prognosis as to how the future is likely to unfold requires seeing that certain things known now (a,b,c,…) allow us to predict the risk of dying at a time in the future. For example, an article or text might say that 90% of the people with inoperable non-small-cell lung cancer who take no chemotherapy or radiation will be dead within six months. The same idea could yield a continuous expression of the likelihood of being alive, or a contingent prediction that illustrates the effect of different treatments or events.

Some elements of these common strategies are important to highlight. First, all prognostications of mortality yield a likelihood of survival at a particular time or over time, not "how long does he have to live?" Second, no prediction of survival will capture all of the variation and be precise, both because the elements used in prediction are not all known or well-measured and because some of the elements that actually shape the future are actually unpredictable for individuals (though some of these might be predictable for large numbers of people). Third, all predictions of the future rely upon past experience, so, to the extent that important circumstances change over time, such as treatment possibilities or complicating co-morbidities, predicting the future becomes unreliable. Finally, all prognostications have certain performance characteristics that shape their usefulness: in particular, overall performance in explaining variance, calibration, discrimination, dispersion (especially into the extremes of likelihood), practicality (often especially regarding missing data), and applicability to a new population of interest.

By far the most common way that prognostication has been used to shape the field of "end of life care" has been the claim that the "end of life" is when prognosis is less than 6 months, and the patient is eligible for enrolling in a hospice program. It is intriguing, and perhaps illuminating, that the statute that set forth the 6-month prognosis limit as eligibility for hospice coverage in Medicare did not define that statistic further, and that it has not been defined formally in the twenty years since.[11] Not only does it fail to state any degree of confidence that one would need to have in stating the prognosis, but it even fails to state the threshold clearly. Should a prognosis of 6 months or less mean that the person has less than a 50-50 chance to be alive in 6 months, or does it mean that the person is virtually certain to be dead within 6 months – e.g., with a 90% or 99% probability?

The size of the population to be served is dramatically different with these different definitions. Only a very few people, who usually live for a very short time, can be known to have less than a 1% chance to live 6 months; but many people, for much longer times, can be known to have worse than a 50% chance to live 6 months.[12] In the Government Accounting Office investigations of hospice enrollment, the standard employed seemed to be something like "virtually certain to die," but the recent enthusiasm to use hospice more seems to employ something close to the "more likely than not" standard.[9]

The group of 63 articles that inform the use of prognostication in defining the end of life addressed four major topics. First are reports of multivariable models developed to predict survival over time or to a point in time. Second are reports of expert clinicians predicting survival. Third are tests of either of these approaches in specified patient populations. Fourth are reports that present largely theoretical models that aim to make sense of the contribution of competing causes of death when they are commonplace in a population. While we do not know of a scoring system for the quality of multivariable modeling to predict survival, an on-line text outlines the dimensions of quality[13] and one article catalogues the pervasiveness of shortcomings in prognostication articles concerning the end of life.[14]

Multivariable prognostic models

The first group of research articles raises the question of how well a multivariable model can predict the likelihood of surviving to a future point in time, usually six months. One of the most well-developed models for multiple diagnoses was reported by the SUPPORT project.[15] It allows one to draw a survival curve and to calculate a reasonable estimate of the variance in the estimate for each of nine diagnoses. The SUPPORT model showed that the five hospitals involved had the same adjusted mortality rates and the same associations of all predictive factors with mortality predictions. Furthermore, the SUPPORT intervention did not affect mortality. The SUPPORT models were well-calibrated, they discriminated well even at the ends of the prognostic spectrum, and they dealt with missing data in justifiable ways.

However, the SUPPORT models' performance with regard to finding a population that was likely to die within six months was disappointing. Most of the deaths that drive the equations in SUPPORT occur early after admission to the hospital. The estimates of error in populations with a "middling" prognosis at six months are substantial, often requiring a range of 30 percentage points to encompass 90% of likely estimates. Furthermore, the study population was biased in mostly unmeasured ways, a fact that would greatly complicate application in another population. For example, the SUPPORT patients had come to a teaching hospital and had survived 48 hours in order to be enrolled. The average age at death in SUPPORT was more than ten years younger than in the population as a whole. Roughly twice as many people sick enough to qualify for SUPPORT were not enrolled but were in the community served by one of the hospitals.[16] Either they did not come into the hospital or they died quickly after admission. The people who did not come into the study included many living in nursing homes or who were very old and presumably supported at home.

Furthermore, the SUPPORT prognostic model requires a substantial array of laboratory tests and the patients were mostly getting hospital-level diagnosis and treatment, so the SUPPORT model will not function as well in a population that is not in the hospital. The SUPPORT model is a remarkably informative instrument, and it probably is useful in calibrating the effects of treatments or comparing the quality of life-sustaining care among hospitals or treatments, but it is not a well-calibrated way to sort patients by their prognoses at six months. Contrary to the common assumption that "terminally ill" people are evident, SUPPORT showed that, even very near to actual dying, prognoses stay quite uncertain for many patients. In SUPPORT, the median prognoses within the last week of life were often greater than 50% to survive six months, especially for chronic conditions with intermittent exacerbations like heart failure and chronic lung disease.[17, 18]

Other models for predicting prognosis have similar limitations in reliably splitting the population of very sick people into those who will live longer than six months (or another limit) and those who will die by then. Mitchell et al.[19] developed a model specifically for nursing home patients with dementia using high-quality methods and a large dataset. In testing for the adequacy of the model to predict 6 month survival, the performance characteristics were quite good (Area under the receiver-operating characteristic curve of 0.74 in the development set and 0.70 in the validation set). Nevertheless, that performance would leave many patients enrolled and surviving past six months and many others denied enrollment for what turns out to be their last few months.

In a model-building endeavor that paralleled the SUPPORT model approach, Teno et al[20] reported an initial estimate for frail hospitalized elders. The nomogram presented in this report illustrates the kind of useful translation of results that could anchor more widespread use of prognostic models. Nevertheless, the model has all the limitations of the SUPPORT model, and this one relied upon just 1266 cases and only 505 deaths in 4 sites.

Other papers have focused upon specific lab tests, special settings (e.g., Chow[21]), or especially dire clinical situations. A broad array of such papers might end up building a generalizable approach, but they also might build an incoherent patchwork. Certainly, at the present time, although the various models and approaches yield informative and clinically helpful insights for individuals and yield standards that can anchor research and quality improvement, the models have not been particularly useful in sorting people who should be considered to be "at the end of life" from those with serious diagnoses but longer expected survival.

Clinical Judgment

Rather than developing multivariable prognostic models, some reports tested the clinical judgment of physicians. In SUPPORT, the judgments of physicians were nearly as accurate as the multivariable model, on average, but physicians showed a strong tendency to use only a few points along the spectrum of possible prognoses (e.g., 10%, 25%, 50%, 75%, and 90%), thus reducing the calibration of their estimates and also their ability to separate patients of middling prognosis.

Christakis and colleagues have shown that physicians generally predict longer survivals than patients have, at least when prognosticating for patients being considered

for hospice.[22, 23] Addington-Hall et al[24] found that medical and nursing staff over-estimated survival substantially in 12% of cases and also under-estimated in 9%. SUPPORT found that physicians were accurate on average when the question was the likelihood of being alive in six months. The errors that physicians made in this task had a normal distribution, but fully 39% of the predictions were in error by more than 20% when compared with the SUPPORT multivariable model as the gold standard.[25] Mackillop and Quirt[26] assessed the discriminatory power of oncologists' estimates of survival at 3 months and at one year and found fair discrimination at 3 months (Area under the ROC =0.75) and very poor discimination at a year (A-ROC = 0.57). Higginson and Constantini[27]checked the accuracy of prognoses made by experienced palliative care teams concerning cancer patients referred to their care. They recommended that prognosis be presented as a range, since that doubled the rate of proving to be accurate, but they noted that prognosis "is still very often inaccurate, except very close to death." Indeed, the patient's actual survival time lay outside of the predicted range in 58% of cases.

Prognostication for heart failure seems to be especially difficult. In SUPPORT, the median prognosis for heart failure patients on the day that turned out to be the day before death was just about 50% to live for 6 months.[28] Poses et al[29] tested emergency room physicians providing care for heart failure patients with an acute exacerbation, evaluating the accuracy of their estimates for three months and for one year survival. Their discriminatory ability was modest, with areas under the receiver operating curve of 0.66 for 90 days survival and 0.63 for a year. Indeed, in that study, of 1173 patients with 1603 visits, only 15 patients were estimated to have less than a 10% chance to live 90 days, but one-third of these patients lived that long and 208 others died within 90 days.

Pirovano et al[30] formally combined key elements from physiology and demographics with the clinician's prediction of survival and the Karnofsky performance status measure, thereby forming the Palliative Prognostic Score. In cancer, that score does serve to define three groups with median survivals of 64, 32, and 11 days. The utility for sorting "end of life" from the rest of humanity is limited because the groups have substantial overlap, and the overall survival is short. The strong role of performance status in predicting survival time in cancer was underscored in Vigano et al's systematic review of prognostic factors in cancer[31] which showed that 13 of the 13 prognostic models reviewed had tested a performance status measure and found it to be significant in predicting survival among people with advanced cancer. Vigano identified a number of symptoms that also often appeared to be independent predictors in prior research, although this systematic review underscored the methodological limitations of the studies in existence in 1999.

In SUPPORT, the physicians' estimates were also entered into the multivariable prognostic model and the resulting model performed measurably better than either the physicians alone or the multivariable model alone.

Others have tested expert prognostications. Arkes et al[32] underscored the mismatch between patients, surrogates and physicians, showing that patients were remarkably over-optimistic and physicians generally over-pessimistic. Pearlman [33] presented one case with acute and chronic respiratory failure to 205 physicians and asked for an estimate of survival. The range was from one month to five years with a median of about six

months. Social and preference factors had a substantial bearing on the estimated survival.

Testing Prognostic Estimates

A few reports have tested a prognostic scoring system or model in a patient population, usually seeing the sensitivity and specificity of the test at 6 months. The SUPPORT article by Fox et al[34] showed the generally inadequate ability of the SUPPORT prognostic model to discern what patients with lung, heart, or liver failure were qualified for hospice. Testing a broad inclusion criterion, an intermediate one, and a narrow one, the sensitivity and specificity moves from 42% and 67% for the broad criteria to 1.4% and 99.5% for the narrow criteria. Obviously, the trade-off between sensitivity and specificity was extreme and the criteria did not provide a method by which to identify the potential hospice population without unacceptable error rates of inclusion or exclusion.

Most of the models built around a specific illness have used data from populations that have very few people who are quite elderly. SUPPORT, for example, has an average age at death that is more than a decade younger than the average age at death in the U.S. population. In general, then, the models do not take account of the contribution of advanced age or of multiple co-morbidities that are life-threatening. A series of reports has aimed to build a model for understanding the role of competing co-morbidities, especially in estimating the merits of treatments that affect the survival time from one illness.[35-38] When patients have multiple serious conditions, delaying death from one cause has the effect of making it more likely to come to the end of life with another. In populations like SUPPORT, few patients have more than one fatal illness. In older populations, frailty and lack of reserve capacity in various vital systems often creates a cascade of life-threatening complications. Indeed, Morrison and Siu[39] reported that pneumonia or hip fracture have only about 12% mortality within six months if the patients are cognitively intact, while those with serious dementia have more than 50% mortality. Multivariable models that take account of the interaction among causes of death in making prognostications are not in evidence, though a new specific statistical approach has been developed and applied to AIDS.

Many models do take into account a simple measure of co-morbidity such as the Charlson Co-Morbidity Index, the Adult Comorbidity Evaluation 27, the Index of Co-Existent Disease, and the Kaplan-Feinstein Comorbidity Index.. In all such reports, when adjusted for severity of the underlying illness, substantial additional co-morbidity increased the likelihood of dying. For example, in Piccirillo et al,[40] patients with severe co-morbidity had adjusted hazard ratio for death of 2.56 (95% CI, 2.35-2.81) and even mild co-morbidity carried an adjusted hazard ratio of 1.21 (95% CI, 1.13-1.30), in comparison with patients with no co-morbidity. These measures do add some explanatory power to predictive models, but Piccirillo's models have a C-statistic of 0.7-0.8. Co-morbidity and competing causes of death have multiple impacts upon the likely survival, from becoming primary causes of death or limiting the aggressiveness of treatment to altering the patient's and the family members' assessment of the desirability of undertaking troubling courses of treatment. Nevertheless, in general, the prognostic models that are available for predicting survival for individual patients either did not

include many patients old enough to raise these concerns or did not adjust for these factors.

Indeed, even how to weigh the role of treatment effects upon prognostication is not standardized. If prognosis could be much better with treatment, but the patient refuses or cannot get the treatment, then is the patient's prognosis simply that of the untreated patient? Does it matter if the patient who initially refuses could change his or her mind for a substantial period of time? These issues have not yet been part of the discussion over prognostication, perhaps because they are largely irrelevant in hospice enrollment when the patient's physicians must certify prognosis. In a gesture to limit the risk of choosing to accept an earlier death and thereby to qualify for hospice, enrollment now requires that the prognosis rely upon "the normal course of the individual's illness."[41]

One report did examine the association of age, aggressiveness of care, and survival, showing that older patients did get less aggressive care and did have shorter survival, but that these two findings were not themselves associated. At least in the SUPPORT database, survival was not affected by care patterns at each hospital or by the intervention, which aimed to increase communication and awareness of prognosis.[42] Volicer et al.[43] built a model for predicting survival of dementia patients after an episode of fever. The model's two strongest elements are treatment variables: the management strategy as to whether to pursue a palliative approach or a conventional approach, and the recency of having been admitted for long-term care. These had odds ratios of 4.25 for palliative care and 7.78 for having recently been admitted, while physiological severity and age had odds ratios only a little more than 1. It is not clear that prognostic models should simply incorporate treatment strategies. At least at the extreme, a treatment strategy can be self-enforcing with regard to survival: consider the effect of deciding to implement terminal sedation.

The status of the category "end of life"

This review of the literature shows that various concepts of the "end of life" are in actual use, and none of them have had substantial empirical validation of potential defining characteristics. Prognostication models and clinician estimates are useful for generally forecasting a patient's future; however, they are not sufficiently precise or generalizable for splitting those with short prognoses who are to be eligible for services tailored to the end of life from those with longer prognoses who are to continue to use the ordinary health care system. Furthermore, the definitional strategies other than prognostication have only clinical experience behind them, without any formal definitions or examination of their performance characteristics.

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43. Volicer BJ, Hurley A, Fabiszewski KJ, et al. Predicting short-term survival for patients with advanced Alzheimer's disease. 1993;41(0002-8614. 5):535-540.

Appendix B1. NLM Search Strategy

**First Strategy for End of Life from NLM in PubMed –
Trajectory Issues NOT included**

April 8, 2004

1. palliative care[mh] OR attitude to death [mh] OR death [mh:noexp] OR terminal care[mh:noexp] OR hospice care[mh] OR hospices [mh] OR bereavement [mh] OR terminally ill[mh] OR "death and dying"[All Fields] OR "dying loved one"[All Fields] OR "dying patient"[All Fields] OR "dying patients"[All Fields] OR "dying people"[All Fields] OR "dying person"[All Fields] OR "end of life"[All Fields] OR "limited life expectancies"[All Fields] OR "limited life expectancy"[All Fields] OR "limited life span"[All Fields] OR "limited life spans"[All Fields] OR "limited lifespan"[All Fields] OR "limited lifetime"[All Fields] OR "imminent death"[All Fields] OR "imminent demise"[All Fields] Limits: All Adult: 19+ years, Publication Date from 1990 to 2004, English, Human   **Total: 10,543**
2. health care quality, access, and evaluation[mh] OR "outcome and process assessment (health care)" [mh] OR consumer satisfaction[mh] OR personal satisfaction[mh] OR quality of life[mh] OR quality of health care[mh] OR value of life[mh] OR questionnaires [mh] OR interviews [mh] OR psychological tests [mh] OR clinical trial[pt] OR clinical trials[mh] OR psychotherapy[mh] OR reproducibility of results[mh] OR predictive value of tests[mh] OR psychiatric status rating scales [mh] OR (rating AND (scale OR scales)) **Total: 789,126**
3. #1 AND #2   **Total: 7,870**
4. sociology [mh] OR continental population groups[mh] OR socioeconomic factors [mh] OR education [mh:noexp] OR health education [mh] OR age factors [mh] OR sex factors [mh] OR sexuality[mh] OR life style[mh] OR interpersonal relations [mh] OR morale [mh] OR internal-external control [mh] OR social distance [mh] OR cooperative behavior [mh] OR attitude to health [mh] OR religion [mh] OR personality [mh] OR emotions[mh] OR mental competency[mh] OR family[mh] OR caregivers[mh] OR friends[mh] OR sexual partners [mh] OR social environment [mh] OR visitors to patients [mh] OR communication[mh]
                                                                             Total: 261,455
5. #1 AND #4   **Total: 5,258**
6. palliative care[mh] OR attitude to death [mh] OR death [mh:noexp] OR terminal care[mh:noexp] OR hospice care[mh] OR bereavement [mh] OR terminally ill[mh] OR "death and dying"[All Fields] OR "dying loved one"[All Fields] OR "dying patient"[All Fields] OR "dying patients"[All Fields] OR "dying people"[All Fields] OR "dying person"[All Fields] OR "end of life"[All Fields] OR "limited life expectancies"[All Fields] OR "limited life expectancy"[All Fields] OR "limited life span"[All Fields] OR "limited life spans"[All Fields] OR "limited lifespan"[All Fields] OR "limited lifetime"[All Fields] OR "imminent death"[All Fields] OR "imminent demise"[All Fields] Limits: All Adult: 19+ years, Publication Date from 1990 to 2004, English, Human   **Total: 10,395**
7. health services needs and demand [mh] OR health facilities [mh:noexp] OR academic medical centers [mh] OR health facilities, proprietary [mh] OR health

facility environment [mh] OR health facility size [mh] OR hospital administration [mh] OR hospital units [mh:noexp] OR intensive care units [mh] OR hospitals [mh] OR residential facilities [mh] OR community health services [mh:noexp] OR community mental health services [mh] OR home care services [mh] OR home care agencies [mh] OR counseling [mh] OR suburban health services [mh] OR urban health services [mh] OR rural health services [mh] OR women's health services [mh:noexp] OR health services for the aged [mh] OR health services, indigenous [mh] OR health services [mh:noexp] OR community health nursing [mh] OR professional-patient relations [mh] OR public relations [mh] OR decision-making, organizational [mh] OR decision support systems, clinical [mh] OR institutional management teams [mh] OR patient care management [mh] OR role [mh] OR health personnel [mh] OR attitude of health personnel [mh] OR patient care [mh:noexp] OR critical care [mh] OR nursing care [mh] OR life support care [mh] OR health care economics and organizations [mh] OR resource allocation [mh] OR government [mh] OR government programs [mh]

Total: 158,202

8. #6 AND #7 **Total: 4,465**
9. #3 OR #5 OR #8 **Total: 8,944**
10. terminal care/economics OR terminal care/psychology OR terminal care/standards OR terminal care/trends OR terminal care/utilization OR terminal illness/psychology OR hospice care/economics OR hospice care/psychology OR hospice care/standards OR hospice care/trends OR hospice care/utilization

Total: 1,570

11. #9 OR #10 **Total: 9,154**
12. letter [pt] OR news [pt] OR editorial [pt] **Total: 83,393**
13. #11 NOT #12 **Total: 8,778**
14. #9 NOT #12 **Total: 8,585**
15. euthanasia [mh] OR suicide, assisted [mh] OR pregnancy [mh] OR pregnancy complications [mh] OR fetal death [mh] **Total: 60,908**
16. #13 NOT #15 **Total: 8,018**
17. #14 NOT #15 **Total: 7,912**
18. (palliative care OR bereavement OR grief OR terminal care OR hospice care OR terminally ill OR hospice OR hospices OR Kubler-Ross OR (attitude* AND death) OR "death and dying"[All Fields] OR "dying loved one"[All Fields] OR "dying patient"[All Fields] OR "dying patients"[All Fields] OR "dying people"[All Fields] OR "dying person"[All Fields] OR "end of life"[All Fields] OR "limited life expectancies"[All Fields] OR "limited life expectancy"[All Fields] OR "limited life span"[All Fields] OR "limited life spans"[All Fields] OR "limited lifespan"[All Fields] OR "limited lifetime"[All Fields] OR "imminent death"[All Fields] OR "imminent demise"[All Fields]) AND (in process [sb] OR publisher [sb]) AND 1990:2004 [pdat] **Total: 447**
19. #16 OR #18 **Total: 8,465**
20. #17 OR #18 **Total: 8,359**
21. #19 NOT case reports [pt] **Total: 7,047**
22. #20 NOT case reports [pt] **Total: 6,961**

Appendix B2. Q2-Trajectories Search Strategy

QUESTION #2:
DATABASE SEARCHED: PUBMED
TIME PERIOD COVERED: 1990-2004
OTHER LIMITERS: ENGLISH ONLY, HUMAN ONLY

SEARCH STRATEGY 1A:

heart failure, congestive OR dementia OR neoplasms

AND

terminally ill OR chronic disease OR critical illness OR metasta* OR advanced

AND

patients[majr] OR patient*[ti] OR family[majr] OR family[ti] OR families[ti]

AND

spirituality OR pain OR emotions OR dyspnea OR depression OR attitute to death OR population characteristics OR psychology[sh]

AND

quality of life OR quality of health care OR patient satisfaction OR patient advocacy OR decision making

NOT

gene OR genetic* OR chromosom* OR surgery[sh] OR radiotherapy OR drug therapy[sh] OR pathology OR epidemiology OR case report OR treatment outcome

SEARCH STRATEGY 1B:

heart failure, congestive OR dementia OR neoplasms

AND

terminally ill OR chronic disease OR critical illness OR metasta* OR advanced

AND

health care facilities, manpower and services OR quality of health care OR health services research OR health services OR insurance, health OR patient care management

AND

quality of life OR quality of health care OR patient satisfaction OR patient advocacy OR decision making

NOT

gene OR genetic* OR chromosom* OR surgery[sh] OR radiotherapy OR drug therapy[sh] OR pathology OR epidemiology OR case report OR treatment outcome

NUMBER OF ITEMS RETRIEVED FOR BOTH SEARCHES: 961

Appendix B2. Q2-Trajectories Search Strategy

Appendix B3. DARE Search Strategy

DARE -Database of Abstracts of Reviews of Effects

We searched DARE using the following individual terms:
Caregiver, coordination, continuity, advance care planning, advance care, DNR, resuscitation orders, communication, dyspnea.

We also searched for systematic reviews in the area of pain by combining 'pain' with the following disease-specific terms:
Cancer, neoplasms, COPD, CHF, chronic obstructive pulmonary disease, congestive heart failure, dementia, cirrhosis. The term 'pain' was combined with all other disease categories.

Category:	Number of Citations
caregiver(s)	31
advance care planning	0
resuscitation	21
DNR	1
dyspnea	12
continuity	20
coordination	20
communication	103
pain + disease-specific terms	92

One of us (KL) completed a title review on all citations identified, yielding a set of citations that was subjected to formal abstract review (using our systematic review screener).

Appendix B4. RAND Search Strategy

REVISED STRATEGY FOR END OF LIFE QUESTION 1, PUBMED
Roberta Shanman, 4/20/04

#1 Search death[ti] OR death[mh:noexp] OR "dying loved one" OR "dying patient" OR "dying patients" OR "dying people" OR "dying person" OR "last year of life" OR "end of life" OR "terminal illness" OR "terminal illnesses" OR terminal care OR "death and dying" OR "limited life expectancies" OR "limited life expectancy" OR "limited life span" OR "limited lifespan" OR "limited life spans" OR terminally ill OR critical illness OR frail elderly Field: All Fields, Limits: Publication Date from 1990 to 2004, English, Human 16:16:25 40006

#2 Search delivery of health care OR quality assurance, health care OR "outcome and process assessment (health care)" OR quality of life OR quality indicators OR quality of health care OR patient care management OR continuity of care OR outcome[ti] OR outcomes[ti] OR consumer satisfaction OR patient satisfaction OR personal satisfaction Limits: Publication Date from 1990 to 2004, English, Human 16:17:11 1418497

#3 Search pain/th OR pain/psychology OR "pain management" OR "pain assessment" OR "relieve suffering" OR "relieve symptoms" OR palliative care[mh] OR pain[ti] OR "pain relief" OR discomfort OR "physical comfort" OR "comfort care" OR "symptom distress" OR "symptom burden" OR "symptom control" OR "symptom intensity" OR "symptom management" OR "symptom relief" OR "pain distress" OR "pain easing" OR "pain free" Limits: Publication Date from 1990 to 2004, English, Human 16:18:17 72663

#4 Search "psychological distress" OR psychology[sh] OR wellbeing OR "well being" OR anxiety OR anxious OR anxiety disorders[mh] OR depression OR depressive disorder[mh] OR depressed OR "attitude to death" OR neoplasms/psychology OR "emotional health" OR spiritual OR emotions OR support[ti] OR supportive OR communication OR relationships OR religion OR religiosity OR "treatment decision" OR decisionmaking OR "decision making" Limits: Publication Date from 1990 to 2004, English, Human 16:19:56 445112

#5 Search home care services/standards OR home nursing/st OR hospice care/st OR "nursing assistance" OR nursing homes/st OR residential facilities/st OR intensive care units/st OR life support care/st OR "home care" OR hospice* OR "nursing homes"[tiab] OR "nursing home"[tiab] OR "intensive care"[tiab] OR icu[tiab] OR icus[tiab] OR "place of death" OR health care facilities, manpower and services OR caregiver* OR caregivers OR "care giving" OR family[mh] OR family[tiab] OR families[tiab] OR "social services" OR "social support" Limits: Publication Date from 1990 to 2004, English, Human 16:20:48 247909

#6 Search #1 AND #2 Limits: Publication Date from 1990 to 2004, English, Human 16:21:30 22453

#7 Search #3 OR #4 OR #5 Limits: Publication Date from 1990 to 2004, English, Human 16:21:51 669678

#8 Search #6 AND #7 Limits: Publication Date from 1990 to 2004, English, Human 16:22:07 14020

#9 Search #8 NOT (letter[pt] OR news[pt] OR editorial[pt] OR case reports[pt]) Limits: Publication Date from 1990 to 2004, English, Human 16:22:56 11505

#10 Search #9 NOT (ethics[mh] OR euthanasia[mh] OR suicide, assisted[mh] OR pregnancy[mh] OR pregnancy complications[mh] OR fetal death[mh]) Limits: Publication Date from 1990 to 2004, English, Human 16:24:59

TOTAL TITLES 8,284
When compared with NLM search, 3,748 new and unique titles identified by this search strategy.

Appendix C. Health Canada Reports

Table C1. Health Canada Reports- Relevant to Key Questions

Study	Report Title	Relevant to Key Questions
Wilson, D (in press) [1]	Outcomes and Evaluation of end of life care	Yes
Wilson, D (in press) [2]	The needs of dying persons	Yes
Wilson, D (in press) [3]	End of life case management	Yes
Wilson, D (in press) [4]	The needs of the families of dying persons	Yes
Wilson, D (in press) [5]	Continuity of end of life care	Yes
Wilson, D (in press) [6]	Managing End of life pain and other symptoms through non-pharmacological means	Yes
Wilson, D (in press) [7]	End of life spiritual and psychosocial issues	Yes
Wilson, D (in press) [8]	End of life care in acute care hospitals	Yes
Wilson, D (in press) [9]	End of life care in residential continuing-care facilities	Yes
Wilson, D (in press) [10]	Culture and end of life care	Yes
Wilson, D (in press) [11]	The home as a place of end of life care	Yes
Wilson, D (in press) [12]	Gender differences in the experience of the dying process	Yes
Wilson, D (in press) [13]	End of life care in intensive care units	Yes
Wilson, D (in press) [14]	End of life care in rural or remote areas	Yes

Appendix C. Health Canada Reports

Table C2. Health Canada Reports - Not Relevant to Key Questions

Author	Report Title	Relevant to Key Questions
Wilson, D (in press)	Australia site visit report	No
Wilson, D (in press)	Bereavement	No
Wilson, D (in press)	Canadian end of life care programs, models, and approaches	No
Wilson, D (in press)	End of life topics addressed in randomized controlled clinical trials research	No
Wilson, D (in press)	Palliative day care	No
Wilson, D (in press)	Integrated end of life care: a Health Canada synthesis research project	No
Wilson, D (in press)	New developments in end of life care	No
Wilson, D (in press)	Pediatric end of life care	No
Wilson, D (in press)	End of life prognostication	No
Wilson, D (in press)	Web-based questionnaire data analysis report	No
Wilson, D (in press)	End of life respite care	No
Wilson, D (in press)	Literature reviews that have focused on end of life care	No
Wilson, D (in press)	New Zealand site visit report	No
Wilson, D (in press)	International end of life care delivery models or approaches	No
Wilson, D (in press)	Provincial home care data analysis report	No
Wilson, D (in press)	Education in Canada for end of life care	No
Wilson, D (in press)	Canada site visit report	No
Wilson, D (in press)	Aboriginal end of life care	No

Appendix C. Health Canada Reports

Reference List

1. In: Wilson D. Outcomes and Evaluation of end of life care. Edmonton, Alberta Canada: University of Alberta. draft in press.

2. In: Wilson D. The needs of dying persons. Edmonton, Alberta Canada: University of Alberta. draft in press.

3. In: Wilson D. End of life case management. Edmonton, Alberta Canada: University of Alberta. draft in press.

4. In: Wilson D. The needs of the families of dying persons. Edmonton, Alberta Canada: University of Alberta. draft in press.

5. In: Wilson D. Continuity of end of life care. Edmonton, Alberta Canada: University of Alberta. draft in press.

6. In: Wilson D. Managing End of life pain and other symptoms through non-pharmacological means. Edmonton, Alberta Canada: University of Alberta. draft in press.

7. In: Wilson D. End of life spiritual and psychosocial issues. Edmonton, Alberta Canada: University of Alberta. draft in press.

8. In: Wilson D. End of life care in acute care hospitals. Edmonton, Alberta Canada: University of Alberta. draft in press.

9. In: Wilson D. End of life care in residential continuing-care facilities. Edmonton, Alberta Canada: University of Alberta. draft in press.

10. In: Wilson D. Culture and end of life care. Edmonton, Alberta Canada: University of Alberta. draft in press.

11. In: Wilson D. The home as a place of end of life care. Edmonton, Alberta Canada: University of Alberta. draft in press.

12. In: Wilson D. Gender differences in the experience of the dying process. Edmonton, Alberta Canada: University of Alberta. draft in press.

13. In: Wilson D. End of life care in intensive care units. Edmonton, Alberta Canada: University of Alberta. draft in press.

14. In: Wilson D. End of life care in rural or remote areas. Edmonton, Alberta Canada: University of Alberta. draft in press.

Appendix D1. Sample: Abstract Screening Form

End of Life Care and Outcomes
FINAL ABSTRACT SCREENER

1. Article ID: _____

2. First Author (last name): _____

3. Reviewer: **(CIRCLE ONE ONLY)**
   Dy......................................1 Mularski 5
   Hughes.............................2 Shugarman 6
   Lorenz ....3 Sun 7
   Lynn ....4 Wilkinson 8

   Other ....9 (specify_____)

4. Population, intervention, outcome **exclusions**:
   (CIRCLE ONE ONLY)
   Not about end of life care ....1 **STOP**
   Related only to sudden, violent, non-chronic
       deaths ....2 **STOP**
   Evaluating chemotherapy, surgery, stents, laser,
       or radiation interventions ....3 **STOP**
   No outcomes specified ....4 **STOP**
   Outcome unrelated to patients, family, non-
       professional caregivers ....5 **STOP**
   Primarily useful as a background paper ....6 **STOP**
   Primarily about prognosis or trajectories ....7 **STOP**
   Data is older than 1990 ....8 **STOP**
   None of the above...9

5. Study population: **(CIRCLE ONE ONLY)**
   Human..1
   Non-human ....2 **STOP**
   Unclear..3

6. Subjects: **(CIRCLE ONE ONLY)**
   Adults (≥19 years) included...................................1
   Only children (≤18 years) ....2 **STOP**
   Mix or Unclear 3

7. Study location: **(CIRCLE ONE ONLY)**
   US, Canada, Europe, or Australia / NZ 1
   Non-Western ....2 **STOP**
   Mix or unclear...3

8. Design: **(CIRCLE ONE ONLY)**
   Qualitative research 1
   Systematic review or Meta-analysis 2
   Non-systematic review ....3 **STOP**
   Any observational study (< 30 cases) ....4 **STOP**
   Any non-intervention observational study (≥ 30
       cases) 5
   Any intervention study (**Answer Q9**).....................6
   Unclear..7

9. Does the study report an intervention?
   (CIRCLE ONE FOR EACH QUESTION)   Yes No Unclear

   Does the investigator control assignment?
   .... 1..........2 3

   Is there a comparison / control group?
   .... 1..........2 3

   Is the intervention a non-chemotherapy drug?
   .... 1..........2 3

10. Topic(s): **(CHECK ALL THAT APPLY)**
    A 'good death', 'quality of dying'............................ ❑
    Patient/family satisfaction with terminal care......... ❑
    Methods paper (e.g. measure development) .... ❑
    Measures (outcomes or intervention related):
        Family or informal caregiver concerns (*non-
            bereavement*) .... ❑
        Family or informal caregiver concerns
            (*bereavement only*) .... ❑ **STOP**
        Advance care planning .... ❑
        Continuity and coordination .... ❑
        Symptoms:
            Pain .... ❑
            Dyspnea .... ❑
            Depression, delirium, anxiety, other
                affective/ behavioral symptoms........... ❑
            Other symptoms (**STOP** if only one checked) .. ❑
        Other (**STOP** if only one checked)........................ ❑
    Unclear .... ❑

    IF *OTHER SYMPTOM* OR *OTHER MEASURE* ONLY, THEN STOP

11. Type of disease(s): **(CHECK ALL THAT APPLY)**
    Lung cancer .... ❑
    Breast cancer... ❑
    Colorectal cancer .... ❑
    Other or mixed cancer .... ❑
    Heart failure (CHF)... ❑
    Other or mixed heart disease............................... ❑
    Advanced chronic lung disease .... ❑
        (e.g. COPD or other)
    End stage liver disease.. ❑
    End stage renal disease .... ❑
    Dementia.. ❑
        (e.g. Alzheimer's, multi-infarct, HIV, and other)
    Stroke or other neurodegenerative disease .... ❑
    HIV / AIDS.. ❑
    Multiple chronic illnesses of aging – frailty .... ❑
    Other single cancer.. ❑
    Other mixed cancer.. ❑
    Unclear .... ❑

12. Secondary review required: **(CIRCLE ONE ONLY)**
    Yes...1
    No 2

    Notes:

Appendix D2. Sample: Systematic Review Short Form

**End of Life Care and Outcomes
SYSTEMATIC REVIEW FINAL SCREENER**

1. Article ID: _____

2. First Author (last name): _____

3. Reviewer: (CIRCLE ONE ONLY)
   Maglione........................1
   Other 2
   (specify_____)

4. Primarily useful as a background paper?
   Yes...❑
   No ....❑

5. Topic: (check ALL that apply)
   A 'good death', 'quality of dying' ....❑
   Patient/family satisfaction with terminal care.......❑
   Methods paper (e.g. measure development) ....❑
   Measures (outcomes or intervention related):
      Family or informal caregiver concerns (*non-bereavement*) ....❑
      Family or informal caregiver concerns (*bereavement only*) ....❑ **(STOP)**
      Advance care planning ....❑
      Continuity and coordination ....❑
      Symptoms:
         Pain..❑
         Dyspnea...❑
         Affective/ behavioral symptoms.............❑
   Other end of life care.......................................❑ **(STOP)**
   Not end of life care..❑ **(STOP)**

6. Type of disease(s):   (check ALL that apply)
   Lung cancer ....❑
   Breast cancer ....❑
   Colorectal cancer..❑
   Other or mixed cancer ....❑
   Heart failure (CHF) ....❑
   Other or mixed heart disease ....❑
   Advanced chronic lung disease ....❑
      (e.g. COPD or other)
   End stage liver disease.....................................❑
   End stage renal disease....................................❑
   Dementia ....❑
      (e.g. Alzheimer's, multi-infarct, HIV, and other)
   Stroke or other neurodegenerative disease ....❑
   HIV / AIDS ....❑
   Multiple chronic illnesses of aging – frailty .....❑
   Other single cancer..❑
   Other mixed cancer...❑
   Unclear ....❑

7. Year literature search ended?

   (enter 9999 if not reported)   ___ ___ ___ ___

8. Year of publication?

   (enter 9999 if not reported)   ___ ___ ___ ___

9. Study Design: (check ALL that apply)
   Systematic Review ....❑
   Meta-analysis ....❑
   Review ....❑ **(STOP)**
   Other..❑ **(STOP)**
   Unclear..❑ **(STOP)**

10. Were the following study characteristics reported?
    (CIRCLE ONE ONLY)

	Yes	No
Search strategy	1	2 **(If No then STOP)**
Inclusion Criteria	1	2 **(If No then STOP)**