

Attitudes towards end-of-life care in California

Survey of California residents to describe attitudes towards and experiences with end-of-life care and wishes, with attention to ethnic differences, funded by The California Healthcare Foundation,

(<http://www.chcf.org/topics/chronicdisease/index.cfm?itemID=127262>), and posted November 2006. This website has numerous documents available as PDF ppt slides.

Highlights include:

- Compared to 1989, twice as many Californians now die at home, and less than half die in hospitals.
- The majority of respondents with recent death of a loved one reported that their loved one's wishes were respected with regard to end-of-life care, although this demonstrated variation by ethnicity (83% white, 74% Latino, 62% African American)
- Seventy percent of Californians believe there are some circumstances in which a patient should be allowed to die, although views on a patient's right to die varied significantly by ethnicity. Whites were far more willing to allow a loved one to die than any other ethnic group.
- Eighty percent reported that they would not want to be kept alive on life support if they were in a coma with no hope of significant recovery.
- Although 83% believe it is somewhat or very important to have end-of-life wishes in writing, only 36% actually have a written document.
- While the vast majority of respondents (82%) familiar with hospice care view it positively, almost 30% have never heard of it.
- Use of hospice care in California has increased 93% since 1996.
- The majority of hospice users were white (70%).
- One in four hospice patients sought care during the last 5 days of life

Extremely brief overview of SUPPORT and HELP

The purpose of these projects was to improve appropriateness of care for critically ill hospitalized adults by focusing on identifying and promoting patient informed preference. It was undertaken in the mid 1980s in response to concerns about increasing resource use, including the use of expensive emerging technologies, in patients who were in their last few months of life. Phase I produced insights into existing practices with regard to end-of-life care, and Phase II tested an intervention developed using those insights.

Phase I – Interviews with patients, family members and physicians to help answer the following questions

- How is care provided to seriously ill patients?
- To what extent are patients' preferences being addressed?
- How accurate are physicians' perceptions of patient prognosis and preferences?
- How are prognostic estimates being used to guide clinical decisions?

Phase I work included the development of prognostic models based on clinical and physiological information to produce objective estimates of survival for seriously ill hospitalized adults.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10809479&dopt=Abstract

The conclusions from Phase I (4301 patients at 5 different clinical sites) included:

- Patients could be interviewed during the acute phase of life-threatening illness and preferences and outcomes for a population could be described from these interviews.
- Physicians often misunderstood patient preferences, especially when patients did not want high-technology, life-extending care.
- Patients often died after prolonged hospitalization in critical care settings
- DNR orders were often written just before death
- Prognostic models based on clinical and interview data provided better prognostic estimates than those made by physicians alone
- Pain was a clinical factor commonly reported among SUPPORT patient participants, regardless of diagnosis
- The median age of SUPPORT participants was 65, therefore another arm was added to the study to specifically focus on hospitalized patients older than 80 (HELP).

Phase II - The SUPPORT intervention included providing a dedicated nurse specialists to help intervention patients and physicians with prognostic information, determination of treatment preferences, and facilitation of communication among caregivers, patients and families. They were expected to assist patients and families in determining goals of care, to assess and communicate pain control to intervention physicians, and to provide counseling and psychological support as needed. Intervention physicians received reports of patient prognosis, and patient degree of understanding of their prognoses, and patient preferences for care. Nurses and physician leaders from each clinical site were given specialized training for their responsibilities, and adherence to the model was demonstrated through review of reports and contact logs generated during the trial, and through follow up questionnaires and focus groups with the intervention nurses. Despite excellent adherence to the model, the SUPPORT intervention failed to change:

- The frequency with which physicians understood patients' preferences to withhold CPR
- The timing during the clinical course of care when physicians signed a DNR order
- The frequency with which patients and physicians discussed resuscitation
- The duration of ICU stays before death
- The duration of ventilator use before death
- Pain control
- Resource use

Rethinking Fundamental Assumptions: SUPPORT's Implications for Future Reform.

Lynn J, Arkes HR, Stevens M, Cohn F, Koenig B, Fox E et al.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=10809478&dopt=Abstract

This paper is a synthesis of findings from SUPPORT and other sources to explore flaws in and alternative views to the conceptual models on which the SUPPORT trial was based. The authors conclude that strong psychological and social forces underlie present practices, and that improved decision-making is unlikely to result in practice change.

Four specific assumptions that are inherent in a Decision-Making Model for intervention are discussed in detail:

1) Patient preferences are stable, important and expressible

- Patient preferences are not fixed but change with changing context because people have difficulty accurately imagining alternative states of health
- Attitudes around specific adverse conditions change as that condition occurs
- People near death have different values than people not near death

2) A decision opportunity will be recognized

- That which is established as the usual course of care may not be perceived as a series of decisions by either patients or physicians.
- Physician practice may be characterized by 'recognition-primed decision-making' or pattern matching and not as a series of situations amenable to individual choice.

3) People are willing to take responsibility for making a choice

- Not making a decision is not consistently viewed as an active choice
- Regret is more likely to be associated with a decision to act than with a decision to refrain from acting

4) Participants are willing to use information in a rational decision-analytic approach

- Physicians and patients are unfamiliar with using prognostic estimates and utilities
- Most patients are unwilling to trade quantity of life for quality of life
- Self-perception of one's role as decision-maker is not influenced by medical literature or prognostic estimates

Implications for change

- Patient self-determination is unlikely to have a significant effect on end-of-life care reform, because the current system cannot respond effectively.
- Usual patterns of care are deeply entrenched, both because there are underlying cultural reasons they became common patterns in the first place, and because

- people are more comfortable with the status quo as opposed to taking responsibility for trying a new course.
- The most promising course may be to establish a default pattern of treatment that should be common in the absence of stated patient preference. This default pattern of care should reflect what most people would want. All default care should include opportunities to incorporate individual decisions.
 - Future interventions may be more effective through system level quality improvement efforts as opposed to focusing on the individual patient level. .

Elderly Persons' Last Six Months Of Life: Findings from the Hospitalized Elderly Longitudinal Project

Somogyi-Zalud E, Zhong Z, Lynn J, Hamel MB. [J Am Geriatr Soc](#). 2000 May;48(5 Suppl):S131-9.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstrActPlus&list_uids=10809466&query_hl=30&itool=pubmed_DocSum

Patients age 80 or older were recruited after a hospital admission of at least 48 hours for all diagnoses except elective surgery, need for hospice care, psychiatric admission, AIDS or multiple trauma from 4 clinical sites participating in the SUPPORT trial. Patients transferred from another acute care facility were excluded. Patients and surrogates were interviewed at regular intervals over the next 12 months or until death about symptoms, functional status, preferences for life-extending treatment and CPR, satisfaction with medical care, impact of care giving on family members, and post discharge use of healthcare resources. For those patients that died during the study, surrogates were interviewed 4 to 10 weeks after death. This report is an analysis of the provided information analyzed as a function of time before death. The main results compare 3 groups, those dying during the enrollment hospitalization, those dying during the 1 yr follow up, and survivors at 1 year. Patients who died during the enrollment hospitalization had higher intensity of treatment and resource use: 54% received care in the ICU (20% among survivors), 43% received ventilator treatment (6%), and cost of care was almost double (\$11,100 compared to \$6400 for patients dying during the follow up period and \$6000 for those surviving 1 year). 81% had a DNR order. 70% of each group preferred comfort care and very few expressed a preference for life extension with pain. More than 30% of patients who died during the enrollment hospitalization rated their chances of survival as greater than 90%. During the last month of life most patients preferred not to be resuscitated, and ¼ reported severe pain. During the last month of life 1/3 families reported a significant effect from care giving most commonly giving up employment, loss of savings or becoming ill.

Dying with Cancer: Patients' Function, Symptoms, and Care Preferences as Death Approaches

McCarthy EP, Phillips RS, Zhong Z, Drews RE, Lynn J. [J Am Geriatr Soc](#) 2000 May;48(5suppl): S110-121.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=10809464&query_hl=32&itool=pubmed_docsum

This report is an analysis of data collected during the SUPPORT trial among enrollees with metastatic colon cancer or advanced non-small cell lung cancer who died within 1 year (61% of colon cancer patients and 80% of lung cancer patients) of index hospitalization. Results are presented from time before death. Prognostic models demonstrated steadily decreasing estimates of survival during the last 6 months of life. Colon cancer patients spent fewer days in the hospital per time interval as death approached, and lung cancer patients spent increasing proportions of time in the hospital. Functional status steadily deteriorated and most patients had 4 or more impairments during the last 3 days of life. Severe pain was common, and most patients indicated significant pain during their last 3 days, but only modest levels of anxiety and depression. Two thirds of patients expressed a preference to forgo resuscitation in the last 3 days of life. Families reported significant financial burdens, which had been sustained by 3 to 6 months prior to death. **Conclusions:** Persons dying with cancer have a well-described trajectory toward death, as compared to persons with other chronic conditions, but experience many shortcomings in ideal end-of-life care.

The Last Six Months of Life for Patients with Congestive Heart Failure

Levenson JW, McCarthy EP, Lynn J, Davis RB, Phillips RS. J Am Geriatr Soc 2000 May;48(5suppl): S101-109.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=10809463&query_hl=34&itool=pubmed_docsum

This report is an analysis of data collected during the SUPPORT trial among enrollees with a diagnosis of acute exacerbation of congestive heart failure who died within one year of index hospitalization (539/1404), analyzed by time until death. Those who died had more resource-intensive index hospitalizations, and higher rates of ICU care during the index hospitalization (71%). Although the last six months of life were characterized by decline in functional status and increasing severity of illness as reflected in Median Acute Physiology Scores, the model-based median estimate for 6 month survival was 54% 3 days before death. Forty-one percent experienced severe pain and 63% experienced severe dyspnea during the 3 days before death. Preference for DNR rose from 33% at 3-6 months before death to 47% at 1 month to 3 days before death. Perceived quality of life did not change as death approached, and 29-58% of patients reported good to excellent quality of life in all intervals before death. **Conclusions:** Persons dying with heart failure do not experience a decline in perceived quality of life as death approaches, and are difficult to identify using prognostic predictive models.

Living and Dying with Chronic Obstructive Pulmonary Disease

Lynn J, Ely EW, Zhong Z, McNiff KL, Dawson NV, Connors A, Desbiens NA, Claessens M, McCarthy EP. J Am Geriatr Soc 2000 May;48(5suppl): S91-100.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=10809462&query_hl=36&itool=pubmed_docsum

This report is an analysis of data collected during the SUPPORT trial among enrollees with a diagnosis of COPD who died within one year of index hospitalization (416/1016, 41%), analyzed by time until death. Of 416 dying within one year, 116 did not survive the index hospitalization. The median physiologic score based predictive model indicated a 48% prognosis for surviving 2 months for those who did not survive the hospitalization. Seventy-eight percent used the ICU during that hospitalization. Patients surviving the index hospitalization but dying within the year spent up to half their time in the hospital during the last 6 mos of life. Self-reported quality of life was rarely better than “fair” or “poor” throughout the last 6 months, and ADL scores decreased significantly as death approached. Seventy-seven percent had DNR orders written within one month of death; 30% had no decision regarding preference for ventilator use documented during the last month of life. **Conclusions:** Persons dying with COPD experience significant symptoms and decline as death approaches, but predictive models do not reliably identify the last month of life.

Dying with Acute Respiratory Failure or Multiple Organ System Failure with Sepsis

Somogyi-Zalud E, Zhong Z, Lynn J, Dawson NV, Hamel MB, Desbiens NA. J Am Geriatr Soc 2000 May;48(5suppl): S140-145.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=pubmed&cmd=Retrieve&dopt=AbstractPlus&list_uids=10809467&query_hl=52&itool=pubmed_docsum

This report is an analysis of data collected during the SUPPORT trial among enrollees with dying during hospitalization with acute respiratory failure (ARF) or multiple organ system failure with sepsis (MOSF). Because many of the patients in this group were confused, intubated or comatose, 63% of the interview data were collected from surrogates. Patients/surrogates reported impairment in more than 1 ADL during the 2 weeks prior to the index hospitalization in those that died in the hospital and those surviving less than 1 year. Orders to forgo ventilator support were written on average 3 days before death; DNR orders were written 2 days before death. Dying patients spent an average of 9 days on a ventilator although their prognostic scores were high (mean score 61 out of possible total of 71), indicating poor likelihood of survival.

Patterns of Functional Decline at the End of Life

Lunney JR, Lynn J, Foley DF, Lipson S, Guralnik JM. JAMA 2003 May 14;289(18):2387-92.

<http://jama.ama-assn.org/cgi/reprint/289/18/2387.pdf?ijkey=1sqWTFuhRgRY2>

Self-reported physical function from interview data provided by persons age 65 and older participating in the prospective longitudinal Established Populations for Epidemiologic Studies of the Elderly (EPESE) study was analyzed by months before death for 4190

participants giving interviews in the year before death. Patterns of functional decline were examined for patients dying of sudden death, cancer, organ failure and frailty. Persons dying of sudden death were highly functional in even the last year of life; cancer patients were highly function early in their final year with rapid decline in the last 3 months before death; decedents with organ failure

Bereaved Family Member Perceptions of Quality of End-of-Life Care in US Regions with High and Low Usage of Intensive Care Unit Care

Teno JM, Mor V, Ward N, Roy J, Clarridge B, Wennberg J, Fisher ES. *J Am Geriatr Soc* 2005; 53:1905-11.

<http://www.blackwell-synergy.com/doi/abs/10.1111/j.1532-5415.2005.53563.x>

Family members listed as informants on death certificates were surveyed about their end-of-life care experiences in HSAs (hospital service areas) characterized by very high and very low use of ICU or CCU days during decedents' last 6 months of life. If the informant identified a different person (usually a family member) as being the most familiar with the circumstances of the decedent's death, that person was interviewed. Decedents in high-intensity ICU HSAs were more likely to be black and to live in nonrural areas, but did not differ with regard to gender, education, age, marital status or leading causes of death. The survey instrument included assessments of five domains of end-of-life care: physical comfort and emotional support of the decedent, shared decision-making, respectful treatment, attending to family needs for information, and attending to family needs for emotional support. No measure of quality was better in the higher-intensity HSAs, and scores were significantly lower in higher-intensity settings in three domains (shared decision-making, respectful treatment and attending to family needs for information). **Conclusions:** Dying in regions with a higher use of ICU care is not associated with improved perceptions of quality of end-of-life care.

Attitudes of Patients With Incurable Cancer Toward Medical Treatment in the Last Phase of Life

Voogt E, van der Heide A, Rietjens FAC, van Leeuwen AF, Visser AP, van der Rijt CCD, van der Maas PJ.

<http://jco.ascopubs.org/cgi/reprint/23/9/2012>

Patients with cancer were recruited within 2 months of being informed that their cancer was unlikely to be curable. Data were collected by a survey followed by an interview about attitudes towards treatment, preferences in care, and most desirable outcomes of further medical treatment. Patient attitudes could be categorized into three different profiles: striving for quality of life, striving for length of life, and no clear preference. Younger patients were more likely to strive for length of life, and fatigue was associated with striving for quality of life. Length of time since diagnosis was associated with a trend towards favoring quality of life; patients tended to strive for prolonging life early in the course of the disease, and favor quality of life as death approaches. Patients who

favorable quality of life at baseline were more likely to complete an advance directive. One third of patients were unwilling or unable to express a preference.

Accepting Critically Ill Transfer Patients: Adverse Effect on a Referral Center's Outcome and Benchmark Measures

Rosenberg AL, Hofer TP, Strachan C, Watts CM, Hayward RA. Ann Int Med 2003 June;138(11):882-890.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?itool=abstractplus&db=pubmed&cmd=Retrieve&dopt=abstractplus&list_uids=12779298

ICU and hospital length of stay, ICU readmission and hospital mortality rates were collected for 4579 consecutive admissions to an MICU at a tertiary care university hospital. Compared with directly admitted patients, patients transferred from another hospital had significantly higher Acute Physiology Scores and the time of admission and discharge. After adjustment for case mix and illness severity, transfer patients had a 38% longer ICU stay, a 41% longer hospital stay, and 2.2 times greater odds of dying during the hospitalization. Incorporating the standard APACHE III admission source correction reduced the effect of ICU length of stay, but not ICU mortality. **Conclusions:** Benchmarking and profiling efforts should capture admission source, otherwise tertiary referral centers may be at a disadvantage with regard to reporting of quality performance